Medical anthropology: essays and reflections from an Amsterdam graduate programme

van der Geest, S.; Gerrits, T.; Challinor, J.

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This volume is a collection of twenty articles by graduates of the Amsterdam Master's in Medical Anthropology (AMMA) at the University of Amsterdam. The university is known for outstanding and innovative work in the field of medical anthropology and a teaching approach that combines a strong ethnographic basis with thorough theoretical grounding.

More than two hundred students from across the world graduated from the AMMA programme, which resulted in a global network of medical anthropologists working in a wide range of positions in their respective societies. When the AMMA programme ended in 2012, some staff and alumni decided to mark the occasion by publishing a book with essays and information about the AMMA programme, which resulted in this edited volume. All contributions are based on the authors' exemplary master theses and provide a glimpse of the diversity of the students' backgrounds, interests, fieldwork, and theoretical approaches. The articles address experiences of health and illness, sexuality, violence, drug use, local healing, body and embodiment, children's perspectives on health and body, self-harm, gender, obesity, autism, older people, nurses and homecare, reproductive decision-making, parenthood, HIV/AIDS, treatment choices, hospital ethnography, meditation, body techniques, intersubjectivity, illness vocabularies, and hygiene and dirt. The essays are organized in seven themes: Wellness and Illness, Treatment and Efficacy, Gender and Parenthood, Care and Autonomy, Children's Worlds, Body and Subjectivity, and Research and Theory. This collection of essays responds to a growing interest in ethnographic fieldwork as a didactic tool in learning qualitative research methodology and self-reflection. The reader will find inspiration from the articles and evidence of the critical importance of a medical-anthropological approach to investigating health and illness in any setting worldwide.

Sjaak van der Geest was lecturer and dean of the AMMA programme at the University of Amsterdam.
Trudie Gerrits was lecturer and director at AMMA.
Julia Challinor is a graduate of AMMA and edited many AMMA theses.
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MEDICAL ANTHROPOLOGY

ESSAYS AND REFLECTIONS FROM AN AMSTERDAM GRADUATE PROGRAMME

SJAAK VAN DER GEEST
TRUDIE GERRITS
JULIA CHALLINOR
(editors)

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This book is dedicated to all AMMA teachers and alumni (1997-2012)

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Cover: Van Marum Graphics
Cover picture: Ogi inspecting a flat tire in Bosnia by Selma Tanovic.
“Ogi suddenly stopped: he saw a parked car, an old and ragged abandoned VW Golf 2. His eyes sparkled in amusement. He approached it slowly, walked several times around it, as it was a precious art piece in a museum. He touched the half blown tires on its wheels, its rusted bumpers, and its broken door handles. Then he pressed his nose and his cheek to a dirty window, inspecting the interior. This was what he did every time he saw a car that he liked.” (An excerpt from Selma Tanovic’s fieldnotes).

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Preface

The launch of the Amsterdam Master’s in Medical Anthropology (AMMA) in 1997 was the international breakthrough for the Medical Anthropology Unit at the University of Amsterdam. Fifteen years of intensive teaching and studying resulted in a worldwide network of fledgling and mature professionals in the field of health, culture and society. More than 200 AMMA alumni are now working in public and clinical health care, academic teaching, health development programmes and NGOs, research, media, policy-making, institutions for long-term care, and other professional settings. AMMA gave these graduates a vision of the social and cultural embeddedness of health and illness and a scholarly arsenal with an applied focus rooted in a sound theoretical grounding. However, AMMA did more. The one year of close cooperation and study forged friendships across borders of country, culture, profession, religion and age.

AMMA’s closure in 2012, an administrative effort to streamline graduate education at a time of concern about the future cost, was a big disappointment to both staff and alumni. Approximately eighty alumni wrote personal letters to the director of graduate studies, and a colleague from the Philippines criticised the leadership for throwing away one of the university’s “crown jewels”. A touching selection of excerpts from these pleas can be read in the introduction to this book. Unfortunately, the appeals did not change the fate of the programme. After fifteen years, AMMA ended; but a medical anthropology programme for both Dutch and international students continues in the Master’s of Medical Anthropology and Sociology (MAS), albeit in a new form.

This book heralds AMMA’s achievements, students and teachers in twenty essays based on AMMA theses covering a wide range of subjects. It also provides written and pictorial evidence of AMMA’s history, students and teachers.

I want to thank all those who contributed to this valuable volume: the authors, the editors and particularly Julia Challinor who copy edited the essays, Trudy Kanis who did much of the archival AMMA research, Piet van Peters who refurbished the group pictures, Chris Aldenhuis who painstakingly organized the placement of nearly all AMMA theses on the Internet, Sarah Limburg who scanned and digitalised the missing theses and Tony Holslag and Amina Gadri who identified key terms for the theses. The Health, Care & the Body program of the Amsterdam Institute for Social Sciences together with the Graduate School of Social Sciences financed the production of this book. Finally I want to
thank all alumni, teachers and other staff members who made AMMA what it became: a home for personal and professional enrichment and a model for hands-on learning across disciplines in an international classroom.

ANITA HARDON
Professor Anthropology of Care and Health
AMMA teacher (1997-2010)
Director of the Amsterdam Institute for Social Science Research
AMMA’s Logo

For many years this was AMMA’s logo: an African grandmother with her grandchild.

Who is she? Her name is Akua Mansah. I met her in 1994 when I started my research on growing old and the care of older people in Kwahu Tafo, a rural town in Southern Ghana. I saw her every day because she was my neighbour. She was usually sitting in front of the house doing something useful. She lived there together with her daughter and a few of her grandchildren. She always looked cheerful and was open and direct in the three long conversations I had with her. Here is a quote from our last conversation: “When I was young, I made my own farms and got money by selling my farm products. But now I am old and penniless. I have to depend on my daughter and the rent from my son's house to eat. Old age catches a person quickly and money is like a bird. If you do not handle it well, it will fly away and leave you behind.”

When we needed an attractive picture for our AMMA logo in 1997, we chose one of the pictures I had taken of her. She appeared on the AMMA brochure and a large poster. When I visited Kwahu Tafo, in 1998, I took the poster with me, but Akua did not see it; she had died a few months earlier. I gave the poster and
some money to Akua’s daughter who hung the poster in the house as a memory to her mother.

This picture shows Akua Mansah in her characteristic position, between the corn leaves. Her daughter used the leaves to wrap the kenkey (food made of corn), which she sold to schoolchildren. Till her death, Akua Mansah tried to be useful around the house.

SJAAK VAN DER GEEST
Introduction

Essays in medical anthropology and the AMMA experience

Sjaak van der Geest,1 Trudie Gerrits,2 Julia Challinor,3 & Ria Reis4

In 1997, the University of Amsterdam initiated an international postgraduate master’s course in Medical Anthropology, AMMA (Amsterdam Master’s in Medical Anthropology). The programme soon became a hothouse of academic learning and discussion focused on both theoretical and applied concerns regarding health and care in a wide social and cultural context. In spite of its success and popularity, the course ended after fifteen years. Managerial concerns about the cost-effectiveness of the course outweighed students and staff’s pleas for the continuation of AMMA.

This volume is a tribute to AMMA students and teachers and brings together twenty articles by students over the fifteen years of the programme. All contributions are based on the authors’ master theses. The articles provide a glimpse of the wide variety of students’ background and interests.

1 Sjaak van der Geest was one of the founders of AMMA and taught and supervised AMMA students throughout the fifteen years of AMMA. He did most of his fieldwork in Ghana, covering various topics in the field of medical anthropology (see: www.sjaakvandergeest.nl). He is now emeritus professor of Medical Anthropology. Email: s.vandergeest@uva.nl.

2 Trudie Gerrits is a medical anthropologist and was an AMMA teacher and supervisor from the beginning in 1997. In the last two years of AMMA, she was the director. Currently, she is an Assistant Professor in the Department of Sociology and Anthropology at the University of Amsterdam and co-director of the Master’s Medical Anthropology and Sociology (MAS). Most of her research work is related to infertility and assisted reproductive technologies (ARTs), both in the Netherlands and in Africa. For more information, go to: http://aissr.uva.nl/staff. Email: g.j.e.gerrits@uva.nl.

3 Julia Challinor is an international oncology nursing consultant and medical anthropologist working in countries with limited resources. She had been collaborating in nursing partnerships across Latin America before attending AMMA in 2007. Following graduation from the AMMA, Julia acted as a volunteer academic support teacher for the AMMA programme. Most recently, she has been advising in a new paediatric oncology department in Ethiopia. Email: pantaleonNL@gmail.com.

4 Ria Reis chaired the team that developed the AMMA programme and taught in the programme from the early beginning. Her core research interest is children and young people’s health and wellbeing at the crossroads of anthropology and psychology (see http://aissr.uva.nl/staff/). She is now Associate Professor at the University of Amsterdam and professor of Medical Anthropology at Leiden Medical University Centre, Dept. Public Health and Primary Care (LUMC). E-mail: r.reis@uva.nl.

5 This is the second AMMA book. An earlier collection of essays was published on the occasion of the tenth anniversary of the AMMA programme (Park & Van der Geest 2010). That volume focused on how medical anthropology had made an impact on work and life of both AMMA students and teachers.
We made many friends, but we also lost some over those fifteen years. Three obituaries commemorate the lives and work of two AMMA teachers and one student who died. In the appendices, the reader finds information about the AMMA students and teachers, group pictures of all fifteen classes, and a complete list of theses produced by AMMA students.

The beginning

Medical Anthropology at the University of Amsterdam became a specialization for teaching and research in approximately 1980. The ‘founding fathers’ were Klaas van der Veen and Sjaak van der Geest. The latter was appointed as professor in Medical Anthropology in 1994. Other chairs in Medical Anthropology soon followed: Anita Hardon, Pieter Streefland and Corlien Varkevisser. The last two held part-time chairs funded by the Royal Tropical Institute. In 1984, Stuart Blume, a professor of Science Dynamics, joined the Medical Anthropology Unit together with two colleagues and added historical and sociological approaches to the existing research programme. Approximately ten years later, the Unit had expanded into a team of about ten senior staff members and a similar number of PhD students. Research foci included pharmaceuticals and immunization, primary health care, gender and reproductive health, children and youth, cultural psychology and psychiatry, and ageing and long-term care.

How and when did AMMA come into being? It all started in the early 1990s with short intensive courses in applied Medical Anthropology in Thailand, the Philippines and Bangladesh organised by the Amsterdam Medical Anthropology Unit for partners in our collaborative projects in Asia and Africa. Our partners continually requested more formal training in the field; thus, in 1995, when the Board of the University of Amsterdam created a fund for the development of so-called ‘contract-education’, we jumped at the opportunity. Ria Reis was a doctoral student in the liminal post-contract stage between finalizing and defending her thesis. Anita Hardon recognized Ria’s profound passion for education and encouraged her to write proposals for this funding, including a rather audacious proposal for a postgraduate international master in Medical Anthropology, which was submitted in March 1996. Three months later, in June, the Board awarded us a then huge sum, the equivalent of 55,000. September 1, 1996, Ria became the programme manager and was soon joined by Trudy Kanis as AMMA secretary.

In September 1997, we celebrated the birth of the Medical Anthropology program with eleven participants from nine countries. A management team was

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6 Mahidol University in Thailand, De La Salle University in the Philippines and BRAC University in Bangladesh.
installed which guaranteed a high quality of teaching and smooth incorporation of students. The programme was baptised the ‘Amsterdam Master’s in Medical Anthropology’ chosen for the acronym, AMMA, which also stood for the principle that true learning involves personal growth and therefore true teaching must involve ‘motherly’ support (‘AMMA’ means ‘mother’ in many languages). Indeed, AMMA became a caring and vibrant environment that helped both teachers and students to develop and grow into true academics, health professionals and inspiring personalities.

The programme

The main objective of the AMMA was to enable students to formulate appropriate research objectives for medical anthropological research, develop feasible study designs applying relevant theories and concepts, and provide them with the means and tools for solid research and reporting, which hopefully contributed to solutions for health-related problems.

AMMA teaching incorporated current developments in medical anthropological theory and methodology, relevant to emerging concerns. Therefore, the programme was not based in a particular theoretical orientation. Students were encouraged to choose concepts relevant to their research. In hindsight, there was a gradual shift from an emphasis on interpretative approaches to praxis theory and science dynamics, with critical anthropology as a continuous underflow.

The first module was a general introduction into cultural anthropology. For those who had studied anthropology before, this was a refresher course; for those with a medical or related professional background, this module felt almost like brainwashing, or at least a radical adjustment to the new anthropological glasses they were supposed to wear from then on.

The second module consisted of five intensive weeks of medical anthropology, reflecting on illness and disease, the body, and patients and doctors, only to find that none of these terms could be taken for granted. The students were confronted with new theories and concepts. A special AMMA reader with key publications in medical anthropology (Van der Geest & Rienks 1998) helped to introduce the students to this new discipline.

The calendar year ended with the module ‘Studying Health and Diseases’ a module in which the students learned to compare epidemiological and

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1 After three years of programme management, Ria Reis succeeded Sjaak van der Geest as the AMMA director in 2000 and continued until 2010, when Trudie Gerrits assumed the position. Trudy Kanis remained the secretary and admission officer throughout the fifteen years of AMMA. Peter Mesker (2000-2009) and Tony Holstlag (2009-2012) served as managers of the course, organizing the modules, communicating with the teachers and serving as the students’ first contact. Several organizations provided scholarships for AMMA students; Nuffic, Ford Foundation, ICDRB and BRAC were the main funders.
anthropological perspectives and methods, making them aware of the various paradigms of these two disciplines.

The new year started with the Winter School modules, which included several options such as Gender and sexual and reproductive health, children, AIDS, cultural psychology and psychiatry, chronic illness and care, and human rights and medicine.

After the intensive modules of the Winter School, two modules followed. One was a regional module on Africa, Asia and Latin America, which included reading ethnographies and served as preparation and inspiration for the ethnographic work that the students were going to conduct and write about in their theses. The other was the ‘Research Methods’ module, based on the ‘Applied Health Research Manual’ (Hardon et al. 1994/2001). The module resulted in extensive research proposals.

Fieldwork was conducted within six weeks followed by six nervous weeks of thesis writing. In August, the thesis was defended in front of the student’s supervisor and a co-reader.

**Students’ appreciation**

The students’ high level of appreciation for AMMA was well known within the programme, but was prominently expressed when they heard about AMMA’s possible closure. Many alumnae wrote personal letters to the university authorities asking them to change their plan and keep AMMA alive. They explained how AMMA had changed their lives, helped them in their professional careers and spread the anthropological perspective on health and health care to places and countries where ‘medicine’ was largely restricted to a biological fixture. While praising the course, they emphasised most that the *intercultural and interdisciplinary dialogue* among the students was a crucial element in their learning experience. A few quotes:

> The AMMA course was an opportunity for me to learn and unlearn a lot of things — not just from the modules (content and the process) and the teachers, but more importantly from the other participants. The AMMA was an opportunity for dialogue and learning. We learned to appreciate each other’s experiences, views, knowledge and skills… valuing and respecting the self and the others.

> Our research interests and experiences were vastly different, as well as our professional backgrounds and future goals. Yet, in all of our differences, our year of study felt more like a celebration of our commonalities, with

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8 Several of the quotes that will be cited here also appeared in the richly illustrated ‘AMMA 1997-2012 Remembrance Book’, composed by Trudy Kanis and Julia Challinor (AMMA 2012).
each student providing an important perspective and worldview. Throughout the year, we collaborated in small groups as an interwoven community, discussed social science theory, and directly inspired and challenged each other’s research questions, fieldwork experiences, and final writings.

I believe this is one of the few master’s programmes where both medical professionals and social scientists are put together for a year, forced to understand the limitations and benefits of either discipline as well as ways to better work together and address contemporary global health problems.

Voices and stories from all corners of the globe could be heard: a traditional healer from South Korea, a physician from Nigeria, AIDS workers from the Philippines and Indonesia, a physician from Vietnam, social workers from the Netherlands and Bangladesh and so forth.

The bonds of friendship that students established during their AMMA course remained after they left for their various destinations and continue to be a source of inspiration:

Not only did I study and learn from all of my colleagues in the AMMA programme; I lived with them as well and made lifelong friends and professional contacts.

As an AMMA graduate (2004), I left Amsterdam having made friends and professional contacts across Southeast Asia, Africa, Europe and South America. AMMA enriched my professional network, not to mention my personal one, far more than my four undergraduate years at Yale. My classmates and I continue to learn from each other and support each other’s efforts to make a difference.

AMMA students learn so much from each other and maintain those connections after graduation, establishing the basis for a lifetime of global collaboration and understanding.

The high quality of the programme and the intensity of teaching in combination with the close relationship between teachers and students proved to be another part of the ‘success story’:

The gold secret of why AMMA is so special and successful is the combination of excellent academic contents and topics with the diversity of personal experiences regarding those topics shared in the classroom, making readings
and stories to feel near and real, not mere research reports.

At first it was quite strange for some of us who were not used to calling teachers by their first names – Pieter, Els – because from where we come from, it would have been Doctor, Professor, Sir or Ma’am. Teachers were helpful, very facilitative. It helped, too, when teachers would say, “Hmmm, that’s something new I learned today.” Teachers learning from us – that was great.

The programme was a breath of fresh air. Colleagues and fellow students who had taken time away from their working lives to learn together, professors who prepared us to think critically, work collaboratively and bring our perspective into the work that we do in the world, and a classroom experience that combined book learning with the real lived experiences of our peers.

AMMA’s focus on applied research in combination with its emphasis on theoretical grounding proved another attraction, especially for students who had taken a year off from their professional work in health care and expected new inspiration to continue their work. However, many anthropology students too were explicitly looking for an anthropological career in a practical or policy-relevant position:

I used to work with the leading health research institute of Bangladesh, ICDDR,B. The institute traditionally conducted mainly epidemiological researches, but with a growing demand, in the mid-nineties it started to employ Anthropologists from abroad to conduct medical anthropological research. However, after my return from AMMA in 1999, I took over a number of medical anthropological research projects at ICDDR,B. Many of those researches [sic] have been applied for policy changes.

AMMA broadened my horizons beyond typical biomedical or public health approaches to health issues in India; it taught me to reflect on my own stand, values and judgments before attempting to bring out any change in the behaviour of individuals or communities. The programme instilled critical thinking and made me aware of larger politics of knowledge production and complexities of health issues.

Students with a biomedical or other more practical background pointed out how the anthropological perspective had enriched their approach in health care:

Reflecting on our role as professionals, on situating our practice and finding our own way to engage with the subjects of our studies or the
beneficiaries of our professional activities was also fundamental part of our intensive coursework… I came to the course with a background in biology and some working experience in international development. Several months after I had finished and returned home I realized I had learned to think as a social scientist, one that tried hard to be critical and engaged.

As an academic surgeon in my last year of training, I can say beyond a shadow of a doubt, that my academic career and professional growth was in large part due to the year I spent in AMMA.

In AMMA I found an entire new world of knowledge and experiences regarding health, culture and sickness, and mainly, a new and valuable perspective from which to think of and understand such entities. During the last 15 years, I have developed my career as psychologist for children with cancer in the national childhood cancer programme of my country. Some important psychosocial aspects impact negatively on the efforts of the team in saving children’s lives, and it was my permanent idea to understand those aspects and improve the possibilities for saving these children…I realized that I was looking for some key answers using the wrong perspective.

It is true I am not practicing medical anthropology in my daily work (even if I regret this), but it is thanks to these studies that I could and I still can bring a different approach to my work as a doctor and as a coordinator and supervisor of many expatriate and national workers.

For some, the AMMA experience was a submersion into a new way of thinking that had a lasting effect on their later life and enabled them to take a critical stand against the dictates of ‘culture’:

On a personal front, AMMA made me realize that I am not a passive agent in a larger web of what we call ‘culture’, the thing that makes us conform to a certain way of leading life. Rather the programme provoked me to finally take a stand for what I believe even if it goes against the cultural norms and traditions. I realized, each one of us is actively shaping and moulding culture in our own ways and that definitely was an empowering feeling.

I consider AMMA as a rite of passage toward my ‘third birth’, combining a Muslim family background and a Western tertiary academic training on medical anthropology. With the two domains in myself, I feel like being
born the third time with more critical views on religious issues particularly pertaining to gender and women.

Several students wrote that they took the tools and methods of the AMMA course home with them and employed them in their own medical anthropology teaching or in other activities:

Throughout the first years of my career in public health...I realized that medical anthropology was the missing piece of the public health puzzle. We need an approach that allows public health interventions to develop in response to and with respect for the multiple cultures that come together in our country...Having returned to my work in community health, I've used the skills that I learned through AMMA innumerable times.

Nowadays, our colleagues in the foundation are reviewing the literature to determine what is appropriate for a prospective Medical Sociology and Anthropology course that we are trying to start in Teheran medical universities. The AMMA collection is considered a ‘gold mine’ in this way. Moreover, three books, which were introduced in AMMA, are being translated to eventually enrich the resources in Persian.

I learned to include the anthropological context as a cross cutting issue in my work, as therapist, trainer, researcher and lecturer. The positive impact on my work is reflected in the response of people I am working with: “You talk about real people with real problems, about us.”

In their attempts to make the university authorities change their minds and salvage the AMMA course, several students pointed at the global reputation that the University of Amsterdam enjoyed thanks to AMMA and which would be lost if they terminated the programme:

We believe the international reputation of the University of Amsterdam will be compromised if the decision is made to close down the AMMA programme...The AMMA programme is the reason we first learned about the University of Amsterdam. AMMA offers a unique opportunity for professionals around the globe, in particular from countries with limited resources, to collaborate and learn from a diverse group of experts in health care and anthropology here in the Netherlands...AMMA links Amsterdam and the Netherlands to the rest of the world ...and creates qualitative researchers who are in short supply internationally.
AMMA students have great memories of the University of Amsterdam, its openness, pragmatism, creativity, and effectiveness, combined with a great humanity. They strongly contribute to spreading the excellent reputation of University of Amsterdam around the world.

Through AMMA teachers in Bangladesh, our students were exposed to the University of Amsterdam and the rich heritage of AMMA’s wonderful teaching in applied medical anthropology. Every year or alternate year, at least one student comes to AMMA from Bangladesh and AMMA has been instrumental in shaping the career of young anthropologists and social scientists in Bangladesh.

On another note, ‘Amsterdam’ became a special place to be for the majority of students. Known as a very liberal – for some ‘sinful’ – city, the town became a place of freedom and cosmopolitan respect, full of ‘distractions’ and yet intense concentration. The bicycle (‘fiets’) replaced tulips, windmills and wooden shoes as national symbols. The canals fascinated those coming from dry countries as well as students from places that are literally flooded by water. For all, the beauty of the city and the whims of the weather remained an indelible part of their AMMA experience. Here are a few lines from one of the speeches that AMMA students delivered at their graduation:

We learned:
How to adjust to Amsterdam’s weather: four seasons in one day.
Where to buy the cheapest phone cards.
How to fall off our bikes.
How to survive with the used winter clothes from previous students that we found in the storage room.
How to taste somebody else’s food off their plate.
How to botch the Dutch language when we pronounce “Spui, Oudezijds Achterburgwal, dank U wel, alstublieft, lekker, gezellig, leuk, dag, doei, TOT ZIENS!”

What made AMMA special was the intertwining of respect, friendship and academic study that took many forms. The personalisation of culture and the self-reflective approach to Medical Anthropology started with the first assignment on the fourth day of the programme, inspired by the famous Nacirema article.1 The students were asked to look as strangers at their own culture and describe one particular phenomenon “with amazement and amusement.” The responses

1 Using the semi-palindrome ‘Nacirema’ Horace Miner (1956) wrote this tongue-in-cheek essay about the ‘exotic’ body rituals in his own, American, culture.
took us by surprise; they showed a playful combination of closeness and distance to the students’ own cultural identity.

Another example was the way the students told personal stories to one another in class, stories that revealed more about the riddles of culture than anthropological handbooks. There were heated, but respectful, discussions about growing up, physical punishment, wearing a veil, male / female interaction, love and marriage, belief in God, and so forth.

**Contributions**

This collection of twenty articles reveals only a tiny sample of the benefits of the variety of students and their interests as expressed in the quotes above. The articles address (in an absolutely random order) experiences of health and illness, sexuality, violence, drug use, local healing, body and embodiment, children’s perspective on health and body, self-harm, gender, obesity, autism, older people, nurses and homecare, reproductive decision-making, HIV/AIDS, treatment choices, hospital ethnography, meditation, body techniques, intersubjectivity, illness vocabularies, and hygiene and dirt. We have tried to ‘organize’ this wide selection of topics into seven themes (although many other options were possible): Wellness and Illness, Treatment and Efficacy, Gender and Parenthood, Care and Autonomy, Children’s Worlds, Body and Subjectivity, and Research and Theory.

The twenty authors of the articles originate from 16 nationalities and conducted their research in thirteen countries on four continents: Bosnia, Benin, India, Ireland, Italy, Mexico, Mozambique, Nepal, Netherlands, Philippines, Tanzania, Thailand, and Vietnam.

It was our intention to have at least one contribution from each AMMA year, but unfortunately, due to withdrawals and lost email addresses, four years are not represented: 1999, 2000, 2003, and 2009. Other years have one or two articles in this volume. As mentioned earlier, all articles are based on research for the students’ theses that concluded the AMMA programme. Some students summarized their thesis, while others focused on a specific theme or used their thesis as a point of departure to reflect on their present position or ideas. Four articles were previously published in the journal *Medische Antropologie*.

This volume is more than a nostalgic remembrance for AMMA alumni. We believe that the contributions address highly relevant and urgent concerns regarding public health and developments that affect the well-being of people globally. Some of the authors are now involved in teaching or policy and the practical work of ameliorating complex life conditions in various parts of the world.

Finally, we want to emphasize that medical anthropology in Amsterdam is flourishing and growing. It is true that the intensive AMMA course with its special
charm of a lively intercultural ‘mature’ student community of health and anthropological professionals from countries with limited resources as well as high-income countries and intensive nature no longer exists. However, both Dutch and foreign students now attend the MAS programme (Medical Anthropology and Sociology master’s degree), which currently includes about forty students; almost one third are from abroad. Students in the MAS are enthusiastic about the international character and welcome the contributions of students from various cultural and professional backgrounds. Medical Anthropology in Amsterdam lives on …

The editors of this book thank the authors, all alumni and former AMMA teachers who have made the work on this book a delightful experience, and a chance to relive fifteen years of AMMA learning and friendship.

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Wellness and Illness
A ‘Gay Paradise’?

Exploring adverse mental health outcomes among gay men in the Netherlands

Sanjay Aggarwal

Gay men in the Netherlands experience anxiety disorders and mood disorders three times more often than heterosexual Dutch men. Moreover, they have ten times the rate of suicidal self-harm. Epidemiologists report similar findings elsewhere in Western Europe and North America. In the United States, these findings are often understood in terms of “minority stress” — namely as the outcome of discrimination and the internalization of stigma and homophobia. However, in the Netherlands — known around the world as a leader for gay rights — how can these mental health disparities be understood? For my AMMA thesis, I used ethnographic techniques to bring an anthropological approach to this question. After an opening anecdote, I briefly review the international literature on gay-heterosexual mental health disparities and on homosexuality in the Dutch context. The results section draws from fieldwork conducted between 2009-2010 to highlight life-history narratives of Dutch gay men. Three main themes are discussed, starting with the internalized adolescent struggle against a homosexual identity and the social processes that fueled this struggle. The second section presents informants’ concerns after having accepted their homosexuality (having come out of the closet), rife with desire and disappointment in the quest for a long-term relationship. Finally, a brief consideration is given to informants’ varied experiences in gay-specific settings, in which being physically beautiful was a valuable asset.

[homosexuality, mental health, Netherlands, minority stress, ethnography]

Introduction

Martin is a 38-year-old man who lives in Amsterdam. On first appearance, he does not seem different from most other Dutch men. He has a good job and

1 Sanjay Aggarwal was born in Canada, of parents born in Kenya and grandparents from India. It is perhaps this intercontinental family background that inspired his interest in anthropology. After studying biology and later medicine, Sanjay worked in multicultural Montreal for five years as an academic family doctor. Looking for a change, he attended the AMMA program in 2009-2010. He has since returned to his position as an assistant professor at the Department of Family Medicine at McGill University, with renewed enthusiasm for his dual roles in patient care and medical education. Sanjay has also pursued medical anthropology by presenting his research findings at annual meetings of the American Anthropological Association, the Canadian Anthropology Society, and the College of Family Physicians of Canada. He credits his AMMA teachers and fellow students for helping him to again see the world with ‘fresh eyes’. Email: sanjay.aggarwal@mcgill.ca.

Acknowledgements: The author wishes to thank all the study participants, his advisor René Gerrets, his teachers and fellow students at AMMA, Cor van Harn, and everyone else who provided valuable input into this article.
appears healthy. He lives alone in his own apartment and has many friends. However, Martin’s closest friends know that his reality is more complex. Since adolescence, Martin has struggled with depression. Particularly difficult was the period just before coming out of the closet (admitting to friends and family that he is gay). He reveals hesitantly:

I did my first suicide attempt when I was fifteen or sixteen years old. I wanted to hang myself in the hay barn. I was standing ready. I had made the rope and stuff. Everything was planned out. I didn’t do that. I don’t why I didn’t do that.

A couple of weeks later, Martin admitted to being gay to a friend for the first time. This was the beginning of a coming-out process that would take several years. Martin continues:

I did a second attempt when I was in my early twenties. I wanted to jump off the flat [apartment] building I was living in. I had carefully planned and arranged it all. I had made notes and practical arrangements and everything, but decided not to do it either. Then I decided it was time to talk about it with a doctor.

He sought help and, under treatment, his mood remained relatively stable for over ten years. Martin revealed his homosexuality to most of his family, friends and colleagues. He had a serious relationship and made progress in his career. Eventually, the relationship ended, but Martin still seemed to be doing well. A couple of years ago, however, his problems returned:

In 2008, I did a third attempt. I tried to suffocate myself by using gas. I ended up at the psychiatric unit because the ambulance and police found me. In February of this year, I started to develop plans again and was losing control. I informed a friend and I said that I was not sure of myself. He advised me to go to the hospital. Since February, I am taking antidepressant therapy and see a shrink [psychiatrist] every three or four weeks.

Distress among gay men: A larger problem?

While Martin’s story might seem extreme, his is not an isolated case. Large Dutch population surveys suggest that gay men, as a group, have much higher rates of mental health disorders than heterosexual men (De Graaf et al. 2006, Sandfort et al. 2001, 2006). Mood and anxiety disorders – such as depression, panic, and obsessive-compulsive disorder – occur three times more often among Dutch gay men than heterosexual men. While 39% of gay men in the
Netherlands have experienced a mood disorder at some time in their life; this rate is only 13% among heterosexual men. This three-fold difference between gay and heterosexual men also holds if looking only at the preceding twelve-month period. This suggests that the elevated risk for anxiety and mood disorders among gay men is life-long.

When it comes to suicidality, the differences between gay men and heterosexual men are even larger. Gay men are ten times more likely to make a suicide attempt than heterosexual men, meaning that almost 15% of Dutch gay men have engaged in some sort of suicidal self-harm as compared to 1.6% of heterosexual men (De Graaf et al. 2006). This phenomenon does not seem to be limited to a subgroup of gay men, such as those who are HIV positive or those with immigrant backgrounds. On the other hand, the differences seem to be restricted to men, since Dutch lesbians show little difference in mental health compared to heterosexual Dutch women (Sandfort et al. 2001).

Disparities in mental health between gay and heterosexual men have been found in other countries where epidemiological surveys have been conducted (Lewis 2009). This includes the United States (Bostwick et al. 2010, Cochran et al. 2003, Cochran & Mays 2009, Herek & Garnets 2007), Canada (Brennan et al. 2010), England (Chakraborty et al. 2011), and Denmark (Mathy et al. 2011). In the United States, Canada, and the Netherlands, suicides among young gay people have drawn widespread media attention to problems of bullying (e.g. CBC News 2011, Cluskey 2012, Hubbard 2010).

What could explain such major differences in psychiatric health between gay and straight men? Many North American and European researchers attribute psychological problems among gay men to “minority stress” (Meyer 1995). Minority stress studies, typically conducted using quantitative psychological tools, look for correlations between adverse mental health outcomes and measures of self-reported discrimination, stigma, and internalized homophobia. Some studies suggest that minority stress is relevant in the Dutch context (Franssens et al. 2010, Kuyper & Fokkema 2011). Epidemiological studies conclude that Dutch gay men with psychiatric difficulties are particularly likely to live alone, report discrimination, have poor self-esteem, and engage in “emotion-oriented” coping (De Graaf et al. 2006, Sandfort et al. 2001, 2003, 2009). However, an anthropological approach has largely been absent from the international discussion on gay men’s mental health. Ethnographic methods can make valuable additions to epidemiological and psychological studies by focusing on the informants’ own understandings of the problem, yielding variables or elements not previously considered by researchers. Moreover, these methods focus on the social processes and contexts that give rise to health disparities.
The Dutch context: At the forefront of gay rights

The disparities in mental health between Dutch gay and heterosexual men are surprising given that the Netherlands is often regarded as a leader in advancing gay rights. In fact, I was often told by (presumably heterosexual) informants that homosexuality was “not much of a problem” in the Netherlands. There is indeed a long history of gay activism in the Netherlands. The COC, or Cultuur en Ontspanningscentrum (Centre for Culture and Leisure) was founded in 1946 in Amsterdam and is the oldest lesbian, gay, bisexual, and transgender organization in the world (COC 2010). During the course of the sexual liberation movement in the 1960s, the COC worked for homosexual equality with a vision of integrating homosexuals into mainstream society (Hekma 1999). Homosexuality came increasingly into the public eye and, in 1971, was decriminalized. A string of legal advances for gays ensued, culminating in the introduction of same-sex marriage in 2001. This latter event is thought by some to signify the achievement of full legal equality for Dutch homosexuals (Keuzenkamp et al. 2007).

Today, many Dutch people seem to consider tolerance of homosexuality as a point of national pride. Keuzenkamp et al. state, “where homosexuality was in the past seen as a threat to society, acceptance of gays and lesbians is today seen as a measure of good citizenship” (2007:27). Keuzenkamp et al. (2007) report that the Dutch are world leaders in endorsing general statements that affirm homosexual rights. When asked whether “gays and lesbians should be free to live their lives as they choose,” 89% of Dutch people agree.

However, other data indicates that Dutch attitudes towards homosexuality may be somewhat ambivalent. Keuzenkamp et al. (2007) note that 35% of Dutch people agree that sex between two men is disgusting. This also holds for 38% of Dutch young people between the ages of 11 and 24 years. When it comes to public displays of affection, 49% of adult informants are offended by two men kissing in the street as opposed to 16% if a man and woman kiss (Keuzenkamp et al. 2007). Furthermore, three-quarters of Dutch gay men say that they have had a negative reaction to their homosexuality (Kuyper 2006:177-8). Most of the time, anti-gay incidents take the form of verbal censure that serves to enforce norms (Kuyper et al. 2007, Kuyper 2006:177-8). Although strangers are most often identified as the perpetrators, discrimination also occurs in familiar settings (Keuzenkamp et al. 2007, Kuyper 2006).

The situation of young homosexuals has received particular attention. One-quarter of gay men report negative reactions to their homosexuality in school during the previous twelve months (Kuyper 2006). Sexuality researcher Laurens Buijs notes that behaving ‘normally’ is especially important for homosexual students and teachers to be accepted in schools (interview with author, June 1, 2010). Research on coming-out suggests that homosexuality is perceived as a negative difference in the Netherlands, and the process usually involves a
protracted period of internal struggle (Keuzenkamp et al. 2007, Van Bergen & Van Lisdonk 2010). At approximately 21 years, the average age of coming-out is surprisingly consistent across lines of religiosity, ethnic background, and level of education. The researchers explain this finding, which stands in contrast to the expectation that gays in religious or ethnic minority settings would come out later, by the importance of social conformity even in secular and educated families (Keuzenkamp et al. 2007:63). It therefore seems that young people’s homosexuality – despite appearances of widespread acceptance – continues to be a difficult topic for many people in the Netherlands.

My study

For my AMMA thesis, I conducted an ethnographic study to explore how and why Dutch gay men so frequently experience psychological distress. Mental health disparities between gay and heterosexual men have primarily been studied using psychological frameworks, as explained previously, but anthropologists have rarely turned their gaze to this issue. I wanted to learn about the socio-cultural forces that may generate adverse mental health outcomes. Rather than taking minority stress for granted, especially given the mixed data on attitudes towards homosexuality in the Netherlands, it seemed important to look at the understandings of Dutch people. Finally, a goal was to consider how factors in the minority stress model (discrimination, stigma, and internalized homophobia) and in epidemiological studies (“perceived discrimination”, poor self-esteem, living alone, and “emotion-oriented coping”) played out in people’s stories of their own lives.

Data was collected between April and July 2010. There were twelve in-depth life history interviews, producing approximately 25 hours of recorded material (Atkinson 1998, Cole 1994). I also interviewed ten experts including prominent social scientists, epidemiologists, health officials, and activists. Informants had the opportunity to read and edit transcripts, and their names and certain other details are modified to preserve anonymity. Perhaps most importantly, I drew from one year of participant observation while living in the Netherlands (Green & Thorogood 2004). It was this ‘hanging out’ with informants that produced honest, heartfelt accounts (Tillman-Healey 2003).

Results

The findings in this article are organized into three sections, reflecting the dominant themes identified through interviews and participant observation. Although there is no heterosexual ‘control group’ in this study, informants identified many of the dynamics as particular to gay men. The data is largely presented as informant quotations. I chose this approach to highlight the power
of ethnographic techniques and to retain as ‘human’ a tone as possible. It is also congruent with the goals of the study to look at understandings of gay Dutch men themselves, as well as to focus on socio-cultural phenomena.

The kind of person you don’t want to be

Eric, 25 years old, grew up in a small town in Groningen province. He was a university student in Amsterdam at the time of the interview. Like many informants, he began to realize in puberty that he might be gay. He was unhappy with the idea and resisted it, despite growing up in a family that he described as ‘gay-positive’. He explained:

I remember the first time I was aware that I was gay, or that I could be, I was about 11 years old. I did not talk about it of course. I was kind of attracted to a friend of mine. I did not talk about it and I ignored it. During my whole high school period, I also did not talk about it and I ignored it. I knew that I was gay but I made myself believe that I wasn’t. I never found it negative if someone was gay. I was raised that gay rights are a good thing and that everyone is equal. But for me it was different, because I didn’t want to be part of that group.

Like Eric, many interviewees had struggled to accept their homosexuality during adolescence, whether they grew up in Amsterdam or a smaller town. They often felt that their sexual impulses were in conflict with their cognitive and social preference to be heterosexual. Many spent years trying to deny or ignore their sexual desires. They preferred to be seen, and to see themselves, as ‘normal’.

How did Eric decide that he did not want to be gay? He did not report being teased or bullied at school. Rather, he said that his classmates did not suspect him of being homosexual. He was also aware that his parents would be open to the idea of having a gay child. He nonetheless did hear pejorative comments relating to homosexuality and homosexuals. Eric recounted:

I remember when I was working in a grocery store. My colleagues were calling each other, in a negative way, ‘homos’. I remember that. That really bothered me. It made me feel uncomfortable. They were always talking very negatively. I remember that hurt my feelings. That made me think, “Oh shit, I can’t say anything.”

Other informants described a similar sensitivity to negative representations of gay men, particularly during their adolescence. This often took the form of remarks or jokes in the mass media or a range of settings – home, school, work, or with neighbours. Television footage of Canal Pride – Amsterdam’s annual gay pride
parade – was cited as presenting a deviant image of gay men. Even if these derogatory portrayals were relatively rare, they were described as very powerful. In short, many men saw homosexuality as stigmatized – an undesirable difference.

While some men had positive experiences telling their family about their homosexuality, others’ accounts revealed dimensions of this undesirable difference. Gijs, who grew up in the Catholic south of the Netherlands, told his story:

The reaction of my parents was different than expected. I expected that my father would be very furious. But my father was very wise. He said “I will inform the rest of the family.” On the contrary, my mother kind of freaked out. That disappointed me, actually, because she was afraid of what the neighbours would say, what her friends would say, … The reaction of my sister was, “It’s all ok by me, as long as you don’t wear a dress or make-up or stuff like that.”

For Gijs’ family, concerns about gender and the opinions of others figured prominently. Indeed, many men were discouraged by portrayals of gay men as feminine or marginalized. As adolescents they yearned for gay role models who were masculine, like normal men.

The period of inner conflict with one’s own homosexuality was described as rife with psychological distress. Eric (cited at the beginning of this section) maintained his silence throughout his university years, since he was reluctant to assume an ‘abnormal’ identity. He described a growing tension within himself during this period, eventually arriving at a crisis point: “I was stuck with what I should do. I think I was really depressed then, but I handled it myself. For a lot of gay men in that period, especially if they don’t come out of the closet at all, I am not surprised that they may be depressed and suicidal.” Indeed, Martin (cited at the beginning of this article) understood his own suicide attempts in the following light: “It related to the fact that I didn’t belong, that I was different. A major part in that is of course being gay. Very, very low self-esteem. Very much a feeling of not being good enough. It is different in the negative sense of the word.”

Beyond the closet: The struggle to find a relationship

Dutch studies suggest that increased rates of depression, anxiety, and suicidality continue among gay men for decades after coming out of the closet. Why do these problems continue even after having ostensibly accepted one’s own homosexuality?

One element seems to be ongoing stigmatization and discrimination. Such processes were not restricted to adolescence, but rather remained relevant in adult spheres of family, friends, and work. Gijs, for example, spoke of the
environment in his blue-collar job as challenging. Thirty-eight years old, he explained what bothered him:

I feel the bad jokes as well, around the house, at my work. I play along but they don’t know that I’m gay or I’m not gay. I just play along. In the meantime, I think, “Well, why do you have to make jokes about groups of people who are not in the majority?” It still hurts, or it can hurt, although I just play along to not show that I have problems with it.

Gay informants often minimized ‘minor’ acts of discrimination, particularly those in familiar circles, and tended to dismiss anti-gay jokes as normal. Some seemed genuinely nonplussed. For others, these experiences resonated with adolescent memories and reproduced feelings of marginalization.

Most informants’ stories of the post-coming-out period focused on their desire for a long-term relationship and the challenges in establishing one. Mark, 38 years old, grew up in an affluent area outside of Amsterdam. Speaking of the consequences of the coming-out process, he explained:

It’s a preoccupation that people who are straight don’t have. You are not thinking about how you are straight, why you are straight. You don’t have that secret, that shame, any of that going on. Gay people tend to focus and get stuck on that for a couple of years and therefore can’t focus on other things. That can hold you back a couple of years. Because of that, you have your first relationship with a guy later. You basically hit your puberty later than you would otherwise. I think the first time I had sex was [when I was] 20...it sort of delays what goes on emotionally.

Adolescence was often represented as a time of lost opportunities. In particular, informants said that they had missed out on chances to experiment sexually and to develop relationship skills. This could make intimate relationships more challenging for years or decades later. For Eric, coming out of the closet allowed him to feel more free and optimistic. Referring to his situation at the time of the interview, he nonetheless lamented:

The bad part is that I don’t have that much experience. I’m not really good in relationships. I think that’s mainly because of the whole gay thing. I was pretty late in developing the skills that you develop when you go out and you meet people. That’s a struggle for me now. I’m not in a relationship. A lot of people around me are. I wonder – should I be?

Beyond a lack of relationship skills, there were other reasons for the difficulty in finding a long-term partner. Gijs was unusual amongst interviewees in that he had
entered into a ten-year relationship soon after coming out of the closet, while still living in a small Dutch city. At the end of the relationship, he moved to Amsterdam. Even after eight years in the ‘big city,’ he had not found another boyfriend. Ironically, he cited the large number of gay men in Amsterdam as a problem:

Amsterdam is like a big pond of fish. One day you catch a beautiful fish and it looks good and it tastes good. But instead of keeping it and being happy with this beautiful species, you just throw it back because you don’t know what bigger fish you could catch the next day. There are too many fish out there in the pond.

Gijs elaborated on the challenges:

It is difficult in the internet time to be seriously involved with somebody. Yesterday I had this date. I really liked him. I came back later in the evening and I went online. I immediately chatted with other guys and had plan B and plan C already.

As technology and geographic location made single men more accessible, commitment became more elusive. Despite engaging in ambivalent behaviour at times, many men described how the difficulty in finding a partner could be harmful to their well-being. Gijs explained:

You have the feeling that you are on your own, literally, more often, because it’s difficult to find a permanent partner. You are more single than a straight man...The combination of being single and therefore being on your own, and having to cope with life – you can’t really talk to just friends about what’s bothering you. And with a partner you can. You have more opportunity to reflect.

A partner offered companionship and emotional intimacy, while being single was often regarded as a lonely time – rendering one more vulnerable to feeling depressed. As Gijs indicated above, this was a problem gay men saw themselves as experiencing more commonly than heterosexual men.

Being single could be a let-down in itself. Just as Eric asked himself whether he ‘should’ be in a relationship, many men felt that they were not meeting a social norm by remaining single. As such, they risked disappointing themselves and others. Gijs reflected:

I think I am quite ready to go for a relationship. I see myself as a failure now, being alone while a few of my good friends are in steady relationships, or are getting married, or having children. I am almost 38,
in two weeks, and when I look around, what do I have? I am still single. It's a bit of disappointment maybe, sometimes. …Time is ticking. If you wait a little bit longer, you are 45 or 50 years old. And then what? You are starting to count to the end.

In summary, many men felt that a partner provided emotional support and company, thus staving off depressive feelings. Being single, on the other hand, was seen as additionally negative because it represented a failure to meet prevailing norms. While these experiences may also apply to heterosexual men, gay informants saw themselves as facing unique, more daunting obstacles to finding a long-term partner.

**Gay life: Friend or foe?**

Many gay men tend to migrate to larger cities, anticipating that they will feel more accepted there. Urban centres also provide possibilities to seek out 'gay life': gay-dominated venues or events that might offer friendship, support, or sex. Respondents described links between these settings and their mental health.

Some informants felt that their experiences in predominantly gay settings enhanced their well-being. Fritz, 40 years old, grew up in a farming area in the province of Noord Holland, but now lives in Amsterdam. He is tall, blonde and likes to work out at the gym. One of the main focuses of his social life is circuit parties (electronic dance parties) like Rapido. He explained their appeal:

I think no heterosexual can imagine what it’s like to be in Rapido – a crowd of half-naked, sweating, dancing, really happy people next to each other. I think it’s basically tribalism, giving people a really good feeling about being gay, and being gay together. Probably most of the gays there would perceive themselves as having more fun than any heterosexual man their age would have in their entire life.

In contrast to Fritz, other men felt that such events could reproduce feelings of marginalization and inadequacy. They felt excluded and their self-esteem was challenged. Fritz addressed some reasons that people did not like Rapido:

A lot of people don’t like it because they think it’s superficial. They think that people don’t talk. They only look at each other, and the better looking you are, the more attention you get. People are only having fun because they use a lot of drugs. I think that’s all true in a way.

The focus on physical appearance was often cited as a particular pressure faced by gay men. Gijs remembered going out to gay bars with a former friend:
He was a very beautiful guy, working part-time as a model. When I went out with him, he got lots of attention. People came to talk to me and, noticing my friend, all of a sudden the attention was completely to him. They used to comment to me, “he’s very cute, very nice”. . . One time he got a question about me, asking what he was doing with me, because I was so ugly.

While many gay men considered that heterosexual women, like them, faced pressure to appear beautiful, they did not see heterosexual men as experiencing a similar challenge. In summary, gay venues seemed to have varying relationships with mental health, enhancing some informants’ sense of well-being while threatening others.

**Conclusion**

My AMMA thesis was inspired by a problem in public health: the existence of increased rates of depression, anxiety, and suicidality among gay men as compared to heterosexual men, in the Netherlands and elsewhere. Informed by existing Dutch epidemiological and social science research, as well as the psychological model of minority stress, I applied ethnographic approaches to this issue. One objective was to give voice to Dutch gay men – looking at their own understandings. Another goal was to shed light on socio-cultural processes that play a role in such disparities. Results included stories about how the gay identity was tarnished for youth, largely as a consequence of social prejudice, and how their internalized struggles with this unwanted identity contributed to anxiety and depression. The years of conflicted adolescence led many men to feel impaired in establishing long-term relationships once they came out of the closet. Often single, these men saw themselves as missing out on companionship and emotional support while engaging in self-criticism for failing to meet social ideals. Experiences of exclusion were also potent sources of distress, in both ‘gay’ and ‘mainstream’ life. Gay settings could bring a particular, intense pressure to be attractive. These conclusions, as the product of an exploratory study, are tentative and may raise more questions than they answer. They ideally serve as a basis for future study. In reflecting on the project, perhaps my most central memory was how anthropological approaches gave voice to informants’ narratives – simultaneously striking and heart-breaking in their candour.

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Women’s suffering

Teaching psychological violence in Mexico City

Michelle Allport

The term psychological violence seems self-evident, but like all psychological categories, it is defined within social, cultural and political contexts. The idea that psychological violence is quantifiable across cultures is a sign of the global trend broadening the definition of violence. The term’s history, particulars, and uses vary from place to place. This analysis of ethnographic research in Mexico City conducted in 2008 is a contribution to that history.

Situated in a gender equity non-governmental organization (NGO), I found that women’s suffering that was once ‘normal’ and acceptable is now experienced as overwhelming and wrong. Human rights discourse is used to teach women that they have a personal responsibility for their wellbeing. Women are learning to view their suffering through a social critique of gender relations, in which it is not a source of individual pathology, but, rather a result of the society in which they live. During treatment, the acknowledgement of being psychologically violated becomes a symbol of modern knowledge. Women begin to believe in their right to health and happiness, and dedicate themselves to teaching this message to all women.

[psychological violence, violence against women, human rights, Mexico, feminism, trans-cultural psychiatry]

My husband did not give me enough money for living expenses or food. He had a girlfriend who also had two children. I sometimes made my small children ask him for money because he did not listen to me. He said I was crazy. I was very skinny and sick. I was taking sleeping pills and had headaches all of the time. My sisters and sisters-in-law said that this was marriage, nothing to get too upset about; infidelity and insults were not worth causing problems in a marriage. But one day a girlfriend who was

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physically abused for years told me I was suffering from a different kind of violence – ‘violencia psicológica’.

This was how most women I met in Mexico discovered a name for what they were experiencing. High statistics of violence, international pressure and an internal mix of feminists, academics, and activists have shaped Mexico’s growing use of human rights and violence awareness campaigns. The global discourse on human rights argues that violence is not necessarily actions of force, but rather the lack of social and gender rights. The United Nations defines violence against women as “any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivations of liberty, whether occurring in public or private life” (Rutherford et al. 2007:677).

In 2007, the first federal, and the most broadly defined, law addressing domestic violence in Mexico was enacted: The General Law of Access for Women to a Life Free of Violence (Ley General de Acceso de las Mujeres a una Vida Libre de Violencia). This legislation clearly identifies and criminalizes psychological, emotional and economic violence. For example, if a husband verbally insults his wife or restricts her family members from visiting their home, it is a federal violation and criminal act.

The concept of psychological violence seems self-evident, but like all psychological categories, the definition is situated within specific social, cultural and political contexts. The idea that violence is quantifiable across cultures is a sign of the global trend broadening the definition. The history of psychological violence, its particulars, and uses vary from place to place. The concept of human rights translates to many as universal rights, but rights have a social anchoring and cultural identity (Merry 2001).

What was normal or tolerated twenty, ten, five years ago — or only a week ago for some women — may now be perceived as a violation. The state has engaged in the private space of women, entering a home with human rights legislation that for many Mexican families has been governed by the value system of the Catholic Church. Women have been raised to stay by their husband’s side (Boyer 1989). Preserving marriage is the ‘right’ thing to do no matter what happens behind closed doors; it is considered ‘the price a woman pays’ and illuminates the value of female suffering within Mexican culture.

**Field site and methodology**

This ethnographic study was conducted in the summer of 2008, situated at a gender equity non-government organization in a middle-class neighbourhood, which I will give the pseudo-name Gender Equity Centre (GEC). The centre educates women and professionals on gender violence, as well as
providing individual and group treatment. One can hardly imagine the grandeur of Mexico City, an extreme urban setting with a population of over 20 million people. I knew the country’s capital, but I still found it remarkable upon arrival. The megalopolis is the centre of most aspects of political, economic and modern cultural activity in the country; pollution, over-crowding and high rates of crime all come with the benefits of living in this modern city.

Martha, a charismatic 52-year-old woman founded GEC in 1992. She has worked in Mexico City as a feminist psychologist for 25 years. Five days a week she sees individual clients and two nights a week facilitates self-help groups. There are also three other psychologists working full time. I conducted 19 interviews with eleven women, which included extended day trips to three women’s homes and attended eight self-help groups. The majority of women had been married for decades. Friends, family, and media campaigns had referred the women to GEC. Occasionally even abusive partners recommended treatment. For example, Patricia, 39 years old, has been coming to self-help groups since her partner, David, who was attending self-help groups for men addressing gender violence, suggested GEC. The couple has three-year-old twins together and although David no longer attends meetings, he and Patricia remain a couple. All the women I met are part of this article, but a special focus is put on Patricia. She was a translator and an assistant during my fieldwork; over time we developed a close relationship.

**Mexico’s Catholic Mother**

The relationship my informants have to suffering and The Virgin of Guadalupe, also referred to as Our Lady of Guadalupe, or for the locals, La Virgin, is part of a story that connects bodies, pain and history. The cherished saint is considered by many to be the mother of Mexico. The meaning attributed to her influences worldviews and subjective understandings of health and suffering. The relationship Catholics have to saints is rooted in the Mediterranean. Peter Brown in *The Cult of the Saints* (1981) argues that a shift occurred in the late fourth century when Mediterranean people began to look to fellow humans for guidance, friendship, inspiration and protection. Modern Mexican saints are a mix of the European Hispanic Catholicism and indigenous gods that dominated the area prior to colonialism. The best example of this is La Virgin, who quickly gained popularity with locals after being discovered on a hill where an Aztec goddess (Villalpando 2004) also resided.

Religion has a strong presence in Mexican society; the early constitutions of the 19th century claim that the “Catholic Religion shall be the only one, with no tolerance for any other” (Lomnitz 2002:266). Since 90% of its population remains Catholic (Miranda 2006:60), the church continues to guide Mexican values and advocate for the traditional family. Mexican women are socialized to
believe in the greater good of the family. Children are the most prized possession of a family and it is the mother who holds a family together. Women I met often said that life was hard, but that the pain one endures makes one good and strong; with pain, one has compassion and knows sacrifice. Womanly sacrifice is part of Mexican culture. This type of sacrificial suffering taught by grandmothers and mothers was illustrated in the popular phrase: *Es tu cruz* (It’s your cross to bear), which referred to the burden of caring for one’s husband and children.

In order to gain insight into what Our Lady of Guadalupe meant to Patricia and other women, I showed them an image of the saint and asked what they felt and thought. Patricia grew up with an atheist father and a Catholic mother; greatly influenced by the former, she does not consider herself religious, but admitted: “Mexico is very guadalupena, she is like our mother. I ask her for help when I am very desperate. I inherited all of my grandma’s statues of Guadalupe; they are very beautiful. Sincerely, I believe that she is a super woman, good, sweet, and we should all be like that.”

The intimacy women share with *La Virgin* continues to make and remake their worlds, reinforcing their subjective value of suffering. Their regular practices and interactions with her connect them to heaven above on a daily basis. Through saints, the world can be apprehended and personalized, says Orsi (2005). One’s relationship with saints is connected to religion but cannot be analysed as merely a result of a dominating ideological power. Suffering is where the human and the divine meet; healing becomes “the material manifestation of Christian power” (Kleinman 1997:322). *La Virgin* is not only an image — she is both friend and mother with supernatural powers, as women’s remarks below will show:

A few days ago I felt the need to ask her for help and she listened to me, we talked ‘woman to woman’ about suffering.

She gives me peace and I feel that she protects me in every way; she is always with me.

Like *La Virgin de Mexico*, she is our mother, mother of our god, we find her worthy of respect, kindness and adoration, and she is like all mothers so human beings turn to her a lot.

She is a mother we always pray to and most often in the moments that we are most desperate.

Everyone sees her as the mother of our home and we teach that she is the true mother offering protection to our children and like her we should serve and sacrifice for them.
She is a woman that existed at some time on this planet. There are many people that have faith in her, like I have had in her in other moments of my life.

Despite their adoration for La Virgin and a life-long socialization of suffering, her ways have become less practical and women at GEC were struggling to fulfil the expectations of the sacrificial mother; they felt that their lives were unfair and difficult. The relationships that they relied upon had become unbearable. “I am tired and I cannot do it anymore,” was a common remark. While they still wanted to be good women, many had reached a point where the work of everyday life had become unmanageable. “I am exhausted and need the tools to make this pain more bearable,” said a new arrival at GEC.

**Modern symptoms of self-sacrifice**

Some historians have claimed that in the recent past, lack of responsibility towards family and public disrespect for a wife was dishonourable and morally unacceptable. “The husband was answerable for abusing the balance of order and justice that he was supposed to maintain with the marriage” (Lavrin 1989:20). This is no longer the case. In contrast, the World Health Organization claims that one in five women experience gender violence daily (McCue 2008:104), and a 2007 study authored by GEC found that 64% per cent of women (between 12 and 29) in Mexico City were victims of one or more types of violence. Consequently, unless a woman has a family that is capable and willing to morally and economically support her, she is most likely going to remain with her partner. This position has led to modern symptoms of suffering in response to self-sacrifice.

For example, almost all women I met complained of ‘gastritis’, an irritable stomach condition that is acknowledged to be somatised feelings of stress and anger. Likewise, Kaja Finkler, (2004:2046), an anthropologist, while observing a hospital in Mexico City, noted that physicians diagnosed female patients with gastritis or colitis due to outbursts of emotion; for example, a doctor attributed a woman's condition to anger and emotional distress resulting from conflicts with her husband.

In addition to gastropathic illnesses, I noticed an openness in discussing suffering that fit the symptoms of clinical depression. This could be accounted for by the fact that Mexican and Mediterranean societies view suffering as a central aspect of everyday discourse. Gaines and Farmer (1986:305) wrote that while women exhibited symptoms of depression, it was actually a part of the “rhetoric of complaint” where people complain to prevent others from feeling envious of one’s life. “In tradition, life is seen as a constant struggle against overwhelming
odds. suffering is ennobling” (299), which places human responsibility and autonomy in the background (Alberro 2001:60).

However, women’s comments were disturbing: “I felt very sad. I had lost interest in many aspects of my life. I just wanted to be able sleep through the night.” The most common descriptions of suffering were angustia, depresión, and tristeza. From my short time in the field, I came to understand the three terms to be associated with common complaints by women: angustia refers to intense fear and anxiety; depresión is associated with apathy and not wanting to get up and out of bed; and tristeza with sadness or disappointment, which causes crying. All of these states can cause a lack of sleep and eating problems.

Psychological discourse is used in everyday language, and many of my informants framed their distress in phrases such as, “I have psychological or emotional problems.” However, psychological treatment is stigmatized in Mexico. I heard countless times that “psychologists are for crazy people,” and psychological treatment is a sign of weakness — “you must be strong” and “pick yourself up” when things are difficult. Therefore, only three of my 21 informants had seen a psychologist, while seven had visited a general practitioner: all seven women were prescribed tranquilizers, most often diazepam. Sleeping pills, as they referred to them, were cheap and easily affordable, and they helped them get through the nights and often the day as well. In contrast, anti-depressants, which one woman was prescribed, are extremely expensive; she stopped taking them after two months due to their high cost.

These above symptoms show how the relationship women have to suffering is shifting; women are looking for comfort and support in various ways, through family, friends and doctors. In addition, some women find their way to local government’s Unidades de Atención y Prevención de la Violencia Familiar (Care Units and Family Violence Prevention Centres), I will give these centres the name VPC. They are known for endorsing traditional values, like keeping the family together rather than separation of a marriage. Writing about laws on domestic violence in Latin America, Macaulay (2006:106) argues that Latin American policies “make conciliation between the two parties in conflict an obligatory first stage and primary aim of court intervention.” My Mexican informants told me that this conciliation process is called amigable composición and requires that the judge use all legal means to resolve the domestic conflict in a manner that preserves the unity and harmony of the family, while encouraging the aggressor to change his behaviour.

VPC uses conciliation and psychological approaches that claim both the abuser and the abused may have psychopathologies. Psychological perspectives describe men as having low self-esteem, a lack of self-control, or reacting to the effects of substance abuse. While women may be innately masochistic, experiencing learned helplessness, or “psychic numbing” (Chornesky 2000:483). The VPC in Mexico City welcomes women with psychological assessment
interviews that result in referrals to their weekly support groups. In contrast, at GED, divorce is actively encouraged, and they use cases of psychological violence as a way to discuss human rights violations. Although support groups may have helped women or their symptoms are temporarily relieved with medications, my informants did not feel they were getting the treatment they needed for their pain until they understood that they were suffering from violence.

**Learning psychological violence**

The psychologists at GEC do not diagnose mental illness. There is an agreement that all psychological labels are unnecessary. Norma believed that the women knew themselves best and did not need to be given a pathological diagnosis: “They have mental problems, but they are from their relationships.” Unlike the government support groups, that were cathartic and focused on conciliation, GEC had a clear and determined message of self-help and autonomy building. Patricia was one of the women who visited the local VPC. “I first went there before GEC, it was nice, but there were not enough psychologists, you only saw one when you first entered, then there is only the support groups.” Patricia described a recent visit to the VPC support groups and explained why she preferred self-help groups at GEC:

> At GEC it is more didactic, more for learning, like school. Over there you are not going to learn anything; it is more therapeutic. They try to bring out emotions to connect with the other woman, but there was not enough time. So a woman spoke, and another and another and they were all very distressing stories. A woman would be talking while the others cried and I felt very sad when it ended. Also they do not have a table and I feel, I don’t know, I feel less protected, you know. All the women are in a circle, without a table. And the female psychologist sits in the circle with everybody. And the psychologist is no more than us, doesn’t do more than guide.

At GEC, the self-help groups were arranged around a U-shaped table. Norma usually lectured on a particular topic. Women opened notepads and rapidly scribbled notes throughout the meeting. There were children running around the room, food on the table, and women passed the evening with laughter and tears. It was a relaxed atmosphere that was looked forward to every week. The women were dedicated to each other and most importantly the ‘mission’ of GEC: to educate as many women as possible about violence against women, especially non-physical violence. They made sure I understood that although I did not live in what they called their “macho” country, American and European
women were also suffering from gender violence. “When a boyfriend or husband looks at your mobile phone to see who is calling, or disrespects your work in the home, that is violence,” said Lupe.

Women were not embarrassed or hesitant to discuss their experiences; they actually seemed to embrace the label of violence and its narrative. The process of ‘narrativization’ not only provides a re-making for an individual (Good 1994), and a community, it is also a political act that has the ability to alter experience, and for women at GEC, the idioms of violence gave meaning and endowed them with a sense of purpose. Being psychologically or economically abused was not a sign of weakness or pathology, but rather a symbol of knowledge and enlightenment. Parson (2010) found a similar phenomenon at a gender violence centre in Chile. Her leading informant, Luz, “conceptualizes her engagement in this transformation work as being for herself, but also for the world. This work gives meaning to her life and is creative of new social orders” (p. 79).

Although countries like the United States have a longer history addressing domestic violence than Mexico, Erwin (2006:195) claims international organizations should proceed cautiously in exporting U.S. ‘models’ of intervention in domestic violence as their use of psychological and criminal approaches are not as promising as “a more holistic approach, incorporating an analysis of the relationship between health, culture, and economics with violence against women.” For example, the satisfaction women received from treatment at GEC resembles Humphreys’ and Thiara’s (2003) findings that women prefer help in naming their experiences rather than focusing on their mental health. And like the women at GEC, whose children were being passed from the lap of one woman to the next during meetings, they wanted the acceptance of their children or childcare options.

States and international organizations that have been addressing the issue of domestic violence since the 1990s tend to use a human rights framework; the popularity of the human rights perspective grew out of the UN’s Declaration on the Elimination of Violence Against Women in 1993, which views violence against women within a gender relation’s framework (Erwin 2006). Modern human rights discourse provides a new global moral order (Sjoberg et al. 2001, Boli & Elliot 2008), which guide the ethical and legitimate treatment of individuals. This institutionalization of human rights has sacralised the individual (Elliot 2007) along with their wellbeing and health.

With the use of a human rights approach, a significant part of addressing violence against women is bringing attention to non-physical violence. Yet, it can be said that the broader our definition of human rights, the more pervasive and inescapable violence and ‘unhealthy’ lives become. This growing category of ‘violence’ draws on a broad notion of ‘health’, which now belongs to all aspects of social, emotional and intimate lives, with health becoming the dominant way
of narrating and disciplining societies and selves (Foucault 1988, Crawford 1994). This shift from self-sacrifice to self-preservation places moral and religious meaning out of the mainstream, and instead supports a trajectory from a Christian discourse of discipline and control to that of progress and individual improvement and responsibility. Kleinman argues that nowadays “no one admires or uses humiliation, but rather classifies it as a personality pathology” (1997:320). The modern discourses of human rights and individualistic notions of self-care are now intermingling with many women’s notions of guilt and sacrifice. For example, at GEC, the belief in La Virgin that values shameful sentiments is a sign of marianismo that should be abolished: “Marianismo is a set of behaviours that have been said to be the female response to machismo that include: “silence, long suffering, mothering, virginity, passivity — attributed to the Virgin Mary” (Rodríguez 2008:314).

Encouraged by new representations in the media, friends, family members and even some male partners, women enter self-help groups where they come to understand and share with each other that what they are living through is ‘violence’. Staff and fellow women encourage the women to acknowledge and take control of the suffering that has long been absorbed into their everyday lives.

Choosing health

GEC stresses individual accountability, women must own their daily decisions and choices or they are living in ‘bad faith’. Gastritis was discussed as internalized negative emotions, but also as a sign that women were not taking care of themselves or their health. As a result, personal health was often framed as a reason for leaving partners. A self-help group interaction demonstrates how women have internalized the idea of the possible ‘fatal’ consequences of their relationships:

Melba, self-help facilitator: You need to feed yourself good and healthy foods. Not just junk and sugar. You are also hurting your bodies by staying in an abusive relationship. What will happen if you continue to internalize all the pain, anger and suffering year after year?

The women (shouting): We’ll get cancer!

Women came to see psychological violence as keeping them from full lives, from healthy lives. The importance of health was a message GEC emphasized at every self-help group – participants came to see personal health and happiness as more important than the value of marriage. The ability to leave relationships was ritually acknowledged with claps and screams of joy. Rounds of hugs were
shared when a woman in a self-help group signed divorce papers. Once a woman was single, she would have the time to care for herself; for example, women were asked what they would do with their time if they were free of their partner.

Melba: What do we not have time for?  
(The women shout out answers as she writes them on the white-board):  
Plan weekends  
Finish career education  
Work more  
Take courses  
Pleasure (a vacation in Cancun)  
Repair my life

Emboldening women to leave their relationships is meant to confront the Mexican culture’s demand that women stay with the father of their children: “I can’t leave my children without a father” (No puedo dejar mis hijos sin padre) was commonly heard. Therefore, a woman becomes a doubly ‘bad’ mother if unable to leave her partner or if she chooses to stay. These multiple pressures contribute to the distress of women. Plesset (2006:39) in her ethnography Sheltering Women: Negotiating Gender and Violence in Northern Italy calls this phenomenon a type of ‘double shame’, arguing that shame comes from opposing sources, “women may feel embarrassed that they have not exercised their autonomy as a ‘modern’ women should, by leaving an abusive relationship, even as they wonder if the violence was provoked by their failure to fulfil their ‘traditional’ responsibilities as wife and mother.”

Patricia struggled with this double shame daily. She believed she was socialized to be overly dependent and felt ashamed that she was unable to permanently separate from her boyfriend:

I feel weak in relationships and I would like to be less dependent. David, my partner, is not a good provider and an alcoholic, but he is not a bad man. He has tried to change. He even went to meetings that help men who are abusive. But he still cannot stop being aggressive and drinking.  
There is a popular expression here for women: la vida es un valle de lagrimas (life is a valley of tears).

Patricia’s and my other informants’ experiences are part of a larger Mexican narrative. The Mexican state, along with global health protocols and human rights discourse are shaping society’s perception of violence. Most people think of physical abuse when discussing domestic violence, however the majority of the women I spoke with at GEC said that they were suffering from psychological, economic, and emotional violence. Mexican society is in a time of
transition as women are accepting “a new way to think about themselves and their relationships, adopting language of the law and reinforcing and expanding its legitimacy” (Lazarus-Black 2007:88). The modern idioms of non-physical violence are embraced and actively used by women at GEC, blurring the distinctions between physical and psychological violence.

**Conclusion**

Patricia’s story allows a glimpse into the complexities of violence and the need for its cultural and historical understanding. Although Patricia may have been critical of the meetings at FVP, she continued to seek assistance and support from both FVP and GEC, “I still like going to FVP and seeing the women there.” This may be because she, like many women, identifies with both the ‘traditional’ female role and that of the ‘modern’ independent woman. Moreover, she remains loyal to *La Virgen*, a woman she confides in that understands her struggles and acts as a role model of kindness and genuine womanhood. Patricia may seem inconsistent, but like most, she does what comforts her; “I may not be in the perfect place in my life” she says, “but I am more confident than before and relatively happy these days.”

Moore (2007:17) argues people are not limited to one subject position; like Patricia, they are contradictory and conflicting, “individuals constitute their sense of self through several, often mutually contradictory, positions rather than through one singular position.” This was made most clear by Patricia’s partner and other men who introduced the services of GEC to the women they abused, again illustrating the complexities of domestic violence and the fact that “to be a gendered individual is to be marked by the effects of power, but not to be wholly determined by them” (21).

The growing awareness of psychological violence is providing an education in gender relations. After years of suffering from self-sacrificial lifestyles and modern illnesses due to changes in society, women have become critical of health and gender equality, which have alleviated many of their symptoms. While some women feel better, their new knowledge has also caused shame by creating unrealistic expectations of leaving partners and undermined their value in Catholic ways of suffering. Even so, most women claimed GEC had given them the greatest purpose of their lives: to change themselves and to improve the world for all women.

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The ‘imperfect child’

Parents’ expectations disrupted by the birth of an infant with a rare disease

Alice Larotonda

Loving our own children is an exercise for the imagination. (Salomon 2012:1)

During an ethnographic fieldwork conducted in an Italian paediatric hospital, I analysed the personal struggles of families, who faced the birth of a child with a rare disease. Having a child diagnosed with a rare pathology plunges the family into a state of extreme uncertainty and disrupts their expectations for a future life. In this article, I focus on the early phases of the parental experience and describe how the discovery of the illness unsettles parents’ expectations and desires for their imagined child. Borrowing the concept from the clinic’s psychologist, I focus on the parents’ experience as they give birth to an ‘imperfect child’, a child who is in many ways different from the one the parents were expecting. I discuss the complexity of this phase of the illness experience, and its importance as the first step for parents to face and start to cope with their child’s illness. Through the analysis, I show how the parents’ acknowledgement of the existence of an initial phase of disruption and desperation represents a way of interweaving their story into a meaningful narrative and, consequently, constitutes a means to start coping — through narration — with the disruption that their child’s illness has caused.

Introduction

The setting of my research was a paediatric hospital in Italy, where I conducted a seven-week-long ethnographic fieldwork investigating the illness experience of families affected by rare diseases. My fieldwork was guided by a question about the impact of the diagnosis on the parents’ experience, and how the parents make sense of the situation. My focus was on the early phases of the illness experience, when parents are still trying to come to terms with the news of their child’s illness. I was particularly interested in the parents’ expectations and desires for their imagined child, and how these expectations are disrupted by the discovery of the illness. I aimed to understand how the parents make sense of the situation, and how they cope with the disruption that their child’s illness has caused.

1 Alice Larotonda earned her Bachelor Degree in Cross-Cultural Communication at the University of Turin (Italy) with the thesis “Ethnographies of parenthood: Anthropological Observations on Parent-Child Relationships in the Migratory Context,” after having trained and researched at the migrant-health centre “Centro Frantz Fanon” of Turin, Italy. Her growing interest in Medical Anthropology pushed her to achieve a Post-Graduation certificate in “Anthropology of Health: Cultural Competence in the Clinical Setting” at the University Institute ISCTE-IUL of Lisbon (Portugal). Subsequently, she joined the Amsterdam Master’s in Medical Anthropology, and graduated with honours with the thesis “In, On and Through the Body: Experiencing and Negotiating Uncertainty and Difference in Paediatric Rare Diseases.” Email: alice.larotonda@gmail.com.

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children affected by chronic rare diseases and their parents, and exploring how their experiences of being ill were lived and negotiated (Larotonda 2012). In my thesis, I described the parents having a co-experienced illness with the child; however, this aspect of the parents’ experience is beyond the scope of this article.

Through participant observation and in-depth interviews with parents, ill children and healthcare professionals, I collected information about the experience of having a rare disease, which I analysed and interpreted with a specific focus on bodily and incorporated dimensions of the illness experience. In this article, I consider only one of the many analytic aspects that emerged from the research, focussing on the experience of the ‘imperfect child’, that is, on the disrupting moment when parents realize that their child is not (and will not be) as they had imagined, and when their dreams and expectations of pregnancy fall apart. In the case of rare diseases, this moment can be particularly problematic because these pathologies often visibly affect the aesthetic aspect of the child’s body, constituting a substantial obstacle to parental acceptance and coping.

Giving birth to an ‘imperfect child’ is often an experience of disruption and desperation in the life of the parents, who need time to process the fact that their child is ill, construct meaning and make sense of their feelings to adapt. I argue that this process also comes through narrative coping mechanisms, in which parents make sense of their experience through narration; by emplotting narratives about their experience, past and present events and feelings come to constitute a meaningful whole, reassigning coherence to the disruption of illness.

I illustrate my argument by presenting two cases, where the ‘visual’ impact of the imperfect body of the infant plays a fundamental role in parents’ reaction to illness. I leave space for parents’ narrations and then interpret and analyse them using narrative theories.

Experiencing rare diseases

According to the European Commission for Health and Consumer Protection, a rare disease is one with prevalence lower than 5/10,000 people affected (Fregonese and Aymé 2008:2) including a wide range of pathologies of various origins. The experience of having a rare disease presents specific consequences that may or may not be different from other pathologies that are not ‘rare’, but which entail an experience of illness that is – in my interpretation – peculiar. In my informants’ narratives, these specific problems involved achieving a precise diagnosis, which was difficult due to clusters of undefined symptoms, and the selection of a treatment plan. Having a child affected by a rare disease is an experience that plunges parents into a state of extreme uncertainty, in which illness comes as a disruptive event. Following their child’s first symptoms, the parents started long and extended diagnostic journeys – or ‘pilgrimages’ as I have defined them due to characteristics of desperation and faith – consulting many
specialists and having a significant number of tests. Once a diagnosis has been made, the best hope for parents is often to find a treatment that addresses their child’s organic malfunction.

Having a child diagnosed with a rare disease is a disrupting experience, in which the parents’ expectations and dreams for who their newborn will be and become are completely unsettled. Some children’s pathologies affect their body in a visible way, since they are caused by genetic syndromes with a specific phenotype, malformation, or unexpected pattern of growth. These features can make the pathology visible or recognizable — and consequently, concretely tangible — on the child’s body, making it even more difficult for parents to accept their newborn.

In this article, I present two cases that are particularly dramatic, but more importantly, also eloquent examples of the disruption that illness can cause for the experience of parenting, and the role of the bodily dimension of disease in this disruption. I focus on one aspect of the illness experience exclusively, namely the disruption of pregnancy expectations. I prioritize extracts from the parental interviews to give voice to the parents.

The ‘imperfect child’: Dealing with disruption

Having a child who is affected by a rare disease is a complex experience for parents. The disease is unexpected and plunges the parents into a world of uncertainty, where events take place that had never been imagined. This is an experience of disruption (Becker 1997) in which the plans and dreams that characterized the project of giving birth to a child are abruptly unsettled.

The project of giving birth to a new life — whether planned or accidental — is loaded with an emotional investment and delightful expectations that are violently burst by disease. The newborn comes to incarnate the sickness, not just by symbolic representation, but — often, in the case of rare diseases — also by incorporating it with distinguishable, visible body marks. The initial phases of the life histories of illness are thus particularly painful and represent a crucial moment in the narrative of most parents.

Disruption of pregnancy expectations

Valeria started the interview by speaking about her job as the clinical psychologist of the hospital’s rare disease unit, and describing the parents’ experiences in a simple, but revealing way.

I work on the experience of the ‘imperfect child’, of a child that is very different from what was desired. As it is normal, during pregnancy everybody expects to have a healthy child. Here, however, we work with people who have children who are not, and who are very far from what
parents expected they would have been. Actually, this is not very different from the experience of any parent: all children are very different from what parents expected. [...] However, in rare diseases the impact is stronger, because this child is profoundly dissimilar from the one that was imagined, and adapting to this distance requires time. 

Pregnancy expectations are connoted by joyful dreams about whom the new child will be, what it will look like, what it will become. Whether the child was programmed or unexpected, when couples decide to carry a pregnancy, they start to build expectations, trying to imagine what the future experience will be like. The process of representing this new life, however, no matter how open to possibilities, takes place within a spectrum of what can be considered not only desirable and most of all, imaginable. Children who are born with a chronic rare disease are not only distant from the imagined child, but they are, in my interpretation, outside the imaginable.

*Imagined children, longed for children*

Some parents are conscious of the risks and possibilities that their child will not be healthy: some of them medicalise or even over-medicalise pregnancies, trying to prevent bad surprises with the help of new technologies. However, the hypothesis of having a sick child normally represents more of a personal fear, often discredited as a useless ‘negative thought’ that can only generate anxiety in the expecting mother, or experienced as a ‘preventive’ thought, to ward off what anthropologists would call ‘misfortune’. When tests are run, it is just to make sure, or better, to confirm that everything is perfectly fine.

The emotional investment involved in the experience of pregnancy is enormous, and the disruption represented by illness is proportional to it. Loris is “the fruit of an IVF [in vitro fertilization],” as Lena defines him. Lena particularly desired to have a child, because of a series of unfortunate events that marked her family history. With much emotional and economic investment, she and her husband opted for IVF. To their surprise and happiness, Lena became pregnant on the first try. However, now Lena is suspicious that the IVF process might have been the cause of her child’s illness, since this type of medical intervention actually seems to involve a higher risk for genetic mutations.

Lena: I am quite angry, because they should have told me that there was an increased risk of having a child with …
Alice: Nobody ever told you there was an increased risk?
Lena: No... they ran all the tests, also the chromosomal screening, which is a very expensive test to see if you are a carrier or if you are healthy… it was all negative. So we were happy, you know! ... I don’t know, I
would never have expected this. Also my age: I wouldn’t have said I had the age for expecting to have a child with…because with older age, risk increases. But I am 28. Never would I have imagined this.

Loris is a child who was much longed for and dreamt of. At the moment of his birth, disruption intruded violently in his parents’ lives. Lena remarked:

He was born like this. I haven’t seen him immediately because my husband did not allow the [doctors] to bring him to me. I had just had a C-section, before term. […] They showed Loris to my husband immediately. They asked him if they should show him to me as well, but he said: “No, don’t tell her anything today, let 24h pass after the operation.” After that, they came to pick me up and took me to the nursery. I immediately understood there was something wrong, but I did not know what it was. They gave him to me so that I could hold him. “This is your son,” they said. And I said: “No. He is not mine, I did not give birth to this child.” I wouldn’t accept him. […] You feel awful; it is something you do not expect! In that moment I thought he was the only child like this in the world. Actually, at the beginning I immediately thought he had Down syndrome. “This is a Down child, and he is not even mine, they mistook him for my son.” But well…he was mine, indeed. It’s not that I did not want him; I just had imagined him differently. Those days were very hard. It’s not that I did not love him… I hadn’t understood what… The guys from the neonatology unit downloaded some stories from the Internet, but I had run away with the idea that one day soon he would leave me. I told God: “Take him! I don’t want him anymore.” […] I did not expect this, so I would say: “Take him away immediately, I don’t want him.” These are the things that were in my mind. […] It is not that I didn’t love him, I loved him from the very first moment, but it was hard. I thought he would not survive, I had this idea in my mind, so I didn’t want to accept him at all. […] Other mothers from the association of Beckwith-Wiedemann syndrome have come here and they told me that at first they had thought of leaving their babies at the hospital. […] I didn’t. I never thought of such a thing. I would just say: “He’s not mine.” I was fed up with God, because I was afraid Loris wouldn’t make it.

Lena’s experience is not unique but it is particularly strong because of some peculiarities of Loris’ case, and especially the visual impact of this child and his body. Beckwith-Wiedemann syndrome is a genetic disorder for which the main consequences are abnormal growth, tumour predisposition and congenital malformations (Shuman & Weksberg 2011). At birth, Loris was macrosomic.
(overgrown for his chronological age), and affected by macroglossia (an abnormal enlargement of the tongue) and hemihyperplasia (the disproportionate growth of one side of the body). Additionally, he had developed an umbilical hernia. When I saw him at the hospital, he was a beautiful smiling child, but his malformations were noticeable. His red tongue was sticking out all the time, giving him the funny look of someone who is constantly poking his tongue teasingly. His umbilical hernia was already the size of a tennis ball, but Lena kept it well hidden under his rompers, while his right side – mainly his leg – was chubbier than the left. To non-experts, Loris represented a remarkable figure, if anything. Lena was initially struck by these visible ‘defects’, and at the moment of the interview, she was still in the process of negotiating them. This baby was very different from what she had imagined.

The moment of birth, with its emotional charge, becomes disrupted for the parents and their expectations. After delivery, the babies are taken away to the nursery or to the neonatal intensive care unit (NICU), in a gesture that is neither reassuring nor encouraging for mothers who have just given birth. They are babies – or ‘bodies’ – that have to be hidden. At the nursery, the mothers are allowed to see their children, but the confrontation with the – concrete or imagined – angelic beauty of the other newborns is unbearable.

Giovanna’s narrative about Mattia’s birth is explicit about this. Immediately after birth, Mattia was taken to the NICU. Giovanna explained:

Mattia had the body of a seven-month-old baby and the head of a nine-month-old. He was disproportioned; he was born with a big head and a small body. As a matter of fact, they immediately said it was hydrocephalus, without even running tests. They told me he had 95% chance to remain in a vegetative state. […] First I started crying, and then I got angry. [My husband] Paolo did not talk, he was even sick, he passed out, […] because, poor thing, Mattia had his umbilical cord wound around his neck five times [at the moment of delivery]. Then, the following day I got very angry. Paolo was devastated, so he had gone home for a while. I asked a father whose wife had just given birth – of course, a beautiful child – to take me down to the nursery. Because after the delivery they take the baby away, you cannot see it. They wrap him up and take him to the incubator. I asked if I could please see him, and they wouldn’t let me: they only showed me his face. So the next day I asked this man to take me downstairs because I wanted to see the baby. […] All of these perfect babies at the nursery. Then he was taken to the NICU and we went there to see him. […] They complained because he was crying all the time, then we checked his file, and we found out he hadn’t been fed since he was born, the night before. What I will never forget was that he was crying like crazy, and they let me in and allowed me to put my hands in the
incubator. I touched him and said: “Mattia, I am here, your mum is here.” And it was impressive I don’t know whether he recognized me, but as soon as I touched him, he stopped crying. I touched him with my hands, and he was so tiny.

These imperfect children are distant from the imaginable. Reactions differ: Lena started with denial, while health professionals tried to help her accept her child; Giovanna, on the contrary, fought against the medical staff who, in her narrative, had already condemned her son to a vegetative state. These differences depend on circumstances, on the odds that doctors see for the child’s survival, and the social environment and support that parents receive. However, above all, the reactions vary according to individual values, beliefs, and experiences.

No matter how they are emploted, these narratives of disruption reveal much of the feelings and thoughts that assail parents when they are faced with the reality of their chronically ill children, who are painfully different.

Parental feelings of disruption

Meaning-making processes about the experience of illness come only retrospectively each time the parents emplot their narratives. When these narratives are told, mothers and fathers depict themselves as lost characters, suddenly lacking control over their lives in these early phases of disruption. They describe emotions that are already distant in time and experience, and which are now extraneous and unfamiliar. Sometimes, they describe dreadful past feelings of denial, repulsion and disgust. Here, too, the body of a sick child becomes a protagonist in shaping the lived-experience of parents.

Imperfect children, imperfect bodies

The parents’ imperfect children live in imperfect bodies, which incarnate their very exceptionality, making it concrete and inescapable. It is the bodies that sometimes ‘need’ to be hidden, masked, or forgotten.

This was the case in Mattia’s early infancy. His body was not only imperfect, but also difficult to cope with for his parents. After the first suspicion of hydrocephalus at birth, Mattia and his family underwent a long diagnostic process that eventually discarded a genetic syndrome for lack of evidence, but revealed a severe growth hormone deficiency. At the time of my fieldwork, I had known Mattia for some years through personal contacts, so our meetings always took place outside of the hospital setting. One night, while I was sitting at the living room table of their apartment, Giovanna and Paolo, Mattia’s parents, started recalling the frustration of the first months when they had to start dealing with
their child’s imperfect body. Mattia enthusiastically provided me the visual evidence by showing me photographs from a family album.

Paolo: The thing that was most impressive was that Mattia was disproportional, you know? It was really something [unbearable].

Mattia: I’ll show you the pictures!!! [Rushing to get the photo album from the library shelves]

Paolo: See, how here he has a big head and a small body? And here he was already one year old.

Giovanna: [Whispering to me] What was really impressive was his thinness … [They try to change topic, while Mattia is still showing me his pictures. I look at the album and comment with him, while also listening to Giovanna and Paolo].

Giovanna: So then, when he was born, his paediatrician came home … [To Mattia, still flipping the pages of the photo album] Oh, but here you were already quite chubby!

Mattia: You indeed took very few pictures of me! [The attention goes back to the pictures, even if nobody responds directly to Mattia’s provocation]

Giovanna: This is when we came home. The only picture we took. After this I didn’t want to take anymore. That was it. See? He couldn’t even keep his head straight!

As Mattia noted, they did not take many pictures of him as a newborn. The contrast with other children’s albums is probably very clear in his mind. His parents did this purposefully. Mattia was a baby who was not pleasant to look at, but most of all, those pictures would have evoked unbearably painful memories. They would have represented memories to be forgotten. The absence of ‘visual proof’, thus, helped these parents to cope and find meaning more easily in this more mature phase of their experience.

Lena also admitted trying to hide her baby Loris during the first months of his life. He was born during the winter, so she would wrap him in a big green blanket in order to hide him as much as possible. At the very beginning, starting to adjust to her baby, she would try to go out with him shopping, or to the park. But people started staring, asking questions about his remarkable body, and this hurt her profoundly. Judging, invading gazes reminded her of how her son was irremediably different from other children, and thus, the object of an impolite and unwelcome curiosity. She stopped going out with her child, and would wait for her husband to be back from work to go out herself. If someone visited her, she would hide Loris. At the time of the interview, she was still suffering from the ‘visibility’ of her child, but struggling hard to overcome her fears. Before our first interview, however, when one of the residents was introducing me to her, she repeatedly asked rhetorically: “Have you ever seen a child like this?” For her,
it still was a remarkable body, which impressed and surprised her; his body was something unseen, unknown, and uncommon and scared her profoundly. It was the incarnation of the disease that disrupted her life.

Imperfect bodies strongly affect the experience of parents who, in the first phases of their children’s life, have to manage them constantly, touching them and caring for them, while trying to make sense and adjust to disruption. The day-by-day dealing with the ‘imperfectness’ of their children constitutes an emotional burden that is well translated in these parents’ narrations, representing thus an interesting element for analysis.

Narrating the experience of the imperfect child

The parents’ narrations are full of emotion and come in a retrospective analysis of facts that allows them to find meaning in what they have undergone. Medical anthropology has dedicated much attention to narratives as an empowering means to make sense of the human experience of illness (Kleinman 1992). Studying chronic illness has specifically led to an in-depth examination of the social and cultural dimensions involved in living in sickness and suffering (Smith-Morris 2010), and this analytic method seemed quite appropriate in the case of paediatric chronic rare diseases, when illness often accompanies the child during its entire life.

According to the existing literature, which was confirmed by the interviews I had, illness can be considered an experience of disruption that interferes with the cultural and social expectations for a life course and imposes an imperative need for interpretation (Becker 1997). Cast into a world of uncertainty, social actors respond to the need to find coherence by framing their stories in consistent plots to make meaning of their experience, and negotiate ‘normalcy’ (Becker 1997). In the attempt to reconstruct a significant personal history into an acceptable universe of meaning (Becker 1997, Mattingly 1998), people who are sick (or, in this case, the parents of a sick child) become storytellers (Kleinman 1992; Becker 1997; Mattingly 1998) – construing an emplotted tale with a “beginning, middle and ending” (Becker 1997:191) – which allows them to express and convey the affective and moral dimensions of their illness experience as an embodied experience.

Narrating experience becomes a way to create order and make sense of events by giving them a narrative structure that is coherent to the teller, and becomes understandable to the listener, because it is built following shared narrative themes, that correspond to what Mattingly (2010) identifies as narrative genres. In her work, Mattingly sees the ‘narrative genre’ as “a narrative infrastructure that offers a rich cultural resource through which minds are read, actions are emplotted, stories are told, and futures are envisioned” (2010:54). These infrastructures are “performed and embodied” (2010:54) by social actors.
who use them – more or less consciously – as narrative scripts that allow them to locate their story in pre-established cultural frameworks, which can be moulded to individual narrative exigencies.

I suggest that the narratives of my respondents could be understood in a similar way. The genre of ‘the imperfect child’ could be said to build on the theme of the disruption of pregnancy expectations, to give voice to a particularly problematic phase of the parenting experience. Through narration, parents find themselves allowed to express even particularly dreadful feelings into a language (or in a form of speech) that is understandable and acceptable both to the audience and to themselves. By locating these feelings in the past, at the beginning of a longer experience of maturation in their experience of parenting an ill child, it is possible to acknowledge and face the feelings. From their present position of caring and loving parents, the initial phases of hesitation, personal crisis, or even repulsion and denial can be acknowledged without fearing judgement by the audience. Parents depict themselves as the characters in a tale at the apex of their crises, before finding the courage and strength to walk the right path.

In my interpretation, the elaboration of such narratives of disruption constitutes a ‘safe’ means for parents to acknowledge, understand and rationalize these past feelings and also to distance themselves from them. The disruption of their expectations came abruptly, sweeping away all their dreams and expectations. The emotional investment during pregnancy for the life of the expected child and of the family fell apart with the cruel reality of disease, and uncertainty gradually became a way of life that the parents have to become used to.

The experience of the imperfect child can be elaborated to find meaning in the disrupted experiences of parenthood in the case of paediatric rare diseases, giving parents a means to let out past dreadful feelings and to ‘re-work’ them from a new perspective. Narrative theory provides a useful theoretical framework in which to place the analysis; it allows for an understanding of these life histories of illness as coherent wholes, composed by the tellers in order to find meaning and transmit their experience in an understandable and accepted way.

**Conclusion**

The experience of the ‘imperfect child’ is an experience that parents of children affected by a rare disease have to face. Children who are born with a chronic illness and with remarkable bodily features do not respond to the expectations that parents had built during the pregnancy and while giving birth. The disruption of these expectations comes with the onset of illness, and with the realization that the child will be profoundly different from what had been imagined, and parents may need time to adapt.
In this essay, I have given voice to the parents of two children to describe the experience of the ‘imperfect’ child. In both cases, the visual impact of the child’s body played a fundamental role in the parent’s striving for coping and accepting the new-born baby. Through narrative analysis, I have tried to sketch the profound disruption that parents have to face in addition to the daily difficulties of caring for their baby.

I argued that for parents, narrations constitute a means for elaborating and understanding experience. By looking at past events and recognizing the disruption that characterized the first moments of their parental experience, parents can gain distance and find meaning in their painful experience, finding a way to express and share their lived experience. Acknowledging disruption may also be a way for parents to manage their present situation in a more serene way.

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Nepalese adolescents’ perspectives on local vocabulary, types and meanings of distress

Nawaraj Upadhaya  

This essay is based on an ethnographic research aimed at understanding Nepalese adolescents’ emic perspectives on distress [dhuka] conducted among students aged 13-18 years in a government high school. Out of a total population of 111 adolescents, 35 participated in the study. The data were collected in focus group discussions, in-depth interviews and by participant observation. The research instruments were pre-tested and necessary modifications were made. Adolescents in this study were approached as social actors. They described four main emic perspectives on distress: poverty, discrimination, emotional suffering and existential meanings. Distress was viewed both positively and negatively. Positive meanings were related to the struggle for existence. Distress was accepted as a part of life, while negative meanings of distress were related to unbearable and unmanageable experiences that obstruct the growth of an individual in all aspects of his/her life.

[distress, adolescents, high school, social suffering, dhuka, Nepal]

Introduction

Distress is defined as mental or physical strain caused by pain, livelihood difficulties, worries and anxieties. Distress also implies a notion of suffering (Woodgate & McClement 1998) that can be experienced disparately (Kleinman & Kleinman 1991). Hussain and colleagues (2008) explored the relationship between academic stress and adjustment among adolescents in public and

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government high schools in India. They found that though the magnitude of academic stress was higher in public schools compared to government schools, a significant relationship between academic stress and adjustment was found in both groups.

In Britain, researchers examined the cultural concepts and language used by young men to voice their distress (McQueen & Henwood 2002) and found that dominant British masculine identities, positions of power, privilege and marginality influenced the way adolescents voiced their distress. Eccles and colleagues (1993) documented adolescent psychological distress as a result of a mismatch between the needs of a developing adolescent and the opportunities available in the social environment in their school. Their study also showed that adolescents don’t want to be emotionally detached from their adults (parents and teachers); rather they desire a gradual increase in opportunities for self-determination and participation in decision-making. The greater the mismatch between the individual’s needs and societal opportunities, the greater is the risk for psychosocial distress (Eccles et al. 1993).

Hirschfeld (2002:615) argues that “children are not incompetent members of adult society; rather they are competent members of their own society which has its own standard and its own culture.” Hardman (2001) has similar arguments that children and adolescents reveal some portion of their society’s beliefs, values and social inter-actions and therefore, they should be treated as independent informants within their autonomous socio-cultural world. But, the irony is that contrary to the idea of both Hardman (2001) and Hirschfeld (2002), in many developing societies like Nepal, adults often take the role of gatekeepers (Hood et al. 1996:117) and speak on behalf of the children/adolescents thus excluding them from participating in the decision-making for matters related to their lives.

In agreement with Woodgate and McClement (1998:5), who argue that “like any other cultural groups, children have unique culture of their own with shared understanding of what it means to be distressed,” this article argues that a child-centred approach is needed to understand children’s perspectives on distress.

Methods

All the students aged 13-18 years studying at the selected government high school were eligible for the study population. Since students from several castes (Newar, Brahmin, Chhetri and Dalits) and religions (Hindu, Buddhist and Christians) attend the school, the sample represented a variety of students. The school has a total of 320 students and of this group, 111 were between 13-18 years and clustered into four groups based on major caste/ethnicity. There were 46 students from the Chhetri caste, 44 from the Janajati caste, 19 from the Dalit caste and two from the Bahun caste. There were 53 girls and 58 boys. Four separate lists according to caste were made and each student was assigned a
number in front of his/her name. Then the list (without names) was sent to an anonymous assessor and he was asked to select 12 students from Chhetri caste, 12 from Janajati caste, five from Dalit caste and one from Bahun caste (based on the percentage represented). Out of 111 students a sample of thirty students was selected for the focus group discussions (FGDs). Later, five students volunteered to participate in the study, so they were also included making a total of 35 research participants (students). Participant observation, FGDs, and semi-structured in-depth interviews were the main data collection methods. The collected data were checked and edited on the basis of relevancy and completeness and then divided into themes for analysis. The result of the content analysis is discussed hereby in this article.

**Results**

The free listing exercise was conducted among the students of grades eight, nine and ten. They were asked to list all the vocabularies related to distress in Nepal with the following results.

<table>
<thead>
<tr>
<th>Local terms used for distress/distressful events</th>
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<tbody>
<tr>
<td>1. <strong>Dukha</strong> (pain)</td>
</tr>
<tr>
<td>2. <strong>Manko Dukha</strong> (pain in the heart/ emotional pain)</td>
</tr>
<tr>
<td>3. <strong>Pir, chinta</strong> (fear and anxiety)</td>
</tr>
<tr>
<td>4. <strong>Kasta</strong> (physical and mental difficulties)</td>
</tr>
<tr>
<td>5. <strong>Pida</strong> (deep emotional pain)</td>
</tr>
<tr>
<td>6. <strong>Bechain</strong> (restlessness)</td>
</tr>
<tr>
<td>7. <strong>Manko ghau</strong> (wounds of the heart)</td>
</tr>
<tr>
<td>8. <strong>Manko bhawana</strong> (feelings of the heart)</td>
</tr>
<tr>
<td>9. <strong>Tanab</strong> (tension)</td>
</tr>
<tr>
<td>10. <strong>Aptahro mahasush</strong> (feeling uncomfortable)</td>
</tr>
<tr>
<td>11. <strong>Bhawana ma tesha pugnu</strong> (deeply hurt in the feelings)</td>
</tr>
<tr>
<td>12. <strong>Durbebahar</strong> (mistreatment)</td>
</tr>
<tr>
<td>13. <strong>Bhedbhav</strong> (discrimination)</td>
</tr>
<tr>
<td>14. <strong>Marka parnu</strong> (unfair treatment)</td>
</tr>
<tr>
<td>15. <strong>Aptahro parishiti</strong> (difficult circumstancs)</td>
</tr>
<tr>
<td>16. <strong>Khana launa napauunu</strong> (not having enough food to eat and clothes to wear)</td>
</tr>
<tr>
<td>17. <strong>Jiban ma aune samasya</strong> (problems that come along with life)</td>
</tr>
<tr>
<td>18. <strong>Naramilo ghatana</strong> (unhappy event/ situation)</td>
</tr>
<tr>
<td>19. <strong>Yatana</strong> (torture)</td>
</tr>
<tr>
<td>20. <strong>Attyachar</strong> (extreme suppression)</td>
</tr>
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</table>

Table 1 shows that the students described eleven Nepali terms for the experience of emotional distress (1-11), and nine terms for general stress (12-20). When the students were asked how they would define distress, they came up with four
‘definitions’. They defined distress in terms of livelihood problems, discrimination/intimidation, philosophical view and emotional distress. In regard to meaning, for the adolescents to be distressed was to be poor, discriminated against, emotionally hurt or facing normal livelihood challenges with a hope for a brighter future ahead.

**Livelihood difficulties (poverty)**

While defining distress, the adolescents repeatedly mentioned poverty, which included: not having enough food to eat, no clothes to change or educational materials for the school. For example, Kamal (boy, age 15), defined distress thus: “in my opinion distress means the problems of food, clothes and shelter. Distress also means the situation when you can’t have food of your choice, clothes of your choice, and can’t take care of your family members.” Another adolescent, Hari, (boy, age 15) gave similar remarks. He said, “In my opinion distress means living hand to mouth, not being able to attend school regularly and not having anything in the name of property.” The observation of the houses and village environment also showed that the community was very poor. Most of the parents were farmers, and only a few members of the community had government jobs. The rest of the community depended on farm products, mainly maize. During the interview Reena (girl, age 16) said:

> The main cause of distress is poverty, which creates many other causes for our distress. For example, we are poor at home so we don’t get good-looking clothes, pencils and exercise books and because of that the friends and teachers discriminate against us, sometimes we are sent out of the class, bullied based on our social and economic status and because of that poverty we are living with constant fear whether we will finish School Leaving Certificate (SLC) or not.

**Discrimination/intimidation**

Some adolescents defined distress in terms of discrimination. Caste discrimination and gender discrimination is prevalent in the community where the school is situated. Shashi (boy, age 14) said, “In my opinion, distress means cheating, many rich people and influential people cheat the poor and the marginalized.” The adolescents expressed distress in terms of domination, hatred, as well as misbehaviour and violence by the family, society and the state. The adolescents blamed the state’s discriminatory education policy for their distress. The adolescents linked distress with intentional humiliation, deprivation and discrimination. In the words of Sangam (boy, age 17):
Distress is the difficulties when community boycotts you on the basis of poverty and not being able to pay for the credit of things bought at the local grocery shops. Distress arises when people intentionally pinch you and speak derogatory words to you; distress actually is the result of extreme suppression and inhumane behaviour.

Both boys and girls defined distress in the form of discrimination based on caste, socio-economic status, level of education and their own status within their family. But contrary to the boys, the girls also felt discriminated against when family members or community members placed severe restrictions on their mobility as a prevention of sexual harassment. The FGD excerpt from Sauravi (girl, age 15) illustrates this. She said:

 Distress means the difficulties experienced in life and the misbehaviour by other people to you. Distresses are of two types. Personal distress is related to the difficulties to feed oneself and continuously facing domestic violence and societal distress is related to caste and class discrimination, backbiting, unnecessary gossiping [about sexual behaviour] and bullying.

**Philosophical view on distress (struggling with existential meanings)**

Some adolescents defined distress as a positive thing, a necessity of life and a reality of the human world. They saw distress as a struggle for improvement. One of the girls, Samjhana (age 16), said: “Distress is the door to the brighter room,” while Sambar (boy, age 16) remarked: “Distress is the element that takes you to your goal and gives you happiness.” These adolescents took distress as a natural teacher who tells them how to struggle and to manage life problems and search for happiness.

The adolescents compared distress, life difficulties and happiness to a tributary of the river of life. They believed that without distress a happy situation is not possible; happiness comes when distress is experienced and managed rightly. This is illustrated by the excerpts of the interview with Shankar (boy, age 13) who said:

 Sukha Dukha yautai sikka ko duita pata huna [Distress (pain) and happiness are the two sides of the same coin]. Distress, life difficulties and happiness are the three rivers, which have to meet with each other to accomplish the goal of reaching the ocean. So, why be unhappy when confronted with painful circumstances? You just need to struggle like rivers struggle to reach their destination; this struggle teaches you how to live life in a real sense.
The philosophy of distress in life was expressed in various ways. Some adolescents took it as a normal phenomenon of life, while others saw it as life problems created by individuals being too ambitious. The following excerpts from the FGD illustrate this point.

In my opinion distress is the début of human life. To live a meaningful life you need distress more than happiness because distress is part of your life, which should be carried on till your death.

I feel that distress is part of everybody’s life, from poor to rich, and happiness does not come when you have not mastered how to manage your distress. So, I take distress as a normal phenomenon and try to deal with it as much as I can.

In my opinion distress is the problems in your life, which make your life dark and miserable. If you are truly happy with what you have, distress disappears by itself.

*Emotional distress*

When defining distress, the adolescents used psychological and emotional terms. For most of them, distress was deep emotional pain, hurt, misbehaviour and hatred. Harihar (boy, age 14) defined distress as, “Every painful situation such as deep emotional pain, deeply hurting situations and other problems related to one’s life,” whereas for Sita (girl, age 15) “Distress is that thing which unnecessarily gives pain, anxiety and violence.” Distress is experienced by adolescents as a bad event or a bad emotion that affects their growth in life. In the words of Rohan (boy, age 14), “Distress is a bad event which makes people sad and steals their hopes, interest and aspirations.”

The bad feeling or bad emotion is connected to how others relate to individual adolescents and behave with him/her in a social environment. Distress and difficult social circumstances were found to be closely related because the adolescents believed that social problems give rise to physical and mental tension that later develops into distress. For example, Krishnamaya (girl, age 15) in an interview explained: “Distress means difficult situations where we don’t get helping hands, friends become enemies and relatives behave indifferently.”

A close link emerged from the data between emotional distress and expression related to *mana* (heart-mind). Adolescents often pointed at their hearts on their chest and minds on the side of their forehead to express emotional feeling and used the word *mana* to explain the impact of distress at the heart level (feeling) and mind level (thinking). In response to the questions, Rita (girl, age 13) elaborated on this:
Distress is that thing which negatively affects the *mana* (heart-mind), and the physical body. Distress also means having deep pain or obstruction in the heart-mind. You know, distress is that thing which unnecessarily gives pain, anxiety and violence. I see distress as obstructions to my positive efforts, the solution for which becomes difficult.

The concept of *mana* and its association with emotional distress is clear from the excerpts of the interview with Reena (girl, age 16). She said:

Distress is a bad emotion, physical and mental tension and bodily reaction to difficult times; all these things hurt people’s *mana* (heart-mind). Distress is also a kind of problem or pain, which is created by different reasons for example when an expected result is not achieved from your work, when others behave badly toward you and when you are confronted with things that create anxiety.

Sangam (boy, age 17), in an interview, also mentioned *mana* (heart) and *manasik chinta* (worries and anxieties), “In my opinion distress is the state when your heart is restless, you have no confidence in yourself and your mind is full of worries, anxieties and tension.”

**Discussion**

Some adolescents understood distress as a part of life, while others understood distress as an obstruction in the path of life. Despite the differing perspectives, all adolescents agreed that the moment of experiencing distress was not a happy one. Distress is an unhappy event, which occurs in everybody’s life sooner or later and makes you feel desperate at times.

Although in the free-listing exercise, distress [*dukh*] was defined as a problem, an obstruction and bad luck, in the FGDs and interviews the adolescents also mentioned positive meanings for distress. Table 1 showed that the distress terms do not have gender dimensions; all the terms can be used by both genders. In all conversations, not a single term was given to that would normally be used for male distress or female distress. Distress terms seemed fairly neutral. This is striking in a society where gender discrimination is prevalent and women are frequently accused of causing misfortune. In addition, distress terms are also morally neutral; there is no stigma associated to them. It is further remarkable that in a society where mental health problems are heavily stigmatized, terms referring to psychosocial distress are stigma-free. It is argued that the lack of separate distress terms for women and men and lack of stigmatizing words for mild levels of emotional distress are the reflection of the existing socio-economic conditions in which distress is generally shared.
therefore a normal condition of life. Every member of Nepalese society is distressed in one way or another. From generation to generation the suppression of lower castes by upper castes and political hegemony of some elites over general public has generated widespread social suffering.

The concept of dukha (distressing pain) in general, and adolescents’ broader meaning of dukha both refer to social suffering. The physical and mental pains caused by poverty, discrimination, restriction on mobility and structural violence reflect the collective social suffering of the adolescents. The approach to human suffering proposed by Kleinman and Kleinman (1991) has been helpful in this research. They argue that since the suffering and transcendence are central to the day-to-day lives of the survivors they deserve the self-conscious subject matter of ethnography. This means that as ethnographers we have to constantly reflect upon the puzzles of daily life and the context responsible for suffering. Similar to Kleinman and Kleinman (1991), I argue that to understand adolescents’ collective suffering in Nepal, they have to be understood within the local context of Karma and fatalism. Karma is the unalterable consequence of one’s prior misdeeds (Bista 1991) and fatalism encourages the individual to accept problems with the belief that whatever comes to one’s life is already determined by fate and all one can do is live with the problems with an expectation that they will disappear at some point when the impact of past bad deeds is over.

Adolescents related emotional distress with social and cultural conditions at school and in the home/community. These findings are in agreement with Good’s semantic network of heart distress in Iran (1998:65); emotional distress is a dynamic product (resulting from individual’s relationship to one’s social and cultural environment) perceived as a complex phenomenon that includes physical sensations and emotional distress. The semantic network of distress provides what Kleinman and Kleinman (1991) call symbolic pathways of words, feelings, values, expectations and beliefs. The association of distress with livelihood problems points to widespread poverty and poor resources at school. The findings suggest that there is a direct relationship between distress and poverty. If a person is not able to manage his/her distress on time and if the same distress continually reappears, he/she will be looked down upon as an incapable person. Their inability is related either to material or intellectual ‘poverty’.

The definition of distress in the form of discrimination and intimidation reflects the structural violence, deprivation and marginalization in Nepalese society. Similarly, I suggest that the philosophical (existential) view of distress is embedded in a belief system based up on the idea that everything is decided from the deeds of past lives and the best one can do is to accept and live with it.

This brings me to the point that the concept of dukha in Nepal has to be understood in the context of a particular conceptualization of the relationship between mind and body (Kohrt & Harper 2008). The adolescents repeatedly mentioned the relationship between mana (heart-mind: heart as the feeling part
and the mind as the thinking part) on the one hand, and emotional distress on
the other. If they had thought that distress affects the (physical) brain,
stigmatizing words such as pagal (crazy) could have been expected. The findings
suggest that for the adolescents, distress was considered to be at the mana level.
The implication is that they are not stigmatized as having mental health
problems. Though this is an important discussion point for the distinction
between the brain and mind and mental illness, I do not have enough space to
go further on this topic in this article.

The study findings touch upon major issues that have a negative effect on the
quality of the public educational system in Nepal. First, the research showed that
both students in vulnerable situations and students considered not vulnerable
showed significant emotional distress due to physical beating, public humiliation,
bullying and discrimination in their school, home and community. Similar
findings are reported in the Inter-Agency Standing Committee (WHO 2007)
guidelines on psychosocial and mental health in emergencies, which emphasize
social strategies to promote psychosocial wellbeing. This reflects an assumption
that distressful situations are related to social conditions and the reaction to these
distressful situations is socially constructed. In the case of Nepal, the distressful
situations related to discrimination, bullying and beating are associated with social
conditions of caste, ethnicity, poverty, alcohol abuse and domestic violence.

Second, though the local vocabularies of distress in Nepal are gender neutral,
the findings suggest that girls are discriminated against at home and in the
community but supported at school, whereas the opposite is true for the boys. In
Nepalese society, boys are more valued at home in the family than girls. Several
traditions demonstrate this, for example the belief that only by a son’s action
during the death ceremony (lighting the mouth of the dead parent with fire
during the funeral) can parents go to heaven. Girls are treated differently than
boys because their status in the family is temporary; they will soon move out and
become member of their husband’s family. This reflects the ambivalent position
of females and a double standard in Nepalese society for females; on the one
hand, daughters and unmarried sisters are respected and almost regarded as
goddesses, but on the other hand, the wives and daughter-in-laws are physically
and mentally abused, treated badly and often neglected.

Third, the explanatory model of boys and girls for distress is more or less the
same with the difference that girls are more harmed by gossip about their sexual
chastity than boys. In addition, girls fear being married off before finishing high
school. The boys blamed the teachers more for their distress while the girls
blamed the attitudes prevalent in the society and the family environment.
Therefore, I agree with Akello et al. (2010) and Khort et al. (2010) who are of
the opinion that such explanatory models of adolescents’ distress experiences at
various ecological levels (the individual, his/her home, school and the
community) have to be situated and analysed within their socio-cultural context.
Fourth, the philosophical (existential) definition of distress has been found to be helpful and somehow has become a long-term strategy for adolescents to manage their distress. Adolescents have philosophized distress as a normal phenomenon of every human around the world. The acceptance of the existence of distress, pain and sorrow in everybody’s life guides them on how to face and manage distress. I argue that Nepalese adolescents intentionally choose this strategy as part of exercising their agency, because by keeping silent they can still influence the situation rather than talking back to their elders. Here the structure has become an internalized part (‘habitus’) of agency or ‘social navigation’ (cf. Lindegaard 2009).

**Conclusion**

In this article, I showed that local Nepalese vocabulary about *dhuka* (distress) offered by adolescents is gender neutral and stigma-free. I have also argued that the levels of distress shared among adolescents in low-quality government schools who come from marginalized and deprived environments are not considered a mental health problem. I presented socio-cultural explanations of how distress is defined and understood in the Nepalese social context. The findings show that for adolescents, distress was either a negative experience, for example due to poverty, discrimination, marginalization, and family problems or distress was seen as a normal part of life that eventually could lead to true happiness. Distress was defined as an unbearable and unmanageable life experience that obstructs growth in life by blocking feelings, interests and aspirations. Distress was also taken positively in that by pain and distress individuals gain experiences and using the right experiences at the right time meant distress could be converted into happiness.

**References**


Injecting drug users and sexual relationships in Vietnam

Nguyen Tran Lam

HIV transmission in Vietnam is generally linked to drug injection, but there is a potential for a sexual epidemic. HIV education programs focus on the personal responsibility model of risk, yet fail to adequately address other aspects of AIDS risks in social contexts. Based on ethnographic fieldwork conducted in 2002, this paper examines the association between AIDS risks (unsafe drug use and unsafe sex) and gender relations among injecting drug users (IDUs). I analyse three patterns of relationships: IDU and IDU; IDU and smoker, and IDU and non-user. Data shows that intimate relationships play an important role in managing AIDS risks among IDUs. I argue that HIV prevention strategies must pay due attention to the specific contexts of IDUs' lives. Implications of the study findings are discussed and relevant recommendations are proposed.

[injecting drug users; sexual relationships; AIDS risks, Vietnam]

Introduction

In Vietnam, the HIV epidemic has been primarily associated with drug injection. In some areas, the prevalence of HIV among IDUs was as high as 65% (A & Lam 1999, Hien 2002). The rate of syringe and needle sharing (hereafter sharing) among IDUS in some urban cities was high (Hien et al. 2000, Nguyen et al. 2001). Studies showed that sharing among IDUS is socially situated (Hien et al. 2000, Vinh 2002). IDUS not only share needles and syringes, but also buy and sell sex. Nearly 25% of IDUs in Hanoi said they had bought sex in the past year, and most had not used a condom (Monitoring AIDS Pandemic 2001). Another emerging problem is that there are an increasing number of sex workers (SWs) injecting drugs. Thus, the AIDS epidemic in Vietnam is predominantly situated among IDUS, yet there is a worrying potential for the wider spread of HIV.

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2 Most of the literature cited in this paper is old (before 2002) since the research was conducted in 2001 and the first paper was written in 2002.

Acknowledgements: This paper is draws on my thesis at AMMA (Lam 2003). For the completion of the thesis, I would like to express my gratitude to the Medical Anthropology Unit (University of Amsterdam), and to the following individuals in particular: Pieter Streefland (my supervisor), Robert Miller, Ria Reis, Han ten Brummelhuis, Anita Hardon, Sjaak van der Geest, Diana Gibson, Trudoe Gerrits, Nicolette van Duuren, Gean Paul, Phan Quynh Hou, Tran Quoc Tuan, and Nguyen Thi Phuong.
Epidemic HIV prevention programmes focused on IEC (information-education-communication) activities. Various campaigns on HIV were launched nationwide at various times of the year and thousands of IEC materials on harm reduction were distributed. Yet, there was community backlash against needle exchange/distribution programmes (Vu 2001). HIV education merely focused on the personal responsibility model of risk in risk-reduction messages, yet failed to adequately address other aspects of HIV risks in social contexts such as drug life or the sex work environment.

Contemporary research on AIDS shows that IDU relationships with their sexual partners (SP) are sculpted in a double risk: unsafe drug use and unsafe sex (Farmer 1996, Kane 1999). Drugs and sex are highly interrelated (Iguchi et al. 2001). There is variability in the effects of drug use on sexual performance and sexual history (Carlson 1999). Drug use and drug dependence and sexual practices influence each other (Sherman & Latkin 2001). But how do sexual relationships relate to risk-taking behaviours?

According to Singer (1994), Sobo (1993), and Rhodes (1997), a focus on drug-related relationships seems especially relevant when HIV risk behaviours are increasingly considered to be less of an individual phenomenon than socially embedded; hence, these risk behaviours are highly sensitive to the context and nature of people’s relationships. The interplay of social factors, such as the distribution of power and control and particularly the division of money and drugs between injecting couples, may influence the ways in which HIV risks are habitually managed (McKeganey & Barnard 1992, Barnard 1993). There are inconsistencies between sexual experiences and the stereotype of male dominance and control of women’s sexual decision making (Carlson 1999). The perceived risks attached to both sharing and condom-less sex may be reduced (Barnard 1993). Injecting relationships have been found to have an equalizing influence on couples’ drug consumption (Rhodes 1997). Emotional elements, such as love and trust, may play a key role in patterns of sexual and relationship risk management as well as HIV transmission (Sobo 1993, Rhodes & Cusick 2002). Furthermore, Rhodes and Quirk (1998) suggest that drug users’ sexual relationships should act as key sites of risk management and behavioural change.

In sum, the above-mentioned studies have shown the linkage between drugs and sex as well as the important role of sexual relationships in shaping risk behaviours among IDUS. However, since IDUS may engage in various partnerships during their drug life, such studies have not shown to what extent each pattern of drug-related relationships affects risk behaviours, and how these interactions are contextualised and interpreted by IDUS and their SPs. This paper analyses the association between sexual relationships and AIDS risks among Vietnamese IDUS, focusing on intimate heterosexual relationships (whether conjugal or para-conjugal). Based on social theories of risk (Douglas & Wildavsky 1982, Douglas 1986, Douglas 1992, Rhodes 1997), three patterns of intimate relationships are analysed: 1) IDU-IDU relationship,
2) IDU-smoker relationship, and 3) IDU-non-user relationship. By examining the situational contexts of risk-taking behaviours within such relationships, we attempt to provide insight into the dynamics of AIDS risks and gender relations among the Vietnamese IDU population.

Methods

This paper presents findings from a qualitative study of IDUS' sexual relationships and risk behaviours. The research combines an exploratory and a descriptive approach. Emic views of IDUS and their SPs about AIDS risks and their relationships are analysed from a cognitive-symbolic perspective. The social contexts and meanings of their risk-taking behaviours are carefully taken into account.

This study was conducted from August to December 2002 in the two provinces of Hanoi and Quang Ninh, northern Vietnam. In Hanoi, 76% of the 2,879 cumulative HIV cases reported in 2001 were IDUS. The HIV prevalence in this population increased rapidly from 3.3% (1998) to 17.5% (2000). The HIV prevalence among SWs increased from 0.8% (1997) to 10% (2000) (Hien 2002). Quang Ninh is ranked the third in Vietnam for the number of HIV cumulative cases per 10,000 inhabitants. Most Vietnamese IDUS are male (99.2%) and very young (57% are under twenty years old). This group has a high prevalence of HIV (32%) and a high rate of sharing (50.7%) (Hien 2002).

Table 1 - Composition of IDUS and SPs sample.

<table>
<thead>
<tr>
<th>Informants</th>
<th>in-depth interviews (n=53)</th>
<th>case study (n=3)</th>
<th>FGDs (n=19)</th>
<th>total (n=75)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>male</td>
<td>female</td>
<td>male</td>
<td>female</td>
</tr>
<tr>
<td>IDUs (incl. SPs who are IDUs)</td>
<td>21</td>
<td>22</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>SPs (incl. smoker SPs and non-addict SPs)</td>
<td>3</td>
<td>7</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

The sample consisted of 75 individuals (53 in-depth interviews, three case studies and 19 people participating in three focus group discussions). The composition of the sample is given in Table 1. Further characteristics of informants are described in Table 2. At the time of the study, most respondents were injecting heroin (64% women; 76% men). Only a minor percentage of informants were smoking heroin. Although some informants reported having used poly-drugs sometimes (amphetamine, dolagan, seduxen etc.), heroin was the main choice. Most individuals (83%) described themselves as heterosexual. About half of the informants were living with an injecting sex partner. Few informants were living with a smoking partner or a non-using partner (Table 2).
Table 2: Characteristics of the sample (in-depth interviews and case studies)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>N</th>
<th>women (n=31) (%)</th>
<th>N</th>
<th>men (n=25) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (years)</td>
<td>24.2</td>
<td>range 17-32</td>
<td>27.5</td>
<td>range 20-39</td>
</tr>
<tr>
<td>EDUCATION</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(number of years attending school)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>3</td>
<td>10</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>6-9</td>
<td>24</td>
<td>80</td>
<td>17</td>
<td>68</td>
</tr>
<tr>
<td>≥10</td>
<td>4</td>
<td>12</td>
<td>7</td>
<td>28</td>
</tr>
<tr>
<td>INCOME</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(six months prior to interview)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- unemployed</td>
<td>28</td>
<td>90</td>
<td>17</td>
<td>68</td>
</tr>
<tr>
<td>- prostitution only</td>
<td>25</td>
<td>80</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>- illegal sources (theft, pimping, drug dealing)</td>
<td>17</td>
<td>54</td>
<td>19</td>
<td>76</td>
</tr>
<tr>
<td>RESIDENCE</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(six months prior to interview)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- lives with sexual partner</td>
<td>19</td>
<td>61</td>
<td>12</td>
<td>48</td>
</tr>
<tr>
<td>- lives with own kin</td>
<td>8</td>
<td>26</td>
<td>6</td>
<td>24</td>
</tr>
<tr>
<td>- no stable residence</td>
<td>17</td>
<td>55</td>
<td>15</td>
<td>60</td>
</tr>
<tr>
<td>- in rehabilitation/detoxification</td>
<td>3</td>
<td>10</td>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>- in prison</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>MEDICAL HISTORY</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- reported STDS</td>
<td>12</td>
<td>38</td>
<td>5</td>
<td>20</td>
</tr>
<tr>
<td>- reported HIV +</td>
<td>3</td>
<td>10</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>DRUG USE</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- mean age of first drug use</td>
<td>22.1</td>
<td>range 14-28</td>
<td>19.3</td>
<td>range 16-33</td>
</tr>
<tr>
<td>- mean age of first iv use</td>
<td>25.4</td>
<td>range 18-31</td>
<td>23.8</td>
<td>range 18-30</td>
</tr>
<tr>
<td>- currently injecting heroin</td>
<td>20</td>
<td>64</td>
<td>19</td>
<td>76</td>
</tr>
<tr>
<td>- currently smoke heroin</td>
<td>6</td>
<td>19</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>- in detoxification</td>
<td>5</td>
<td>16</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>- ever injected liquefied opium</td>
<td>28</td>
<td>90</td>
<td>20</td>
<td>80</td>
</tr>
<tr>
<td>- ever injected heroin+other narcotic drugs</td>
<td>12</td>
<td>38</td>
<td>11</td>
<td>44</td>
</tr>
<tr>
<td>SEXUAL RELATIONSHIP PATTERNS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(six months prior to interview)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- live with IDU sex partner</td>
<td>18</td>
<td>58</td>
<td>11</td>
<td>44</td>
</tr>
<tr>
<td>- live with smoker sex partner</td>
<td>6</td>
<td>19</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>- live with non-using sex partner</td>
<td>1</td>
<td>3</td>
<td>8</td>
<td>32</td>
</tr>
<tr>
<td>- no partner</td>
<td>6</td>
<td>19</td>
<td>4</td>
<td>16</td>
</tr>
</tbody>
</table>

Standard multiple-starting point ‘snowball sampling’ outreach techniques were used in several locales to maximize subject variation (McCoy et al. 1996). Four main methods were used for data collection: a) focused ethnographic
interviews, b) focus group discussions (FGDs), c) participant observation, and d) case study. All interviews were tape-recorded and transcribed verbatim in Vietnamese as necessary. Data were organised and condensed according to the research themes. The emerging themes were used in subsequent interviews and FGDs. The data were processed by hand. Extensive field notes and various slang terms used by IDUS were carefully collected and used as an important supplement to the data analysis. Prior to all interviews, informed consents were obtained after a clear explanation of the objectives, use of the research, the rights of informants and use of tape-recorders and field notes. In addition, anonymity for participants was also secured in field notes.

Results

**IDU-IDU Relationship**

Having the same injecting habit was viewed as the most important element in forming and regulating cohabitation between two partners. IDUS saw their partner’s acceptance of drug use as crucial in preventing relationship problems. This relationship pattern was viewed as ‘safer’ and ‘simpler’ than the other ones because IDUS didn’t have to hide or to lie about drug use and consequently, they didn’t have to deal with the risks associated with the failure to keep ‘the secret’. Because of the advantages, this relationship pattern was the most prevalent among IDUS.

Sharing and condom non-use were the most salient risks in this relationship. These two behaviours were quite frequent and seemed to be a ‘norm’ among injecting couples. Sharing occurred on a basis of trust between two partners. ‘Trust’ here communicates a sense of the relative security of a shared destiny and was used by IDUS as a means to avoid risk. Many IDUS believed that by limiting sharing to their sex partner, they could somehow minimize the risk of infection. Trust was also the main reason given by IDUS as a justification for their risk acceptance and fatalism:

> Spousal sharing is safe. Nothing to worry about when you are husband and wife (18f: Female injector, Hanoi).

> Once we are spouses, no need to avoid it [sharing]. (8m: Male injector, Quang Ninh)

> We don’t fear anything [being HIV infected through sexual route] once we have lived together, let alone sharing. (17m: Male injector, Hanoi)

Sharing makes it easier to reject using a condom because sharing *per se* implies infection. Furthermore, IDUS must weigh the risks posed by AIDS (condom-less
sex and sharing) against the benefits they receive from the partner (love, trust, relationship, and even heroin). Taking such risks may therefore be acceptable. This ‘risk choice’ challenges many uncertainties inherent in this relationship: uncertainty about risks in sharing events, uncertainty about risks of sexually transmitted infections and uncertainty about a SP sharing or having sex with outsiders. In these circumstances, using a condom may be viewed as a risk itself since it hinders the development of meaningful relationships. Condoms may be used erratically at the onset of cohabitation, but as the relationship becomes ‘stronger’ or more ‘meaningful’, the tendency to reject them becomes clearer. Often, neither partner suggests condom use because they fear that such a proposal may denote infidelity on their part or cause the other to be suspicious. In the following excerpt, a female injector described how her drug life was structured around love, risk and fatalism:

It is said that lovers don’t care much [about risk]...it is true. We love each other because of love so we don’t have to think about it [condom]. If something goes wrong [being HIV infected] we should be responsible for each other...if he [my partner] happens to share or something like that, even I get infected [from him] or something...[smacking the lips]...nothing to regret. Yes, I accept it [being infected]. I don’t want to lose him though...(15f: Female injector, Hanoi)

What we observed in these relationships were actions to prevent the relationship from being broken. Unfortunately, love, trust, and loyalty were inadequate tactics to manage these relationships. Therefore, IDUS and their SPs had to create other pragmatic strategies. First, there was a division of labour between the two partners, which was evidenced by the phrase ‘Tao di an cap, may di lam pho’ (I go stealing, you go prostituting). Often, female IDUS had to work as SWs to finance their own (and sometimes their SP’s injecting habits). These women say that they did not want to go work in the street in a state of craving and so shooting up before going out was important for them to maintain their job. Therefore, a couple had often ‘entertained’ a shot before the woman left home. In this context, if there was insufficient drug for both partners, the man might ‘give in’ and leave a bigger portion of the drug to his female partner. This ‘generous action’ was labelled in the drug scene as ‘chat nhuong nhin’. While the concession can be viewed as a means of managing the relationship, this puts the woman at a heightened risk because this situation occurs daily.

Meanwhile, male IDUS tended to make money by engaging in criminal activities, such as drug dealing, stealing, house breaking, etc. Interestingly, these ‘men’s jobs’ were expected and admired by female injectors in the drug scene. If men cannot work illegally, the relationship would seem to be more difficult to manage and this could lead to a break-up due to conflicts derived from money
matters. Second, hiding one’s occupation as a SW became another way to manage the relationship. Some female injectors even kept their ‘job secret’ from their injecting partner. The reason for this concealment was sculpted in the strong societal stigma in general, and of men in particular, towards women using drugs. Although this hiding tactic seems to be fragile and merely superficial, it reflected the women’s strong desire to be respected by the society:

I never forbid him to have relations with other women, provided that we respect each other... I think that I am a gai nghienn [injector] and I also lam gai [SW]...clearly my SPs know [that I am a SW], but on the contrary they never went to my workplace. They never saw me go with a client. I hide [my sex job] in that way [Lam: Why should you hide it?] both of us never talk about my job…neither I told him what I was doing...sort of superficial hiding only. What I need is that they don’t open their mouth saying that I am a con pho [SW]. (24f: Female injector, Hanoi)

**IDU-smoker relationship**

In this pattern, IDUS and their sex partners face two distinct types of drug-using patterns: injecting and smoking. In general, injecting procedures are simpler than smoking ones. An injection was said to get a person high faster and more ‘directly’ (via vein) than by smoking (through mouth). While this difference may lead to minor conflicts at the onset of their cohabitation, couples tend to acknowledge reality and work to negotiate their relationship. Everyday routines and rules are established to mitigate the potentially negative effects that a partner’s behaviours may actually have on a relationship. Injectors seemed to be more sympathetic to share the ‘feeling of difference’ than their smoking partners. In contrast, some smokers could not sympathize with their injecting partner because the feeling of shooting a drug into a vein was still new to them and made them feel uncomfortable when watching their partner inject. This can force smokers to switch to injecting so as to have a ‘drug use harmony’ with their partners. Often, the smoker was pulled into injecting by the shooter. This ‘drag in effect’ was called ‘dua vao doi’ by IDUS:

When we met one another, we were both smokers. Later when I got used to shooting, I brought him into the [injecting] life with me. You know, many times he tried to persuade me...many times he brought me to detoxification centres... that sort of things. But it is of no result [for me]. At last he started shooting. (20f: Female injector, Hanoi)

IDUS and their SP not only had to work towards harmony in drug use, but also harmony in their sexual life. While injecting partners didn’t seem to be interested in having sex, smoking partners often had higher sexual desire than their SP.
Female smokers frequently reported having a high sexual demand during the smoking phase. This desire could lead to rejecting a condom:

We were living together for two years. Both were smoking black (opium). After a few months he shifted to shooting first and later I did the same. We did not use condom because... to be more frank, playing black [smoking opium] made me feel much more aroused [than injecting opium]. (3f: Female injector, rehabilitation centre).

The difference in sexual interest may also force some IDUS (often males) to manage their sexual life with a smoking SP by pretending to be ‘normal’:

As she [my smoking partner] requested to have sex, I had to please her by trying to show off my sex enjoyment, although I did not want at all...I feel that because of responsibility I have to fuck her, otherwise she would think that I don’t fancy her anymore. (16m: Male injector, Hanoi)

The social organisation of this relationship pattern was structured around two processes: ‘onwards transition’ (a move from smoking identity to injecting identity) and ‘reverse transition’ (injecting to smoking). For some IDUS, the act of injecting was considered as a ‘risk boundary’. The smoking and injecting identities were not mutually exclusive, yet there was slippage and crossover between them. In fact, many smokers could not maintain their oral use for long and often ‘pass’ this boundary to intravenous use. But more commonly, they were dragged into injecting as a result of being in this relationship. The motives for onwards transition lie in the relationship itself, possibly a desire to feel close and similar to their partner or a wish to have an equal share of drugs (cf. MacRae & Aalto 2000). This also means that the IDU-smoker relationship pattern tends to shift to an IDU-IDU type as a result of the smoking partner’s change in drug use.

In other cases, however, smokers could be positively influenced by their injecting partner in that they may sustain their oral habit for a long time. Furthermore, some novice injectors could return to oral use (reverse transition) as a result of the cohabitation with smoking SPs (although the likelihood of success is very slim). Thus, changing patterns of drug use (from smoking to injecting) may lead to changing patterns of relationships (from IDU-smoking to IDU-IDU type). Conversely, the relationship also has impact on the chance to change behaviours (from injecting to smoking).

**IDU-non-user relationship**
In the course of their drug career, an IDU may engage in relationships with non-using partners. It was observed that female IDUS tend to live with non-user men more than male IDUS living with non-user women. It was also more likely for
non-user women than non-user men to accept an injecting partner. This gender difference in choosing a SP was rooted in the social stigma towards women using drugs. As an emotional need, however, some female IDUS went on seeking a non-using SP for cohabitation. For other female IDUS, cohabiting with a non-user could be viewed as a means to make money and to form socially appropriate relationships. Similarly, young injecting men may see money as the most important motivation in their search for non-user girls. To achieve these goals, both male and female injecting partners had to hide their identity as a drug addict right at the formation of the relationship. But, maintaining such a non-disclosure strategy was difficult for injecting partners as they have to struggle with differences arising from two distinct lifestyles—injecting and non-using. The drug-sex conflict is always out there:

For sex matters, he couldn’t meet my demand but he treated me very well. Another thing incompatible is that because he does not use drug, I can’t ask him to go and buy some drugs for me when I feel sick. Then I had to go and buy myself. And when I can’t shoot myself, I have to call others to shoot for me. Therefore, sometimes I feel sort of difficult to say [to him] because he is a non-user. For example, sometimes [at night] he was looking for me so he went to my place [street sex work] to pick me home [to have sex]. At that time I did not have a shot yet, but I had to go home with him anyway. When we arrived...it was already the time of my craving but he insisted on having sex. I felt very annoyed then and I did not want to fuck at all! As always, I should seek for thuoc [drugs] first. (3f: Female injector, rehabilitation centre)

I am an addict and he is not. When sleeping [together] I feel sort of unpleasant. When I shoot...he stares at me...I don’t agree at all. When having sex after a hit ... [my SP’s] desire is quite high you know. It means that [I] want my sex partner to have a long sex with me. If he sort of wants to fuck fast I want to drive him out! (15f: Female injector, Ha Noi).

Many male IDUS faced the difficulty of hiding their addiction status while pretending to have a ‘normal’ sex life. In contrast, female IDUS complained that their SPs did not satisfy or sympathize with their sexual or drug needs. This ‘double difference’ was seldom acknowledged and rarely discussed openly by both partners and thus exerts an influence on the initiation of condom use. In general, non-using partners were constantly assessing their risk of HIV. When they are not sure about their partner’s level of addiction, they may agree to have condom-less sex. During this phase, however, the drug-using partner may have shifted to intravenous use while the non-user is possibly unaware. When non-users find that their partner injects (rather than smokes), their concern for HIV
rises. In general, when the ‘hiding tactics’ used by the injecting partner are still effective, the non-using partner may agree to have sex without a condom. Since this pattern was usually short-lived, and non-using partners may be involved in other sexual relationships after breaking-up with injecting SPs, this posed the possibility of cross-transmission among IDUS and their non-using SPs, and subsequently from these non-users to the populace.

Another important point is that in many cases injecting women refused condom-less sex even when a [non-using] casual client had become their private SP. This finding differs from other study reports, which show that women often use condoms with ‘casual SPs’, but not with ‘regular’ or ‘private SPs’ (Schoepf 1992, Sherman & Latkin 2001, Wojcicki & Malala 2001). The reason the female IDUS in this study denied rejecting condom use is rooted in the social condemnation toward a female addict in general. In this context, the woman is said to feel degraded or that she has lost dignity because the man comes to her for the sake of penetrating her; therefore, she is like a ‘sex tool’ rather than a lover. This also implies that she is ‘an addict’ and thus ‘dirty’, and he is ‘a non-user’ and thus ‘clean’. Her insistence on condom use did not mean that she wants to keep safe for someone she loves. Rather, it can be seen as the resistance against the stigma inherently residing in the man’s thinking:

I met him in the street when he was a client. Later we lived with each other but I still used bao [condom] with him because I simply did not like it [condom-less sex]. I don’t know why. For many other men [injecting SPs], I never use bao. But for this man [my non-using SP] who met me in that environment [street work] and used to be my client and he came to me for a sex and I came to him for money… I always used condoms with such kind of men. (14f: Female injector, Hanoi)

In sum, IDUS and their non-using SPs were constantly struggling with differences associated with their drug use and sex. The management of drug and sex conflicts was located in and affected by the management of the relationship. The ‘double life’ was felt to introduce uncertainty and mistrust between partners. Thus, this pattern could be considered as the most fragile relationship in comparison to IDU-IDU and IDU-smoker relationships.

Discussion

Meaning of AIDS risks and intimate relationships

This study shows that IDUS’ denial of AIDS risks has, “a level of meaning and cause beyond the narrow confines of immediate experience” (Singer et al. 1990).
Choosing or shifting to risky behaviours is normalized in the drug scene. This has several reasons.

First, *IDUS*’ risk perceptions were often fraught with a myriad of uncertainties inherent in the complexity of drug and sex behaviours. There was always a contradiction between safe sex and safe drug use. *IDUS* often gave themselves and their SPs more leeway around issues of safety when it came to their discussions of sexual practices than they did for their drug-using practices. The risks of sexual disease transmission are not considered as serious as the risks of infection through sharing (cf. Sibthorpe 1992, Rhodes 1997, Kane 1999). While sharing was more attached to physical pleasures, non-condom use was more attached to emotional meanings. Furthermore, perceptions of acceptable risk were said to shift in keeping with the length of relationships and expressions of commitment.

Second, *AIDS* risk was often left to chance once multiple choices and risk reduction attempts had been made. While *IDUS* and their SPs tried to manage *AIDS* risk and relationships in their own way to prevent infection and the break-up of their relationship, this often entailed many obstacles. In the event of risk management being overly complex or impossible (e.g., a female partner has to agree to have condom-less sex to show her fidelity or a couple has to share a syringe because the second one can’t be bought at night), it is then inevitable that recourse was made to alternative solutions of risk acceptability, destiny and chance.

Third, feeling secure in an intimate relationship often connotes trust (usually accompanied by love and intimacy), making a sense of security and safety for both self and the relationship possible (Rhodes & Cusick 2000). Trust was the main reason given by *IDUS* as a justification for their acceptance of risk and fatalism. In *IDU-IDU* relationships, trust was expressed by mutual agreement to share a syringe and have sex without a condom. In other relationship models, trust was represented by mutual consent to have condom-less sex.

Fourth, dispensing with a condom was a means to define the relationship as ‘sincere’ and ‘committed’. This explained why female injecting partners tend to use condoms with their clients at work; however, they tend to forgo them with male partners at home since condoms signal a distance that is inappropriate in the context of an intimate relationship. Since trust, love and intimacy play such an important role in *IDU* relationships, broaching the subject of condom use may be a violation of these elements and bring suspicion and disequilibrium to the sexual relationship (cf. Wojcicki & Malala 2001).

Thus, in the context of *IDU* intimate relationships, the meaning of *AIDS* risks and relationships interact with each other. *AIDS* risk, characterised by syringe sharing and condom refusal, is an important determinant of relationship status. Although trust, love and intimacy are sometimes confounded by the elements of doubt and uncertainty, *AIDS* risk should be re-configured as one aspect of relationship security.
Implications for HIV Prevention

Gender and power

The literature on heterosexuality among IDUS has generally ignored women’s economic self-sufficiency while preferring to discuss behaviours that are deemed to be deviant or immoral. This study suggests that many Vietnamese women support themselves and their male partners, even via sex work. Most women in the study seemed to have a firm sense of agency and considered themselves financially independent from men. Often, male IDUS who were dependent on women for money were forced by circumstances to ignore the risks their female partners may be exposed to while engaging in commercial sex. In this case, the women did not assume a subordinate role vis-à-vis these men and exerted considerable control over sexual decision-making and condom use. These women are ‘breadwinners’, so they have more power and assertion in sexual negotiation. This can be seen as social change accompanied by changes in the conceptions of sexuality and gender (Streefland 1998). The influence of Confucianism on women’s passive roles becomes less valid in this context. Therefore, HIV prevention programmes should not always be based on a normative gender model of hierarchical gender relations and role expectations as it is commonly portrayed in contemporary studies about AIDS in Southeast Asia. Such generalized models often contradict real life experiences, at least in the case of the IDUS presented here. It is also critical to examine why – as this study shows – some women exercise control in their sexual decision making while others do not.

Care and responsibility

In the drug scene, care and responsibility confer distinct meanings. Often, IDUS are blamed for their low self-esteem, high-risk lifestyle, and lack of self-care and responsibility. This is not always the truth. Our data showed that many IDUS did not label themselves as such. In fact they had multiple ways to care for themselves and for others (e.g., giving a portion of drug to a partner before she goes to sex work, taking risk-reduction measures in their own ways, making sure their children are cared for when an IDU is arrested, educating peers to inject safely, providing a homeless friend a place to live, providing first aid when a fellow IDU overdoses). Although some of these care patterns maybe risky, responsible behaviours towards oneself and others should be emphasized as the means to curb the spread of the AIDS epidemic. Given that many IDUS were involved in multiple relationships, there is a possibility for HIV strategy designers to build on existing identities (injecting, smoking or non-using) to encourage
responsible drug injecting and/or sexual practices, rather than to bank on the ritualised slogans ‘don’t share’ and ‘practice safe sex behaviours’.

Drugs and sexuality

This study shows that drugs and sex are closely related in several aspects. Drug use is associated with trading sex for drugs/money and often means unsafe sex (see also Brummelhuis & Herdt 1995, Iguchi et al. 2001). Lex (1990) also showed that couples using heroin might use opiates together to enhance sex. Further, our data suggests that there was tremendous variability in the perceived effects of heroin on sexual experience. Some IDUS reported a positive relationship between heroin and other stimulating drugs and sexual performance. Many female smokers also reported that smoking enhances their sexual desire. In contrast, some IDUS confirmed a negative relationship between heroin and sexuality. While some junior IDUS preferred having sex right after injecting, seniors didn’t. In addition, women seemed to have a more positive attitude than men with respect to sexual pleasure. This variability therefore should be integrated into HIV risk-reduction counselling. An experienced heroin injector may not respond to the message ‘always use condom’ because sexuality for him is likely to be unimportant. Attention should be paid to situate the variability in sexual history and history of drug use, specifically with respect to the effects of drug use on sexual experience. NGOs and self-help organisations may want to reconsider their approaches.

Social stigma

A common trope in the discourse of AIDS is that IDUS and SWs were often presented as ‘vectors’ or ‘bridging populations’ of disease transmission. Because risk is defined on the basis of occupational description, being an IDU or a SW is synonymous with ‘high risk groups’ or ‘social evils’. The chain of infection was often configured as IDU-SP-populace or SW-client-wife-children and thereby perpetuating the negative image of these groups at risk. IDUS and SWs have become the diseased other and responsible for AIDS in society, while clients of SWs are absolved of responsibility. As a result, many women attempt to distance themselves from the stigmatised ‘sex worker’ identity. The account “I have to work as gai [SW] to support myself” was partly a reflection of the felt stigma, to borrow the term of Jacoby (1994). The stigma was so strong that many female IDUS even hide their occupation as a SW to their male injecting partners. Some men often said something like “I would rather die for my wife, but I never accept her as a prostitute.” It is therefore unwise for society to support tapping into the already existing and inappropriate negative stereotypes of risky sexual partners, such as ‘con diem’ [SW] or ‘thang nghiên’ [junkie]. Instead, preventing
stigma and discrimination towards IDUS and SWs (and people with HIV/AIDS) requires a new multidisciplinary approach in which the resistance of stigmatised individuals and communities may be utilized as a resource for social change (Parker & Aggleton 2003). In the context of Vietnam, the following were immediate measures being taken to reduce stigma: mass media campaigns on stigma alleviation, information dissemination, coping skills acquisition, greater access to treatment, and training for health professionals on social aspects of AIDS. For a long-term strategy, a change in the law and public policy should be considered so that they both censure this stigma rather than sanction it.

Conclusion

As research on AIDS has developed, greater sensitivity to the complex process of the negotiation of AIDS risk and relationships between men and women has yielded new insights that contrast with prevailing views. Indeed, many IDUS shared syringes not only because of syringe unavailability or drug scarcity, but also because sharing was an expression of trust and necessity. Many women did not use condoms, not because they lack negotiation skills, but rather because the non-use of a condom was a denotation of love and attachment. It was emotional need that was at stake (rather than financial gains) and served as the motivation for having unsafe sex among IDUS. Paradoxically, prevention messages stressed the use of condom in sexual relationships, but did not take into account the positive aspects of condom non-use (and syringe sharing) in a loving, trusting relationship. Similarly, merely emphasizing the risks of sharing and telling IDUS to stop this behaviour are both inadequate. Instead, harm reduction programmes should be integrated with safer injecting training (Lam 2003). There was an advantage to utilize aspects of IDUS’ own culture to change behaviour. Intervention programmes that target this group must take into account the specific context of their lives; programmes designed for ‘uniform IDUS’ would be of little help. In this study, we have seen how intimate relationships have an impact on risk behaviours and vice versa for IDUS. Finally, we suggested that ideological constructs regarding heterosexual relationships mediated the impact of political and economy forces on IDUS’ drug use and sexual decisions. In order to cope with the emerging epidemic effectively, there was a critical need for more comprehensive approaches that would address the root causes of the epidemic—causes that are embedded in the structuring of political-economic and gender relations in the contemporary society.

Postscript

This conclusion was written in 2002. However it is still valid for Vietnam today. It has been twelve years since this research was conducted in Vietnam. Since then the
HIV epidemic has changed significantly, both in scope and prevention approach. It is interesting, however, that interventions targeting people who inject drugs and their sexual partners are limited. Globally, the 2013 UNAIDS Report (UNAIDS 2013) showed that people who inject drugs and their sexual partners accounted for 68% of new HIV infections in Iran, 40% in Eastern European countries and 36% in the Philippines (the report does not provide figures on Vietnam). Dr Prasada Rao, Director, UNAIDS Regional Support Team Asia and the Pacific said that “HIV prevention programmes targeting the female partners of men with high-risk behaviours have yet to be developed in Asia, but are clearly essential.” (UNAIDS 2013:49). In Vietnam, recent research shows that HIV epidemic is still driven by injection drug use. Most IDUs are sexually active and may infect their sexual partners (SPs). While many SPs remain at risk for HIV, this population has been seriously underserved (Hammett et al. 2012).

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Treatment and Efficacy
Body and bone:

Cultural embodiment in Northern Thai bone healing

Sasitorn Chaiprasitti

This ethnographic study about the healing practice of an elderly Thai woman shows how Northern Thai culture is practiced in bone fracture treatment and how this medical knowledge is recreated by the healer in response to patient needs over the last three decades during the rapid socio-economic and cultural change in Thailand. This article also demonstrates the power of shared, internalized and unconsciously communicated familiar symbols in Northern Thai everyday practice. These taken-for-granted symbols are implicitly expressed through the therapeutic environment, patient-healer conversations, Northern Thai dress, and culturally defined body language exhibited by healers. This form of bone healing appears to be extremely powerful when it is situated in a context in which, familiar and meaningful symbols are condensed and encapsulated, as in the healing practice of the elderly woman and surrounded by the powerful signs of Buddhism or spirit worship. The practice of healers and patients includes the experience and reproduction of the past and present Northern Thai social and supernatural world.

Northern Thai bone healing features comprehensive local knowledge of human anatomy embedded in ritual. Like other Northern Thai medical knowledge systems, it is part of a shared culture of Thai and surrounding ethnic groups in Southern China, Laos and Vietnam (Mulder 1985, Rhum 1987). Rooted in magical-religious belief, bone healing is dynamically adapted to socio-political change. Bone healers create their own treatment activities, a mix of personal insights and various kinds of available knowledge. The female bone healer in this study, for example, combined bone fracture treatment with massage therapy, egg-rubbing, and biomedical knowledge. In an egg-rubbing treatment, the white

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of a boiled egg is squeezed around a silver coin and wrapped in a handkerchief. After that, it is blown over with charms (khatha), and the painful area is rubbed gently. The coin turns black or green, which indicates the type of toxic substance in the patient’s body. Green indicates a toxin from a bad spirit and the patient will be told that he or she should consult a specialized healer.

In Northern Thai cultural belief, bone-healing treatments require supernatural power. A healer has to receive the potent charm or khatha called khwak sui, which is believed to be a strong khatha or charm. During treatment, the healer blows his khatha over the reset fracture, and then wraps the area tightly with elastic bandage or a bamboo cast. Khatha is also breathed over the painful area during spot-pressing massage. Sometimes it is called a hot khatha in the sense that people who receive this khatha must have special power to control it. Such persons are men who have already been ordained as a Buddhist novice or monk. It should be noted that as a rule healing treatment involving magic is carried out by men, since it is cultural belief that the female body is polluted and can destroy the magical power. Moreover, most charms were written in Northern Thai manuscripts, which most women cannot read (Brun & Schumacher 1994:37). According to my interviews with five traditional healers, if a woman (such as the female bone healer in this study) does read and write Northern Thai and was born under a strong astrological constellation, she can overcome this taboo.

In Northern Thai as well as in other traditional beliefs, illness is not only caused by a disorder of the physical body but also from ruptured relations between people or between human beings and spirits. If a patient’s physical disorder is diagnosed as due to a violation of cultural taboos and/or the disruption of social rules, the healer will suggest that he consults other ritual healers for specific ceremonies to ask for forgiveness from other spirits or to reconcile himself with other people in the kin group or community. Such a patient may, for example, be injured in a car accident, or suffer from severe and chronic pain due to the violation of taboos or social rules. Northern Thai bone healers deal with patients’ problems not only in relation to their physical bodies, but also with regard to their social relations with other people and spirits.

It should be noted that in the twentieth century, when Northern Thailand became part of the Thai nation-state and underwent the rapid changes of the globalization era in the 1980s, Northern Thai culture, including bone healing, experienced great changes as well. Significant changes appear to have happened during the period of Thai national identity policy together with the policy of the tourism industry in which Thai massage, spa businesses and medical tourism are heavily promoted. Moreover, the National Institute for Thai Traditional Medicine (NITTM) of the Department for Development of Thai Traditional and Alternative Medicine, under the Ministry of Public Health, which was established in 1994, has provided many supporting activities and substantial funds to community based organizations, non-governmental organizations (NGOs),
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local health care centres, hospitals and the business sector to promote ‘Thai’ traditional medicine. Northern Thai traditional knowledge has been therefore reproduced and reinvented to legitimate itself among these powerful interventions. To understand the reproduction and reinvention of Northern Thai culture in the context of such change, then, insight into bone healing as Northern Thai cultural practice is of critical importance.

This article aims to illustrate the ways in which an implicit Northern Thai culture embedded in everyday life has been practiced as a response to the dominated Central Thai medical knowledge and commercialization during bone healing treatment. The article is based on ethnographic fieldwork between June 2003 and August 2004, and in May and June 2005. The information about ‘Northern Thai bone healing’ was collected through participant observation and intensive in-depth interviews with a female bone healer, her descendants and their clients. During my study (in October 2003), Ui Chan, the female bone healer passed away, which implied a great change in the meaning and representation of Northern Thai bone healing. Therefore, this article offers a good opportunity to study the changes and reinventions of bone healing practice created by her descendants.

To focus on the practice of Northern Thai healing, I found it useful to use the notion of habitus as elaborated by Bourdieu (1977, 1990). This concept leads us to concentrate on cultural power in practice. Bourdieu shows how culture is embodied and regulates people, and, in turn, how people actually practice cultural rules. According to his theory, an individual is not a totally free agent, as one’s actions are formed by habitus, a shared cultural structure that is embodied in a person or in a certain group. A person has, however, some ability to creatively represent him or herself or to ‘improvise’ under the shared cultural rules. This shared cultural rule is a “structure embedded in the agents’ bodies in the form of mental disposition schemes of perception and thought” (Bourdieu 1977:15, 78).

This common cultural rule and the symbolic strategies that people use to shape this rule work unconsciously in practice. For Bourdieu, this social practice is both a process of repetition and reconstruction of the shared socio-cultural system. Since practical meanings are dynamic and cannot be understood out of context, I focus on the healing context and the processes of patient–healer interaction and communication. These interactions take place, for example, in therapeutic settings, through the symbolic meanings of the body, the charisma of the healers, and the idioms of communication (Pratt & Mason 1981, Young 1987).

Northern Thai bone healing treatment: The case of Ui Chan

A Northern Thai perspective, as embedded in the practice of bone healing, can be seen in the case of Ui Chan (Grandmother Chan), an 85-year-old female
bone healer. She provided treatment at her house in a small village about three kilometers from the main road. Without the help of signposts, patients found the way to her house from the information given by friends or relatives who had been treated by her. On the cement wall surrounding her house was written, in large Central Thai and in Northern Thai script, ‘ban Ui Chan’ (Ui Chan’s house). Since few people can read and write Northern Thai, the inscription in this language can be seen as a representation of her authentic Northern Thai healing. In fact, many other aspects of this therapeutic setting are typical of Northern Thai culture.

Meaningful ritual space

When Ui Chan was still alive, her place appeared as an old, shaded, Northern Thai style home, surrounded by fruit trees. The wooden house was raised about one and a half meters above the ground. On the front of the house, near the roof, an inscription noted the year it was built: Buddhist Era 2501 [1958]. There were three more houses, belonging to her daughters, and a rice granary near her house. In the past the strict rule was that relatives had to build their house near that of their parents and keep rice in the family granary. This practice has now become rare. Near the entrance steps of the house, there were a large number of walking sticks left behind by recovered patients. Culturally, keeping used walking sticks in a house suggests that the owner of the house has strong magic and moral power to control bad luck. Since a walking stick is a symbol of a bad fortune or suffering, it is forbidden to keep it in a house after a patient has recovered. It is suggested that the patient leave a walking stick in a special place that can control evil, for example in a temple or a house of a person who has strong charms. For many patients, the presence of these walking sticks was a confirmation of her bone healing expertise. Middle-class people perceive the image of Ui Chan’s house as a symbol of their own childhood home and their imagination is led to recall the past.

Ui Chan’s house was an old shaded local style filled with a sacred atmosphere. It represented a relaxed environment and the simplicity and serenity of the Northern Thai life style that I dreamt of. Ui Chan’s smiling face looked kind and trustworthy and many clients were waiting for her treatment. I was rather convinced the first time I visited her house that she must be an expert traditional healer. Moreover, she met my own criteria that an expert traditional healer should not be a talkative person, but a calm and practical person. (Interview with Malee, a 55-year-old female, lecturer at the Faculty of Medicine Chiang Mai University, 11 February 2004)
The first time I visited Ui Chan’s house, I felt as if I went back home and was free from ‘tough business’. It seems that time passes very slowly at that place. She reminded me of my mother since they were at the same age and dressed in the same style outfits. It made me remember a happy childhood when I lived with my family in a similar style house. At that time, I felt pain in my whole body and she provided an egg-rubbing treatment for me. She gently rubbed my almost naked body with a warm squeezed egg wrapped with a handkerchief. At that moment, I felt as if I had become a child again and was being taken care of by my mother. I asked her to be my second mother and we continued our close relationship until she passed away. (Interview with Peng, a 54-year-old male, owner of a lathe plant, 7 June 2004)

However, nearby villagers perceive this house as a common and familiar place, very different from the hospital.

Before I had a treatment by Ui Chan, I was examined at a private hospital. They asked 80,000 baht for an orthopaedic surgery, which was too expensive. I also went to a district [public] hospital and had a physical therapy for almost two months. I did not recover. My neighbours told me about Ui Chan and accompanied me to her house. Within two weeks I felt better and could sew clothes all day. During the two weeks I had a treatment at her house, I went there very early in the morning with my prepared breakfast [food and rice] hoping to be the first client. I usually helped her cook food in her old style kitchen. After that we had breakfast together, rested and talked before beginning the treatment. She sometimes gave me fruits and local snacks her clients had given to her to take home. It is certain that I never met such an atmosphere at any hospitals. (Interview with Nui, a 50-year-old female dressmaker, 5 February 2004)

The whole scene of both Ui Chan’s house and her treatment session told familiar stories of Northern Thai culture and the spiritual beliefs that are practiced in daily life. Below the ceiling of the east wall of the house, was a shelf with four Buddha images and two electric candles. Pictures of the King and the Queen were hung on this wall below the shelf. On a table under this shelf, there was a local foot-tall red offering-tray (khan) with flowers, candles and popped rice, where patients placed the teacher spirit fee. Flowers, candles and popped rice are the three basic offerings for worshipping teacher spirits. Traditionally, patients have to bring them from their houses. Many people did not know this tradition; so Ui Chan prepared all three items for them. To the left of this khan was a directive whiteboard announcing the treatment fees. The teacher spirit fee was
108 baht and a bottle of rice liquor, whereas, the treatment fee for fixing fractured or dislocated bones was 1,000 baht and 150 baht for massage only. Since a minimum wage of workers is 100 baht per day, the treatment fee is rather expensive for villagers.

It should be clarified here that showing the teacher spirit fee, as well as the detailed treatment fees on the directive whiteboard, was a new way of management invented by Uï Chan’s son. It was a clever method that brought some criticisms from a few elderly persons such as Uï nan Khwai, Uï Chan’s cousin. Here are some of their criticisms.

Traditionally, a healer should extend treatment to all sufferers, even if they have no money. In such cases, the healer has to provide the money to the teacher spirits. [rather than the patient] (Interview with Uï nan Khwai, a 78-year-old male traditional healer, 18 May 2003)

Uï Chan’s son felt that to force his mother to pay for the teacher spirit fee was unfair. She was very old and received small sums of fee. Some of her patients cheated her. They disappeared when they were recovered, just leaving her with a headache because the teacher spirits had been offended. Generally, people understood why the son had helped by putting up the directive board for his mother. He told people informally about his reasons. From my point of view, people understood her generosity because Uï Chan gave the money back to her community. She made generous donations to Buddhist monks and needy elders on special merit making occasions. Moreover, the directive but not mandatory teacher spirit fee was not practiced strictly, especially in the case of local needy people. If the illness was not serious, such as a suffering from mal-alignment of sen (invisible lines that pass through muscles and are attached to joints), Uï Chan only rearranged the sen free of charge. In these non-serious cases, she used only her technical knowledge and did not require the teacher spirits to intervene.

On the floor, near a set of tables, for the installation of a Buddha image, stood a money tree, decorated with crisp clean bills as her personal donation to the temple near her house. It is quite common that when local people want to donate a large amount of money for some temple activities, such as for the construction cost of a new building; they normally prepare a money tree (tou ngoen). The trunk and branches of a tree are made of bundled straws. Each branch is decorated with crisp, clean money bills that look like they were leaves of a tree. This money tree will be put in a prominent place within the house in order to invite other people to join this temple fund raising. Another wall was covered with photographs of Uï Chan and her relatives. Near the top, on the right side of the wall, was a picture of her mother. Another picture showed her uncle who taught her the art of bone healing. Two pictures of her deceased husband and one of herself hung on this wall. Other pictures, of her deceased
son, of herself while traveling or while attending her son’s graduation ceremonies, were hung lower.

The therapeutic scene described here expresses Northern Thai cosmology, which is a mixture between spirit cults, Brahmin and Buddhist beliefs. The hierarchical arrangement of the pictures on the walls of the house depicts the structure of power relations according to Northern Thai belief, of which, Lord Buddha has the greatest power. The King and the Queen, considered as deities themselves, have less power than the Lord Buddha but more power than ordinary persons. The teacher of bone healing and a healer’s relatives have approximately equal power. The teacher spirits have less power than the Lord Buddha and the deities, but more than a healer. The belief of hierarchical power is expressed through the routine practice of *wai* that marks the beginning of each traditional treatment. *Wai* is a gesture of respect bringing both hands palm to palm and raising them to the face or forehead. A patient *wais* the Buddhist statues first, then the picture of the King and the Queen, and after that he or she should place the teacher spirit fee on the offering-tray and *wai* the teacher spirit. Simultaneously, while paying respect, the patient usually asks Lord Buddha, the deities and the teacher spirits to grant supernatural power and to support the treatment procedure.

Another important contrast within the therapeutic contexts of commercialized ‘Thai’ traditional medicine and biomedicine is the meaning of money or therapeutic fee. A modern calculation of the cost of those treatments in terms of time used for treatment (per hour) implies treatment as therapeutic business transaction. In contrast, the money given for the treatment by Ui Chan has cultural symbolic meaning. Although patients were explicitly informed of the treatment fee, it was charged on the basis of a patient’s illness. By putting money on the red offering-tray it implies that the money has been received by the teacher spirits. The money tree near the Buddha shelf suggests that this money in part went to the temple. In other words, and in accordance with Buddhist belief, offering money for therapeutic treatment is an indirect way of gaining merit. In addition, the fact that all treatment procedures were practiced in front of the symbols of Lord Buddha and the teacher spirits seemed to testify to the healer’s moral rectitude.
Moral bone healing expertise

While all therapeutic settings display Ui Chan’s qualification of her healing effectiveness like doctor’s certificate hanging on his clinic wall, Ui Chan’s expertise and morality were represented through symbols of Northern Thai culture. This was expressed in both her healing practice and her charisma.

In the house of Ui Chan, two cupboards with glass doors stood near the wall, below the picture of her relatives. One cupboard was filled with pillows for use during treatment, a certificate as an expert of Northern Thai bone healing from the NITTM (1999), and a certificate as a great Buddhist, awarded by the district religious committee in 2000. These two certificates were put in a case. They were not put on display as they usually are in other healing settings. As Ui Chan saw it, certificates were not very important to underwrite her expertise. Healing expertise in Northern Thai culture is not expressed in the form of certificates but through complicated symbols, such as, large piles of walking sticks left behind by the recovered patients, in combination with their narrative accounts, which symbolize the effectiveness of her healing. Moreover, according to Northern Thai culture, the technical skills of a healer increase with the morality of her or his environment. The relationship between Ui Chan’s morality and her expertise was obvious. Patients perceived her high morality in the way she represented Buddhist ideology and in her charisma of being a great Buddhist.

Ui Chan’s Buddhist understanding of life and death is implied by the more than twenty large, beautifully crafted silver-like bowls called sa-lung, on prominent display in another cupboard. Almost everyone, including myself, asked Ui Chan about the purpose of keeping such a large number of silver-like bowls. She replied that she kept them for her funeral ceremony, a gift to monks. Although Buddhists generally see death as a fact of life, to prepare for it as Ui
Chan did is certainly unusual. It indicates her attainment of the supreme Buddhist value: to be not attached to possessions, not even to her own life. This not only represented her morality but also implied that she gave treatment not primarily for financial reasons, but to achieve merit (*bun*). This value is further attested to in the stories told about her. Her son and daughters and the villagers reported that she had prepared spun cotton threads for tying her wrists after she died and a local reed mat to wrap her body in. According to Northern Thai traditional belief, a corpse is arranged in the *wai* position of giving respect to Lord Buddha. The hand palms are vertical placed against each other; the wrists are tied by cotton threads and raised above the chest. Flowers, candles and joss-sticks wrapped in banana leaves are put between the two palms. Thus the deceased brings the three basic offerings – flowers, candles and joss-sticks – to worship Lord Buddha. Before placement in the coffin, the corpse is wrapped in a *sua* (local reed mat). Another story frequently told is about her donation of a large amount of money for Buddhist activities such as the ordination of novices and the construction or repair of temples.

The charisma of *Ui Chan*, rooted as it was in Northern Thai belief, provided crucial evidence of her strong healing power. A bone healer needs more than technical skills to provide treatment, and must possess a strong charm (*khata*), called *khwak sui*, to connect his or her healing power to the power of the teacher spirits. It is a common cultural belief that, if a bone healer fails in following strict observance of the five Buddhist precepts (refrain from killing, refrain from stealing, refrain from lying, slandering, gossiping and spreading rumours, refrain from sexual misconduct, and refrain from taking intoxicants), *khwak sui* can create negative effects. Not only will his or her (magic) power diminish, but it will also affect the healer’s body and possessions. The healer’s skin will darken, he or she will look dirty and poor, and his or her home will appear uninviting and insignificant. Only in an environment of high merit can a healer control this strong *khatha*. The positive consequences of a healer’s capability to control this strong *khatha* are that he will increase the effectiveness of his healing and accumulate greater charisma. People believe that this kind of charisma is noticeable via a healer’s body, and that his abode spreads a sense of warmth. Since *Ui Chan* was an attractive old woman with a light complexion and a smiling face, and because her house looked charming and inviting, she met the criteria of a healer who is able to control the strong power of the *khwak sui*.

After the death of her husband, *Ui Chan* usually went to the temple to practice meditation during the nights of every Buddhist day (*wan phra*). She had nothing to worry about so that she could maintain her moral purity. She never gossiped or talked to people with bad words and never killed any kind of animal. She offered a lot of the money she received from her patients to the temple and the elders. She was the kind of older
person who thought and did only good things. She was a rare commoner [not an elite person] who was able to offer a chaw pha, the spire of a temple’s roof [which people consider as providing much merit or bun baram]. She did many good deeds so that the older she became, the more she looked charismatic and respectful. (Interview with Su, a 55-year-old housewife, 10 September 2003)

I deeply believe, Ui Chan’s khatha was very efficacious. If she said that this wound would recover, it really happened. Her words were very powerful (sak-sit). Nearly all my family members were her patients. [...] As a ‘female’ bone healer, she never drank alcoholic beverage [whereas a male bone healer often does]. She was very kind and polite, never talked to people with bad words. As a widow whose daughter and sons had already grown up, she was able to lead a very strict life of a devout Buddhist. This is why she still maintains charisma. Her house looked appealingly warm and openly radiating, whereas other [male] healers who had received such a kind of strong khatha have an opposite personality and had only a few possessions. (Interview with Lamoon, a 67-year-old housewife, on 23 May 2004)

The raised floor

Ui Chan provided treatment on the raised wooden floor of her house, called toen in Northern Thai language. It is the main area of the house. On this floor, near one of the house pillars stood a beautiful old basket for mak (a set of areca nuts and betel leaves smeared with lime which elderly persons in the past commonly chewed), a dish with miang (fermented tea leaves for chewing), bottled drinking water, glasses, and fruit or local snacks such as rice crackers. These were provided to anyone who visited the house (see Figure 1). An earthenware water jar (mo nan) stood in the other corner of the house for those who preferred drinking water from the well. Mak, miang, muli (cigarettes) and the jar comprised the traditional set to welcome guests. Nowadays, these items have all but disappeared from Northern Thai life, though they were still present in this house.

When there was no patient, the raised portion of the floor was used to receive guests, to carry on daily activities, take meals and sleep on the reed mat (suea). Some patients rested briefly after the massage; others brought food to share for lunch with Ui Chan. During the process of treatment the raised floor was a special treatment area. The patient and Ui Chan with her assistants (her daughter and a niece) sat on the raised floor. Others would sit on the lower floor while observing the treatment. The setting was like that of a stage act, including performers and audience. During therapy, all elements of the house seemed to play a role because of their symbolic meanings. Everything surrounding the raised floor, such as the Buddha statues on the top shelf of the east wall of the
house, the picture of the King and Queen near this shelf, the picture of the uncle who was Ui Chan’s teacher, and the ritual tray under the shelf of the Buddha statues – all of these turned into elements of a stage ritual. Even the rather expensive treatment fee shown on the directive whiteboard was overshadowed by the meaning of the ‘big’ money tree. The scene evoked trust in the effectiveness of Ui Chan’s treatment. Ui Chan’s therapeutic environment was a curious combination of a warm, welcoming house and a meaningful healing area.

**Movements of the body**

Not only was the house full of symbols, but Ui Chan’s dress and the way she moved were symbolic as well. Her bodily movements represented the aura of a gifted Northern Thai healer that deeply touched people’s feelings. Ui Chan naturally represented herself as an authentic Northern Thai traditional healer who brought the past to the present. The patients’ feelings were induced by the symbolic expressions of her body. Besides her warm-hearted personality, interpreted as a result of her high morality and religious conduct, her dressing style also contributed to her charisma. She dressed in neat and rather expensive clothes, a white lace blouse and a long traditional skirt (sin) (see Figure 2). It corresponded with her beautiful antique basket for mak and the ritual setting described above. She always chewed mak while sitting on the floor in a typical traditional manner, folding both legs beside her erect body, the pub-piap position, which is considered polite conduct, but rarely practiced nowadays (see Figure 3). For some patients, especially those from a middle-class background, her style of dress and posture met their image of an authentic Northern Thai woman. Some of them mentioned that Ui Chan reminded them of their mothers or grandmothers.
Although Ui Chan looked kind and calm, while providing treatment her bodily movements showed a combination of physical strength and modest cultural refinement. Her healing process was not an exotic treatment, as practiced by the spirit mediums studied by Tanabe (Tanabe 2002) and Thawat (2002). In simple cases she relied on her knowledge of anatomy only. For more complicated treatments she invoked the power of her teacher spirits by quietly reciting charms, while rearranging bones or sen of patients. Since her spirit and the teacher spirits were connected through the ritual ceremony of receiving the teacher spirits (rab khun khru) when she was young, she did not need to go into trance. The power of the teacher spirits could be transmitted into her body merely by reciting charms or khatha. During treatment she usually taught patients the local knowledge of the invisible human anatomy, by pressing certain spots on their bodies to let them feel the existence of sen that link those spots to typical areas by the feeling of prickling at certain points. Moreover, the way she welcomed patients as neighbours and kin, called herself ui or grandmother instead of mo or doctor, and her attitude made patients feel at home as if being taken care of by a relative.

Treatment involved not only knowledge of Northern Thai human anatomy but also the Northern Thai hierarchy of power. This is expressed in the way Northern Thai position their body. When a patient lies down, the head as most superior part of the body should point east, toward the Buddha images. But when Ui Chan kneeled on the floor, her head bowed, to blow her khatha over younger persons’ feet; the inversion of the hierarchy prescribed another direction. For patients and their relatives, Ui Chan’s positioning of her body in this direction provided them with an impression of a kind-hearted healer who did not care for her higher position while giving treatment.

Whereas the standardized Thai traditional masseuses used their fingers, hand palms, elbows, legs and heels, Ui Chan and her assistants used only their hands and sometimes their feet to give spot-pressing massage. It should be noted that the way they used their feet – culturally considered as an inferior part of the body – to give spot massage is culturally appropriated. This way is called yiap kha phae (using a foot to press someone’s crossed legs). A patient lies on one side with crossed legs, the lower leg in a straight position and the upper leg crossed over in an angled position. The healer stands on the patient’s straight leg and presses certain spots with her foot (see Figure 4). It is a technique frequently practiced by the Northern Thai in the past. It evokes the feeling of a journey back into the past for patients who learned of this familiar technique from their parents or grandparents.

When I got yiap kha phae massage by Ui Chan’s descendants, I remembered my village life. When I was young, I usually massaged my parents and grandparents with this technique. Since they worked at the
paddy fields, they came back home with strained muscles. I remembered that I began to massage them when I was only six or seven years old. The weight of a child at that age is suitable for standing on an adult’s body. Although at that time I did not know how to do a good massage, they told us step by step how to press certain spots to relieve their strained muscle. Now I have two children but I cannot ask them to massage me. Life is not as it was. (Interview with Thim, a 35-year-old woman, an owner of a big floral shop, 27 June 2005)

Ui Chan’s therapy, then, is enriched by subtle symbolic meanings that Northern Thai experience through their bodies. As she carried out her integrated ritual and body treatment, it seemed that all people who participated in that process – healers, patients and their relatives – knew automatically how and where to position themselves suitably. Nobody needed to arrange the order of this ritual ceremony. It is their habitus or embodied culture that regulates communication and practice according to a pattern familiar to them from childhood. Remarkably, Ui Chan did not strictly follow the cultural rules. She invented new ritual ceremonies, which were represented through her house arrangement, her body language, and especially through symbolic meanings related to the therapeutic fee. These are unconscious symbolic strategies that meet the demand of the modern Northern Thai.

After the death of Ui Chan

The symbolic meanings related to Northern Thai bone healing are, like other symbolic meanings, not static. A sudden and significant change occurred due to the death of Ui Chan. Villagers and patients felt that her house now looked gloomy. It appeared no longer as a home-like therapeutic setting any more. Since nobody lived in Ui Chan’s house and it was open only when her daughter and son provided treatment there, it seemed to be mere clinic, even if the style was Northern Thai. The scene around the house was rearranged to make clear
that the new healers were *Ui* Chan’s successors. The main teacher spirit tray (*khun khru luang*), which had always been in *Ui* Chan’s bedroom, was now conspicuously suspended from the ceiling of the *toen*. It was the same ritual spirit tray as the one received by her son during the *phi thi khvam khun khru*, the ritual ceremony of separating *Ui* Chan’s spirit from her teacher spirits, conducted before her dead body was carried away to be cremated in a community forest. It is believed that through this ritual ceremony *Ui* Chan’s spirit is freed from her teacher spirits and her son’s spirit is connected instead. This ceremony was led by a layperson who for a long time had been a Buddhist monk, so that he had sufficient power to control the spirits. *Ui* nan Dang, a 78-year-old ex-monk, who officiated this ritual ceremony said that while he informed the teacher spirits about the death of *Ui* Chan and conveyed the request of her son to receive her *khatha*, the grand ritual tray (*khau khru*) in *Ui* Chan’s bedroom was overturned (*khvam*) and touched by her son. This meant that his spirit was accepted to become connected with his mother’s teacher spirits.

On the table under the shelf of the Buddha images were two pictures of *Ui* Chan placed in front of the red offering-tray. In the first picture she was dressed in a white blouse and a brown *sin*, sitting in the *pub-piap* manner. A small microphone hung on the collar of her blouse. It was a picture that was taken when she was interviewed by staff members of the National Institute for Thai Traditional Medicine. The second picture portrayed *Ui* Chan sitting in front of a large money tree. She was in a meditation dress, a white blouse and a white *sin*, while holding a traditional red tray with flowers and candles. Sometimes these pictures were decorated with jasmine garlands by her daughter and son. The whiteboard with the information about the therapeutic fee was now covered with a sheet of paper announcing the new fee. The price for spot-pressing or *sen* treatment had increased from 150 to 160 baht. The set for *mak* and *miang* (areca nut and fermented tea leaves) had disappeared from the *toen*. Other new information was the home telephone number of *Ui* Chan’s daughter and the number of her son’s mobile phone.

Since *Ui* Chan’s daughter was usually busy with her domestic work, and because the son worked outside the village, they preferred patients to make an appointment by calling them. This new way of contacting the healers, the new meaning of the house and the increase of the treatment fee without a clear cultural meaning suggested that treatment was seen as a career rather than as treatment to help sufferers. The new healers still followed their mother’s techniques by providing spot-massage and bone treatment. However, they could not match their mother’s reputation as Northern Thai bone healer. Besides the changes in the therapeutic context, their appearance, dress, and bodily movements represented a modern Northern Thai middle-aged healer. Both of them wore Western-style apparel – T-shirts and pants or shorts. Like other
Northern Thai nowadays, the daughter could no longer maintain the pub-piap sitting position.

On the other hand, once Üt Chan’s successors gave treatment at the patients’ houses they started to create new symbols. The first symbol was Üt Chan’s leather handbag, filled with many of her belongings for treatment and usually was carried by her son. For him, this bag symbolized that his mother was present and supported him as he performed treatment. In the eyes of the patients however, the handbag represented the transmission of Üt Chan’s knowledge to him. Another powerful symbol, unconsciously created by Üt Chan’s successors to demarcate the ritual healing area from the remaining space of a patient’s house, was the local reed mat or suea. It should be pointed that suea is commonly used in daily life by local people. When I observed and interviewed the local people about the meaning of suea in everyday life, I found that its meaning depends on the context. If the local people prepare a suea for a guest, the space on the suea becomes a special area for this person. Usually, people sit elsewhere or at the edge of the suea. But if the local people use it in their daily life, such as for chatting, sleeping or eating, the suea becomes a relaxing space where all sit or lie down to enjoy themselves.

While the healing scene at Üt Chan’s house was full of intense symbolic power, as described above, the simply organized ritual space of a suea spread on the floor suggested the combination of modest power of a healer and a sense of a family-like treatment. No matter if a patient’s house was of Western design, as soon as the healers spread the suea over the floor to start their treatment, the atmosphere became dominated by the character of Northern Thai ritual healing. Everyone participating in the treatment automatically positioned himself such that the healers were in the center or superior position. Only patients and healers sat on the suea, while the others sat elsewhere. This is not an explicit rule, but it is embodied in Northern Thai everyday practice. Surprisingly, the healing performance taking place on the suea and the way people organized themselves

![Figure 5. Daughter and son of Üt Chan providing treatment on the suea spread over the floor of a western style house](image)
looked similar to how things were on the raised floor of Üi Chan’s house. The healers and patients seemed to act as performers, and the others attending the ceremony became the audience.

Conclusion

Bone healing treatment is one element of Northern Thai culture. Although it seems at first to be a mechanical treatment, cultural aspects appear to be embedded in every component of it. The crucial point is that culture is not expressed explicitly, but it is subtly communicated in a powerful form that the Northern Thai normally do not explicitly acknowledge, but take for granted. This study shows that the power of Northern Thai bone healing is the result of an actual healing practice which has been able to encapsulate and integrate the fragmented knowledge of Northern Thai physical and cultural bodies. Moreover, it is able to communicate this meaningful knowledge to the patients explicitly and implicitly during treatment. The ritual healing context, combined with the symbolic bodily movements of a healer, makes for a crucial environment where this practical knowledge is condensed and transmitted in a way that patients can touch, feel and perceive through their bodies and memories.

The nationalization and commercialization of the Central Thai healing knowledge do, in turn, evoke a feeling of nostalgia for Northern Thai healing with some Northern Thai who feel alienated in the rapid change of society and culture. The power of this knowledge is increased when healers represent themselves and their knowledge as authentic Northern Thai. The magical-religious belief that is practiced by both healer and patient during treatment confirms to the healer that his or her skill will be supported by supernatural powers. For the patient, it affirms a healer’s morality. To practice bone healing, then, is to practice Northern Thai culture. However, the practice of this culture is not a simple repetition of what has been transmitted; it is continuously reconstructed to fulfil the requirements of both patient and healer. This constructed healing practice is culturally accepted by those who are involved, because they share some basic cultural meanings. The article shows that familiar symbols practiced in everyday life can be important cultural capital for a healer when mobilizing and reconstructing Northern Thai healing.

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An anti-addiction drug?

Reflections on efficacy and safety issues within the Ibogaine subculture

Sara Brewer

Ibogaine has been reported to interrupt chemical dependency and has been used as a catalyst in drug treatment programmes, despite the lack of clinical data to support its efficacy and safety. In the absence of such data, providers and patients alike put themselves at risk for harm. How providers and the wider Ibogaine community construct risk and make efforts to establish data will determine Ibogaine’s wider acceptance. Harmful experiences can and do occur, meaning that the Ibogaine community should better organize to promote the safe use of Ibogaine and document its effectiveness. In doing so, they can better legitimize Ibogaine’s use and contribute to the wider discussion of how traditional, complementary and alternative medicine (TCAM) therapies can bridge the divide between ‘traditional’ and ‘biomedical’ medicine.

[Introduction, Ibogaine, Iboga, risk, safety, efficacy, TCAM therapies, addiction]

Introduction

Drug abuse is a complex problem. Often the use of drugs begins as a voluntary act, but quickly becomes driven by cravings, compulsive drug seeking and use, usually with devastating consequences to a person’s life. Because drug abuse and addiction have so many dimensions and disrupt so many aspects of an individual’s life, treatment is not as simple as taking a pill and being cured (National Institute of Drug Abuse 2009). Treatment programmes often involve behavioural and sometimes chemical interventions over a long period of time. Because of the difficulty in overcoming abuse, it is common for users to relapse and try a variety of treatments or methods to rid themselves of their addiction.

The drive for overcoming addiction leads some people to turn to Ibogaine, a hallucinogenic substance traditionally used sacramentally in Gabon, Congo and Cameroon to reach transcendent states of self-reflection where “the visionary content of …[a] drug experience helps to identify the cause of the individual’s

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illness...and how it should then be dealt with” (Helman 2001:154). Although the exact mechanisms of actions are not yet fully understood, Ibogaine is reported to remove drug withdrawal symptoms and drug cravings while simultaneously providing a psychoactive space for drug users to understand and reverse their drug-using behaviour (Sandberg 2001). Through the medicinal properties of Ibogaine, some people have reported the benefits of addiction interruption from heroin, methadone, cocaine, methamphetamines, prescription opiates (such as oxycodone), alcohol and tobacco.

The experience of using Ibogaine is reported to be gruelling, and yet despite the lack of understanding and the exhausting nature of the treatment, people all over the world swear by its effectiveness. Despite Ibogaine’s illegal classification in many countries, people still provide treatments across various formal and informal settings to those who come to them for help to end their addiction. In 2010, I conducted research about providers of Ibogaine treatment, including their perspective on how and why Ibogaine is effective (and its value as a medicine), how they constructed the risks of using the drug to their clients, and the measures they took to ensure their clients’ safety (Brewer 2010). I also focused on constructions of efficacy and how the inability of Ibogaine to conform to randomized controlled trials would inhibit its acceptance within the biomedical paradigm. This included a brief overview of existing clinical or observational research up to 2010, which was limited to Phase I trials or anecdotal evidence.

The three providers I spoke with were not especially concerned about the need for formal controls to prove Ibogaine’s efficacy, because in their experience, they saw positive results. Moreover, all three felt that the benefits outweighed the risks associated with treatment. They felt capable of ensuring their clients’ safety because they knew what they were doing, and saw laws prohibiting or restricting the use of Ibogaine as unnecessary. As such, they continued to provide Ibogaine ‘underground’ despite associated risks.

This chapter presents a portion of my original research, and follows up with current efforts to promote the acceptance of Ibogaine’s efficacy and safety through observational studies currently underway in 2013. I also followed up with the providers I had spoken with in 2010, and found that two of the three had encountered serious problems with treatments and had suffered severe consequences as a result. Following this update, and despite the limited interest by these providers in clinical trials, I suggest that the current trials and others are valuable not just to prove Ibogaine’s efficacy, but also to provide safety data that can be used to better regulate Ibogaine and protect providers as well as patients. Additionally, the manner in which the evidence is being generated will be of service to other traditional, complementary and alternative medicine (TCAM) therapies that seek to cross the divide between ‘traditional’ and ‘biomedical’ medicine.
Ibogaine as a treatment

Ibogaine is a prime example of the indigenization of a medicine from one context to another – considered a life-saving medicine by some, and a recreational drug by others. Iboga, or *Tabernanthe iboga*, was historically used in Gabon and Cameroon in the Bwiti religion “to induce a spiritual enlightenment, stabilize community and family structure, meet religious requirements and to solve problems of a spiritual and/or medical nature” (Samorini 1993). Traditionally, the root bark was used for initiation rites such as coming-of-age ceremonies, and various acts of healing. Ibogaine is a less potent psychoactive alkaloid derived from the roots of the *Tabernanthe iboga*.

Ibogaine has been used in psychotherapy “to facilitate a reduction of ‘pathologically acquired or learned’ associations of cues or internal representations with corresponding motivational states and behaviour” (Freedlander n.d.) and for spiritual exploration. While in an altered state of consciousness, a person is transported to a physically and psychologically pre-addicted state, where he/she can evaluate his/her habits from the standpoint of a non-addict without having to suffer terrifying withdrawal symptoms. Researchers currently theorize that Ibogaine fills the opiate receptor sites that stop addiction cravings and “effectively hits the reset button on the brain’s neurotransmitter mechanisms. At the same time, the liver metabolises it [Ibogaine] into NorIbogaine, which is thought to have powerful detoxifying and anti-depressant properties which help eliminate the pain and danger associated with withdrawal” (New Zealand Drug Foundation 2011).

It is frequently reported that subjects using Ibogaine experience visions of an informative or healing nature directly related to the problem that prompted them to seek help (I Begin Again 2003). Thus, when treatment is focused on addictive behaviour, the dissection of the root problem can give one the psychological power and energy to break an addiction. The real locus of healing power is said to lie with the spirit or energy of the Iboga, which guides people through the treatment encounter. I was told that, “Iboga will tell you where it’s going” (personal interview). A woman in the Netherlands who used Ibogaine to overcome heroin and cocaine addictions said she “heard a voice telling her to make a choice, to choose a new beginning or choose to die struggling and suffering alone” (I Begin Again 2003). A journalist describing his Ibogaine journey also said, “While startling at the time, such an encounter with a seeming ‘spirit of Iboga’ is a typical vision produced by the Bwiti sacrament” (Pinchbeck 2003).

People reportedly establish a relationship with the spirit of the Iboga in order to identify the parts of them that need restructing. It is the spirit of the agent who is working with the patient, and not the provider. The provider assumes the role of ensuring a safe treatment environment, including proper dosing. In the
treatment of addiction, the chemical properties also play a detoxification role on a physical level. According to the providers and client testimonials, the spirit of Iboga is infinitely more powerful than the providers.

Ibogaine is generally not advocated as a cure of drug abuse, but rather as a catalyst of a larger, longer-term rehabilitation or therapy strategy. Ibogaine is considered a powerful, sacred visionary plant, and can be a harsh and uncomfortable experience as the process of self-reflection can be brutal if a person has severe life events to overcome. However, these brutal experiences are often considered necessary to the process. While Ibogaine is non-addictive, it does have serious side effects such as nausea and vomiting, and can cause psychosis if improperly administered. Studies have suggested that there is a significant risk of brain damage associated with high dosages, and there have been at least twelve documented deaths linked to ingestion (New Zealand Drug Foundation 2011). For example, in July 2013, a woman who had not been properly informed of the associated risks was reported to have died during an Ibogaine treatment in New Zealand (3 News New Zealand 2013). This woman’s death raised concerns in the New Zealand Ibogaine treatment community, and emphasized the importance of establishing clear treatment protocols, which were not followed at the facility where the death occurred (MAPS 2013).

Attention to Ibogaine has grown considerably since the 1960s when a 19-year-old heroin abuser named Howard Lotsof inadvertently discovered the addiction reversal properties of Ibogaine. The first written records of Western discovery of Iboga date back to 1819 (it was actually marketed in France from 1939 to 1966 as an anti-fatigue medication) (Paicheler 2007:119). In 1962, in New York City, Lotsof had been given Ibogaine to try recreationally. He was completely surprised to discover after a 36-hour hallucination that he did not crave heroin or experience withdrawal symptoms. He had also gained incredible personal insights that he spoke widely about. Believing Ibogaine to be an invaluable solution for drug users like himself who wanted to quit, Lotsof set out to develop the drug and bring it to the pharmaceutical market.

According to a 2001 study conducted by Alper et al. (2008:18) in the US, the total number of recorded individuals who have used Ibogaine therapy is 3,414, of whom 68 per cent were motivated by treatment of substance-related disorders. However, this figure does not include ‘hidden’ participants in the ‘Ibogaine subculture’ and this number has certainly grown since then. Ibogaine has even found its way into the storylines of popular US television shows, such as ‘Law and Order: SVU’ (2009) and ‘Homeland’ (2013). However, Iboga is associated with other hallucinogenic substances and is therefore illegal in many countries. Ibogaine’s medicinal value is overlooked, and it is classified as a Schedule 1 substance in the US, a policy that is mirrored by most European countries. Many advocates of Ibogaine have used it to overcome their own addictions, and as
such, recommending its use is sometimes considered to be an effort by drug users to legalize illegal substances (Alper et al. 2001:253).

In general, interest in TCAM has grown considerably. This interest often comes after biomedical technologies have not effectively addressed a person’s affliction. Many authors have noted an increasing distrust in synthetic biomedicines resulting from the ‘medicalization’ of non-medical domains of life (Whyte et al. 2002). Generally biomedicines are seen as unnatural, toxic, impeding the body’s natural immunity, while critics point to the commercial character of pharmaceutical production (Whyte et al. 2002:63). Often people turn to alternative or traditional medicines such as Ibogaine without a biomedical understanding of their efficacy.

**Pharmaceutical development**

In my original research, the obstacle I identified to Ibogaine’s more mainstream acceptance was the global Ibogaine community’s inability to generate enough scientific evidence to conform to formal efficacy standards of acceptability. Additionally, without this evidence, safety could not be guaranteed for people undergoing treatments according to national drug regulatory bodies that rely on clinical trial data. Originally, I focused on Ibogaine’s limitations to conform to the requirements of evidence-based medicine (EBM), and specifically the ‘gold standard’ of randomized control trials. I argued that EBM purports to separate subjective or intuitive methods of individual clinical practice from the rigors of the scientific method, and that the use of Ibogaine does not conform to EBM methods since they would be both impossible and unethical. A person cannot be ‘blinded’ by an Ibogaine placebo, as they are quite aware when nothing happens. Furthermore, to give a placebo to a withdrawing addict would cause tremendous suffering and harm once his or her withdrawal symptoms began. It was suggested that this argument was out-dated, and that other types of evidence-generating studies exist that could be conducted to determine the efficacy of Ibogaine (Van der Geest 2012).

There are other reasons why Ibogaine has not been developed or fully accepted. Howard Lotsof’s company, NDA International, attempted to work with several pharmaceutical companies (such as Lilly and Dupont) to develop Ibogaine into a marketable pharmaceutical. However, all interviewees and researchers in the literature reviewed in my 2010 research believed that the pharmaceutical industry would continue to block its development for economic, political and moral reasons. Because Ibogaine is not a maintenance drug, there is little profit incentive for private companies to invest in its development, particularly when the target population of drug users are often without significant financial means. Moreover, as drug users are often stigmatized, the development of an addiction treatment medication could reflect poorly on the companies that develop it.
Many political bodies also questioned the moral component of drug use, preferring policies that punish drug users instead of appearing to cater to weak behaviour.

Most clinicians and pharmaceutical company representatives seem to dislike the waking visions that Ibogaine produces. Many advocates argue that trying to isolate the chemical derivatives of Iboga results in an insufficient experience of the total drug effect. Clinicians attempting to isolate the chemical properties for the market did so because they recognized the unpopularity of the visionary component and thought that this was the only way Ibogaine would ever be developed as addiction treatment medication. One provider I spoke with said that the psychedelic effect, “is what the pharmaceutical industry doesn’t want, but I think that exactly this visionary stuff, these psychedelic pictures if you like, are the reason for why Iboga can help so well” (personal interview).

Despite the lack of scientific evidence, Ibogaine providers accept Ibogaine as an effective treatment option. As one provider said to me, “Why I do this is just the reason that I am convinced that this plant, or rather this root, can really help many people and has already helped. Iboga doesn’t have to provide any proof anymore. That has been provided a long time ago” (personal interview). In November 2009, the government of New Zealand supported classifying Ibogaine as a prescription drug for the treatment of opiate addictions on the grounds that it is less harmful than methadone (New Zealand Medicines and Medical Devises Safety Authority 2009). New Zealand is the first country to legalize Ibogaine based on clinical evidence. However, Ibogaine is not an approved drug in New Zealand, and the New Zealand Medicines and Medical Devises Safety Authority (Medsafe) has not evaluated its safety or efficacy. It was classified as a prescription medicine in New Zealand under the Medicines Act in 2010, which allows registered medical practitioners to prescribe unapproved medicines for the treatment of patients in their care.

**Current clinical research**

Since December 2010, the Multidisciplinary Association for Psychedelic Studies (MAPS) in California, US, and academic partners have been collecting observational data for the first prospective Ibogaine outcome study conducted at independent clinics in Mexico and New Zealand to contribute to the growing scientific literature about Ibogaine as a treatment for drug addiction. This is the first observational study to determine the efficacy of Ibogaine-assisted therapy for producing extended periods of opiate drug-use abstinence, reducing opiate drug use, and improving the associated impact of these behaviours. Interesting preliminary results validate much of the anecdotal efficacy of Ibogaine, and re-emphasize the need for further evidence.
This observational study uses the Addiction Severity Index Lite (ASI-Lite) as the tool to measure composite scores over a period of twelve months following therapy (Kingsley Brown et al. 2012). The secondary objective of the study is to investigate whether changes in ASI-Lite scores after treatment relate to the subjective intensity of the Ibogaine experience. Using a Subjective Opiate Withdrawal Scale (SOWS), researchers assess if Ibogaine treatment reduces withdrawal symptoms.

A total of thirty subjects seeking Ibogaine treatment for opiate drug use interruption at a treatment centre in Baja, Mexico were enrolled in the first study site. A baseline survey of substance use was conducted prior to the treatment, and a control group of an additional thirty people with addiction who were not medically fit enough to receive Ibogaine treatment were also followed. In total, 67 people were enrolled in the study in Mexico, and none of those who received the Ibogaine treatment (thirty eligible subjects) experienced adverse safety effects.

Preliminary published results found that 1/3 of patients in this study relapsed within the first month, 60% relapsed within the first two months, and 80% relapsed within the first six months. The researchers also found that 20% of the participants were drug free for longer than six months (five of six without any aftercare); four out of thirty (>1/8) stayed ‘clean’ for more than one year following a single treatment. From these results, the researchers concluded that Ibogaine is an ‘interrupter’ of addiction, but not a cure, and more long-term research is needed. Moreover, they highlighted the importance of managing patients’ expectations.

This study is still underway in Mexico, and a similar study is beginning in New Zealand. In New Zealand, nine subjects have been enrolled since August 2013. The researchers of the New Zealand study have highlighted that scientific studies like these can demonstrate efficacy beyond doubt, as well as offer providers and patients the chance to better assess the drug’s efficacy and risks, and determine best practices based on collective and shared data (Kingsley Brown et al. 2012). The latter point is particularly relevant to my initial research, where I investigated how providers construct and communicate risk (discussed below).

Additionally, by making these initial trial results publicly available, researchers, clinicians, regulators and the public can make early and informed decisions about Ibogaine and its treatment opportunities. While this study is being conducted on a small scale, it will likely add positive or negative weight to the debate over the efficacy and safety of Ibogaine. It could also serve as a model for the wider issue of generating evidence for TCAM therapies. If indeed this and future evidence can effectively demonstrate Ibogaine’s efficacy and safety beyond doubt, other therapies can also follow suit and gather momentum in redefining what is considered useful evidence for regulators.
Representing Ibogaine

Websites are an important tool for marketing Ibogaine experiences, as well as communicating what Ibogaine is, how it works, risks, safety mechanisms, and other valuable information to all audiences. Websites are particularly helpful for interested parties to find providers. Indeed, all of the providers I spoke with had clients who had found them through their websites. In my original research, I found that risks associated with Ibogaine were communicated in various ways. In the absence of regulated standards for how to communicate risk, safety and efficacy – whether biomedical or other – comes the potential for misinformation and harm. The websites I reviewed and providers I spoke with all clearly associated some degree of risk with ingesting Ibogaine. However, how they communicated this to patients varied. This highlights the patients’ difficulty in knowing where to go for safe treatment. Providers put themselves at legal risk when not effectively communicating the risks associated with Ibogaine. Finally, use of the internet allows charlatans to create websites and trick people with fake treatments out of money.

Most providers consider Ibogaine to be inherently risky, with additional potential risk based on the health of the person ingesting the treatment (Brewer 2012). For example, one website says, “While Ibogaine may represent a major medical breakthrough, there is an inherent level of risk with Ibogaine treatment. Ingesting too much of the substance, being excessively thin, or suffering from liver or heart problems are dangers associated with this type of treatment.” They recommend gathering advice from many providers, and state that “any treatment provided by an experienced and knowledgeable Ibogaine therapist will include a medical and psychiatric review for the patient’s safety” (New Zealand Drug Foundation 2011). Ultimately this is because, in the absence of formal medical drug safety approval by a regulatory agency, the end users assume the risk of determining the safety and efficacy of the treatment vis-à-vis the provider. This is a very dangerous situation, given the risks associated with Ibogaine, since not all providers may be genuine, and many people seeking treatment are desperate to overcome their chemical dependency issues and may not be as discerning as they could be.

One Ibogaine website (New Zealand Drug Foundation 2011) admits that without the proper scientific body of evidence to support the safety and risk profile, Ibogaine should be approached with caution.

Despite enthusiastic endorsement by many who have used it, these serious risks cannot be ignored, and the fact is, we just don’t yet know enough about how the drug works to be sure its use is safe. Considering Ibogaine’s potential to do harm, medical professionals should be extremely cautious before using it as a treatment option until there is a robust body of knowledge about its effectiveness and safety in humans.
Ibogaine’s day may come, but until we know more about it and how to use it safely, we are better off sticking with proven treatments.

As the suppliers of Ibogaine, providers ultimately assume the responsibility of safety and risk, and rely on the honesty of their clients (in the absence of drug tests) to communicate their state of withdrawal and health to determine safety. Two of the providers I interviewed who offered Ibogaine treatment out of their homes said they recognized that things can go wrong if the clients have not been entirely truthful to them about the recommended medical test results, health conditions, or when they last used drugs. They said they inform the person of the risks associated with Ibogaine; however, they also recognize that informing people of the risks of Ibogaine aids in legal protection, demonstrating that if necessary, they were as responsible as they could be according to biomedical protocol. As one provider said to me, “Often we communicate for several weeks from the moment they contact me to when they are finally with me…we exchange ideas and some of them ask very explicit questions…and I enlighten them as much as I can beforehand about the risks and what can happen in terms of dangers. Ibogaine is not a children’s toy, definitely not” (personal interview). This provider further said,

And there you are, giving something really quite harmless and safe, and monitoring them this whole time, to the point where I ended up buying a defibrillator and a patient monitor like you find in the hospital because I was absolutely paranoid about anything bad happening. And they were all good things to have, to show I was doing good clinical practice (personal interview).

At the same time, this provider recognized that he could also be blamed for over-medicalizing Ibogaine, so “it’s an impossible situation” (personal interview).

Putting the notion of inherent risk into context, one provider I spoke with pointed out that psychiatrists are prescribing medicine all the time with various side effects that they likely do not fully disclose. Some drugs “are horrendous, life threatening, but you don’t tell them [the patient] that, and I don’t get you to sign something to say you’re taking this at your own risk. You send them out the door and say take it at home and good luck” (personal interview). Many drugs have been cleared as safe by regulatory bodies without a full understanding of their mechanisms of action, yet the risks associated with these medications are considered safe because regulatory bodies have weighed the concerns and approved them for consumption. Rarely does anyone thoroughly know what goes on behind the scenes of a clinical study or the interests involved with those approving a medicine. However, patients must trust the informed opinions of regulators to ensure drug safety, which are not always entirely accurate.
In the absence of regulated, standardized dosage regimens, various lay materials exist that give a weight ratio for determining dosage according to the reason for treatment. In an effort to standardize safety protocols, Howard Lotsof developed a providers' manual, which contains “inclusion and exclusion criteria, Ibogaine regimen and doses, and considerations for post-treatment care” (Lotsof & Wachtel 1996). The presence and open availability of a safety manual suggests some attempt to mitigate risk. Lotsof said that the manual was “intended for lay-healers who have little or no medical experience, but who are nevertheless concerned with patient safety and the outcome of Ibogaine treatments” (Vastag 2002:3100).

None of the providers I spoke with talked of using this online safety manual. One provider suggested they are rules for the sake of rules, and are in place to reinforce the fear associated with Ibogaine and a marketing tool to attract people to their medically oriented clinics. All of the providers said determining dosage involves a feeling or intuition about what the person needs. One provider said:

> When I see the person in front of me I can always tell pretty well, “This dosage will work well,” and most of the time, I'm right. If I am not right I still have the possibility through Ibogaine to add another dosage within a few hours. There is a specific border I cannot cross, because then it becomes dangerous, I am aware of that (personal interview).

One provider was adamant that the presence of a manual or an international federation of providers would not guarantee safety, since there is nothing that enforces people to follow those standards and nothing to be done if something does happen. However, she offered no alternative and she also communicated mistrust of the government and of pharmaceutical companies.

**Provider follow-up**

At the time of my initial research, the three providers I spoke with had not encountered serious problems, and were confident in their abilities to maintain the safety of their patients. However, two of the providers I had originally spoken with in 2010 had experienced treatment sessions when they were unable to fully protect the person undergoing treatment. The psychoanalyst provider I spoke with was subject to a disciplinary hearing by the General Medical Council of the UK (Dyer 2011. 343:x6699). After having given an Ibogaine treatment to a 25-year-old man obsessed with pornography, the patient reportedly experienced months of mental health problems, including insomnia, paranoia and psychosis (Enoch 2011). Because Ibogaine was unlicensed, the doctor was expected to have fully informed the patient of the relevant benefits and risks of the treatment. During our interview, the doctor told me that he had conveyed the risks, but a
family member of the patient had not fully understood. The family member was
effectually the reason the case was brought against the doctor. The doctor was
reprimanded for not having informed his patient of the unlicensed status of the
drug and the possible risks or alternative treatments, providing treatment in the
patient’s home and not keeping accurate notes. He has since left his practice.
Although the doctor’s website reported the associated risks of Ibogaine, the
medical council determined that the website did not adequately stress the
seriousness of the risks and therefore found the doctor negligent.

Another provider interviewed for the original thesis had been charged with
manslaughter after a 28-year-old man she was treating in her home became
aggressive and inconsolable during his hallucination. He insisted on leaving after
only 36 hours, although he had intended to stay for ten days to receive after care
and support. She took him to a hotel and sent someone to check on him shortly
after. However, presumably whilst hallucinating, he left the room, was hit by a
truck on the motorway, and died in the hospital the next day.

Discussion and conclusion

It is clear that in light of the developments that occurred with the providers I
spoke with, some mechanisms of support for both the patient and the provider
are needed. While Ibogaine is classified differently in their respective countries,
both providers eventually faced the inevitable legal charges associated with
treating patients without a suitable framework for ensuring safety. The second
provider described above had successfully treated hundreds of people in the
course of her twelve-year practice, and was well known and respected in her
community. Clearly provider intuition and experience may contribute to safety
most of the time, but it only takes one drastic event to darken the already shaky
credibility of Ibogaine.

Taking the notion of mistrust of the government and pharmaceutical
companies into perspective, and the underground nature of the Ibogaine
subculture, it will be interesting to see how the clinical development of Ibogaine
will unfold. Although I have spoken of the ‘global Ibogaine community’, it does
not seem to exist in an organized manner, although the potential is there. For
example, all of the providers I had spoken with had some connection to the
more outspoken and organized advocates working towards Ibogaine’s
acceptance, but none of the providers knew of each other. Moreover, the belief
that a standardized safety and treatment manual would not be of use in the event
of an emergency further suggests the need for external support. It seems that
providers, researchers and patients would benefit from a better-organized global
community. This would allow for greater exposure of evidence, for organizing
people willing to engage in generating evidence, and ideally protection of both
providers and patients against adverse effects. In this way, the Ibogaine
community could shed more light on the people being helped, putting the numbers being hurt into perspective.

Providers must (and often do) take care to understand that problems can arise, regardless of the various precautions they take, or the amount of experience they have. The harmful occurrences that happened under the care of the providers I spoke with, as well as other reports such as the death of the woman in New Zealand, only strengthen the argument for further studies to generate evidence of efficacy and produce regulated, standardized treatment guidelines. Igobaine’s efficacy as a treatment is also demonstrated through its safety.

The presentation of existing clinical trial data and results is a positive first step in overcoming associated risks and safety concerns, and promoting Ibogaine’s wider acceptance. Longer follow-up studies are needed, since the newest evidence suggests that Ibogaine is not an effective long-term treatment. Studies including counselling and support would also be of value to harness the ‘catalytic’ nature of the treatment, which again could be sourced from providers who integrate Ibogaine into a broader therapeutic package. Perhaps Ibogaine’s value is not long-term at all, but an effective means for providing a window of sobriety that allows drug users to gain some clarity and a time to get their attention. I believe there is significant value and opportunity in that.

In hindsight, I would revisit the arguments I made in my original thesis about evidence-based medicine to further explore other methods for generating evidence. In theory, these other methods do provide evidence, though not at the same level as the ‘gold standard’ of double-blind randomized controlled trials. In practice, however, it remains to be seen how acceptable these Ibogaine trials would be to regulatory bodies, which could very well be where the TCAM scepticism stems from. This is not the place for exploring the latter idea, but further follow-up studies of Ibogaine’s efficacy and safety could contribute a great deal to wider discussions surrounding the efficacy of TCAM therapies.

This follow-up article has tampered my original enthusiasm for Ibogaine, making clear the need for more work towards evidence. If the evidence already exists, then it should be documented, because without that evidence it is clear that Ibogaine can be more harmful than helpful, and it is up to the people with knowledge and experience to ensure the research is done. Ultimately, people will continue to provide and ingest Ibogaine regardless of regulatory and safety frameworks. Hopefully future studies will enable the safe and efficacious use of this potentially helpful medicine.
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Gender and Parenthood
“HIV-positive women shouldn’t make children just like that”

When a right becomes ‘acceptable but not advisable’ in Maputo, Mozambique

Mónica Rodríguez García

This article sheds light on the reproductive decision-making of HIV+ female pacientes peritos [expert patients] (PPs). It draws on in-depth qualitative research on these women working in public HIV/AIDS services in the Chamanculo health district in Maputo, Mozambique. The article challenges orthodoxies entrenched in Gender and Development (GAD) and global health discourse like the one that states that African women have more children than they want/should, and that this is due to a lack of access to family planning services, together with the centrality of motherhood in defining African women’s identity. My study findings suggest that although HIV+ women pregnancies are considered by public health policy to be a reproductive right, health staff and PPs’ co-workers did not actually sympathize with this view. Their perspective was influenced by population policies and GAD’s dominant discourse. The article further questions the workings of ‘therapeutic citizenship’ for PPs due to their double role as patients and adherence-counsellors. The young female PPs’ responsibility of being an example (of having control over their reproductive life) for others clashes with their reproductive rights and leads to a state of ambivalence. Female PPs of childbearing age feel as entitled as any other woman to bear children, and feel confident about their future child’s HIV negative status due to their access to antiretroviral treatment and prevention of mother-to-child transmission drugs. Despite this confidence, the PPs are compelled to pragmatically negotiate their reproductive rights with health staff and other PPs, bumping into the contradictions of women’s everyday lives and the interests of dominant discourses and policy-makers. These contradictions paradoxically constrain their reproductive rights.

[HIV/AIDS, expert patients, reproductive decision-making, reproductive rights, therapeutic citizenship, Mozambique]
Introduction

In Mozambique, the HIV/AIDS epidemic has changed enormously since the appearance of the first cases in the 1990s that were surrounded by denial, secrecy, accusation and discrimination. With the advent of free and public antiretroviral treatment (ART) in Mozambique, in 2004, the hazards of an HIV diagnosis have changed from a death sentence to the depiction of AIDS as any other chronic disease. Nowadays, many women living with HIV (WLHIV) have dramatically improved their health condition and want to regain ‘normal’ lives, and for these women, this entails bearing children.

Between 2004 and 2008, I worked as a psychosocial support advisor for an international NGO (i NGO) supporting the Ministry of Health (MOH) to implement and improve the psychosocial support strategy for helping patients adhere to ART in Sofala and Manica, two central provinces of Mozambique. I worked with HIV+ lay adherence-counsellors, and our main objective was to help others achieve success with ART. At that time, due to the fragility of the prevention of mother to child transmission (PMTCT) services, HIV+ women’s pregnancies were manifestly condemned by public health professionals and policy-makers. I personally struggled with this stance, although I acknowledged that from a public health perspective, HIV+ pregnancies were challenging and involved preventive efforts to mitigate the spread of the HIV epidemic and demographic concerns regarding high African fertility rates. However, these pregnancies also involved reproductive rights and choices. For female HIV+ lay adherence-counsellors, pregnancy was a constant source of uncertainty. In my AMMA research I wanted to further explore the HIV+ lay adherence-counsellors perspective; these counsellors were called pacientes peritos PPs (expert patients) in the i NGO were I performed my fieldwork.

My AMMA research, in October and November 2011, was inspired by Van Hollen’s statement that there is a lack of social studies on women and HIV/AIDS analysing the relationship between global and local processes considering the constraints of structure and agency, specific sociocultural contexts, and the pragmatics of HIV+ women’s reproductive decision-making (2007). Moreover, little work has been done to investigate the particular situation of PPs in general and those in Mozambique in particular.

PPs in the Chamanculo health district in Maputo city, Mozambique, work in the public health system, although they are hired by an i NGO. This means that they have better working conditions and a better salary than other public health workers. As HIV+ patients, PPs are counselled to maintain a strict lifestyle including adhering to a lifetime ARV treatment and regulating their sexuality and reproductive lives. This regulation implicitly entails the reduction of the number of children they bear. As lay adherence-counsellors the PPs advise other patients, generally through palestras (health talks) at public hospitals. The PPs’ role as both...
lay counsellors and patients creates ambivalence and uncertainties about some of their rights. Although nowadays the rights-based approach pervades the rhetoric regarding HIV+ women’s reproductive rights, it coexists with attitudes contesting and severely constraining PPs’ pregnancies. Constantino, a PP in his fifties and father of five children, referred to HIV+ pregnancies as “acceptable but not advisable”. His attitude was quite common among most of the health workers I talked with during my fieldwork.

During my research, I was particularly interested to note how PPs experienced and managed the tension and ambivalence that was present with respect to their reproductive wishes and choices and the reactions from the health care system. I was particularly interested in the reactions of their closest co-workers, who are other PPs and nurses. I explored how life had changed for the PPs since their diagnosis and the start of their jobs (as PPs) and how they had experienced these changes. The PPs told me that when they decided to go through with their desire to bear a child, they confronted uncertainties caused by having to be an example to other HIV+ patients. Based on the study findings, I argue that although HIV+ women pregnancies are considered by public health policy in Mozambique to be a reproductive right – health staff and PPs’ co-workers on the grounds of health facilities did not sympathize with this view. The perspective of the latter was influenced by population policies and a GAD discourse, which caused PPs of childbearing age to be uncertain about continuing their job if they became pregnant. I show how rights and entitlements are contested, and negotiated in ambiguous ways by PPs in the Chamanculo health district in Maputo city.

**Conceptual framework: Therapeutic Citizenship**

Nguyen (2010) studied antiretrovirals (ARVs) in the context of West Africa and introduced the concept of therapeutic citizenship. This concept is instrumental for analysing the struggles and strategies of WLHIV and exploring how an HIV+ condition became the basis for making citizenship claims in the difficult conditions of impoverished societies where “…antiretroviral programs are likely to be the only significant interaction that many citizens in Africa—or indeed in most of the developing world—have with the complex administrative apparatus, one that parodies the modern welfare state we in the North take for granted” (Nguyen 2010:185). Therefore, therapeutic citizenship means that once people living with HIV (PLHIV) start ART, they also appropriate a set of rights (to cure, health and life) and responsibilities (such as not infecting others by regulating their sexuality and reproductive life).

The stories of PPs in Maputo, Mozambique should be considered within a context of poverty, lack of opportunities and discrimination. Most of the PPs were diagnosed when HIV/AIDS was still a death sentence and had undergone
long journeys of bereavement, loss, hopelessness, discrimination and illness. Since they disclosed their seropositive status, they have suffered severe discrimination from their families and communities, including expulsion from their households, loss of family support and network, and loss of their livelihood. The PPs’ narratives illustrate that since they started their work, they have gained broader entitlements compared to the rest of the HIV+ patients. PPs have been singled out among patients as selected and privileged therapeutic citizens and this has allowed them to rework a devalued identity and gain health and economic means. Moreover, they have gained status from their job as PP, and thus respect and honour. Their narratives also revealed that they have achieved all this at huge personal cost and they often used words such as ‘courage’ and ‘strength’ to describe this process. Today, PPs feel ‘normal’ despite being HIV+. The pertinent question for this article is how WLHIV, who are PPs, balance their reproductive rights and the responsibilities related to their job in this context of poverty and lack of opportunities. I use therapeutic citizenship as a concept to explain the study findings.

Global health and gender and development (GAD) discourses

Global health and Gender and Development (GAD) discourses, practices and studies have produced what Davids and Driel (2011:907) call ‘orthodoxies’. Orthodoxies are convenient outcomes for policy makers that are transformed into extended assumptions and simplistic slogans often repeated by policymakers and development scientists. Orthodoxies rely on dichotomies and often remain unquestioned and under-analysed. The discourse underlying most of the policies, programs and interventions in reproductive health is a GAD discourse rooted in Western feminism, which takes patriarchy and female subordination as universals and thus for granted. The inconvenience of this discourse is that “…in GAD lines of thinking, ‘tradition’ and ‘African culture’ are detrimental to women, being posed in opposition to gender equity and modernity” (Arnfred 2004:13). However, “…whereas ‘wifehood’ in many African contexts indicate subordination, the position of ‘mother’ is central and respected, in all (African) societies be they patrilineral or matrilineral” (Arnfred 2009:3).

Orthodoxies around the feminization of AIDS present in global health and GAD discourses have reduced women to victims of African tradition and oversimplify the complex relationship that PPs have engaging with tradition and modernity. In addition, there is the extended assumption noted by Van Hollen (2007) that ‘third world women’ are subjugated, and have little or no control over their reproductive lives. Population policies implemented to reduce high African fertility rates as a prerequisite to modernization are entrenched in public health HIV/AIDS programs and health workers’ views and inform the perspectives of some PPs as I shall show.
From the moment the PPs received their HIV diagnosis, they have been confronted with many difficulties and frustrations and thus, they had to overcome multiple challenges including severe discrimination by families and communities. On the other hand, PPs have been able to achieve milestones they could never have imagined when initially diagnosed with HIV. These achievements were possible through painstaking self-discipline exercised under the positive living dictum and subsequent adherence to ART. By going through this process, PPs gained courage and strength in their personal lives, which helped them to pragmatically navigate between the positive living dictum, family obligations and their personal wishes and desires. I found that PPs responded to public health recommendations by pragmatically evaluating if such recommendations would improve or worsen their lives. Furthermore, since being employed as a PP, the PPs dependency on the HIV/AIDS administrative apparatus became a matter of everyday survival due to their improved material conditions. Therefore, I frame PP pregnancies as intertwined in a complex “relationship between structure, agency and the pragmatics of HIV+ women’s reproductive decision-making” (Van Hollen 2007:11).

Despite their dependency on biomedicine on the one hand, and on the administrative apparatus of HIV/AIDS due to the advantages they enjoy, on the other, I portray PPs as active agents of their own reproductive lives, not just victims of oppressive social and cultural systems and biomedicine. My research was about the complexity that the women’s pregnancies arouse because of their jobs as PPs for public health in the context of AIDS. I believe it is important to hear the PPs’ voices and learn how they consider and negotiate public health recommendations in their daily lives. The stories of female PPs working in Chamanculo health district of Maputo city become comprehensible within a context of poverty, lack of opportunities, and discrimination.

Methodology

The empirical foundation for this article is based on six weeks of field research in Chamanculo health district in Maputo city. To understand how PPs consider and decide to follow their desire to become pregnant, I returned to Mozambique in October and November of 2011 to perform fieldwork.

The research was a qualitative exploratory study based on observation and in-depth interviews as data collection techniques. My fieldwork was in another INGO based in Maputo city (not the one where I had worked earlier). However, due to my previous psychosocial work in the public ART program, I quickly became familiar with the organization of the services and the PPs’ tasks in the Chamanculo health district. I observed the PPs palestras, which were one of their

[^1]: A set of concrete practices covering physical, nutritional, and emotional techniques purported to strengthen the immune system—avoiding opportunistic infections—and boost self-esteem.
main tasks and central for the purpose of my research because *palestras* are formal occasions when the PPs give advice to patients. I observed multiple *palestras* at several centres delivered to diverse audiences and at various times throughout the day. My observations took place in three hospitals (Alto Maé, Chamanculo and Xipamanine) in the Chamanculo district.

Informality was a fertile space of information during my research. I arrived early every morning at Alto Maé and moved to the other hospitals with the staff in the iNGO’s cars. Cars became a revealing informal space. Towards the end of the working day, when activity at the hospital started to slow down, I enjoyed sitting in the open-air hall of Alto Maé writing my notes when PPs and other staff members came to chat with me. These informal moments and environment were enlightening and fruitful. I also had many informal talks with a wide range of NGO staff and with health workers throughout the working day. As their confidence grew, the PPs changed their narratives moving away from the typical HIV/AIDS activists’ discourse. I describe their more personal narratives later in this article.

In addition to informal conversations, I had formal in-depth interviews with the psychosocial support advisor of the iNGO, seven PPs (three men) and one lay-counsellor. Their age ranged from middle twenties to late fifties, with an average of ten years of education. I was interested in the perspectives of older female and male PPs since they were co-workers of the younger PPs of childbearing age; I aimed to gain insight into how the perspective of the public health system about pregnancies worked in daily practice for PPs on the grounds of health facilities they work daily, despite the MOH policy. All these interviews were held in the health units. Four PPs’ stories about their lives since their HIV diagnosis were revealed during multiple in-depth interviews that were conducted outside the hospital settings.

For the purposes of this article, I do not report on each participant’s perspective. Rather, I use the example of one of the two PPs who got pregnant (Berta), and the view of Berta’s pregnancy by one elder PP (Luisa, in her fifties), who was representative of the view of older PPs and health staff, to illustrate the contradictions of the distinct perspectives.

**Setting**

Like many African countries, Mozambique was devastated by AIDS in the 1990s. Since June 2004, when ART became publicly available and free in Mozambique, the National Health System (NHS) underwent a challenging and highly demanding process to respond to new needs and requirements of what was already called the National Response to Fight against HIV/AIDS. Significant

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1 Headquarters of the iNGO field operations
resources were put in place to fight and mitigate AIDS and rebuild the health of millions of people affected by the disease. Antiretrovirals were finally introduced in Mozambique, but the country faced the significant challenge of medically managing and clinically organizing the demanding treatment. Despite all efforts at that time, patients in need of treatment largely outnumbered local resources, so health coverage was below targets. The target of the MOH from 2004 onwards was to dramatically increase the number of people on ART with a scaling-up process; thus, communities continued to be mobilized. A crucial human resource to achieve outstanding progress made during those years was the use of expert patients (PPs) as lay adherence-counsellors.

In early 2008, the MOH obliged NGOs to work within the public health network. Instead of creating HIV/AIDS vertical services efficiently managed by NGOs, the objective was to integrate AIDS care and treatment services into primary and public health care service process. This integration was a significant challenge for the National Health Service (NHS), NGOs and the patients alike. The use of expert patients turned out to be indispensable for NGOs. PPs were hired during the scaling-up and integration process by frantic NGOs, with the understanding that their condition as patients on ART would be of great help for the organizational requirements of the integration process and to help patients navigate health facilities and adhere to long-life treatment. From the beginning, NGO staff and health workers considered the PPs’ example as patients on ART to be of crucial significance as a tactic to demolish the denial of AIDS, discrimination against PLHIV and suspicions about the effects of ART by Mozambicans. Although, the main requirement to perform the job of PP was the public disclosure of one’s own HIV status daily at hospitals, PPs told me that they accepted disclosure despite their reluctance – as they feared stigmatization and discrimination – due to poverty. Angelica, a PP, revealed this dilemma clearly by declaring, “testimonials [public disclosure] are our burden.”

Mass treatment programs were being established, the medical and clinical management of the treatment at hospitals were getting better organized, the health condition of PLHIV in treatment improved dramatically, and stigma and discrimination were gradually decreasing, yet still present as the PPs narratives revealed. Public health efforts were re-oriented toward presenting HIV/AIDS as “any other chronic disease”, trying to leave behind the perverse association with death and with risk groups. Because of the higher prevalence of HIV/AIDS in Mozambique among women, mass testing of pregnant women in the PMTCT

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1 The number of persons in ART in Mozambique multiplied by a factor of 51 in six years and went from 3,314 in 2004 to 170,198 by the end of 2009 (Conselho Nacional de Combate ao HIV/SIDA 2010:73).
2 Carla Braga’s dissertation (2012) analyses the integration process in Manica province and highlights how difficult and ambivalent the integration process was for patients also.
3 In both rural and urban areas HIV prevalence is higher in women than men. 13.1% of women and 9.2% of men between 15 to 49 years are HIV+ in Mozambique (Instituto Nacional de Saúde 2009:11).
services was performed. Female PPs were recruited as a tactic of showing other women the possibility of having a satisfactory life thanks to adherence to ART and the possibility of bearing healthy children thanks to PMTCT services. Healthy PPs who were already mothers became an example for others. Yet, what happened when PPs wanted to have another baby?

Findings

I begin by presenting two distinct perspectives: the dominant perspective towards PPs pregnancies among health workers and the perspective of a PP (Berta) who wished to bear children. When both perspectives are presented, the paradoxes around PPs pregnancies are clearly visible. I show the tension and conflicting interpretation of the current medical approach. I will use the perspective of two different PPs, (Berta and Luisa), about the same pregnancy: Berta’s pregnancy.

Dominant perspective

From the beginning of my fieldwork I sensed that reproductive rights were ambivalent for PPs. One of the first signs of that was the reaction of the psychologist coordinator of field activities at the NGO where I based my research. After I expressed my intention of following PPs who had become pregnant since they started in the job she said “Ugh!!, [PPs pregnancies] very frequent, too much!” Yet, after she did a quick mental review of the list of PPs (of a total of 24 PPs working in the NGO: 20 were women and four men) only two so far had actually become pregnant since they worked as PPs. Considering that most PPs were of childbearing age, two pregnancies out of 20 female PPs did not seem ‘too much’ to me.

I started sensing something that surfaced throughout my fieldwork—that although I was told that female HIV+ pregnancies were a right as recognized by MOH policy, this right coexisted with attitudes that contested it. Constantino, a PP, revealed this ambiguity, “If HIV+ women have not had children [yet], they could have one and that’s enough, and if they already have one they should stop.” Angelica, a PP in her fifties, told me, “If HIV+ women have no children yet, I understand, like Delfina.” But if they already have, even if it is only one, two …or three, they don’t need more. One, two …or three, that’s all.” Both Constantino and Angelica declared that they had already satisfied their reproductive wishes. Their words and those of the psychologist coordinator expressed what most health workers told me; all echoed population policies and GAD dominant discourse. In response to this perspective, I now present the PP case study of Berta.

1 One of the two PPs who became pregnant.
The wish to bear a child: "We decided we want to have a child"

One of the orthodoxies present in GAD discourse is that African women have more children than they want/should, and this is due to a lack of access to family planning services together with the centrality of motherhood in defining African women’s identity. The paradigm of modernity present in global health and GAD discourses considers that African tradition is detrimental for women. During my fieldwork, health workers often represented women as victims of African tradition constrained by family obligations and compelled to have many children. However, Berta’s story provided me with another view.

Berta is one of the most senior PPs as well as the first to become pregnant while being a PP. She is the mother of two healthy boys. Her first pregnancy, prior to her HIV diagnosis, was unplanned. Berta decided to take an HIV test as part of the prenatal services. When she disclosed her HIV+ status to her husband, he abandoned her. She also had previously lost her family support. Berta took care of the boy on her own, without having a job, money or family support. By contrast, her second baby was conceived by choice with her new partner who was also a PP. What follows is a description of the tension that Berta balanced regarding her reproductive rights, which clearly questioned the above-mentioned orthodoxy.

We decided we want to have a child. I had suffered a lot with my other son because I wasn’t working, I had no money. So I wanted to have a child to be able to feel the soothe of growing a baby in the belly while having money, to raise a child since he is new born, raise a child until he is grown up, being able to buy things, not like I did with my first child. So we discussed and we decided we wanted to have a child. And we had. It was such happiness for us.

Berta’s job as a PP granted her access to health services, so she confidently conceived her baby. I asked Berta what was the reaction she encountered when she got pregnant.

[The NGO] doesn’t like PPs’ pregnancies. When I got pregnant [in 2009]), I was the first one, everybody was telling me “How is it that you got pregnant? Are you going to jeopardize your health?”

However, Berta knew that her health was not in peril, because she had followed medical recommendations. She felt that her co-workers only used this argument to make her feel uncertain. I asked her if there were changes towards HIV+ women pregnancies and she said,
Before it [HIV+ women pregnancies] was condemned; nowadays [2011] as per the MHO policy, it is a woman right. There are recommendations: it is just to have a good CD4⁸, good health and an interval of three years [between subsequent pregnancies] for allowing the CD4 to increase.

Berta’s excerpts show the changes from the exertion of condemning pregnancy to a regulatory control in public policy regarding HIV+ pregnancies. She acknowledges that HIV+ women should consider their medical condition when deciding to pursue a pregnancy, and this is precisely what she did. Berta’s attitude coexisted with a significantly more restrictive attitude towards pregnancy in HIV+ women that was expressed by others as I stated previously.

**Dominant perspective regarding Berta’s pregnancy**

During my fieldwork, elder PPs and nurses referred often to Berta’s pregnancy. I use below an excerpt from Luisa, also a PP. Luisa’s view of Berta’s pregnancy illustrates the most common perspective among health workers.

HIV+ women can make children, but it is not just for the sake of it, they can’t decide this way, they have to make plans. They have to consult the doctor, it [make children] is not their option. On the palestras we tell others [asking a doctor for authorization prior to getting pregnant], [so] we have to give them example. PPs make children just like that, they don’t talk with doctors. How can they give recommendations they don’t follow later on?

I thought this was nonsense, because I knew Berta had followed the rules, with the exception of asking a doctor for authorization. So I asked Luisa, “But patients don’t know if they [the PPs] have asked [the doctor for authorization] or not.” She looked at me, smiled and said, “But we do [know it], and we have to be an example.”

Both Luisa and Berta were talking about biomedical rules. The difference is that Berta understood that she could exert self-regulation using biomedical knowledge that she had acquired through many years of ART treatment literacy, thus she had expertise. However, Luisa understood that a doctor, an authoritative agent of expertise (who would likely recommend Berta to stop bearing children),

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⁸“CD4 (Cluster of Differentiation 4) cells are the most important cells in the immune system. A type of test called a CD4 count tells you how many CD4 cells there are in a small sample of blood. The more there are the better. Decisions about when to start treatment are often based on the CD4 count.” (http://www.aidsmap.com/CD4-cell-counts/page/1327484/ accessed on 29-2-2012). CD4 has become a common term among PLWHA.
should be in control of the biomedical rules. Berta rather avoided getting such a recommendation.

**Bringing normality to a life: “But we are also human beings”**

Many scholars have argued that for HIV+ women and men, the desire for children was perceived as bringing ‘normality’ to their lives. Their seropositivity strengthened their wish for children viewing them as ‘bringing hope and happiness’ and giving them a ‘reason to live’ (Cooper et al. 2007). PPs are enmeshed in a process of identification and negotiation of the multiple aspects of identities handed to them in the positive living discourse and biomedical dictum and these inform the PPs how to live and be. The multiple identities are conflicting and confusing since PPs have to relate to multiple meanings simultaneously,

The problem with (PPs’) pregnancies is that we are an example for the public; but we are also human beings. We want to be happy, to live, become mothers, fathers,... ah, if I could have a child...[Berta].

PPs are caught between the collective and the personal (the two poles of identity politics). In the PPs’ lives we see how various balances are made between common political efforts (to provide family planning services to avoid unintended pregnancies for HIV+ women and to reduce African high fertility rates) and individual endeavours to rework a devalued identity and regain ‘normal’ lives. This ‘normal’ life entails bearing children, especially now that their lives are going well because of their good health and their good material conditions.

I asked Berta if she wanted to become pregnant again. She said, “Yes, as far as the conhidades estejam estaveis (conditions would be stable), I want a girl.” I asked her what those conditions were. She told me, “To have my house finished. To have the house well organized. To have the conditions for my kids to go to school. To have good nutrition and good clothes. For all this I need to keep working.” Berta refers only to material conditions because her job grants her access to health and to PMTCT services. However, her job is insecure and she is well aware that she can lose it any time.

Berta’s understanding of her reproductive rights did not coincide with the biomedical regime that seeks to regulate HIV+ people’s lives. She manifested her nonconformity with the requirements of her job as a PP, thus avoiding a consultation with a doctor prior to her pregnancy, and omitting the consultation when she listed the rules. Berta challenged the regulation in biomedical discourse that confers the control of the rules to a doctor, and in doing so exerted her agency, understood as room to manoeuvre in self-regulation. Nevertheless, co-
workers questioned her pregnancy. Moreover, she also had to manage the uncertainty of what could happen with her prized job. The workings of therapeutic citizenship for PPs should be analysed in the context of an authoritative biomedicine, as referred to by Braga (2012). PPs work in an authoritative health apparatus and their job is based on their exemplariness and on mandatory public testimonials; thus, they can fear losing their jobs if they are found to be pregnant. It takes courage and strength as well as a demonstration of agency to negotiate the PP job requirements with the desire to have a normal life by becoming pregnant, even within the medical rules.

**Concluding remarks: When a right becomes ‘acceptable but not advisable’**

In this article, I focus on how PPs can make claims of recognition of their reproductive rights in a narrow “parallel therapeutic state” (Nguyen 2010) despite the rights-based approach fostered by global health. Population policies and GAD discourse are entrenched in health workers’ and some PPs’ attitudes toward PPs’ right to bear children. My data show that female PPs of childbearing age feel as entitled as anyone else to bear children. They also feel confident about a successful birth due to their knowledge about and access to ART and PMTCT services. However, despite their confidence, the female PPs are compelled to pragmatically negotiate their reproductive rights with health workers and other PPs and in doing so, they bump into the contradictions between the everyday lives of women and the interests of dominant biomedical discourses and policy-making. This paradoxically constrains their reproductive rights.

In a rights-based sexual and reproductive health approach fostered by global health and GAD agendas, women are to be seen as citizens with rights, autonomy and choice. As citizens they are entitled to make claims and to participate in decisions that affect their lives in regard to the health programs promoted by the NHS through national and international agencies and INGOs. From this perspective, the basis for interventions, instead of being the programs of international agencies, should be the citizens’ own understandings and actual struggles (Institute of Development Studies 2003). One of the aims of the rights-based reproductive programs is to empower women to control (understood as the freedom to decide if, when and how often to do so) their own fertility and sexuality by providing information and alternative services. PPs work within the public health system, thus – as they are well informed and have access to health services guaranteed – they have the possibility of maximum choice and minimal health problems, as Berta demonstrated.

During my fieldwork, it became evident that rather than meeting the PPs’ reproductive needs, the approach in the Chamanculo health district was to control the PPs’ fertility, and make them more dependent on medical
professionals. This dependence carried the potential of abuse in the context of family planning programs. Much has been written on women needing to gain autonomy and power to decide on matters that affect their own bodies (Ginsburg & Rapp 1991). PPs have indeed achieved the autonomy to decide on their lives through the years of conscious self-discipline that allowed them to gain ‘courage’ and ‘strength’. Yet, even while this has been achieved, their reproductive rights are still not fully recognized. Population policies seek to govern PPs bodies while neglecting the socio-economic and cultural context in which their lives are enmeshed.

I suggest that the particular conditions under which the dominance of the biomedical discourse comes into play in the lives of female PPs questions the workings of therapeutic citizenship. Although PPs may be considered as privileged citizens due to their larger access to entitlements compared to other patients, their reproductive rights are constrained by the requirement of being an example to other PLWHA. The obligations and responsibilities of some PPs clashed with their rights. Therapeutic citizenship illuminates issues of rights, claims and social exclusion. Nowadays in the Mozambican case, therapeutic citizenship also illuminates that as PPs are being included in the “parallel therapeutic state” as privileged citizens, paradoxically they might be simultaneously excluded from certain rights and their longings for a normal (reproductive) life might be made unachievable.

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Practicing engaged fatherhood

Conversations with men in Mexico City

Mariana Rios Sandoval

In the summer of 2007, I carried out a study in Mexico City to explore the links between masculinity and fatherhood among men practicing a style of parenting virtually absent from the region’s masculinity studies literature: engaged fatherhood. Relying exclusively on qualitative methods – mostly conversations with men around everyday childrearing activities - this research aimed to add nuance to the portrayal of fatherhood practices among Mexican urbanites, and to pay a closer look at how such practices played out in the way these men articulated their own masculinities. In the present article, I take the reader through the main findings of my research.

“What has changed?” I asked the man sitting next to me in a crowded, noisy bar in Mexico City, aware that this was a very vague question. Six years before that Tuesday evening, Julio had kindly agreed to participate in the research that became my thesis at the Amsterdam Master’s of Medical Anthropology in 2007 (Rios Sandoval 2007). At that time, we had talked at length about his experience as the father of a little girl, who was about to turn two-years old. My interest in fatherhood had grown from the observation that most of the literature on

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fatherhood in Mexico and the Latin American region revealed distance and absence – in a variety of forms – as a recurring theme. My aim was to focus on the opposite, on what seemed to be absent in the literature: engaged male parenting. In particular, I wanted to know why men would practice an engaged fatherhood style in a context that seemed to be, at least in the literature, so unconducive to it. Thus, in the summer of 2007, I carried out a study that aimed to explore the actual engaged fatherhood practice of a sample\(^2\) of men residing in Mexico City. Relying exclusively on qualitative methods (mainly semi-structured, open-ended interviews),\(^3\) this research did not pretend to be representative of the universe of Mexican fathers, but rather to add nuance to the portrayal of fatherhood practices among Mexican urbanites, and to provide a closer look at how these men articulated their own masculinities. In the present article, I take the reader through the main findings of my research.

Sitting in a bar six years later, Julio took a long pause to search his mind and feelings for an answer to my question. He took the audio recorder from the table and held it close to his mouth as he began speaking. His words will not be presented here, but have been woven into the conclusions of this article. I have done this for two reasons. The first is I am sure Julio’s words will make more sense after the reader has a glimpse of what the original research was about. The second reason is that just like the screenplay writer of a soap opera, - or a Mexican *telenovela* (soap opera) if you will - I hope to persuade the reader to stay until the end.

**A study of men as men**

Reproduction is a central feature of social life that is inextricably bound up with the production of culture. Therefore, reproductive experiences are a space where cultural understanding and hierarchies are generated, and normative categories including masculinity and fatherhood are reproduced, but also challenged

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\(^2\) My study sample was composed of nine men (three divorced, six married) recruited through snow-ball sampling, who presented themselves as fathers who were actively involved in raising their young children (younger than five years old). Men in the sample ranged from lower- to upper-middle class; more than half had completed or were completing postgraduate degrees (five), while the others had quit university (undergraduate programs) after a year or two. All participants but one resided in Mexico City; one was originally from Argentina, and one lived in Canada where he was pursuing a graduate degree. Names in this article are fictitious, and were chosen by the participants.

\(^3\) I have discussed the methodology, study sample and matters having to do with reflexivity and accountability in the research process at length elsewhere (Rios Sandoval 2009). In that publication, I addressed mainly two issues: the gendered dynamics derived from my being a young female interviewing men and how that might shape the inter-subjective production of results and analysis. I also address matters having to do with distance and proximity, which proved to have little to do with the fact that I was doing my research at home, but rather with the expectations that I, as a researcher, had about the people I set out to study. The latter relates to one of the main conclusions from my research, which is that I was expecting to find a group of men holding a vocal discourse of engaged fatherhood and a rather disengaged practice, but in fact, I found quite the opposite.
Along the same line, my research took reproduction as a privileged space to examine how fatherhood and masculinities were constructed among a group of men living and working in Mexico City. My study was a men-centred one, meaning that it focused on the experiences of men as engendered and engendering beings, that is, as being shaped by gendered and shaping others in gendered terms (Gutmann 2003, 2006). As such, it was framed within the relatively recent field of masculinity studies, which in Latin America has been significantly informed and fostered by feminist scholarship and activism throughout the region (Gutmann 2003).

Most research in Latin American masculinity studies has aimed to show that there is not just one way of being a man. Instead, recent studies have shown that there are multiple practices and meanings attached to being a man that are shaped by socio-economic context, class, and ethnicity. The vast majority of studies of men-as-men, in Latin America and other countries, take Connell’s model of hegemonic and subordinated masculinities as an analytical framework (Connell 1995). Thus, what it means to be a man and a father in Latin America, both in social and personal histories, has often been thought to be best appreciated in relationship to hegemonic masculinity in the region (Gutmann 2003). Recent studies have nevertheless put into question the existence of a single hegemonic masculinity, both within countries and between them (Gutmann 2003, Viveros Vigoya 2003). Latin America, for instance, has undergone a series of major social and economic changes in the past decades, most importantly, economic and welfare reform, a massive inclusion of women into the labour force, and profound transformations in the family structure and personal relationships. Although how these changes have impacted gender and power relations remains largely understudied, there seems to be agreement in that they have affected the perception of what constitutes the hegemonic masculinity (Escobar-Latapí 2003, Gutmann 2003 and 2006, Olavarría 2003, Amuchástegui & Eggleton 2007). Authors have referred to this destabilization of traditionally dominant forms of discourse as a masculinity crisis, pointing out the fact that at least in urban contexts (where most of the studies have been performed), traditional male identity and the old social contracts that used to shape men and women’s relationships are being widely challenged (Amuchástegui 2007, Escobar-Latapí 2003).

In Mexico, part of this traditionally dominant model is the father-breadwinner, whose absence is often portrayed as the most prominent feature of fatherhood throughout the country. However, recent studies show that despite being pervasive, this model falls short of describing the great diversity of fatherhood ideas and practices found across the region (Gutmann 2003, 2007). The research I carried out in 2007 documents part of this diversity.
Fatherhood and emotions

The relationship between masculinity, fatherhood and emotion remains considerably unexplored. Mora (2005) argues that although emotions are often neglected by social sciences, they can tell us much about the reproduction and challenging of normative values. This Mexican scholar argues that fatherhood is a fundamental dimension of masculinity, and that one of the many symbolic elements of the traditional model of fatherhood, namely responsibility, is embodied by the ability to procreate and provide for offspring. Mora argues that research on fatherhood should not be limited to understanding the link between various masculinity codes and diverse fatherhood practices. Emotional issues should be explored as well as a “signifying liaison between identity and action”, and as motor and reflection of transformation processes (Mora 2005:27).

Emotions, he concludes, are situated in space and time and regulated by social and cultural factors, and constitute both a motor and reflection of change. Since the focus of my study was on the practical activities of child rearing (picking up children from day care, preparing food, playing, changing diapers, waking up at night to bottle feed, etc.), I was expecting cut and dried narratives. Instead, men in the study talked at length about their sons’ and daughters’ personalities, favourite activities, cartoons or songs, best friends, and so on. One of them, who happened to be most passionate about films, told me the following about his son’s taste in movies:

Bernardo is an excellent film critic and not just a passive viewer, he knows all the characters, dialogues, and can watch a particular film one or two hundred times. We play the characters from his favourite films. Sometimes he tells me that we should be the same one. I think that is nice because it means that he likes us to be similar.”

Participants also expressed feeling uneasy, anxious or angry in certain situations. This contradicted my fear of hearing a romanticized picture of their experiences. Santiago, for instance, was straight forward about his mixed feelings in the labour room. He described it as a very tough experience, since the baby had swallowed amniotic fluid at birth and had to receive CPR (cardiopulmonary resuscitation). “Frankly,” he said, “it was terrible…it started like something great, when I saw her for the first time, but it developed into something very difficult.”

In her study of divorced fathers, Arendell (1997) found that the majority of men in her sample ignored basic information about their children, such as their birth dates and grades. A small group in her study, however, could easily provide not only birth dates, but also the exact times of their children’s birth. The author confessed to have reacted with some surprise to the fact that those fathers were so knowledgeable about their children, since they were so strikingly different from
most study participants. In my study, however, participants generally provided very distinct accounts; these men were proud to share similar passions with their children, and expressed satisfaction when describing an activity that belonged to the father and daughter/son sphere. When talking about his daughter, this is what one of the participants told me:

Mariana is not a very extroverted person, and whenever she faces a new situation, she likes to observe before exposing herself, physically or emotionally. She is a great observer though, and together we spend a lot of time observing, touching, feeling the texture and the smell of plants. She has come to understand the notion of parenting and growth through observing plants and animals, and she knows that big plants are parents to the small plants, which are the equivalent of babies. Mariana also likes smells and essences, and she has the ability to recognize many different smells with an amazing accuracy. Diego, 37.

I was pleasantly surprised to listen to the participants’ accounts, filled with details and feelings, which I interpreted as an indication of the intense involvement in their children’s everyday lives.

**Everyday life**

Although the arrangements described by the men in the study varied, they all shared similar activities in a typical day. All participants were involved in several tasks and their days were usually organized around their work and the children. They were involved in ‘indispensable’ tasks, such as their child’s personal hygiene (bathing, clipping nails, etc.) or taking them to the doctor. They also participated in tasks more related to housework, such as cooking and doing the laundry, and leisure activities such as going to the movies, playing, drawing, singing, or going on short trips to the countryside. My impression was that the men attached equal importance to all tasks, which was directly confirmed by some participants. Being involved with the children was usually linked with doing domestic chores. They swept, cleaned, cooked and washed, unless they had a maid, in which case neither they nor their partners dedicated much time to those activities.

Some men expressed an awareness that their style of parenting was not common, since other people, such as teachers, doctors, and other parents did not expect them to be as involved as their partners. I asked Santiago, for instance, if there were any activities regarding his daughter Ana that were exclusive to him or his wife. “No,” was his immediate answer. However, he told me he had noticed that other people assumed that was the case, like Ana’s teachers or her paediatrician. He then said: “Even when I’m the one taking my daughter to the doctor’s office, he tells me to communicate to my wife – Irene – how to give
Ana the medicines, though I give her the medicines too!”

Throughout the years, the amount of time men and women allocated to child-rearing activities varied depending on the circumstances. Usually partners relied on one another, even those who were separated, and whenever one of them was less present, the other partner would compensate for that time and activities. For example, Santiago described the bond with his daughter Ana as a very strong one, and said he felt truly happy about seeing his daughter every day, and the amount of time he got to be with her. At the time of our interview, however, it had been a very busy time at his wife’s job. She had to be away a few weekends and, during the week, her work meetings finished late at night. Hence, sometimes Ana and Santiago did not see his wife for days. Far from blaming his partner, Santiago explained that, in his view: “Parents cannot give up their professional projects. Besides, I think we do a good job combining our activities with taking care of her (Ana). It is a matter of supporting each other, and filling in for one another in case something comes up.”

The men, who were less involved, were usually those who did not live with their children. This was a matter of concern for them, and also a central issue in the arguments with ex-partners. The three separated men in the study were engaged in a permanent negotiation with their partners about the time they could spend with their children. When asked about what they wished to change, they all expressed that although they knew it was not possible, they would like their kids to live with them full time. They all reported striving to reach an arrangement in which the kids spent an equal amount of time with their mother and father, something they hoped to accomplish in the near future.

Parenting tasks were not always equally distributed among men and women. However, both were just as likely to participate less or more at a given time. Furthermore, even when a partner’s engagement changed over the years, usually men and women’s participation was on average similar according to the men’s stories. As mentioned before, this outcome was based on one side (the men’s) of a story that necessarily has two versions. Having heard the women’s views would have provided a more balanced picture since perhaps the men’s partners might not have had the same perception of what constituted a ‘great’ amount of time, a ‘fair’ arrangement, a ‘stressful’ period, or ‘fully’ relying on one another. Comments made by participants in the original study suggested that probably most of the partners and ex-partners’ accounts would not have differed significantly at least regarding parenting tasks. For example, half way into the only interview held in a participant’s home, the man’s wife arrived at the apartment with their younger son. The husband took his son to another room for a moment, during which time I had the chance to have a short chat with his wife, Atenea, and ask her a couple of questions I had already asked her husband. Their responses were remarkably similar.
Work and money

Work and financial concerns invariably emerged in the participants’ narratives as central issues of child rearing. In all but one case, the men and women had full-time jobs during the time of pregnancy. Women worked until the third trimester in order to save most of their maternity leave for after their babies were born. All men were able to negotiate some time off work, ranging from a couple of days to six weeks. This negotiation was done informally, since at the time I carried out my research, participants referred to paternity leave as a distant dream, and even today, most men do not enjoy this benefit.

Once a baby was born, participants who enjoyed more favourable working conditions, experienced the first sleepless nights of diaper changing and lullaby singing as a tiresome, but still an overall exciting period. Their basic economic needs were comfortably covered and they could negotiate relatively flexible arrangements regarding working hours. In addition to their family’s support, three participants had the resources to hire extra help from nurses or maids. Santiago’s experience was typical of this group. He and his partner Irene were working full time when their daughter was born. Irene took the three months of maternity leave after the baby was born, and not the 45 days before birth and 45 days after birth, as established by law (then and now). Santiago asked for one month of paid leave, which he obtained by foregoing holidays for quite a long time. Once back home from the hospital, Irene and Santiago hired a full-time (24 hour) nurse to help them out with the special care Ana needed initially, such as injected medication and antibiotics, due to complications at birth. At first, the couple intended to rely on the nurse just for a short period, but after a while they felt well adapted to her nursing support and decided to rely on that help throughout Ana’s first year. During the first month, Santiago, Irene and the nurse would wake up to feed Ana with formula. Santiago affirmed that he did not recall that period to be particularly exhausting. Although they had the nurse’s help and the choice not to wake up at night, they both did so because, as he explained, “the excitement is such that you do feel like waking up.” He continued, “that is why I asked for a month of vacation, to be with my daughter. I did not ask for that month to get eight hours of sleep.” After a while, the nurse

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4 The first ten-day paternity leave was granted in Mexico City only in 2008 by the Mexico City Human Rights Commission, followed two years later by the federal court for electoral matters, the TEPJF. In 2012, the former president, Felipe Calderón presented a labour reform bill that generated public outcry due to the reduction of benefits for workers, flexibility in contracts and outsourcing, but which also included a paragraph for a ten-day paternity leave that would extend the benefit to all 32 Mexican states.

5 Having live-in help is not uncommon for upper-class families throughout Mexico. In a similar fashion, nurses are sometimes hired to provide help at home day or night – during the first days after the newborn’s arrival.
started coming at seven in the morning until seven in the afternoon, when either
Santiago or Irene (after her maternity leave ended) had returned from work.

On the other hand, participants who had an unstable working situation, or a
lower salary, had less negotiation power at work and usually worked longer
hours. Carlos was one of the men grouped in this second category. This is how
he described part of his experience during his first months as a father:

I was so desperate to work [for money] that I took a job at a furniture
shop. I started at eight. It took me two hours to get there and two to go
back. The job I had did not allow Laura (his partner at the time) to stay
home longer than her leave lasted, so she went back to work immediately
after. Plus, we had to support two other kids (kids from his partner's
previous relationship). She went back to her work at the diner, but was
transferred to the night shift. I would pick her up every day from work at
one in the morning. And then during the night I would wake up with
the baby's crying. I would sleep in the bus to make up for the time I was
not sleeping. I just couldn’t help her during the week. Friday and
Saturday I attended to my son at night. I felt such tenderness towards
him. I often sang him a song that John Lennon wrote for his own son. I
did not want to miss those moments with him.

Money was not the only conditioning element affecting the men’s involvement
in caring for their newborn. The experience of being a father could not be
properly understood without taking into account their personal views and
history, the balance of engendered power relations within the household, or how
broader discourses about fatherhood were appropriated. In my study, I found
that a comfortable financial situation was undoubtedly a critical enabling factor.

Laws and norms

During our interviews, the men insisted that to mainstream men's participation
in childrearing, much had to change on paper and in practice. The participants’
outlook on change was often a pessimistic, for which they gave several reasons.
Odiseo, for instance, strongly believed that paternity leaves were not going to
become official any time soon. Similar to other participants, the reason he gave
was the state of the country’s economy; it was impossible for the Mexican
pensions system to absorb additional leaves. Nevertheless, he believed that the
issue was of great importance, and extended the argument to other parental
benefits. Given the current situation, however, he had mixed feelings about the
responsible fatherhood discourse, since it was not realistic to talk about true
engagement as long as public policies to enable men’s involvement in practice
were lacking.
I often heard that establishing paternity leave in the law was just part of the problem. Laws cannot be enforced, said the men I interviewed, if practices are not socially accepted. Mauro, for instance, told me: “Maybe they (paternity leaves) could happen at the policy level, but I think it is unlikely that things are going to change in practice as well.” He explained that in the academic environment where he used to work, it was hard for women to take their maternity leave without having their work negatively affected. “Sometimes women are not granted positions because they might get pregnant, and lower their productivity at least for the first months,” he said. He explained further that the academic system was not set up to absorb the time people are absent on leave, because of a lack of sufficient resources and also because maternity and/or paternity leaves were not seen as a priority. He concluded that another point against paternity leaves was that Mexican society was in general very sexist; taking care of children was thought to be a women’s responsibility. Among all participants, criticism of the commonly held idea that men and childrearing belonged to separate worlds, was followed by references to woman-headed households and same-sex parents so as to argue that things were changing and traditional gender roles were not as valid as they used to be. Furthermore, participants expressed that they were in the midst of change, and expressed an urgent need for new roles to be defined and new ways of being father to be constructed.

Concluding remarks

At the end of the study, I came to understand participants’ fathering experiences as a day-to-day creation of space. This ‘fathering space’ can be viewed as a network of various elements, in which resources, family relations, societal norms, partners, children, personal history and views were interwoven in such a complex manner that it would be impossible to isolate each factor to track its effect. Furthermore, it would make no sense to do so. Fatherhood is an all-embracing cultural practice and, as such, should be addressed in an integral and comprehensive fashion. Men in this study reported to be striving to create the conditions for practicing what they – in their own context – perceived to be an unusual parenting style. However, they also were aware that strategies for achieving some of these conditions were in their hands, and some were not.

The picture of fatherhood that derived from these men’s accounts is one marked by creativity and inventiveness. However, the participants’ experiences did not exist in a social vacuum, but rather were rather the product of their particular milieu, context and history. Consequently, the personal stories stressed the dynamic balance between what were traditional and what were new practices, between change and continuity.

While recounting their stories, the participants navigated across the boundaries of the new and the established, between what they perceived as the
old and the modern way of being a man and a father. This was reflected in the participants’ reports of feeling lonely in their fathering style, and at the same time simply behaving in line with the current large-scale societal transformations that reduce inequality between men and women.

Men in this study considered engaged fathering an uncommon albeit important and necessary form of parenting. Interestingly, however, I found that the justification for a higher participation of men in childrearing was often articulated around gender equality and not a responsible fatherhood discourse. Arguments for the acceptance of involved fatherhood relied more on the acknowledgement of the current flexibility in men and women roles, than in reclaiming fathering as a feature of manhood.

Men in this study did not consider earning an income as the main feature of fatherhood. Rather, work and money were seen as critical enabling factors that had a profound effect on the quality and time dedicated to childrearing. This responsibility was shared with women, whose professional projects were seen as a priority and key element that was taken into account when making major life decisions, just as the men’s professional obligations were. It is worth remarking that my study sample was composed of highly educated men who had usually partnered with equally educated women. Furthermore, although only two participants had high-income jobs, all participants were employed at the time their interview took place, as were their partner and ex-partners. In other words, class position and economic stability probably plays an important role in the shifting of the provider role, traditionally performed by men, to one shared between men and women.

While defining their fathering practices, men in this study made women visible at all times. The fundamental role of women in the negotiation of fatherhood and masculinity, although largely acknowledged in the present study, remained largely unexplored. At the time, I concluded that a future follow-up research should include women’s views. First and most obviously, because parenting stories have necessarily two versions. Furthermore, as I hinted through this article, structural factors such as class position greatly shape men’s experiences as caretakers. Given that society remains stratified by gender, it is likely that women experience child rearing differently from their partners. After all, mothering just as fathering, takes place in a society that views and treats men and women distinctly. Exploring and understanding men and women’s experiences jointly, is therefore critical to get a comprehensive grasp on the negotiation of gender relations and parenting experiences.

Although some things have changed in the Mexico City since I finished writing my thesis, the fatherhood scene has not. According to men in the study – and this is a position I share – paternity leave is a key symbolic and material benefit that would encourage engaged parenthood. However, change is slow and only a handful of employers have granted leave to male parents this far.
“What has changed?” Julio repeated my question during our interview in a bar in Mexico City, six years after our first conversation. He responded:

Not much, nothing comes to my mind... Oh wait!, ‘I thought of something: the context has not changed, but I have. I mean, I would be a completely different person if I had not had my daughter. All my life is arranged around having her; the kind of work I have, my routine, my friends, my choice in partners, my plans for the future. I know much depends on the context, like how I was raised and the city I live in, but I now realise I made several decisions to create the place where I am right now.

As I listened to Julio, I began thinking about ways to analyse his words. “This is an example of the construction of fatherhood space,” I said to myself, “and this is also an example of how structure and agency interplay in the experience of fatherhood,” I added to my train of thought. Julio realised my mind was racing and asked what I was thinking. “Many things,” I replied, “but mostly that I am happy with the topic I chose for my thesis, because I got to know the experiences of such engaged fathers like you.” This is a response, I have to say, I would have never allowed myself during fieldwork, but since we were doing a casual follow-up interview and since we had become good friends over the past six years, I decided to make an exception. He looked happy with my answer, and I was too.

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Care and Autonomy
Between patient, doctor and machine: Nursing in a Dutch intensive care unit

María Fernanda Olarte Sierra

Intensive care units (ICUs) are complex places where death, dying and suffering are central components of the everyday lives of those who work there. In addition, conditions in ICUs raise constant ethical dilemmas due to the availability and prolonged use of life-sustaining technologies. Nurses working in such places are known to strive to maintain human contact and care not only for their patients, but also for relatives, to some extent. I argue that nurses’ caring involves direct contact with patients (and their relatives); but ‘caring nurses’ also supposes that they act as intermediaries between physicians and relatives to guard the patient’s interests during continuous use of life-sustaining technologies. An eloquent example of this occurs in an ICU in the Netherlands. I present ethnographic data that evidences how nurses act on a patient’s behalf by voicing their (or their relatives’) interests. This acting/voicing implies that the nurses develop strategies for negotiating with physicians about when to stop or continue sustaining life. Nurses are able to take this action because of their verbal and non-verbal communication with the patients and relatives.

[nurses, ICU, patients, physicians, technology, care, negotiation, the Netherlands]

Introduction

Medicine is committed to saving lives and this attitude towards life leaves little space to think about death, or about how people face death. It seems that there is a clear trend for modern societies to deny the inevitability of death by developing and using ever-increasing medical technologies to help diagnose and treat very ill patients. The places where these technologies are used are known as intensive care units (ICUs), which were introduced in the 1950s in the United

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The use and availability of high-tech medicine has had an impact on nurses’ roles (Groen 1995). In ICUs, monitors follow the patients’ vital signs, and bedside technology keeps patients alive. However, nurses continue to have a fundamental role in the care of ICU patients.

Ever since the introduction of ICUs, nurses have been in charge of closely monitoring only one or two patients per shift. From the nurse’s perspective, what has changed is that they now have the help of technology for monitoring the patients. Before this technology existed, “they were the alarm” (Groen 1995:18). Despite the omnipresence of medical technologies, ICU nurses still struggle to provide optimal care for patients addressing personal (comfort), and medical (pain control) and technological aspects (following monitors, checking ventilators, completing patients’ data in computers, etc.). ICU nurses care for their patients in multi-dimensional ways that compose the whole of their work, and this is central to patients’ well being (Goode & Rowe 2001).

In this context, I focus on ICU nurses for three main reasons. First, they have had a training that differs from medical doctors and this may represent differences in the way that the information, condition and needs of the patient are interpreted. Second, the nurses interact more with patients and their relatives than the doctors do. “They are acutely aware of the family during this time… More often than not it is the nurse to whom the family has been putting their urgent questions” (Lock 2002:111). In this sense, they represent a connection between the families and the patient in the ICU. However, “nurses’ activities are not confined to administering medications and monitoring the bedside technology. Nurses also engage in types of patients care (e.g. verbalization and … stimulation) that transcend [the] technical” (Anspach 1993:60). These activities produce a deep social interaction between patients and caregivers. Third, nurses mediate the patients’ liminal state in between life and death. Nurses are between the patient (and the family) and the physicians who “have the knowledge for reaching life-and-death decisions, but they may lack potentially valuable sources of information that can only be acquired through interaction [with the nursing staff]” (Anspach 1993:83).

In this article, I address the practice of nursing for ICU patients. I argue that nursing implies first and foremost an ethos of care (Rose 1983, Mol 2008, Puig de la Bellacasa 2009, 2011, Singleton 2011) that involves the patient, relatives and nurses. I develop my argument in three steps. I first address the analytical framework that informed my research. Second, I present the ICU in a Dutch hospital that I studied. Third, I address the various ways and dimensions in which nurses care for patients. I conclude that nursing care practices have had an impact on the dynamics and politics of the ICU where the study took place.
Analytical perspectives

Nursing as a gendered profession

Women have been in charge of caring for the dying, the dead, and the corpse throughout history in their roles as wives, daughters, and sisters. Much caring was (and is) carried out in the home setting as a domestic routine and task. By the 19th century, medicine was established as the authority in health issues. This monopoly of life brought the medicalisation of illness and death became pathologised (Abbott & Wallace 1990, Field et al. 1997, Lock 2002). Under such circumstances, the gendered role of decisions for handling the sick moved from women to men, since medicine (at the time) was an exclusively male domain. This change was followed by the displacement of childbirth, childcare and dying from the home setting to hospitals, which became monuments of knowledge, science, and rational thought. Untrained women were not accepted in such places. Nevertheless, physicians did not take care of the ill; they diagnosed and treated the body. Therefore, the nursing profession was established in response to the high degree of control needed in hospitals and because physicians wanted someone to take care of the patients. This work was initially a philanthropic (or underpaid) task exclusively for women (Abbott & Wallace 1990, Adams 1993, Walter 1993, Field et al. 1997). Thus, the women still had space to be caregivers, albeit this was a somewhat contaminated task of taking care of the dead and the sick body. Meanwhile, the living body was the physician’s domain and the soul was the responsibility of the male priest or other spiritual advisors (Adams 1993).

Today, nursing remains a gendered profession, since all practices related to sustaining someone’s life — that is, all caring practices — are widely feminised. This is not only because women mainly perform these tasks (although not exclusively), but also because such tasks continue to be undervalued (Arango 2011, Arango & Molinier 2011). Caring involves highly invisible tasks related to feeding, cleaning, rearing, and educating, and all of these are fundamental to maintaining someone’s life. In this sense, nursing is first and foremost an enactment of care, and caring practices that necessarily involve a way of doing (Mol 2008:4), that is embodied in those who perform the care (Mol 2008, Arango & Molinier 2011, Pérez-Bustos et al. 2013). For ICU nurses, caring means taking care of acute or dying patients and their relatives. This kind of care, especially for the dying, is rather invisible.

The acquired ability to sustain lives in current medicine created an obsession with death, and all deaths became medical failures (Bronzino et al. 1990, Lock 2002). Thus, the dying have been segregated from social life and their interactions are limited to close family members and health care professionals. One way to explain turning away from death is that in late modernity the body
became the representation of the self and death represents the end for any living entity (Foucault 1980, 1984, Small 1997, Clark & Seymour 1999).

Nevertheless this understanding of death cannot be reduced to the body. “It is impossible to interpret death [as] a merely physical event” (Hertz 1960:76). Death is seen as a risk to the social bond. It represents the fragility of human beings and the breaking of the order, for cultural life supposes the immortalization of the society. The loss of a member supposes a loss in the social body (Hertz 1960, Kearl 1989, Seale 1998). Therefore, ritual practices are set in motion to maintain society as a whole and bear witness to the fact that life has just ended for one person and not for the entire group. Grief and mourning help the survivors continue their lives and society can be perpetuated (Kearl 1989). In this context, a nurse’s role when caring for the dying (known as palliative care) is to help the patient and their families bridge the gap between the social and biological death. It is a way of integrating the very ill patients with their social environment in a time of profound disintegration. It is meant to build the meaning of the dying process together with the patient, and to provide both physical and emotional well being for the person who is dying as well as for their families (Clark & Seymour 1999, Goode & Rowe 2001).

The setting

The data presented here is from my Master’s thesis in Medical Anthropology at the University of Amsterdam. I conducted a six-week hospital ethnography (Van der Geest & Finkler 2004, Zaman 2008) in a prominent academic teaching hospital’s ICU in the Netherlands in mid 2004. The ICU was composed of a complex of six units, and it occupied a large part of the third floor of one of the hospital’s buildings. Four of these units were fully equipped for patients and the only difference was their size. Two other units were used as doctor’s offices and places for future beds. At the time of the study (2004), the ward had the capacity to admit 34 patients, but plans were for this to grow to fifty patients. Beds were distributed in thirteen double rooms and in eight single rooms for very acute patients.

As part of my ethnographic work, I conducted in-depth interviews with five intensive care nurses, (three women and two men). Four belonged to the ethics committee (I address this below); the fifth was a head nurse. All the nurses had the same training and their positions in the unit were equal. The nurses’ ages were comparable (they were in their late twenties to early thirties, except one who was older than the rest). Another common characteristic was that all the nurses were deeply committed to keeping human contact with their patients and families.

All interviews were conducted in English because I did not speak adequate Dutch. Interviews were tape-recorded for later transcription. Nurses’ informal
conversations with each other and with their patients and relatives were in Dutch. I paid attention to the nurses’, patients’ and family members’ body language, intonation and reactions. When I had doubts or needed further explanation, I directly asked the nurses.

It is possible that the ICU environment has changed in the eight years since I did this study. What I present here is part of what I registered for my AMMA thesis. I haven’t gone back to visit the ICU or the nurses. For ethical reasons, all names have been changed.

How to care?

Having set the stage, I now address two points to demonstrate how nurses care, but most importantly, I show how caring is an ethos, an embodied knowledge-practice that positively impacts ICU dynamics. I chose these two circumstances because they were recurrent topics that the nurses discussed with me in our conversations and that I saw during my observations.

Ways of communicating

Nurses perceive their role as much more than just following doctors’ prescriptions. They express that they search for the patient’s well being, can assess the patient differently than doctors do, and are able to know patients’ interests. The nurses’ close contact with patients allows them to have insight into the patients’ expectations for their treatment, moods, and the comfort they desire. Through such contact, nurses have developed skills to communicate with patients, even with those who cannot speak and are unconscious. Annelies, one of the nurses, said:

I’ve learnt how to communicate also with patients who cannot talk...I always want to stay in contact with the patient. Sometime talking is not possible, but we [nurses] certainly communicate. If I feel that there is a sign of communication, I react on it. Sometimes it is the blood pressure or the respirator that shows something...I’m not always talking; I can also touch the patient, be there. It’s more than talking.

This point triggered conversations regarding a nurse’s role in the ICU where the medical technology that surrounds the patients is fundamental for keeping them alive. Nurses expressed that they regard technology as a tool, not the core of care. Care implies the direct and constant contact with patients (both verbal and non-verbal), which constitutes a major source of information. The close interaction with patients, coupled with nurses’ experience working with these patients, led the nurses to differ from doctors about a patient’s prognosis from time to time. It is because of this extra information that the nurses feel they can speak on behalf of their patients. It is this other source of information that moves nurses to sometimes say when they think a patient is going to die regardless of
the charts, if the patient has had enough of a treatment, or that the patient still has a chance to recover. The following are some eloquent examples:

Matthijs: Sometimes I can see on the patient’s face that he is going to die. Even if I don’t look at all the equipment, I can see it on the patient, on how he looks, his skin condition…

Juliette: You see it in the face, in the eyes that the person is going to die. It’s also your experience of course. It’s some sort of instinct that you develop; I cannot really put it into words. Sometimes it’s just a gut feeling. Everything, all the numbers are right and still you have the feeling that things are not going well because too much is going wrong. It’s just too much for one body.

Annelies: It’s a combination of thoughts and feelings. It happened last week. I had a patient, she fell on her head; she had a very bad head scan and everybody though she wouldn’t make it. I was working on this patient and I was thinking totally differently. I felt she was inside, so I started to talk to her and she started shivering. She was reacting to what I was saying and everybody was like “Oh, that’s not possible.” But, the next day somebody by mistake stopped the sleeping medication, so she woke up the next morning. That was not good for her so she had to go to sleep again, but she was reacting and we spoke to her. But, it also happens the other way around, though, that you know that the patient is not going to make it; you know that there are no more possibilities. You’re taking care of a patient and you think “Well every fact is ok but I feel it’s going wrong” then you transfer the patient to the other ward and you think “This patient is coming back” and maybe it’s not today, not tomorrow but the day after they are bringing him or her again. Sometimes you know it.

Jaap: Some patients with good monitoring are doing well, but because of their illness and because of their past, and because of what happens and doesn’t happen you can say “this patient is not going to make it.” That’s possible but that’s tricky, sometimes, maybe two or three out of a hundred times you are wrong and the patient makes it. But often you hear later, when the patient is in another ward or at home that he has died. That’s when you ask about the quality of life the patient had after we dismissed him from the ICU, but I can’t decide of course.

As mentioned earlier, having extra information to assess the patient and not only relying on what the monitor or the exams present is due to the nurses being
involved in a process with patients. Interaction between nurses and patients is a required process, but the nurses also constantly care for the patients’ relatives as well. They do this because the relatives are also going through hardship, and because relatives do know the patient intimately. Juliette mentioned:

I don’t give the [relatives] medical information, but I try to get to talk to them afterwards, after the doctor has talked to them, and see if I can help them to understand the information and to go through this situation.

As the participants stated, they are able to listen and talk with patients and their relatives about their doubts, fears, feelings and ideas of death, the moment of death and, sometimes, after-life. Nurses are aware that they may not be able to answer the patient or family’s questions, but they give support to people in need of care. As some nurses commented:

Mina: It’s of course very hard to comfort somebody, because the only thing that you can assure is that patients don’t have a lot of pain, and you make sure of that kind of thing. But also, if you see that the patient needs to see his or her family for a little while, you give the patient the time, if you can talk to him or listen to him. And also you stay with the family after the doctor has talked to them, because if the situation is bad they will be very sad, it’s never easy on the family and so I also talk to them.

Annelies: I also prepare the family when I feel things are going wrong. They always need to talk, to ask questions, to cry. And I give them the space to do that.

Given these levels of communication with patients and relatives, nurses consider that they are able to voice what is better for the patient and what the patient and his/her relatives want in relation to life-sustaining treatments. From the nurses’ experience, this kind of treatment can have devastating consequences for the patient’s quality of life. In addition to this concern, and as result of this commitment and attachment to patients, nurses recognise that they too suffer in cases in which treatment has gone rather far and has damaged the patient’s quality of life. Nurses go through processes of grief and bereavement when they lose a patient and they refer to these cases as medical mistakes or medicine’s lack of limits that produced the patient’s death in a way nurses consider traumatic for the patients and for themselves.
The ethics committee

In 2002, an ethics committee was created in the ICU as a result of a nurse-led initiative. This was a response to the nurses’ concerns and questions about the limits in modern medicine for the good of the patients. Juliette explained:

The fact that everything is possible, or everything seems to be possible leads to treatments that can last for months and you see that it’s only one complication after another. And I stand up right next to the bed looking at the patient seeing in her eyes that she wants to stop, and still you have to go on because the doctors say so, because they only look at the fragments of the person. They forget about the whole person and that that person is going to die and that’s a really nasty way to die. So we asked, “we can do almost everything, what do we choose to do and when do we choose to stop?”. We always have situations like that, so we decided to start up an ethics workgroup to discuss cases with nurses and doctors.

The ethics committee, however, is not only for the patients’ interest, it is also for the nurses’ well being. Nurses’ work with dying patients is emotionally taxing, as I mentioned earlier. The ethics committee also acts as a space, opened up by nurses, to establish a dialogue with physicians. It is a space to cope with difficult situations, voice their concerns and make sure there is action in situations when they disagree with the physicians. Annelies explained this secondary function of the commission as:

We started the committee because two colleagues suffered post-traumatic stress disorder. There were cases with a lot of suffering for patients and for us. So we knew that things had to change. The committee is communicating about what’s happening with the patients and about how to bring together the differences regarding how to treat a patient, and how you can create a possibility to exchange and to decide together.

The ethics committee, as Annelies and Juliette mentioned, was formed because the nurses felt the need to talk and to react about patients who were suffering from life-sustaining treatments. It was an effort to ensure patients’ and nurses’ well-being. But as Annelies remarked, the need to have such a space to dialogue was triggered by an extreme situation that deeply affected the nursing staff. When I asked Jaap about the reasons for setting up the committee, he said:

A patient was treated to death you can say, nobody wanted to stop, nobody wanted to see the patient in bed, they [the doctors] only looked at the literature, and the figures. But for us [the nurses] there was a patient
in bed going worse and worse and worse, and she had a lot of pain, and she was bleeding. The doctors did not want to see that she was a terminal patient and that she was suffering a lot, and after a lot of suffering she died a horrible death, but doctors don’t want to see anyone die.

In order to avoid this kind of situation, the committee meets quite often to discuss all ICU cases. Juliette explained how it works:

Every day we discuss one patient in full depth and everybody is there, all the nurses, all the staff. If after that meeting we still disagree with the treatment we have a longer discussion with all the staff in charge of the patient and also a psychiatrist and a person who studied ethics who leads the discussion. Everybody can say what they think and what they know about the situation and about the patient’s and his or her relatives’ wishes. Sometimes it works and we agree, but sometimes we remain in disagreement…

In this context, it is possible to state that the ethics committee is a space in which nurses extend their care for the patients, relatives and themselves. This shows how nurses’ caring is not limited to the bedside, but also permeates to other practices and the logic and dynamics of the unit. Suffering, death, and dying are double-sided issues. One side is about bearing unnecessary suffering with the patient in the central role and what is at stake is the patient’s own good. The other side is about coping with a confrontation with suffering and death in which the nurses are central. Thereby, the ethics committee is a two-function space; nurses speak on behalf of patients and for themselves. They seek a better way for patients to die by solving the tensions between professions. They also seek a way to cope and bear the suffering of someone’s life ending.

**Conclusion**

Nursing is first and foremost a caring practice. Care, as understood here, is an embodied ethos that is fundamental for patients’ well being and recovery (Mol 2008, Arango 2011). In this article, I showed that caring for patients involves a close contact with patients and their relatives, which has enabled nurses to develop multiple ways for communicating with them. In acute situations, nurses help construct a bridge between life and death. For patients this brings peace and comfort; for relatives this helps in the mourning process. As a result of this action, nurses feel the need to advocate for the patients’ interests, needs, and willingness to withdraw or continue life-sustaining treatment, especially in moments of disagreement among the medical staff.

In this sense, death has a distinct meaning for nurses and physicians with regard to acute patients. Nurses consider that decisions to continue life-sustaining
treatments should take into consideration the patients’ quality of life, not only while in the ICU, but also upon discharge. In this context, a patient’s quality of life includes more than simply asking, “what else can be done.” The nurses pose questions to themselves and to the physicians about whether the suffering that the person is facing is worth it. This is so because nurses do not necessarily perceive death as a medical failure when patients show or express signs of suffering. For nurses, all efforts should be directed at ensuring that patients do not suffer instead of blindly prolonging a life. As a response to these issues, the nurses set up an ethics committee to discuss cases when the staff disagreed on the patient’s treatment. This committee can be interpreted as an extension of nurses’ care in which they struggle to advocate for the patient, while simultaneously caring for themselves. Intensive care nursing has proven to be an emotionally taxing practice. With the ethics committee, the nurses opened a space for coping with suffering and death, making their work visible and changing the dynamics between nurses and physicians. Nurses’ perceptions of how death should be experienced have triggered changes in the practices in this ICU. They have created a space to solve the tensions amongst nurses and doctors regarding the limits of treatment. The power of the ethics committee is precisely that nurses can mediate between physicians, patients, their relatives and nurses, making evident that another dimension of caring is to regard death as a reasonable option. To care for a patient is also to know when to stop life-sustaining treatments.

Finally, one other dimension of care that is enhanced by the ethics committee is the nurses talking about their own struggles with difficult situations and patients’ needs. Nurses facing patients in difficult situations can actually feel that they must act on behalf of the patients’ interests and voice and can assure the patients that their opinions will be taken into account. In other words, the ethics committee is a tool that helps nurses to cope with difficult situations, move even closer to patients, and change practices in the ICU.

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Controlled freedom

Contradictions in the ideals and practices of Dutch home-care nurses

David Kyaddondo

It is common practice for anthropologists from the North to study health systems in the South. Many studies are concerned with the contradictions in professional ideals and practice, as nurses attempt to survive and work in under-resourced environments. Others sympathise with the local nurses for their heavy workload and enduring Western donor-driven policies that are not socio-culturally sensitive. As a student of medical anthropology and an African raised in a developing country where nursing is predominantly facility-based, I was curious to learn how community nurses in the Netherlands separate professional from personal relationships, and to know their perspective on providing services in people’s homes.

After two months of working with community nurses in Bergen op Zoom, the Netherlands, I found Dutch nurses confronting contradictions similar to African nurses. They endure health strategists’ policies that may contradict their perceived professional values and their patients’ expectations and have difficulty separating professional and personal relations. However, they devise subtle ways of going around the rules to meet their patients’ needs.

[contradictions, home care, nursing, the Netherlands]

Introduction

The common practice is for the North to study the South and to make critical comments on the health care systems. Anthropologists such as Martin (2009) have described the nursing profession of Uganda, a developing country, as full of contradictions. I found the Dutch home-care nurses confronting several contradictions and challenges, similar to those described by Martin. There were contradictions between what home-care nurses perceived as fundamentally ethical in the nursing practice and the structural arrangements of their job. While the definition of tasks by those controlling their work focussed more on

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biomedical professional requirements, in opposition, the Dutch home-care nurses preferred a humanistic (Playle 1995) approach in practicing care. Nonetheless, as active agents, nurses devised various ways around the structured care to engage personal relationships toward their work.

This article is from a study I conducted in the 1998, as partial fulfilment for the Amsterdam Masters in Medical Anthropology. It is not a conventional comparative analysis of two studies (‘Africa’ and the Netherlands), rather, while describing the Dutch situation, I draw on my experience in the health care system in Uganda, where I have lived and participated in several health care-related studies.

An additional reason to reflect on my research of fifteen years ago is the developments in home-care that are presently taking place in the Netherlands. The financial crisis that started around 2009 has led to further cutbacks in the financing of home-care and subsequently in the already tight time schedule that home-care nurses have to operate in. Home-care nurses who complained about their work conditions in 1998 would not have believed that things could become still worse.

**Background**

Home-care is a crucial component in the Dutch health care system and one of the basic health provisions in the country. It involves providing care and support in activities of daily living (e.g., feeding, washing, toileting, transfers from bed and chair, dressing, and mobility in the house), support in medical care (e.g., supervision of medication, therapy, diet), as well as instruction and supervision in the use of aids and equipment (National Association of Homecare Workers 1997).

In the 1990s, home-care was one of the fastest growing health sectors with a demand increase of 4% per year (Lietaert 1997). This was due in part to the demographic changes in the Netherlands. The number of elderly, who are the most frequent recipients of home nursing services, has increased over the past years. By 1993, nearly 13% of the population of the Netherlands was 65 years or older and projection of persons above 75 years was 7% of the total population in 2010 (Huijsman 1993). Conversely, the country experienced demographic and life style changes, which led to a relative increase in the single-person households, mostly elderly women, and thinning of the social networks for family support. As such, the number of home visits to patients of age over 70 years increased sharply (Arts et al. 1996). It was, estimated that the use of home-care nursing would increase with 6% by the year 2005 (National Association of Homecare Workers 1997).

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1 Personal communication, Sjaak van der Geest.
The increase in the numbers of home-care patients implied an increase in expenditure on home-care services. While the budget grew by 4.5% between 1991 and 1994, it was not proportionate to growth in demand and did not compensate for inflation (Schrijvers 1997). Ewoud Lietaert (1997) estimated that at a rate of 4% increase in demand for services, the sector would require an additional 120 million guilders (then Dutch currency and approximately 54.5 million euro) to cope with the growth.

Similar to changes in health systems in developing countries during the 90s (Hansen and Twaddle 1991), several home-care reforms to improve efficiency and reduce costs took place in the Netherlands in the same period to address increasing demand. One of the reforms was a change in the financial mechanisms, from a previously government-dominated financial operation to an increasingly collective public insurance participation with personal client contributions. The increase in demand and budget costs required that clients paid more for community nursing services (Huijsman 1993).

The management and work determination of in-home care was detached from the work of the community nurses. Insurance companies took over the responsibility of determining tasks, regulation, work definition and pace of home-care nurses for specific patients (Schrijvers 1997). In pursuit of efficiency, managers of home-care nursing quantified the content and pace of nursing tasks, which was expressed in technically performed activities, or using Playle’s (1995) terms, the scientific status of nursing was emphasized. Consequently, home-care nurses lost control of their activities including patient recruitment and nursing tasks.

As the Dutch government made reforms in the entire health system, it reduced patient numbers and hospital days by transferring their care to in-home. Reduction of patients in the hospitals not only led to an increase in numbers of patients in the home-care system, but also affected the characteristics of this patient population. Patients being cared for at home were sicker than before and home-care nurses took on more curative activities (Huijsman 1993). As patients became more care dependent and required more intensive care, an increase in technology and specialized services in homes became essential. This change reflected Van der Geest’s (1988) argument about the African medical system that when there are changes in one structure, this leads to changes in another.

Despite the increase in demand for services, managers of home-care organizations recruited fewer full-time staff and used more part-timers and rationed services. This not only had implications for the accessibility of in-home health services, but it also affected staff workload. Pool comments on the human resources in home-care in the 1990s when he points to too much work pressure, difficult working conditions and a discrepancy between expectations and reality of the job (Pool 1997:208-10). As a form of dealing with the human resource gap, managers of home nursing allowed lower cadres to perform tasks they were not qualified for.
This practice is also common in African countries, like Uganda, where nurses do diagnostic and prescription tasks for which they are not qualified.

**Methodology**

I conducted this study in 1998 in the town of Bergen op Zoom, in the south of the Netherlands. Bergen op Zoom had total population of 63,989 of which 6% were elderly as defined as 75 years and above (Gemeente Bergen op Zoom 1997).

I spent six weeks at Thuiszorg Bergen op Zoom, a home-care organization. I followed four nurses to patient homes and watched them carrying out their home-care activities for a number of days. In total, I had 32 observation contacts with 19 patients receiving care (some patients were observed more than once). During these observations, I paid attention to how nurses provided care to patients and how they interacted with them. During the care process, I would help nurses to lift and help patients walk and hold informal conversations with patients and their family members, particularly spouses. In addition, I participated in day-to-day activities at the home-care organization. These included orientation to a new patients recording system, interviews of patients in the hospital for registration in home care, and interactions with nurses at the home-care office in Bergen op Zoom.

In addition to participant observations, I conducted in-depth interviews with 25 personnel involved in the home-care sector in the region, representing several levels. They included fourteen nurses directly involved in providing home-care services and three managers at the organization (one overall manager and his two operations managers). I also conducted interviews with key informants who were personnel supporting home care-related activities including: a home care-hospital liaison and the in-taker of home-care patients, a nurse trainer in communication skills, and a person in-charge of a shop for home-care aides. I also interviewed three patients and two spouses of home nursing clients. I recruited an assistant who helped in translations during some interviews and records review.

I used field notes from interviews and observations to describe and illustrate nurses’ experiences and challenges in meeting their professional ideals. Analytically, I draw from the concept of ‘agency’, that is, home-care nurses as actors and agents in shaping their work lives (Long 1992).

**Ethical considerations**

Prior to the actual commencement of the study, I sought clearance from the relevant authorities. I obtained a letter from the manager to the home-care office, allowing me to conduct interviews and other data-gathering exercises in the organization. I signed an agreement with the organization specifying the terms, which I adhered to during the study. I informed all participants the study
purpose and objectives, and their freedom to participate or not in the discussion. I ensured confidentiality and respect for participants, and I followed ethics of observation. Home-care nurses always notified patients about my visit and asked for permission.

**The practice of home-care nursing in the Netherlands**

**Avoiding the watch of 'big brothers': Career choice**

In choosing to become home-care nurses, nurses considered a number of factors, some of which related to the expected work environment, personal experiences and desires. “I don’t like to work when the big brothers are watching” (Nurse).

Most prominent in choosing to become a home nurse, was the desire for autonomy during work. Physicians in health facilities have been criticized for not viewing nursing as an autonomous sphere, their gate keeping, and their control over nurses’ regular work with patients (Playle 1995). Dutch home-care nurses preferred to run away from the watching doctors in hospital. However, whether or not the nurses realized their aspirations of freedom and autonomy is another story we shall see in the paragraphs ahead.

Almost all the home-care nurses I interacted with started as hospital nurses before joining home care. Working in institutional facilities was part of the curriculum during their training. However, the nurses I spoke with preferred getting away from hospital work conditions and environment, and from the monotony of working on the same floor with the same kind of patients under strict working hours.

**Anticipated reduced workload and gender**

Associated with freedom and autonomy, was the expectation of fewer hours of work. Monica decided to join home-care nursing when she started having children, as did Maureen, who had both a six- and four-year-old child. This prospect for fewer work hours when nurses had children reflects the femininity of nursing (Davies 1995), which is almost universal. All home-care nurses I interacted with in Bergen op Zoom were women and most were mothers.

**Personal and family experiences**

Past personal illness experiences or those of close relatives influenced the career choice for some of the home-care nurses, as one narrated:

I got an accident when I was eight years old and my father was often sick. He had a heart operation and spent six weeks in the hospital. I thought I
should become a nurse. I started working in the hospital at the age of 17, later I thought I should grow in the profession and found home-care better. There was a general view that if a nurse had previously had an experience that required nursing services, she would be more compassionate and devoted in her work.

**Professional growth and closer relations with patients**

The nurses looked forward to closer relations with their patients when they joined home care. The feeling was that unlike in hospitals where patients were brought in, home-care nurses were the ‘guests’ and had an opportunity to have a closer and more cordial interface with patients. Meanwhile, others reckoned that home-care was a form of upgrading their profession. Additional training was pre-requisite to joining community nursing if one had been a hospital nurse. However, when I asked the manager about the difference in the status between a home-care and institutional nurses, it was not clear who was higher in the hierarchy.

**Economic survival**

Unlike in my country Uganda, where economic survival is a key reason for joining nursing (Martin 2009), Dutch home-care nurses did not mention economic gains as a motivating factor to choose their career. On the contrary, they felt that home-care paid less compared to other professions, even ones with lower qualifications as one nurse noted: “My sister is a secretary but she earns a lot more than I do” (Nurse). Home-care nurses noted low pay as one of the reasons why few men joined the nursing profession.

**Nursing as a last resort career**

Some nurses choose their career as a last resort after failing elsewhere. One home-care nurse trainer said that most nurses studied social science subjects as opposed to natural sciences; hence, they had fewer opportunities to join other professions. Joyaneke wanted to become a nun, but ended up becoming a nurse. Another reported, “I had never thought of becoming a nurse, but I could not get any other field for study, then I joined nursing” (Nurse). Yet, there were those who joined on the advice of friends, as this one remarked, “My friends told me it was good, then I joined and I like it” (Nurse).
Marian: A home-care nurse at work

I moved with Marian, a community nurse (wijkverpleegkundige), as she carried out her activities. A community nurse on duty has approximately six to fifteen patients for a morning session. The numbers might vary according to a day’s workload and care needed by patients.

We started the day at the home-care office at 7:30 am. At the office, Marian perused the patient records’ book, taking their details, i.e., names, addresses, telephone numbers and required care for each on that day. This took her about twenty minutes. Four other nurses were also reviewing their patient records. During the process, some discussions were taking place (in Dutch) among the nurses. Marian explained to me that they agreed on re-distributing patients for that morning (she got fewer) to give her an opportunity to explain some of the home-care activities to me.

We set off at 7:50 a.m. in Marian’s car and in about five minutes, we reached our first patient. She was an 80-year-old woman staying alone. She was incontinent and visited twice a day to change her urine bags. She could do other things such as cooking and cleaning on her own. We found that she had laid all the required care accessories on a table. After greetings, Marian started right away attending to the patient. During the process, they were discussing, smiling and laughing. Marian cleared the used material while the patient removed the unused materials, which she put back into a locker. Marian signed a yellow form, putting her name and time spent. The whole process took about fifteen minutes but Marian recorded ten minutes. Immediately we left. As we were leaving, the patient made a comment and Marian laughed. I asked her what the joke was, and she translated what the patient had said; “The sister always does quick, quick, quick, she doesn’t have time to talk.”

We drove to our second patient, and arrived in about five minutes. He was male, 70 years, married with one daughter who was twenty years old. Unfortunately, his daughter was mentally retarded and blind. On our way, Marian warned me that the home we were going to was not a clean one. She added that the wife of the patient had emotional problems possibly because of the physical condition of her husband and daughter. “I think she [the mother] needs emotional support, which she doesn’t get,” Marian said. The patient had a wound on his throat and used an apparatus, which he put on one of his cheeks to aid him produce some sound while talking.

The instrument was rented from the Thuiszorg (home-care organization). The patient was also incontinent, and had been in this condition for two years. Like the first patient, we found the accessories for the care already prepared. Marian started by cleaning the patient’s throat, then changed his bandages and cotton gauze. The wife was helping with the cleaning water and handing other materials in the process. Initial care was provided in the living room, but the
The patient was transferred to the bedroom where his urinary bags and catheter were changed. Marian told me that one of the tubes used for urine was improvised because the right one could only be given in the hospital. I asked the patient how he felt about this improvised tube and he answered: “I don’t mind, if it is not done that way I would be in the hospital, which I don’t like.” The whole process of care took about 25 minutes. Meanwhile, during the process, the wife complained about pain in her ankle and Marian promised to look at it. After attending to the man, the wife sat on the bed and Marian started examining her ankle. She massaged it for some minutes and started explaining and demonstrating to her how she should stretch it to ease the pain. This took another ten minutes. Marian signed on the chart, recording thirty minutes and we left for the next patient.

The third patient was also male, 82 years old, staying alone and had no children. He had a wound on his ankle, which needed dressing. From his story, he got the wound in 1940s during World War II, though it was not a result of the war. We found the care materials for dressing the wound ready on a small table, which Marian referred to as an ‘operation table’. She started working on the wound, washed it, changed the bandages, and helped the client to wear a clean sock. The patient knew the process very well, and at one time advised the nurse about the sequencing of the bandages on the wound. In the process, the glove Marian was using raptured and she asked the patient for permission before putting on another one. I asked her why she had to ask for permission and she replied that insurance companies do not provide gloves, rather they are bought by patients. Therefore, she asked for permission. The process took about 25 minutes, but Marian recorded thirty minutes. She explained to me that the wound was getting better and less time was required than before. It used to be 45 minutes but now it is thirty minutes. Immediately after signing we left the house rushing to her car and drove to the fourth patient.

The fourth patient was also male, aged sixty years. He was a very fat man and could not stand on his own or walk by himself. He needed the assistance to get out of bed and make other transfers. Marian said he became exhausted from working too hard in coalmines during his youth. He had a wife, but she could not support him alone. They had a daughter and son, but both did not stay with them. When we reached the patient’s home, we right away went to the bedroom where the patient was in bed. Marian removed the blankets from him and started removing his diapers. She washed his lower parts and gave him a wet towel to clean his face and upper parts of his body. We lifted the patient and Marian started dressing him. In the process, the patient lost balance and almost fell down. Marian asked him to lie on his back on the bed and brought a chair close, which she said was for an emergency for the patient to sit on if he lost balance again. After dressing the patient, we supported him to a
wheelchair to the living room, where his wife had prepared his breakfast. Marian went back to the bedroom to clear the used things, but the wife asked her not to bother, saying: “You can go, you don’t have time, I can do the cleaning.” Marian agreed, although she explained to me that she preferred to clean what she had used by herself. Marian signed the form and we left. On our way out, we found a neighbour cleaning the patient’s corridor. Marian said she did it to help them.

The fifth patient was an asthmatic woman, with an oxygen machine aiding her breathing. As we approached her house, Marian said; “This is my patient. This is the home where I usually take a cup of coffee.” The patient lost her first husband five years ago, but has a male friend with whom she stays. Marian visits her twice a week to help her shower and check on the oxygen machine. Marian went to the bedroom where the patient was, while I stayed in the living room with the male friend. Marian helped the patient take a shower and after about 25 minutes, they joined us in the living room. Meanwhile, the friend had prepared coffee.

We took coffee, and spent about 45 minutes in this home, but Marian recorded thirty minutes. On our way to the sixth patient, Marian told me that the male friend helps the patient in many things, but the woman still cries for her dead husband and says that he was a much better man. The patient felt that her new partner wanted to take over both her physical and mental responsibilities. Marian sometimes talked to him about how he should handle things, which may have emotional implications for the patient.

That morning we went to two other patients. One was female who was 85 years old with cognitive and physical problems. Marian helped her with a shower and dressing. The seventh was also a female patient with a wound on her left ankle, which a nurse dressed every morning. The whole process ended at about noon when we went back to the office where Marian selected forms to fill in her day’s activity.

**Freedom and autonomy as myths**

From the above description of working with a home-care nurse, it is clear that while nurses looked forward to working in homes alone with no physicians watching their activities, in practice, freedom and autonomy remained ideal rather than real. While there are notable areas of freedom and autonomy in the work of home-care nurses, such as rescheduling the order of patients and re-allocating of patients amongst themselves, this freedom has major limits and nurses continue to be controlled continue in many ways by managers of home-care organizations, insurance companies and their patients. Moreover, the desire by home-care nurses for less work was not attained since they were always on the run to the next patient.
Home-care managers quantified each care task and as seen in Marian’s case, it was mandatory for home-care nurses to record the time spent at the patients’ homes. Time sheets were one form of technology to control Dutch home-care nurses, to monitor if they adhered to the allocated time. While managers and insurance companies attempted to make home-care an objective profession that could be pre-determined, nurses complained about the way their work is organized and were largely concerned with the practicality of quantifying nursing care. Nevertheless, to some extent home-care nurses accepted and adopted the quantification of nursing care – but also devised means of manoeuvring through these fixed times by under- or over-reporting time spent with a particular patient.

A new form for time recording was introduced on June 15, 1998, with new codes and more information than before. Among the new aspects required in the system of recording is the time spent in travelling from one patient to another. While the managers explain this as being meant to bring more efficiency and effectiveness, nurses perceive the innovation as having nothing to do with improving the care provided to the patient. “Government is always adding more things; it is not this to replace that, but this in addition to that. It is because someone is sitting up there and says: do this (Nurse).” Nurses regard the introduction of new forms of administrative records as an increase in their already significant work burden. They feel that they cannot realize what they aspired for when they joined the profession; giving care to patients was being constrained by increasing control of their activities and engagement in what they regard as administrative work. Apparently, managers are aware that nurses detest the new administration work, but they feel it is their duty to convince nurses to accept them. This, they have done in conducting a series of meetings with nurses. “Nurses are brought up in such a way that they want to give care to people, they look at the new system of record keeping as administrative, so they don’t want it. They are not enthusiastic, but I have to convince them (Manager).” Time for each illness cared for is pre-determined, e.g., injection ten minutes, shower thirty minutes, etc. If more than the specified time is spent with their clients in the community the nurses are required to give an explanation. Home-care nurses feel that some aspects of their work may be outside the injection or the medicine they are to administer that cannot be recorded e.g., respect, listening. Nurses termed the rushed way of care as a “wash and go” situation.

As nurses try to endure the intense pressure to work within the time provided, they are under stress from demands and expectations from patients. Family members of the patients might ask for services such as counselling and care for themselves when feeling unwell, and this care is outside the official tasks. This is not different from my own country where patient caretakers (family or friends) take advantage of the presence of health workers to report their own illnesses.
Despite time limits, home-care nurses feel the moral obligation to provide care, since they are professional nurses and often offer help when asked by family members. However, since this care is not part of their work schedule, they do not record this activity, hence it is not paid for. Moreover, the sick relatives of patients deny home-care nurses the freedom from other crying patients, one of the reasons they originally left health institutions like hospitals.

Home-care patients often wish to have the nurses stay longer in their homes, for other interpersonal interaction including having a cup of tea or coffee. When a nurse rushed through her work to catch up with time, patients would be disappointed especially when they wanted just some conversation or company: “Sister just washes quick, quick, quick and goes.”

Meanwhile, nurses felt the pressure from other waiting patients. Home-care patients knew the approximate time a nurse was supposed be at their homes. When a nurse was delayed, some patients would call to inform the home-care nurse that they were waiting. We would find patients at the doorway anxiously waiting, and exerting pressure on the nurse. Similarly, patients monitored the care process and complained when a nurse missed a step.

**Improvisation as a virtue**

Several studies have characterised African medical systems as operating under improvisation (Livingston 2012, Feierman & Livingston 2011, Martin 2010). However, I found improvisation was also an everyday practice in the Dutch home-care system.

The move to decongest hospitals by the Dutch government led to sicker patients requiring higher medical technology in the home. Some of the technology such as adjustable hospital beds, and urine catheters, such as in Marian’s second patient, were not available in a home environment. In addition, the homes of the patients they visited had fewer facilities such as adjustable beds and washing facilities at the disposal of home-care nurses. Improvisation was, therefore, inevitable for home-care nurses when performing their tasks in settings where they lacked the necessary resources. As illustrated in Marian’s case, nurses washed patients under kitchen sinks, used coffee tables to dress wounds and devised various strategies for supporting heavy patients.

Nevertheless, my interlocutors reckoned that improvisation was a skill and quality a nurse must possess to practice home-care nursing effectively. One nurse remarked, “Home-care needs a creative nurse.” Using the concept creativity as a euphemism for improvising, or in Martin’s words “creative solutions to technical problems” (Martin 2009:148), home-care nurses had to adapt to the available resources in homes to make nursing possible where it perhaps would not be. One supervisor of home-care remarked;
I hear a lot of complaints from the community nurses because of the facilities, such as beds are not at the right level etc. You always have to work alone, even when you think it may not work you have to do it otherwise you leave the patient at home and spend another hour before you are back to do it.

**Professional versus personal relations in home care**

Finally, I would like to comment on the mix of professional and personal relations in the execution of home-care activities in the Netherlands. Anthropologists from the North have often written about health systems in Africa showing health workers mixing informal relations in the management of patients (Whyte et al. 2010). I observed similar practices by Dutch home-care nurses.

I have shown in Marian’s case how the interaction between nurses and patients extended beyond professional care into the personal and social sphere. Dutch home-care nurses discussed patients’ personal lives, which did not directly relate to the condition nursed. Marian had to deal with issues of patients’ children, spouses and former spouses of patients, hence entering their social realms. Moreover, these aspects were not included in the formal chart of tasks provided by the insurance companies and home-care organizations.

Nurses felt that separating social and personal interactions with patients from the biomedical needs of care was fragmenting the reality of home care. One of them expressed their frustration as follows: “Talking is also nursing, but now days you may not be able to do much talking. It is easier to negotiate (with managers) for washing time than talking time, yet it is also nursing” (Nurse). However, despite their agitation about talking time, home-care nurses did not treat each patient the same way. They were intimate with some and distant to others. Most patients wanted the nurses to stay longer and attend to their personal concerns, but only preferred patients received this attention. Patients read and judged this relationship and selected particular nurses to share their personal lives. Similarly, family members chose to ask for help from nurses with whom they had developed trust and personal relations. Such relations with individual nurses determined if family members sought assistance outside the quantified care. Patients would be disappointed when they did not get the nurses they had established close relations with and were always eager to know who would come the following day.

**Conclusion**

I started this article by commenting on the North studying the South, and how Northern researchers point out contradictions in the practice of health
professionals in Africa. My field research in the Netherlands taught me that contradictions in professional expectations and practice also largely apply in home-care nursing, part of the Dutch health system. Thus, contradictions are not unique to under-resourced Africa, but are also present in the Western world, although their nature might be distinct due to context.

There were inconsistencies in home-care nurses’ perception of professional ideals and motivation for career choice, and in what happens during practice. I have shown that the Dutch home-care nurses did not realize their aspirations of autonomy and freedom in everyday work. Instead, they endured busy schedules determined by managers. Time control from managers and patient expectations of more time made home-care nurses ‘victims’ of this inconsistency. Thus, nurses were vulnerable to both managerial control and patient manipulation. Time sheets were like injunctions against home-care nurses privileging their preferred patients by quantifying care.

What home-care managers and insurance companies planned was in contradiction with what home-care nurses perceived as good service delivery. Managers and insurance companies focused on a bio-medical model in allocation of tasks and time with the imperative of impersonality and efficiency in service delivery. On the contrary, home-care nurses were concerned with a humanistic approach to patient care, where love and compassion were often involved during care. Nurses often invoked relations of being friends and guests to patients in practicing care. Moreover, the variations in the way home-care nurses treated their patients was not based on medical needs, but on personal relations instead, which is not much different from Africa, where kinship obligations are invoked during the health care provision.

This study further taught me the importance of context in applying professional ethics and rules, whether it facilitates or constrains them. Working in people’s homes made it difficult for the home-care nurses to restrict their interactions with patients to only bio-medical care. The long-term interaction with home-care patients built a bond with the nurse. Dutch society has less extended family networks and many people live as individuals. Thus, home-care nurses acted as both medical and social resources to the patients they cared for. Given that several patients did not have family members to meet their social demands, home-care nurses filled in this gap. A home-care nurse coming to a patient’s home meant having a person to discuss with personal and social issues. Nurses seemed to enjoy this role of social interaction and sharing of personal lives with their patients.

But these nurses are not just ‘victims’ of an imposed control system, as I may have seemed to suggest a while ago. They prove to have a remarkable amount of agency, as well. Paradoxically, home-care nurses maintained their imagined ideals of being free with relaxed rules and flexibility. Cleary, they did not just accept the managerial control over them that attempted to restrict their freedom of
having intimate interactions with patients. Nurses expressed their agency in several ways, including re-organizing work schedules, rushing activities for patients in homes where they did not feel like staying longer, distancing themselves from some patients for whom they had no personal compassion, and encouraging family members to do some of the activities, e.g., preparing the materials before the nurses came in. Whether the home-care nurses were able to attain some of their expectations depended on how they could manoeuvre through the care of the various patients.

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“Now I want to look after myself”

An ethnographic account of elderly women’s reasons for moving to an old-age home in Kerala, India

Barbara Hahn¹

Despite the fact that caring for one’s elderly parents is a cultural expectation, institutions for the aged are gaining popularity in India. The state of Kerala has the highest number of old-age homes in the country and the majority of the elderly inhabiting these homes are women. This article attempts to shed light on elderly women’s reasons for moving to an old-age home. The anthropological fieldwork took place at the House of Providence, an old-age home located in Ernakulam (Kerala). The elderly women at the House of Providence were my informants. They relocated to the home for the aged due to one or more of the following reasons: familial conflicts, fear of being a burden to the family, desire to live in a religious environment and poverty coupled with advancing age. Certain themes, namely the fragility of kin relationships and self-determination, were central to many women’s narratives. Many of the elderly women at the House of Providence believed that the willingness of relatives to care for them depended on the contribution they could make to the household. In order to avoid straining these fragile kin relationships, they opted to move to an old-age home. Moreover, the majority of the women at the House of Providence took the unconventional decision to relocate to the home for the aged — despite being offered alternate living arrangements and/or facing the opposition of family members — because they felt it would ensure them the best old age.

[ageing; women; old-age home; self-determination; family relationships; Kerala; India]

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In 2005, I went to south India to do fieldwork for my AMMA thesis. At the time, my intention was to gain knowledge about the experience of older women living in an old-age home in Kerala. The voluminous amount of data I amassed during my sojourn in Kerala formed the backbone of my Master’s thesis (Hahn 2005). For the purpose of this article, I have elected to focus on a specific part of it, namely the older women’s reasons for moving to an old-age home.

**Background**

The ageing of the world’s population is one of humanity’s greatest achievements, but also one of its challenges. At the beginning of the 21st century, India was home to one eighth of the globe’s older persons and it is estimated that the Indian elderly population will grow three times as rapidly as that of developed countries (Bhat & Dhruvarajan 2001:622, Gulati & Irudaya Rajan 1999:46). The southern state of Kerala is slightly ahead on the demographic path and the elderly make up a higher proportion of its population than elsewhere in the country. Moreover, contrary to the rest of the nation, there is a feminisation of ageing in Kerala, as women outnumber and outlive men (Kattakayam 2002:235, Gulati & Irudaya Rajan 1999:46-7, Bhat & Irudaya Rajan 1997:34-35).

India boasts one of the highest levels of co-residence in the world (Sokolovsky 2001:163). Indeed, older Indians are still “by and large looked after by their children and near relatives” (Kattakayam 2002:234). Although a large proportion of Indians still live with their kin in their old age, I believe a gradual but noticeable shift is happening in the caregiving system. In India, a new trend is emerging — institutionalized care. The majority of institutions for the aged are situated in South India, with Kerala leading the way. A small, but significant, proportion of elderly Indians now live in old-age homes.

There also seems to be a shift in people’s thinking about living arrangements and the emergence of homes for the aged. Jamuna (2003:129) reports that in a 1984 Indian survey on attitudes towards elder care and living arrangements, “the younger age groups emphatically stated that it is not proper to send the elderly to old-age homes.” However, in the 1994 repeat survey, approximately a quarter of the younger generation “felt that more homes for the elderly might be needed in future, as many are unable to keep their elderly at home” (Jamuna, 2003:129). Similarly, Singh (2004:175 &171) asserted in 2004 that “old age homes are no longer a bizarre concept in Indian cities” and that they “are going to be a usual way of life in the ‘post-modern’ India.” Thus, it seems that the typically

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1 There are between 96 and 134 homes in Kerala depending on the source consulted, but regardless of the actual figure, it is undoubtedly the state with the largest number of old age institutions (Mishra 2004:101; Irudaya Rajan 2002:202; Packiam 2002:219).

2 Jamuna (2003:131) reports that in 2000, 2.73% of elderly Indians lived in institutions.
'Western' practice of having the elderly relocate to a home for the aged is gradually gaining acceptance in Indian society. Despite the fact that old-age homes are gaining acceptance, caring for one's elderly parents is still seen by many as a cultural and moral obligation (Bhat & Dhruvarajan 2001:626, Kattakayam 2002:234). The concept of caring is also based on long-term intergenerational reciprocity and, as such, older parents feel entitled to the assistance provided by their adult children (Bali 2001:94). However, during the past few decades, the structure of the Indian family has undergone significant changes and the joint family system is gradually being replaced by nuclear families (Chang 1992:50, Bhat & Dhruvarajan 2001:625 & 627). In Kerala, there are now significantly more nuclear families than joint families (Gulati & Irudaya Rajan 1999:49). Under the new family structure, intergenerational ties are weaker and the elders' claim to care is jeopardized (Chang 1992:51, Singh 2004:171). Members of the current older generation have fulfilled their duty and taken care of their own aging parents, but they cannot assume that their own children will do the same; they are the 'short-changed generation' (Sokolovsky 2001:163).

Aging in India is intrinsically linked to gender. According to Bali (2001:133), “women tend to age faster” due to factors such as lifelong “discrimination, oppression and exploitation and the cultural milieu.” Since they age faster, women may require care at an earlier age. In Kerala, the majority of the elderly inhabiting the homes for the aged are women, perhaps reflecting their more vulnerable position in the family and the community. Despite the fact that elderly women make up a significant proportion of the Indian population, especially in Kerala where they outnumber elderly men, studies on older Indian women are limited in number. One author goes as far as to say that there is a certain stigma attached to the study of elderly women and their problems (Bali 2001:133). Thus, the rapid growth in the number of elderly women, their social vulnerability and the relative scarcity of studies on older Indian women makes it particularly relevant to focus attention on their situation.

There are few studies exploring in-depth elderly Indians' reasons for moving to a home for the aged. Published reports on the elderly's reasons for moving to a home for the aged are based on information gathered via surveys and questionnaires,4 which may not be the appropriate methods to elicit data that accurately reflects the complexity and richness of the situation in India. This view is supported by Sokolovsky (2001:177), who reports that in order to study the dynamics of intergenerational care, a case study approach is preferable to

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4 The various surveys carried out across the country identified similar reasons for the elderly's move to an old-age home. In all the studies, the main factor seemed to be the lack of a caregiver at home, perhaps indicating that for at least some elders, the changing structure of the family is having an impact on how they live out their old age. Lack of money was the second most commonly cited reason for moving to the old-age home (Mishra 2004, Dandekar 1996, Liebig 2003, Irudaya Rajan 2002).
survey instruments. Anthropological studies are thus needed to provide insight into institutionalized elderly’s motivation for moving to an old-age home in light of the changing caregiving system.

**Fieldwork methods**

This article is based on an exploratory, qualitative research study that took place over a six-week period in 2005.

**Study site**

The anthropological fieldwork was carried out at the House of Providence, an old-age home located in the city of Ernakulam, in Kerala (India). Like the majority of homes for the aged in Kerala, the House of Providence is a free, urban old-age home that is run by a Christian organization. Managed by the Sisters of Charity, it offers shelter, food, clothing and medical care to its residents. Men and women – generally 60 years or older – can gain admission to the House of Providence regardless of their health status, caste and religion. At the time of the study, there were one hundred residents at the House of Providence: 25 men and 76 women.

**Study sample**

The convenience sampling method was used to select informants. I spoke with 25 older women who were residents of the House of Providence and whose length of stay at the home for the aged varied from 18 days to over 18 years. I’ve refrained from using my informants’ real names in this article; fictive names were used instead.

**Data collection**

Data was mainly collected via participant-observation, semi-structured interviews and informal focus group discussions. I completed genealogies and did a photography activity with a select number of women. I also kept a journal throughout the duration of my stay at the House of Providence. Since I do not speak Malayalam, two local university students, came to the House of Providence nearly every day to act as my interpreters. I spoke with whomever was interested in talking to me. Some conversations were short; others lasted well over an hour. Some of the elderly women were interviewed only once; however, there were female residents with whom I talked on a number of occasions.
Moving to the House of Providence

When I asked the women why they had decided to move to the House of Providence, many spoke candidly about their family situation, their life experiences and the reason(s) that brought them to the home for the aged. In some cases, a single factor precipitated the women’s move to the old-age home; in other instances, a number of concerns contributed to their decision. A few cases will be presented to illustrate how each factor played a role in some of the elderly women’s decision to relocate to the House of Providence.

Family conflict

Many of the female residents at the House of Providence disclosed that familial conflict led them to move into an old-age home. Both Elena and Sonia lived with their respective sons prior to moving to the House of Providence. An 84-year-old widow, Elena had been living a mere two months at the House of Providence when I first met her. She stated that she came to the home for the aged, because she now wanted to look after herself. She said, “In my own house, I had some problems. I needed to look after myself, as well as after my son’s needs. I had to make adjustments; I couldn’t do what I liked.” After being informed of her decision, her son’s initial reaction was to refuse to let her come. Elena attributed this to the fact that she receives a monthly government pension and that the house is in her name. She then added, “I managed to come anyways.”

As for Sonia, a 69-year-old widow, she recalled that she had frequent fights with her daughter-in-law. Her son’s wife would always question her about the money she spent, saying, “Why are you buying this? Why do you need that?”, even though Sonia was in fact spending her own money. Sonia only told her son about her impending move to the home for the aged the day before she left. Her son didn’t allow her to go. To convince him to let her go, she argued that she was only going to the institution for two or three days as a trial (even though that was not true).

For some women at the House of Providence, the familial conflicts went beyond simple arguments and involved violence or threats of violence. Such was the case for Anisha a 79-year-old widow with four children. After her husband’s death, she lived in the family home with her youngest son and his wife. According to Anisha, her daughter-in-law didn’t like her. During one of her son’s frequent work-related absences, her daughter-in-law threatened to kill her. Scared for her life, Anisha ran away and moved in with her youngest daughter. Anisha asserts that she has a very loving relationship with her youngest daughter and was happy to live with her. Her son-in-law, however, disapproved of the move. When intoxicated – which was an almost daily occurrence
accordance to Anisha – he became verbally abusive towards her and expressed his discontentment at her presence in the house. After enduring this situation for one and a half years, Anisha moved to the House of Providence.

In some cases, familial conflicts did not bring the women directly to the old-age home, but rather were a catalyst that forced them to make major life changes, which would eventually lead them to the House of Providence. Reshma became a young widow with seven children at the age of 39. According to Reshma, her mother-in-law’s attitude toward her changed after her husband’s death; she became cruel and unkind, to the point of insisting that her daughter-in-law become involved in sex work. One night, Reshma’s mother-in-law brought home a man (from whom she had accepted money) and expected her to dispense sexual favours. Reshma recalled that her refusal angered her mother-in-law, who hit her. In the ensuing struggle, Reshma injured her arm and had to be hospitalized to treat the injury. Upon her discharge from the hospital, she attempted to return home, but her mother-in-law refused to let her back into the house. Reshma was forced to move out, leaving her children behind with her mother-in-law. According to Reshma, her mother-in-law managed to turn her children against her. After being thrown out of her house, Reshma first lived in a hostel and then moved into a rental house, which she shared with women who, like her, worked as maids. She remained there until she moved to the House of Providence three years ago.

Out of the seven women interviewed who had lived with their children, four cited conflict with family members as the main reason for choosing to move to the House of Providence. On the other hand, for all but one of the nine women who had lived with relatives other than their offspring, family tensions were not as a direct factor in their decision to move to the House of Providence, but rather brought on significant changes in living arrangements, which eventually led them to move to a home for the aged.

Poverty and aging

For many of the residents at the House of Providence, the decision to move to an old-age home was fuelled by the fact that they had reached a critical age. Some elderly women had reached an age where it was difficult to continue working at the same pace and earning their living. As Sara, who worked for 42 years in a physician’s home, said “When I felt I was too old to work, I asked them [her employers] to find me a place to live.” The family suggested that she come to the House of Providence and she agreed. Rose shares a similar story. Orphaned at the age of ten, she was taken in by her mother’s relatives. According to her, the relatives did not care for her properly despite their significant wealth. They didn’t feed her adequately and showed no interest in arranging a marriage for her. When she was 20 years old, one of her father’s
friends offered to employ her as a live-in maid. Rose stayed with them until she became too old to work. At that point, her employers told her about the House of Providence and asked her if she would like to live here.

Others felt that they were getting too old to continue living on their own with limited revenues. This was the case for Margaret, a 74-year-old woman who was ten months into her second stay at the House of Providence when I met her. She first came to the institution ten years ago with her husband. At one point, her husband became ill with a fever and decided that he had to leave the home for the aged where he had ‘caught’ this illness. The couple lived with close family friends for the next five or six years; they left when the family’s adult children came back from abroad and the house became too crowded. Margaret and her husband then found a room they could rent for 74 Rs per month. After her husband’s death, Margaret found it difficult to survive on her own. She was receiving financial assistance from a charitable association to help make ends meet. Margaret reasoned that if she came to the House of Providence she wouldn’t have to worry about her financial situation and could rely on the association’s monthly help. “Here, she says, everything is provided. Food, medicines and clothes are provided. There are no difficulties.”

Although Margaret is the only woman who openly addressed the issue of finances, it was clear that all of the women I spoke with had limited financial means. With the exception of Margaret (who had been a housewife), all the women had been employed and had continued working long past the official retirement age of 55 (in Kerala). However, they held jobs that did not provide pensions upon retirement and that likely did not pay sufficiently well to allow them to amass significant life savings. Thus, for these elderly women, moving to an old-age home – where room and board as well as clothing and health care are provided free of charge – ensures that they have a secure old age.

Being a burden

When discussing their home life prior to moving to the House of Providence, a number of elderly women reported that they believed their care was a source of stress for the family. For instance, when commenting on the increasing number of old-age homes in Kerala, Anisha affirmed “in their own houses, older people become a difficulty for relatives...” She later admitted that she thought that she was a burden for her children when she lived in their household. Agatha echoes similar sentiments. The unmarried woman left her job in a convent to care for her mother who was ill. After her mother’s death, she alternated between living with each of her two brothers (and their families). She felt that “they looked after the needs of their own family first” and that she came in second. Agatha

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*A rent of 74 Rs (per month) is equivalent to approximately 1.02 Euro (or 1.34 $CAN).*
acknowledged that she didn’t get along with her sisters-in-law and that she believed her presence was an encumbrance for the family. When she started to feel like a burden for the family, she remembered the House of Providence; she has now been living in the home for the aged for fifteen years.

Other women did not think that their care had been weighing down their relatives, but they were concerned that they might eventually burden their loved one. Their fear of becoming a burden for their kin was a motivating factor in their decision to live in a home for the aged. After Georgina y left her marital home due to her husband’s adultery and physical abuse, she lived with her brother and his family for six years. She then found employment as a cook in a convent in Bombay. When health reasons forced her to return to Kerala, she moved in once more with her brother. However, she felt that it could only be a temporary arrangement; it would become a burden if she stayed permanently with him. As for Alexandra, she lived in a joint household with her three sisters and their families. The unmarried woman moved to the home for the aged because she worried that due to her advancing age, her presence would become burdensome for the family. She says, quite succinctly, “I thought I would become a ‘distress’ to my sisters.”

In India, the family is recognized as the main support system for the elderly. Elderly mothers have invested time, energy and love in the upbringing of their offspring and, through the process of long-term inter-generational reciprocity they expect some care from these children in their old age. However, with relatives, such as siblings, there is no such implicit expectation of care in return for past labour. If an older woman feels that she is unable to contribute to the household in some way (in return for the care she is receiving), she may conclude that she’ll be seen as a hindrance. For instance, when discussing why she didn’t accept her nephews’ offer to stay with them, Clarasaid at one point, “I wouldn’t be able to do housework for them, because of my health.” She was concerned about her participation in the household. Furthermore, Agatha (who lived with her brothers) commented: “When people become old, the family don’t have a favourable attitude towards them. As long as they can do some work, it’s OK. But when they become too old to work, the family is not so interested in caring for the elderly people.” The older women did not seem to think they could expect to receive selfless care. Concerned about their capacity to contribute to the household, they chose to move to an old-age home in order to avoid becoming a burden.

Desire to live in a religious environment

Soon after my arrival at the House of Providence, it became apparent that most of the elderly women were quite devout. I quickly learned that I would need to plan my interpreters’ visits around the daily religious events. Indeed, if there was
a meeting of the Legion of Mary or a special celebration in the chapel, it was next to impossible to speak to the elderly women, since they would most likely be in attendance at these events. Many of the older women would pepper our conversation with statements about their faith. Moreover, visits to the women’s dormitories revealed that many had a combination of religious images, rosaries, crucifixes, bible or prayer books and religious portraits on their night table or around their bed. The majority of the female residents also wore either a rosary or a necklace with a religious pendant. Thus, religion not only provided a certain structure to the women’s days at the House of Providence, but it also influenced their speech, the decoration of their personal space and the way they dressed.

Not surprisingly then, the desire to live in a religious setting influenced some of the women’s decision to move to the House of Providence. For some, the desire to live in a Christian environment wasn’t the principal reason for their move to the House of Providence, but it was certainly a contributing factor. Prior to coming to the House of Providence, Rajani, an 80-year-old widow, lived with her eldest son and his wife in Bhopal. Although she got along well with them, she had some concerns about her living situation. Both spouses worked outside the home, which left Rajani alone most of the day. Moreover, she didn’t speak the local language and worried that if she fell sick, she wouldn’t be able to communicate with the hospital staff. After she developed respiratory problems, she decided to move back home. Her youngest son lived in Emakulam and invited her to stay with him. Rajani declined and chose instead to move to the House of Providence. She declared, “I can pray better in an institution such as this one. I’m happier here than at home...The church is nearby.”

For other women, the yearning to live in a religious setting was their principal motivation for coming to the House of Providence. This was the case for Dominicawho had been living with her two sons since her husband’s death. After trying to help a friend, her eldest son incurred a debt, which quickly became colossal due to the interest. Fearing for her son’s safety if the debt was not repaid, Dominicasold her property for one tenth of its worth in order to obtain money quickly. She then moved to a rental house with her youngest son and his wife. However, since the church was quite far from their new home, she was unable to attend mass as often as she wanted. Despite her son’s objections, she decided to move to the House of Providence so she could go to the chapel as often as she wished. When asked how she feels about living in the old-age home, she replied, “I’m quite happy. I can pray whenever I want.” As for Susana, she had spent most of her adult life in a convent, working as a cook. The death of four of her five brothers within a short time span precipitated her return home. She moved in with her remaining brother, but after a while, she felt the desire to live in a convent again. She was thinking of going to Chennai, but the Sister Superior at the House of Providence suggested that she come here since her older sister was already a resident. Thus, these two elderly women left seemingly
problem-free living conditions to move to the House of Providence in order to live near a chapel and under the spiritual guidance of the Sisters.

Discussion

Fragility of family relationships

In India, the family is considered to be the main support system for the elderly and the majority of older Indians live with their children (Irudaya Rajan & Kumar 2003:75). At the House of Providence, a considerable number of elderly women were invited to move in with their kin when they indicated their wish to leave their current place of residence. In many instances, it was not children, but rather siblings, aunts and uncles, or other relatives who offered a place to live to their elderly relative. Yet, the older women decided to move to the House of Providence instead of staying with their kin. When they discussed their reasons for choosing to live in the institution for the aged, the women often mentioned that they feared being a burden to their family. For instance, Clara, who decided to move to an old-age home instead of co-habiting with her sister-in-law’s children, declared, “Right now, there is great love for me, but all that will be lost if I become a burden to them.” Similarly, Martha refused to move in with one of her three brothers after her husband’s death. She declared, “I thought I would trouble them if I lived with them, because they have their own family.” The older women’s comments seem to imply that there is certain fragility to their relationship with their kin. They worry that co-habiting with their relatives – other than their children – may place too great a stress on their relationship.

When discussing the possibility of living with their relatives, the older women at the House of Providence not only voiced their fear of being burdensome, but also expressed their concern about the care that would be provided by their kin. Naveena, a childless widow, was offered a place in her paternal uncle’s house. She commented, “Because I have this sum of money [from the sale of her house], my relatives are happy to look after me. Still I decided to move to the old-age home. I thought that if I ran out of money or became sick, my relatives may change their mind about looking after me.” Elena made a similar statement. When her husband’s brother learned that she was leaving her home due to conflicts with her son, he asked her to move in with him and his family. Elena remarked, “Now that I’m healthy, it wouldn’t be a problem for my relatives to look after me. But if I’m ill, they may change their mind. It’s better to live here at the House of Providence, before I’m actually ill.”

In general, the elderly women who had lived with their children prior to coming to the House of Providence did not express such feelings; in many cases, they had left their home for reasons (i.e. familial conflict or the desire to live in a religious setting) other than the fear of being burdensome and losing their offspring’s love.
Although their kin manifested the desire to care for them, the older women seem to have ambivalent feelings about the assistance they would receive. They believe that, once they become unable to contribute to the household (i.e. due to sickness or lack of money), their relatives may change their mind about caring for them. This view is in accordance with De Jong’s (2005:68) assertion that “old age security has to be negotiated continuously through the agency of the elderly in their exchange relationships with the support-givers.” At the House of Providence, the older women thought that the willingness of relatives to care for them depended on the contribution they could make to the household. Thus, the women’s comments are indicative of the perceived fragility of the relationships they have with relatives.

The women who were actually co-habiting with relatives prior to coming to the House of Providence expressed similar fears. For instance, Georgina remarked, “I worry about misunderstandings with my sister-in-law; there are none, but I still worry about the future.” She later added, “I think if I were to live permanently with him [brother] and his family, I would become a burden to them. I don’t want to stretch my brother’s love.” De Jong (2005:57), who conducted a study among poor elderly Indians living in an industrial suburb of Ernakulam, reports that “no regular support in old-age is expected from ‘relatives’, i.e. married siblings and affines, or in-laws…” Like De Jong’s informants, the women at the House of Providence did not feel that they were entitled to permanent, selfless care from their relatives. Both the women who refused to move in with their kin and those who were actually living with relatives worried that their presence would become an encumbrance to the family. To avoid straining the currently loving relationship they had with their relative(s), the women opted to move to an old-age home.

Self-determination

The elderly women at the House of Providence did not seem to view the old-age home as a last resort, as a place to go to when all other living options have been exhausted. Indeed, many of them had other alternatives to life in an institution for the aged. These women were not ‘victims’ who were unceremoniously left at an old-age home by uncaring family members. They chose to be there. And their choice differs from the expected norm. According to numerous studies, elderly Indians predominantly prefer to reside with their children or family members (Bhat & Dhruvarajan 2001:628, Irudaya Rajan & Kumar 2003:77, Bhai 2002:13). Bhat and Dhruvarajan (2001:628) add that this is the case, even if parents are having problems with their children. The elderly women’s choice of living arrangement, namely an institution for the aged, thus goes against the reported preference of elderly in other studies.
When probed about the reasons that led to move to the old-age home, the older women would often discuss their fear of being a burden and/or mention their conflict-ridden familial situation. While these reasons are legitimate and certainly played a role in their departure to the old-age home, I think the older women were also fundamentally motivated by the desire to do what would ensure a secure and happy old age for them. Since the majority of the women were Roman Catholics and deeply pious, the desire to live in a religious setting likely played a role in their decision to relocate to the House of Providence.

Having the opportunity to attend mass daily and to devote time to religious pursuits was important for the older women. This is in line with Mehta’s findings that when examining perceptions of aging among the elderly, the author found that the “Indian elderly believed that old age was a time to think of God, and to focus on spiritual pursuits” (Mehta 1997:104). Moreover, based on the elderly women’s comments, it seems that they viewed their move to the institution for the aged as a way to improve their quality of life. Clara refused to move in with her sister-in-law’s children because she feared being a burden for them; however, she also mentioned that these relatives had busy jobs and lives and that she thought they wouldn’t have time to look after her properly. In other words, Clara felt that the quality of care at the House of Providence would be higher than at her relatives’ house. Martha and Sara, who both declined to co-habit with their brothers, reported that they had more independence at the House of Providence than they would have had living with their male siblings. Martha also declared, “They [brothers] order me around. It’s better for me to stay here; I only have to mind my own business.” Similarly, Rajani affirmed that she chose to come to the House of Providence instead of moving in with her youngest son, because she wanted independence. The older women viewed their move to the House of Providence as a way to ensure a satisfying old age, one that includes independence and freedom, good care and the opportunity to nurture their faith.

When I spoke with the elderly women at the House of Providence, the majority indicated that they made the decision to come to the old-age home by themselves; it hadn’t been suggested by family members or anyone else in the community. In fact, a considerable number of older women reported that their kin reacted negatively to the news of their impending move to the institution; they mainly encountered resistance from male relatives. The relatives’ negative reactions are perhaps not entirely surprising given the Indian tradition of caring for the elderly at home. However, it is remarkable that despite the opposition of family members, the elderly women decided to persevere with their decision and managed to come to the old-age home. This is no small feat in a society where women are still expected to abide by the decision of the male head of the family. Indeed, according to Stanley Jaya Kumar (1994:60), within the Indian family, “a woman still assumes a secondary role in which the superiority and dominance of the male is taken for granted.” In India, men (i.e. fathers, brothers and husbands)
try to control women’s sexuality and preserve their modesty so as to protect the
honour of the family. Consequently, a woman who is past childbearing age is no
longer seen as a threat to the honour of the family and she enjoys greater
freedom as well as increased respect and authority within the family (Vatuk
1995:295). Aging can thus have positive consequences for Indian women (Vatuk
1995:294-5). It is plausible that, in light of their improved status within the
family, the elderly women were able to convince their kin to accept their choice
to move to an old-age home. However, despite the positive changes in status
associated with aging, it remains that “the traditional social structure, cultural
norms and value systems continue to place Indian women in a situation of
disadvantage in terms of relationships [and] decision-making...” (Stanley Jaya
Kumar 1994:55). Consequently, the fact that the elderly women were able to
assert themselves and carry through with their decision to move to an old-age
home shows considerable self-determination and fortitude. After carefully
considering their situation, the older women chose to move to the House of
Providence even if their decision went against cultural norms and in some cases,
against the wish of their kin. The elderly women chose to put their needs first
and opted for the alternative that would provide them with the best old age. As
Elena, an 84-year-old widow, stated, “Now I want to look after myself.”

**Concluding comments**

The data for this paper was collected through observations, numerous
conversations, photographic material as well as focus group discussions. The
more I delved into the material I obtained in Kerala and reflected on the
significance of these conversations and observations, the more I uncovered new
layers of meaning, which sometimes disagreed with each other in subtle ways. As
a researcher, it left me feeling slightly ambivalent about what I had seen and
experienced.

My feelings of ambivalence may be, in part, a reflection of the elderly
women’s own ambivalence. Indeed, a subtle current of ambiguity ran through
some of the women’s narratives. For instance, they talked about moving to the
House of Providence, because they feared being a burden to their family; yet,
later, they commented that they preferred not to stay with relatives because of
the restrictions on their freedom and independence imposed by their kin.
Furthermore, even though the elderly women attributed their decision to
relocate to the old-age home to the desire to live in a religious environment or
the fear of burdening their relatives, many had recourse, at one point during our
conversations, to the idea that residents of old-age homes are people who have
been rejected by their family. It is possible that the women have internalized the
popular discourse of the ‘bad family’ (i.e. the idea that elderly persons living in
homes for the aged are there because their family has failed them). Or it is
possible that the older women feel ambivalent about the fact that they were not actually abandoned by their family, but instead took the unconventional decision to spend their old age in a home for the aged. They may be struggling with society’s expectation that ideally, Indians age among their family. Given the long-held custom of aging at home and the cultural norm of women following the wishes of the male head of the household, it seems reasonable that older women who have decided to forgo the traditional path may experience a degree of ambivalence. Nevertheless, the women at the House of Providence seem to enjoy their life in the old-age home as well as take comfort in their religious faith and the knowledge that they acted to ensure a comfortable and secure old age for themselves.

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Children’s Worlds
“Being fat is more a social problem than a health problem”

Giving voice to children with overweight

Mariette Derwig

“Being fat is not nice. It is difficult when your clothes don’t fit you
You are bullied very much and that is not nice.”(Dewi, 9 yr)

This essay attempts to explore what being fat means in relation to health and illness for overweight and non-overweight children aged 8-12 years. It illustrates that overweight children experience being fat as a social problem and not merely as a medical or health problem. Their concept of overweight is influenced by the beliefs that are present in the world around them and the problems they face in their social interactions with parents, friends, other children, teachers and other actors in their daily lives. The overweight children internalised the health beliefs that overweight is due to eating too much and therefore, predominantly blame themselves for being fat. In this way, they see overweight as a controllable condition. This notion may be influenced by their experiences in the health system, although the dominant belief that being fat is controllable was also present in the focus group discussions with ‘normal weight’ children. All overweight children saw themselves as fat and were dissatisfied with their body size. They shared the desire to become thin and be like other children around them. They attributed positive notions to their ideal body size, which in all the participating children was slim. In this way, they were also influenced by the present culture of slenderness.

Over the past decades, child obesity has become an emerging ‘disease’. Although childhood obesity is one of the most serious public health challenges of the 21st century.

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century and a very important health problem that needs to be taken seriously, childhood obesity is not ‘just a disease’. Overweight and obesity also have socially constructed meanings and cultural definitions. On the one hand, they are complex constructions influenced by biomedical and behavioural factors. On the other hand, and more importantly, overweight and obesity are also influenced by cultural beliefs and practices as well as social interactions with family, friends, teachers and other actors in the daily lives of children.

To uncover the complex social and cultural context of child overweight, I performed a qualitative study in 2004 using the child perspective. The child perspective takes children seriously in their ability to construct their own meanings and definitions of overweight in their daily lives. The child perspective considers children as social and cultural actors in the construction of overweight. It assumes that children have agency and therefore have the potential ability to negotiate their own meanings of being fat and construct their own strategies to deal with it.

One of the aims of the study was to explore what being fat means in relation to health and illness for overweight and non-overweight children aged 8-12 years.

**Methods**

In-depth interviews were performed with eight overweight children aged 8-13 years old to explore the relationship between being fat and health. All the children had been diagnosed as having moderate to severe overweight and had been treated or were about to be treated for their ‘illness’ in a health care system where moderate overweight is considered a ‘disease’ that needs treatment. Their parents and health care professionals working in the field of child obesity were also interviewed. Focus group sessions were also held with non-overweight children aged 8-12 to understand their perceptions on health and illness in relation to body size.

**Child overweight and obesity**

In the past, many societies saw obesity as a status symbol and regarded it as healthy and attractive. However, in modern society, obesity is seen as an unhealthy, unattractive and even deviant condition. Wilkinson (1996:29-49) describes that during the ‘epidemiological transition’ in rich developed countries, for the first time in history, slenderness became a socially desirable condition. Sobal (1995) claims that in the past decades fatness has moved from a moral conception of fat as bad or failed self-control to the medicalisation of fat as sickness. Despite all efforts of the medical profession to control fatness in the last century, child obesity has become a global problem that is steadily affecting many low- and middle-income countries, particularly in urban settings.
At the time of the study, the basic explanation in the medical discourse was that child obesity was the result of poor diet and a progressively inactive lifestyle. Modern society’s improved standard of living, overproduction of food (especially fast food, sweets, soft drinks, chips and chocolates) and aggressive advertising were often blamed for changing children into consumers of too much sugar and fat. However, modern society could not explain the major increase in the last decades entirely. The aetiology of overweight was considered much more complex. Multiple and complex genetic factors had to play an important role in the development of overweight, moreover, because not all children became overweight when influenced by similar environmental factors. Braet (2001) acknowledged the influence of social factors on the development of child overweight. She stated that when parents make decisions about food and exercise, they primarily observe and consult their own social network. In this way, some parents of obese children think that their lifestyle is not very different from their friends, family and neighbours and sometimes do not recognize that their children are fat. Braet also acknowledges that the media influences children in their perceptions on body size, food and exercise.

Currently, the imbalance between energy intake and energy expenditure is still the dominant notion in the medical discourse, but the fact that childhood weight is largely influenced by shared genes passed from parents to the child is now accepted. This implies that there are individual differences in the predisposition to gain weight and therefore, some children are already at higher risk to be overweight than others (Philipsen & Philipsen 2008). In other words, children in families with overweight family members are genetically predisposed to gain weight more easily than children from families where no one is overweight.

Due to the knowledge that many obese people have an inherited susceptibility of developing obesity and due to the increasing negative consequences associated with it, obesity has become a chronic disease that needs long-term follow-up and if possible should be prevented (Flodmark et al. 2004).

Since changes in diet and inactive lifestyle are given as the main reasons of child overweight and medication as a treatment for child obesity is lacking, changing ‘life-style’ behaviour within the entire family (such as changing to healthy food, stimulating physical activity and discouraging physical inactivity or sedentary behaviour) is seen as the most effective way of challenging the ‘disease’. In this way, children and their parents have to work hard at being fit and healthy and to conform to the new regimes and control their behaviour. Overweight children are required to become active agents in their dietary habits and physical activities.
Being fat: A social or a health problem

All children who participated in this research perceived themselves as fat. Being fat from their point of view implied that they were bullied mainly by other children or received remarks from people around them. Moreover, they had difficulties buying clothes and looking good, experienced problems with physical activities, and found it harder to make friends or have a boyfriend or girlfriend. They felt different than and sometimes jealous of thin or normal children and they often had a problematic relationship with food because they could not eat many sweets (or as many sweets as their friends) and they always felt hungry. These experiences made them feel ashamed, unhappy and sometimes even isolated.

The children did not mention health in their experiences of being fat nor did they consider themselves unhealthy or ill. They sometimes felt unhealthy when they ate unhealthy food, but they believed that only really fat people were unhealthy or ‘bad’ and they for sure did not consider themselves really fat. Some did have medical complaints that they related to their body size, for example, when they were physically active and felt pain in their legs, feet and backs. However, their desire to become thinner and lose weight derived from the problems they faced in their social interactions with other children and people around them. Their health was of less importance and indeed most of the children did not seem to be aware of the health consequences of being fat. These findings were consistent with results from a study done in the United Kingdom where school children aged 9-11 years old seemed not to be too concerned about the health consequences of overweight, but foremost had “social concerns not to be seen as fat.” In their views, they expressed that it was important to be thin and that fat children will be bullied and unpopular (Dixey et al. 2001:77). Thus, the children experienced being fat as a social problem and not as a medical or health problem and in this way, worried more about their social well being than about their health.

In contrast to the children, the parents of the children who were interviewed primarily worried about their children’s health status, sometimes because they had family members who had diseases associated with overweight or because they felt the pressure of the messages they received from people around them, health workers and the media. They also experienced increasing medical complaints from their children as they gained more weight. Nevertheless, all parents were very aware of the psychosocial problems their children were confronted with. Their motivation to seek treatment for their children was to prevent further medical problems, but also to make their children more secure and resistant against the negative messages surrounding them.

The health workers active in the field of child overweight also knew that overweight children in this age group faced many problems and that they sought
help because of these everyday confrontations with their body size. They knew that children view being fat as a social problem, while their parents sought help mainly for the medical consequences. The health workers felt that on the one hand obesity is a major health problem because of the future consequences for the health system, but on the other hand, they emphasized that it is also a social problem that should be taken care of outside the health system to prevent the problem at an earlier stage.

**Reasons for being fat from a child's perspective**

Most children in this study felt responsible for their own body size and blamed themselves for eating too much (unhealthy) food, unlike their parents who placed their child’s predisposition as the first reason for their children’s body size. The children did mention that they are predisposed to being fat, but they foremost blamed themselves for being fat.

Being fat is the way you are; some children can eat everything they like and do not gain a single gram, while other children do not eat that much but suddenly gain a kilo, so in a way if it is inborn, you are born fat (Darrell 13 yr).

The ideas of the children contradicted the belief of most health workers who thought that the overweight children themselves could not be blamed for their body size. Health workers rarely attributed a child’s role in the causality of their overweight and obesity or the prevention of overweight. They primarily believed that the child’s predisposition and the changing society in which we live were responsible.

Health workers did give children an active and very responsible role in changing their body size and therefore changing their eating and exercise patterns. They even felt that treating children and their parents was more effective than treating overweight adults. They also attributed an important role to the parents in teaching their children to deal with a changing society, but they clearly stated that blaming the parents exclusively for the body size of their children obscured the complexity of the causality of child overweight.

Some of the overweight children indirectly blamed parents in general, however, not their own parents for the increase of child overweight. They felt that parents nowadays are not strict enough and give their children everything they like just to make them happy. None of the children accused society, for example, the food industries or food advertisements. They did feel these pressures, but still blamed themselves for eating too much.

Most of the children agreed that they should control their weight and also mentioned many ways to become thin. Some parents felt guilty that their
children were too fat and that they had not watched their children’s eating and exercise behaviours closely enough or had not been strict enough at an earlier age.

**The internalisation of ‘health’ messages**

The experiences in their daily lives and the descriptions of their body images clearly illustrated that both the overweight children and the ‘non-overweight’ children were very well aware of the present health messages in the medical and popular discourses. They were both aware of the dominant notions that overweight is caused by too much food and too little exercise and that to attain well being they have to strive to be healthy and fit. They also knew that sweets, sugar, crisps and chips are bad and that they should play outside and be active instead of watching television and playing computer games.

However, their perceptions on being fat and being unhealthy or healthy differed. The non-overweight children regarded chubby children as unhealthy because of their unhealthy diets, while the fat children did not consider themselves unhealthy. The overweight children however, did consider thin children to be healthier than they were. Both groups of children strongly linked being slim to being fit and healthy and believed that fat children had the ability to become slim if they made an effort to eat less and exercise more.

Most of the children that participated in this study were physically active and according to their parents had more or less healthy diets. However, all children attributed too much unhealthy food to their continuing weight gain.

Burgard (2004) states that on the one hand “we assume that thin people are ‘making better choices’, ‘eating more healthful foods’, or ‘being more physically active’ whereas on the other hand, fat children on the contrary make unhealthy choices and are less physically active.” Burgard asks if fat children ever get credit for their healthy choices “the fatter children who are making an effort never see those efforts being recognized because they are not thin enough to be seen as succeeding,” whereas “thin children must be doing something right by definition” (Burgard 2004:23).

My study also shows that the overweight children accepted and internalised the powerful health messages that unhealthy food and insufficient exercise make them fat. Most of their actions in daily life were influenced by these powerful messages. They felt responsible for their own body size and viewed it as a condition that could be controlled.

The overweight children in the study interpreted and constructed ‘health’ in their own way. They interpreted messages they foremost received from their parents, but also from their peers and other people around them. They associated being healthy primarily with food, physical activity and never being ill, but also related it to feeling good and not being different from other children. These
results showed that these children attributed a wider meaning to being healthy and that they assigned immediate benefits to being healthy.

One has to keep in mind that the overweight children in this study had a history of ‘treatment’ in the medical domain, which also influenced their ideas and interpretations on overweight. Their concept of overweight was thus constructed through the shared medical, cultural and social ideas that were present in their personal world and context they lived in. Therefore, overweight children who have not been in contact with the health system may use other concepts of overweight and hold other ideas and practices.

The overweight children and their parents contested the idea that they were influenced by the media and attendant culture of being slender. On the one hand, the overweight children stated that they only wanted to have a normal body size like other children, but on the other hand, they all chose the thin silhouette as their ideal body size. This shows that they were certainly influenced by the cultural obsession with being slender.

When I am slimmer I will watch myself so that I will never grow fat again and when I am slim, I am good in sports and dancing and will be able to go to ballet lessons and you can run really very fast and suddenly you are not hungry again... (Anna, 8 yr)

Loewy warns that “the more pressure we put on children to conform to the ideal body type, the more we perpetuate the myth that this ideal can be achieved by everyone” (1998:6).

**Recommendations**

As mentioned before, overweight children viewed child overweight more as a social problem than a health problem and were most interested in attaining social well being.

Health workers should be aware that these overweight children blamed themselves for their body size and felt responsible for controlling it. They should also be aware that overweight children idealise the slender body size and that they desire to be slim.

According to the children in this study, having friends and being part of a group is considered an important strategy to attain a positive identity. Acceptance by their peers might alleviate the problems overweight children face in their everyday lives and may contribute to an improvement of their quality of life.

Borra (2003), in a qualitative study to better understand children’s perceptions on preventing overweight in childhood, explored potential avenues for communicating overweight prevention messages. She showed that children wanted to “fit in” and not to be seen as “different.” The acceptance by friends
and peers was especially important and increased with age. They valued parents, grandparents and other relatives, best friends, special teachers and coaches, and famous performers or athletes.

**Recommendations by the children**

The recommendations stated by the children themselves relate significantly to their notion that overweight is a social problem. It should be noticed that their recommendations address the detrimental experiences they face in their daily lives and are generally directed towards their peers. All of them want to teach others that fat children should not be bullied. All want to be treated as normal persons and said that children should be taught to just play together irrespective of what size they are.

**Reflection of the researcher**

During my training in paediatrics at the University of Amsterdam, I felt the need to study health and well being more holistically and decided to study medical anthropology at the Amsterdam Master for Medical Anthropology. My main interest was to explore the child perspective to better understand children’s health and well being. At that time, the obesity epidemic had just been recognized and I decided to study the experiences and perceptions of body size in overweight children. The research for the AMMA Masters took place in June-July 2004 and, in November 2006, I graduated as a paediatrician and applied for position at the Centre for Childhood Obesity in Malmö, Sweden where I worked for four years with children aged 4-18 with severe overweight and obesity. The treatment given is called Standardised Obesity Family Therapy (SOFT) that aims to treat obese children within their families and social networks while taking their own resources and strategies seriously. The Centre for Childhood Obesity started SOFT officially in 2004 as an evidence-based treatment in which the inherited susceptibility of obesity and the importance of the social network were integrated. By explaining the inherited susceptibility of obesity as an ‘allergy against calories’ we consciously tried to take away feelings of blame for their body size and emphasized that their obesity was not due to their lack of control. The ‘therapists’ (nurses, dieticians, psychologists and paediatricians specially trained in solution-focused (family) therapy), explained obesity as a life-long condition for which medication as a treatment is lacking and a ‘healthier’ lifestyle during the rest of their lives is necessary. During the visits, my role as a medical doctor was to examine the medical consequences of obesity, but I also tried to focus on the social circumstances and helped identify persons within or around the family who could support the children in their efforts to change their lifestyle. Aware of the fact that the overweight children in
my study had the desire to be slim, I accepted the fact that the aim of our
treatment was not to become slim, but to find a healthier lasting lifestyle. We
treated children only in the presence of the entire family recognizing the child
perspective and treating all family members as equally important. The child and
their family had to choose lifestyle changes that from their point of view were
easiest to accomplish. We had to trust and support the families in their own
choices and guide them for a long period of time. Working with obese children
and their families and knowing the results of my own study, I felt that SOFT was
the right way to treat these children, but unfortunately my fellow paediatricians
at the children’s hospital in Malmö were very sceptical towards our treatment.
They believed that obesity is a controllable disease that can be cured if families
only limit their energy intake, increase their consumption of fruits and vegetables
and engage in regular physical activity. They did not take the inherited
susceptibility and the social circumstances into consideration. Regrettably, only a
fraction of children with obesity are treated at the Obesity Centre. Primary care
nurses and doctors still think it is hard to recognize children with early
overweight and obesity thus many children are referred to the clinic when their
obesity is already severe.

Currently I work as a paediatrician at the Centre of Excellence for the
Promotion of preschool Child Health (age 0-6 years) in the Swedish province
called Skåne. While working with children with obesity and understanding that
early childhood obesity is the dominant predictor of persistent obesity in
adolescence and even in adulthood, I chose to work in prevention of childhood
obesity and contribute to strategies that try to preclude obesity at an early stage.
Almost all children visit the preschool Child Health Centre during the first year
of life. We know that later food preferences, activity levels and leisure activities
are all influenced by parenting and the home environment in the first years of life
(Rudolf 2009:7–8). We also know that most parents have enough knowledge
about healthy eating habits and the need for physical activity for their children,
but find it difficult to put into practice what they want as parents (Stenhammar
2010:66). We try to help families find strategies that give their children healthy
life experiences from the start that will last in the long term taking into
consideration the families’ cultural beliefs and practices as well as their social
interactions with family, friends, teachers, health professionals and other actors in
their daily lives.

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Moving on

Street children, agency and well-being in Mindanao, the Philippines, twelve years after initial research

Maisie Faith J. Dagapioso

This essay is a reflection on research done in 2001, which explored ‘street’ children’s knowledge and experiences of health, illness and well-being. I write about my conversations with some of the children twelve years after the research was conducted, and describe how they were then and now. The conversations became take-off points for my reflection on the relevance of the research in 2001, and now more than a decade later. I reflect on whether or not children’s agency was taken into consideration at the time, and how it should be central in formulating, implementing, monitoring and evaluating programmes that address the issue of ‘street children’ given current conditions. I also reflect on my own writing process by asking myself which of the children’s stories are privileged in this essay. So much still needs to be done, including challenging our own capacity for working with children by taking into consideration how they express agency in their lives. Moving on, we continually learn about children, and also ourselves.

[street children, agency, vulnerability, well-being, usefulness of research, writing, war, Philippines]

“Omar cooked our lunch today,” said the centre staff, when he offered us lunch one late December day in 2012. I was in the Akay Kalinga Center (meaning Support and Care) with some co-workers. The Centre is run by the Katilingban para sa Kalambuan Org., Inc, the organization I work with. The Centre is home to children who decide to leave the streets or feel they are better off staying away from their families for a while; for others, their stays can be longer. Most of the children go to school. The Centre is also a place and space for children who

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2 The Katilingban para sa Kalambuan Org., Inc. (Communities for Development) is an NGO based in Zamboanga City, Philippines. Katilingban works with marginalized communities, in particular, homeless, landless urban dwellers, on issues related to security of land tenure, livelihood, health, peace and development.
need food or a shower even as they continue to stay in the streets. The Centre is part of the Katilingban program that also does advocacy work about children’s issues among community members and local government units.

Then I saw him. Omar was one of the boys I did my research with in the summer of 2001. He was in the Centre for the Christmas 2012 break helping out with cooking and taking care of the younger children. I do meet him occasionally when I visit the Akay Kalinga Centre or when he comes to the Katilingban office. However, it’s been quite a while since I last saw him or talked with him. He has grown a lot taller, of course, I thought. I thanked him for lunch, telling him how delicious it was. He smiled shyly.

Later in the afternoon, after my meeting with co-workers, we met again. I remarked again about how delicious the food was, how big he had grown, how happy I was to know that he is now in college, and thanked him for cooking lunch. Feeling quite embarrassed at my show of affection, he said, “Na, usay pa kaw maka-move on…” You haven’t moved on yet, referring to my repeated thanks and words of amazement. His remark meant that, of course, he has grown, has learned some skills... no big deal. Get a hold of yourself, don’t dwell on the past, move on.

**Working with children, how it all began …**

Twelve years ago I was an AMMA student doing anthropology in my country (as I still do today), per the instructions from the AMMA teachers. Doing research about children was a challenge-cum-invitation from Fr. Angel Calvo, a Spanish Claretian missionary and the chair of Katilingban’s Board of Directors, who was traveling from the Philippines on his way to Spain and visiting me in the Netherlands. We were in a friend’s house in Gouda, catching up on news back home, and sharing plans.

Upon learning that I was going home and possibly doing research on women’s issues, Angel remarked, “You’ve always worked on women’s issues; why not do something about children?” I was hesitant because I wanted to do research on a theme and with a group that I was already familiar with. Children? Well, okay then, I was willing to go out of my comfort zone and felt quite ‘equipped’ to do so since I had taken the executive course on children. I based my research on three premises:

First, that children’s health is not just a medical issue and that their health is influenced by cultural, gender, political and economic determinants. Second, that children have agency. They are social actors who have knowledge about their situation. They make decisions about different aspects of their lives, including health. Third, recognizing that children are to be studied in their own right, I learn about them from them. I try to seek their stories and relate these as close as possible to how these were shared with me. (Dagapioso 2001:86)
It was a very exciting summer for me, and I learned a lot – about children’s health, children and agency. The research illustrated that children’s definitions of health take into consideration the “physical, mental and social aspects of their lives. Children talked about their need for food, having a job, sleeping well. They also talked about having no problems and being happy, about not getting crazy, about having friends and good relationships.” (Dagapioso 2001:87).

Children’s health experiences reflected what they experienced in the streets:

… as influenced by their physical environment, as well as the social relationships they have. Children’s ways of dealing with their (ill) health experiences are varied, influenced by what they have or do not have (food, shelter, family friends); what they do and do not do (claiming places and spaces, making and breaking ties); what they know and do not know about the cause(s) and effect(s) of their experiences; as well as their knowledge of how people around them perceive them – as vulnerable children who have no knowledge of life or as children who have knowledge and make decisions about their lives. (Dagapioso 2001:89)

The research also illustrated that children’s health experiences reflect social realities.

Their health is a continuous process of inclusion and exclusion, as influenced by being *mabuling* (dirty) and *limpio* (clean), when being either or the other would be advantageous or disadvantageous. Children may get included or excluded, too, because of their gender, age or ethnicity. Being ‘new’ or ‘old’ in the streets also influences whether one belongs or not. Their situation is also a process of ‘leaving and going home’ – of knowing when to leave or go back; of making and breaking ties; of negotiations and compromises; of being ‘rescued’ from the streets and getting ‘caught’. (Dagapioso 2001:90).

I also learned more about myself and doing research with children. “Doing research with them also involves coming to terms with my own feelings and perceptions about them; by doing so, I gave myself the chance to see and hear what they want to tell and show me” (Dagapioso 2001:89).

**Moving on...**

This essay is about moving on by way of revisiting the past and reviewing the journey from then till now. It’s going back to the summer of 2001 and comparing it with how things are now. How they are – children then, young adults now. How have they moved on? I attempt to reflect on the stories of some children and see expressions of agency in their lives. I then answer the question I ask myself: has the research helped in “enhancing programs and services addressing street children, taking into account their point of view?”

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1 Collectively, I refer to them as children even if they are no longer technically or legally children; individually, I refer to them by their names.
I then end by sharing some of my reflections about revisiting my work of long ago.

It has been quite an experience reading and re-reading my manuscript of 2001, most times by myself, a few times with A and Am, my granddaughters, aged eight and six, respectively. Reading the manuscript with them, the questions they asked and the comments they made, helped me ‘see and hear’ the children from another perspective.

December 31, 2012, some notes. I left my computer on the dining table this morning. A read what I had typed earlier. She asked, “What does ‘I now have a job’ mean?” This led to an early morning conversation between grandmother and granddaughter about experiences of health and well-being, the work I did years ago (“I wasn’t around then.”). I told A about asking ‘street children’ about their experiences of being ill, not sick, but not being healthy either. I told A about the children having fever, wounds, not feeling well, but telling me they were not sick, that being sick is when one is lying down and can’t get up or not feeling well enough to collect bottles to sell or to earn money for a bike ride or food. I told her all this as we flipped through the pages of the manuscript of 2001.

“Why are you skipping pages?” It’s a manuscript of 100 plus pages and we can’t read them all now. “I’ve been sick many, many, many, many times,” A said. “I had dengue three times; once I had to go to the hospital to have my blood taken, the same hospital near the beach where the children in your story were playing.” “Is this the children’s swimming pool that Puput showed and told us about, which is now the dancing and coloured fountain?” Am was referring to one of the pictures in the book, of some children in their ‘swimming pool’. At the time the picture was taken, the fountain was not working and had stagnant green-coloured water. But for the children, it was their pool. “Do the children still swim in it?” Nope, I remarked. The fountain is at the end of the park, which used to be a place where the children would play and street education activities were conducted. The park is no longer available for such activities. Any activity to be conducted in the park requires permission from city hall authorities.

New conversations

For this essay, I had new conversations\(^1\) with Nurwisa, Ibrahim, Omar, Dennis, Arnaiz and Ronnie\(^2\) for updates about themselves and others — Anton, Drew,

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\(^1\) A has a longer name. She gave me permission to include her in this essay, but when asked if I could write her full name, she remarked, “Nope. Just A.”

\(^2\) Am also has a longer name. She agreed for me to mention her as Am, “in the story you’re writing.”

\(^3\) Their grandfather. Some of the children who participated in the research also refer to him as ‘mio hombre’ (my man).

\(^4\) ‘Fieldwork’ for this essay took place in November 2012 to January 2013.
Benhur, Sheryl, Cowboy, and Taj. I had conversations with them in the Centre and in the office. I had more time with these children and with other younger, ‘newer’ children, on the beach, on the occasion of Angel’s birth anniversary. Every year this occasion also serves as a reunion of sorts for the children both then and now, celebrating just being together, with each other and the staff.

The children remember ‘the interview’ during my 2001 research; what it was about though, most of them do not remember. Nurwisa and Dennis still agree when ‘prompted’ that children’s health is beyond just the physical. Happiness, relationships and ‘peace of mind’ are other aspects to health. Nurwisa, now a nursing student, could relate to this ‘holistic’ definition of health. Both Nurwisa and Dennis are thankful, though, that they never got sick while living in the streets. “Maybe because we were immune to the germs.”

My reflection on the children’s lives and their continued expressions of agency is based mainly on the stories shared by Nurwisa and Dennis with whom I spent most of my time. I use their stories as take-off points for discussing the stories of the other children. I also integrate my conversations with A and Am, as well as those with Loida and Angel in the essay.

I showed the children my 2001 manuscript, which I had with me during my conversations with most of them. During the conversations on the beach, they looked at pictures of themselves many years ago, doing mandalas or riding bikes. They teased each other about the colour of their hair then; they joked about how some of them now have children while others ‘still’ don’t. They also talked about how they miss the others who were not able to come because they had to work or had moved somewhere else; one couldn’t come because he died some years ago.

The children of the research in 2001 were then between the ages of four and 16, although most ages were approximate. In general, the children didn’t know their birthday or their real age. By now, these children, some of them young adults, are approximately between the ages of 16 and 28. Not one of them stays in the Centre anymore, but most maintain contact with the staff and sometimes visit. Some have returned to their hometown and live with their parents, while others live on their own or with a spouse or siblings. The college and high school students among them are in an ‘independent living arrangement’ and continue to receive financial assistance from the centre for tuition and other school needs.

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9 Ronnie was not part of the research in 2001, but I include him here since I met him soon after the research. It is from him that I learned more about his elder brother, Randy, who was one of the children in the research.

8 Names of the ‘others’ are pseudonyms.

10 Loida Sapalo is the Centre head with whom I also had conversations for this essay.

11 These are those who are now eighteen years old and older, and due to their age are no longer legally children, hence, no longer ‘eligible’ to stay in the Centre. Most of them work to earn money, as the financial assistance they receive is not enough for their needs.
“We’re okay, we’re fine,” was the quick, common reply to the first question I asked. How have you been, however, took a little while to answer. “It was hard being in the streets. We had to earn so we could eat. Even when we were living in the Centre, we had to earn so that we could give something to our parents and our brothers and sisters.”

Life in the streets was hard. But it was not something they regret experiencing. “I do not regret having grown up in the streets, of being a street kid. Because of that experience, I am who I am now,” relates Dennis. Nurwisa agrees. “I’m not saying it was good; what I’m saying is: I learned a lot from being in the streets. Being in the streets also led me to the Centre, and was the reason why I am now able to go to school.”

However, being in the streets – as ‘home’ or workplace – is not something they wish other children to experience. Dennis, a third child, has other siblings who were ‘adopted’ by relatives. “I no longer know them, but I’m glad they are in a better situation. I don’t think they would have survived the same way I did.” According to Nurwisa, “All of us at one time or another lived on the streets. We left our house because there was nothing to eat. I do not blame my parents; they just couldn’t feed all of us. But we had to survive, even if it meant doing so on our own.” Nurwisa has eleven siblings. Her older brother Ibs was the first one to ‘live on the streets’. The rest followed later. Things were not what they wanted it to be, but it could have been worse. They do not have any ill feelings against their parents. At that instance, leaving home and deciding to live on the streets was a major decision, albeit a “scary one.”

Staying in the Centre was another major decision. Living in the Centre meant abiding by the rules set by them with the rest of the children and the Centre staff – no sniffing rugby, attend school, study hard, help out in the household chores, help one another. It was a challenge living in the same place with several other children, coming from multiple places and various cultural backgrounds. It was also a challenge following the rules; in the streets, being on their own afforded them some freedom. Much has changed since then. “We’re better off these days.” These changes are the result of ‘taking stock of their situation’ and making decisions about how their lives should be.

“Do the children go to school?” A asked. Some of them did, and some still do. The majority of the 53 children who were part of the 2001 research were in school; however, after the study was conducted, only about a quarter of them (13) continue in school – four are in college, and the rest are in high school.

Nurwisa, a first-year college-nursing student, is ‘home’ from school for the December break. School is three hours away by bus in another province where she stays with relatives of her father. ‘Home’ for now is shuttling between other relatives’ houses in the city centre, and the Centre, where she assists Centre staff

12 Adhesive or glue used to repair shoes. There are children who sniff rugby, which in some cases can be addictive.
caring for the younger children. Dennis is a first-year college student enrolled in hotel and restaurant management. He is off from school, but works during the holidays as a grill man in one of the establishments serving barbecue chicken. Dennis lives in a boarding house. Ibs, Nurwisa’s brother, is a fourth year civil engineering student, and Omar is a first-year student in hotel and restaurant management.

Going to school was part of the plan these children made about how their life should be. Dennis was in the elementary grades in 2001, still living in the streets, “It was embarrassing to beg for money, to smell bad. I told myself that this is temporary; life will be better.” Nurwisa relates that others might not have expected her to study nursing “but even when I was still in the elementary, I was already interested in nursing.” She was about to graduate from high school when she planned her life then, “building my way to college, building my road for changes in my life.”

With much pride in her voice, Nurwisa related how she was happy to have finished high school and is now a first-year nursing student:

I didn’t pass the nursing entrance exams in the school here that’s why I decided to continue my studies in Ipil. I still have three more years to go but I am determined to finish school. Ibrahim is also determined to finish school so that we can help our parents and other brothers and sisters.

Ibrahim, Nurwisa’s brother, arrived later. Apologizing for being late and for not being able to stay longer, he remarked, “My classmates and I are doing our research, and we have to meet with the officials of this agency.” Ibrahim has one more year to go before he graduates and takes the board exam for civil engineers.

I told A that one of the boys in the story was the first among them who went to Claret School of Zamboanga, the same school she and Am go to now. In later years, several others followed suit. Studying in a private school wasn’t easy for Dennis. First, because “It was a struggle to mingle with rich classmates. Second, I was about three years older than them.” Dennis had to live in a boarding house away from people he was used to living with, in a new arrangement. Plus, he had to work.

For Dennis and Nurwisa, as well as for Randy and Ronnie, going to school and working is a challenge. I told A about other children selling things on the street working hard – “harder, maybe?” I asked why harder and she replied, “Because they have to.” It was necessary, studying and working at the same time - most especially now. When they were younger, in the elementary grades, and staying in the Centre, almost all of the children’s basic needs were met. Randy and Ronnie worked not only for themselves but also for their brothers. They decided to take their brothers out of the Centre so they could be together. By doing so, they assumed responsibility for the needs of their younger siblings,
including one instance when one brother had to be operated on for a broken leg, after falling through a hole in the place where they were living.

As children, most of them experienced the streets as a place to live, play, earn money and socialize. As older children and young adults now, the street has ceased to be a living place. “Living in the streets should stop with us; it should not be the place for other children – our brothers, sisters, even the children that we will have.” This is especially true for those who already have children of their own, like Sheryl, Arnaiz and Taj. They’ve found ways to have a place to live – anywhere but the streets – not only for themselves, but most especially for their children.

Sheryl, Taj and Arnaiz are determined to keep their children off the streets. Doing this is harder for others. Sheryl and her partner used to live in an old building that was originally built as a store. Several days before the year ended, the residents had to leave since it was going to be demolished. Sheryl and her partner decided to move to Basilan, 13 but leaving their daughter in the Centre. “She is better off here”, she told Loida.

Even if the street has ceased to be a living place for most of the children, it remains a place to ‘earn a living’. Twelve years ago, the children worked on the streets collecting bottles and cans to sell, begging, and picking pockets; one of them did massage having undergone training. They continued to engage in economic activities – a job, odd jobs – to support themselves and others.

Today, Anton picks pockets, Sheryl sells vegetables in the market, Madelyn earns money as a pok-pok 14 and Arnaiz, with one child of his own, makes a living driving a pedicab. 15 Ronnie works in a place selling pastries. Taj, after giving birth soon after graduating from high school, supports herself and her daughter working as a sapatero 16 repairing shoes on the sidewalk. “But that is not a real job,” remarked Angel, upon learning about Taj. “But what is a real job,” we asked. Taj is a high school graduate (one of the ‘bright students’) who could easily get a job as a saleslady (given her qualifications), but she decided to be a sapatero. Repairing shoes, she can earn P300.00 a day since she gets paid per pair of shoes. A sales lady gets paid a lesser amount per day, and spends most of the day standing. A sapatero can sit down while repairing shoes. A sales lady would earn even less because she has to spend money to buy make up to look ‘presentable’. Real job or not, any activity that earns them money is acceptable to live. The children continue to make choices, and these are based on what they know about their situation and their own capacities. More than a decade ago, I wrote, as part of the concluding remarks:

13 An island just across Zamboanga.
14 Refers to prostitution.
15 A three-wheeled vehicle to transport passengers. As the name implies, pedicabs are powered by human pedal power.
Presenting street children as having agency does not mean negating the conditions that put them in the streets in the first place. Neither is there an intention to romanticize their expressions of agency. The stories illustrate that they are capable of making decisions about their lives, then, programs aimed at helping them should take into account... children’s experiences, including their need to be in the streets, at the same time recognizing that their continued presence in the streets may be detrimental to them in the long run (Dagapioso 2001:91, 92).

Continuous living in the streets may, however, be detrimental to the children in the long run. How could this be so? Maybe not just living in the streets, but rather the kind of activities they do to survive in the streets.

Dennis relates that when he sees a ‘street child’, he remembers how life was then for him. He was small for his age. “I was beaten several times. There were times the money I earned selling peanuts would be taken away from me. In the streets, you don’t get to eat regularly.” When he sees a ‘street kid’ now – who’s in need ‘as in’, 17 as opposed to one who’s ‘making drama’, just acting – he gives food. “Never money, as this could be used to buy rugby or for gambling.” Dennis recognizes that things could have turned for the worse had he stayed on in the streets.

Nurwisa wonders why, “of my batch who stayed in the Centre, among the girls, I am the only one in school.” While not fully understanding why, she respects the decision of her ‘batch mates’ to be in the streets as a snatcher or as a pok-pok. For Nurwisa, the possibilities of getting a disease and the constant fear of being caught and thrown in jail are situations she hopes don’t happen to her friends.

But worse things can happen. Benhur’s mother, one of the few mothers I met in 2001, was hit by a vehicle. She died. She was in the streets looking for Benhur. Some time later, Benhur, one of the youngest children at the time of the study, 18 was found dead – tortured, they said. He had bruises all over his body. “He was a snatcher; a lot of complaints were made against him, he was getting too much to handle.” Benhur was ‘salvaged’ – summarily executed. 19

“Why do the children collect bottles to sell, don’t you not help them with something else?” (A, February 26, 2013.)

17 ‘As in’ is used to refer to or emphasize something that’s real and not pretended; similar to the phrase, ‘seriously speaking’.
18 Benhur was eight years old in 2001. He would have been 21 now, had he lived.
19 ‘Salvage’ refers to summary execution or extrajudicial killings. This term ‘surfaced’ during martial law years when people who were considered to be against the then leadership were tortured and lynched. It is only in the Philippines that the word has taken on this meaning. Ocampo (2012) writes, “To understand Philippine usage is to know how the multilingual Pinoy used the Spanish adjective salvaje (savage) as a verb sinalbahe. When written in Spangalog as “sinalvaje” and read like English, you get “sinalvage” hence salvage and salvaging.”
“After the initial pleasantries of saying ‘Good morning’, Benhur asked me for money. I asked him why. I will buy bread. It was not enough what you gave me last night, he said. He was referring to the bread I gave him and seven other children the previous night when I met them near the plaza. Benhur’s statement about the bread being ‘not enough’ struck home a point. Are the services and programs addressing the issue of street children ‘enough’?” (Dagapioso 2001:91)

When A asked me that question some time ago, I replied that we (the Centre) do help by also providing the children with their material needs. For some children the support was for everything – food, clothing, school needs; for other children, the support was just tuition money. What I didn’t tell A was that when children decide to collect bottles to sell, they learn to develop capacities for taking care of themselves – doing math, negotiating with potential buyers of the bottles, crossing the streets, and dealing with bullies (or, on some occasions, learning not to be the bully). These are ‘life skills’ that are necessary for the children to learn since these will be useful whether they live in the Centre or in the streets.

During a staff meeting when the discussion turned to the ways children are supported, Loida emphasized the importance of children learning by doing. “We don’t do things for them, we encourage them to do things on their own, of course also provide the information they need; sometimes, they learn on their own.” This was evident, in 2001, when one of Randy’s brothers fell through a hole in the place where they live. “I (Loida) told him (Randy) which government agencies to approach and how, what to expect in the hospital.” This is easier said than done, because even as we believe that children are capable of doing things, we still are caught in the dominant view that children are vulnerable and need protection.

On the bus ride to the beach in late December last year, Loida and I asked ourselves – what is our indicator that we are doing the right thing, or have done the right thing? Is ‘children in school’ the indicator? What do we make of Taj, who stopped school and stays in the streets as a sapatero so she can take care of her child, but still hopes to go back to school? When the children drop out of school, get married or have children, are they failures? Or have we failed them? Where did we fail, where did they fail?

Dennis and the other children are immensely grateful for the support given to them by the Centre – the staff, the organization, the Padre. They are grateful for the shelter, food, education, and most especially ‘just being there for us’. “It is up to us to make use of what we received,” Dennis remarked. Nurwisa agrees, “We all received the same thing – education, food, love, advices [sic].”

Life is better now compared to what we experienced before according to the children today. But life could still be better. Nurwisa and Dennis hold on to this belief. There were times when Dennis and Nurwisa felt discouraged – short on
money and time for studying and working – they remind themselves that life was harder in 2001. It was a time when “ako'y nakakapit sa patalim”20 and choices were limited. You do not give up now”, they remind themselves, feeling hopeful. Life may be hard at times, but can become better.

How about Sheryl and the others? “They made their choices, Taj made a choice, maybe a mistake, but you can see that she is determined to take care of her child, to not let her child grow in the streets. I told Taj, do good, if not for yourself, at least for your child,” remarked Nurwisa. Arnaiz works in the same manner, as a pedicab driver, accepting the responsibility of fatherhood to take care of his child and keep him off the streets.

Perceptions about children do affect and influence how we work with children. Children are viewed as vulnerable, at risk, or potential risks (in this case, of ‘children in the streets’). It does help to challenge ourselves on how we view these children and the basis for such views. In a learning session on ethical issues in research and doing research with a ‘vulnerable group’, children included, a participant challenged the use of the word ‘vulnerable’. He said, “It is situations and our own perceptions about these people that make them vulnerable. They are not vulnerable as they are; we make them vulnerable.” In this essay, I put the word ‘vulnerable’ between quotation marks to illustrate and emphasize that children are capable of making decisions. However, we also have to ask ourselves, can we adults as researchers and program implementers ‘handle’ children’s capacities? Do we have the capacity to work with children as agents in their own right? Are we also capable of believing in children’s capacity to learn to do things and make decisions? Even when some of the outcomes for such actions are not what we intended to happen?

As adults, we also make choices with the children on negotiated terms recognizing their capacities and affirming them as agents of change as well as resources who transcend victimization, while accepting our limitations. After all, as the children have said, “You won’t be here forever, we know that.”

One more question

In this essay, I asked myself some questions – how are some of the children in ‘my’ research now? What are their ‘expressions of agency’ as they move on with their lives? How have we worked with the children? Attempts to answer these questions were presented in the previous sections.

There is one more question to answer, however: has the research been helpful in enhancing programs addressing street children’s issues in particular and children in general? This is a tough one to answer. Yes and no. It depends on the

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20 Literally means, holding on to the knife. It pertains to a context or situation where there is despair, hopelessness and the only choice one has is to ‘hold on to the knife’. Similar terms are ‘clutching at straws’, ‘biting the bullet’, or ‘at wits end’.
time frame and the context. After my fieldwork in 2001, I made a summary of
main points: initial findings, possible recommendations and discussed these with
some staff of the Katilingban. There were expressions of appreciation, especially
on the process that highlighted the children's participation. The methodology
was something quite new to the staff, since they were used to the quantitative,
non-participatory methods employed by students who did research with
‘children as objects’.

Sometime after coming back home following AMMA, I went to the Centre. I
gave a copy of the manuscript to the staff and the children to read and keep.
With the rest of the staff, I also made a presentation. I admitted my dilemma
then about making recommendations because due to a ‘lack of time’ I had had
no discussions with the children regarding ways to ‘enhance programs’. This was
implied in my manuscript, but not explicitly stated. I had more questions than
recommendations. One question I raised was: is the organization capable of
addressing the conditions that put the children in the streets in the first place,
considering that “the presence of children in the streets are embedded in the
economic, political and social conditions?” (Dagapioso 2001:92) At that time, I
did not know if this question was answered at all.

I also talked about agency, and the “challenge to work with street children in
ways that would strengthen their agency instead of constraining it” (Dagapioso
2001:89). In 2001, the discourse on children’s rights and participation was
gaining ground. I remember feeling uneasy talking about agency. I knew I was
not understood. I also didn’t know how to explain ‘agency’ in the context of
children’s rights and participation, even if I knew that these were related
concepts. Agency is central to children’s rights and participation. However, my
research was appreciated by the Centre staff because it revealed the ‘relational’
aspect of children’s health.

Was the manuscript read at all? Yes, some children read part, but not all, of it.
I know because some of them remarked to me afterwards, “This is my story,
how come it has somebody else’s name?” I had been ‘adhering’ to the ethical
guideline of protecting the participants, and used pseudonyms. Fine, but this was
not explained to the children. Was it read by staff? For some staff, it was too long
and the language was ‘quite academic’ even if the style was ‘story telling’.

Was the research helpful? Yes, to some extent, since it affirmed processes already
employed at that time. Some of the recommendations have not been implemented,
but these are ones which people felt were not relevant in 2001 – to conduct more
research on the meanings of sniffing rugby, how children access medicines, and to
compare and contrast street children’s health experiences with that of children ‘at
home’. I haven’t asked if these recommendations are relevant now.

One issue raised in 2001, which this essay has raised again in the preceding
sections, was to continue reflecting on: … the basis for having programs to
address street children’s needs. How do we see these children? Do we see them
as vulnerable beings without knowledge or as children who know a lot about their situation and are able to make decisions about their lives? The challenge is to work with street children in ways that would strengthen their agency instead of constraining it (Dagapioso 2001:93).

In 2001, discussions about children’s participation in research were limited. Over the years, though, this has become more common, not only in discussions related to children in the Centre, but also for how this applies to children in the communities and to child survivors of trafficking. This is not due to my research, but rather to the influence of the agencies funding the programs.

I am part of an organization engaged in community development. I have colleagues who are social workers working as community organizers or community development facilitators. In my role now as program coordinator, I teach myself to find ways to contextualize the discussion of agency in other aspects of program implementation, whether in microfinance, enterprise development, addressing violence against women and children, or organizational development. I remind myself that there are words and concepts in other disciplines that resonate with the concept of agency.

So, this brings us back to the question: has the research on children’s experiences with health been helpful to the Katilingban? In some cases the answer is yes, in other cases no, not yet. But the opportunities and the ‘invitation’ for the research to be useful are open. Issues raised in the research could be revisited and be points for collective reflection. The greater challenge and invitation for Katilingban now is to re-examine how programs can be enhanced to address structural issues – to challenge and work towards changing conditions that create ‘street children’ – taking children’s agency into consideration.

**My own process in writing this essay**

I learned in the AMMA that writing is one way of thinking and reflecting. I also learned on several occasions that writing could be an emotional process bringing about or surfacing feelings that have not been processed. Writing can also be hard especially if writing about themes of children’s participation, appropriate and sustainable service provision, and enhancing lives.

Or could it also be the other way around, that thinking is a way of writing? For this essay, I have ‘written’ in the bus, the bathroom, while supposedly ‘listening’ to a lecture, eating, doing origami, watching TV, and many times while ‘sleeping’. I’ve wished several times that my thinking machine was connected to a computer that would write immediately and make visible what I was thinking about. The thinking-writing process generates many points, but when I write on paper, somehow I get lost, because I start to ‘traffic’ the ‘transfer-of-my-thoughts to paper’.
What is on paper is not everything I have thought of at first. Some information is excluded, lost. Sometimes, this happens because I forget; most times it happens because I was not sure if this information should be included. What information is privileged in the final narrative? On what basis do parts of the children’s stories become included or excluded? Often, emotions influence my decision to include or exclude stories. Am I ready to share part of my ‘emotional’ self that has been affected? Is that allowed in essays such as these? Take for example, the accounts about Sheryl and Anton, or Benhur and Madelyn, or Taj. For me, these are not ‘pleasant-makes-me-feel-good-stories’, not happy endings. But I remind myself that I am not writing happy endings. Besides, who am I to judge whether or not the children’s stories, or their lives for that matter, are happy or not? Could I make a positive portrayal in an otherwise, to me, negative situation? In the end, I tell myself: write. Emotions included. Recognizing that I am affected by their stories affirms my connectedness with them. When I write about the children’s stories, I also write about the world that I share with them.

Write. Because by not doing so, would negate the children’s existence, their capacities to make decisions. Not doing so would negate that they are actors influenced by and influencing their environments. It also means not recognizing and affirming who they are as persons in their own right.

I write their stories, because by doing so, I recognize and affirm that children, then and now, are making decisions based on their knowledge of who they are (although this could be confusing and painful at times), what they want and do not want, what support they have and do not have, and from whom they get support. I write their stories, because by doing so I share with you their expressions of agency in their lives. In this way, I hope that we learn from them. This writing has been a learning process.

Post script: January 13, 2014

So many things have happened since I wrote the first draft of this essay. Where I live, we still continue to have a ‘humanitarian crisis’. The *buno, giera* happened. A rebel group came to the city in the early dawn of September 9, 2013, holding residents hostage in a local village. A military option (read: war) was thought of as the solution to the hostage taking. The war resulted in deaths and massive displacement of residents.  

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There were calls for a peaceful resolution and for a humanitarian ceasefire by some groups in the city. However, these were unheeded. [http://www.mindanews.com/top-stories/2013/09/26/zamboanga-city-standoff-more-deaths-more-bakwits/](http://www.mindanews.com/top-stories/2013/09/26/zamboanga-city-standoff-more-deaths-more-bakwits/). (January 13, 2014).
About eighty thousand people (from an initial number of more than a hundred thousand), continue to stay in several evacuation centres. The majority of those staying in the evacuation centres have nowhere to go home to since their houses were burned. Among the internally displaced are some of ‘my children’, their families and the families of the children who stay in the Akay Kalinga Centre.

Omar’s current address is Tent 6, Zone A, Grandstand. Despite earlier prohibitions to go back to their village, Omar went back to get whatever he could save; of two sets of school uniforms, he was able to retrieve one. He continues to go to school. He and his family hope to go back to their village soon. During the early part of the crisis, Omar did volunteer work helping distribute relief goods. For Sheryl, Ana, Cowboy and their families, their temporary addresses were somewhere in the sports centre (the bleachers, the tennis court) where they had tents or classrooms. After having moved to another place due to the demolition of their living quarters, Sheryl came back to Zamboanga City to earn a living selling vegetables. Her village is one of those affected by the fighting. Sheryl and her family now live in the market in the stall where they sell their vegetables. Ana and Cowboy have since gone back to their respective villages and rent a room with other families.

The children who stayed in the Centre had to be evacuated twice, as bullets also hit the place, including the girls’ sleeping quarters. It was very fortunate that nobody was hit. Several days after going back to the Centre, during five days of continued rains, they experienced rainwater pouring through the holes of the ceiling caused by the bullets. The same rain also caused flooding in the evacuation centres.

A and Am are now nine and seven years old respectively. They had the opportunity to meet with some of ‘my children’ and the other children now staying in the Centre during a learning session on making paper cranes. The paper crane learning session – ‘Cranes for healing, cranes for peace’ – has since spread to other children and adults alike. As part of the process, children wrote their hopes for peace on the wings of the paper cranes: Sana makita ko ulit ang aking mga magulang (I hope to see my parents again), Gusto kong umuwi sa aking bahay (I want to go back to my house), Sana makapagtapos ako ng aking pag-aaral (I hope to finish school). And, as everybody hoped: “Sana matapos na ang giera” (Hope the war will end).

War is ugly, and its effects on children are devastating. The firing and the fighting have stopped, but the crisis continues. The majority of the homeless are also jobless and living in a state of insecurity. Economic insecurity is a concern not only of people whose villages were the centres for the fire fight, but also for majority of the city’s residents; economic activity is at a standstill and people still have to recover from it. Many children are out of school; others have classes, but for fewer hours because some schools became evacuation centres.
The effects on the emotional and mental level of the people are immeasurable; people continue to live in fear and are traumatized by the incident. Psychosocial interventions continue to this day, and will continue for a longer time. After having survived the war, people in the evacuation centres are now at risk for disease outbreaks.

Looking back, and re-reading the manuscript of 2001, I realize that ‘my children’ have come ‘full circle’. Most of them, in 2001,23 became 'street children' because their families had to flee to Zamboanga City due to armed conflict in their areas. Now again they experience war as young adults; some of them with children of their own. With them, is a younger, newer generation of children experiencing war and its effects.

“Katilingban as an NGO is aware that its services are not enough to address the issue of street children. For the time being, however, they hope that the various activities they conduct, especially the availability of the centre to the children, would provide the children some time off from the streets” (Dagapioso 2001:15). Katilingban has since moved on from doing Centre-based activities to advocacy work about children’s rights and children’s participation among various sectors – community-based associations, local government units, and government agencies.

But a greater challenge, as mentioned earlier in this essay, remains: “I must remind myself, though, that agency, like resiliency, can also be overemphasized. A person’s capacity to influence one’s environment is also influenced by the environment one finds oneself in. Agency interacts with structure and the interactions are always within a context” (Dagapioso, 2001:9). This reminder, written more than a decade ago, still holds true today. As we move on working with and for children, the context has remained the same, albeit with some variations. In 2001, ‘my children’ left places of armed conflict as children and came to Zambonga City. Fast forward to 2013 – the armed conflict came here to the place the children have called their home for the past decade, and now their own children experience the war.

We continue to ask questions, some general, others more specific. Finding answers to these is becoming more urgent than ever. How are we addressing the situation that brought these children to the streets in the first place? In this case, armed conflict? How do we continue to advocate for peace and work for social cohesion? How do we take children’s agency into consideration in all the work that we need to do? The work ahead is daunting, and we see more expressions of children’s agency at work. As well, we also see affirmations of children’s capacities and children’s agency.

Children in the Centre facilitated a session in November 2013 on ‘Cranes for Healing, Cranes for Peace’ among nurses, where they shared the story of

23 47 of the 53 children were from areas outside of Zamboanga City.
Sadaku. The children not only taught nurses how to make paper cranes, but also challenged them to address not only the illnesses, but also the situation that brought about the illness in the first place, in this case, war. Work for peace wherever you are was the message of the learning session.

On December 28, 2013, Abdul, aged eleven, was chosen to represent children in the city’s local poverty reduction action team (LPRAT); other members of the team were representatives of other sectors. During the discussion, a few participants questioned children’s capacities to participate in local governance processes such as this. Abdul’s participation was accepted by the group following the reading of legal documents that affirmed the inclusion of children in the LPRAT.

During a session with some children a few weeks into the biruk, giera, a child shared his drawing. In the drawing was a house burning with a helicopter flying overhead. He said, “Our house was burned because of bombs from the helicopter.” However, on the same page, between the helicopter and the burning house, were drawings of a star and a butterfly: signs of healing, and of hope.

So much still needs to be done. We need to move on. Encouraged by ‘my children’ then, and by the children in the Centre now, and children elsewhere, I need to move on. I am hopeful.

References

Dagapioso, M.F.J. 2001 *Walay sakit... dili himsog (Not sick... not healthy...): Knowledge and experiences of health, illness and well-being of street children in Zamboanga City, Philippines. An exploratory study. Master thesis Medical Anthropology, University of Amsterdam.


Sadaku, a Japanese girl, survived the atomic bomb during World War II, but died several years later due to leukemia. Wanting to get well, she made paper cranes, following the belief that one’s wishes would be granted if one made a thousand cranes. Sadaku died without finishing the thousand cranes. The story of Sadaku has been adapted and shared during the sessions with children in the Centre, and in other evacuation centres. A and Am, together with children in the Centre, facilitated some of these sessions on ‘Cranes for Healing, Cranes for Peace’.

Farmers, fishers, informal settlers, health workers, and informal workers were included. The LPRAT is tasked to come up with plans and corresponding budgets that would address the needs of the various sectors represented. In the Philippines, local government units (LGUs) are mandated to organize the LPRAT and ensure their participation in the formulation of programs and plans to be implemented by the LGUs.
Children’s ideas and practices concerning hygiene and disease transmission

Exploration in a rural town in Benin

Miranda van Reeuwijk

In Benin, like many other Sub-Saharan countries, diarrhoea is one of the most prevalent childhood diseases and one with a high mortality rate. Important factors contributing to this high prevalence are a lack of safe water supplies and sanitation and practices of poor hygiene. Because of the household tasks children are involved in, children can have an important influence on the transmission of diseases. They can form a risk group in the transmission of diseases and diarrhoea or help to prevent diseases, depending on their knowledge and ideas about diseases and their hygienic behaviour. Therefore it might be important, for instance for hygiene promotion programs, to obtain knowledge about the ideas of children concerning diarrhoea and disease transmission. This study records the ideas of children in Tchetti, Benin, regarding the topics of dirt, hygiene, disease transmission, diarrhoea and other (gastro-intestinal) diseases and consequences for the practices children display that influence the transmission of diarrhoea.

In the past, children have been viewed by anthropologists as being continually assimilating, learning and responding to adults, having little autonomy, contributing nothing to social values or behaviour except for the latent outpourings of earlier acquired experiences (Hardman 1973). According to this

Acknowledgments: I want to thank the people of Tchetti for their hospitality. I especially want to thank my informants, the children, for trusting me and for all the fun we had. I thank Hugues for interpreting and explaining, my colleagues LeAnna Fries (for editing my work -again-) and Jennifer Fagan (for taking me to Africa), and my family and friends for allowing me to go and for their support. Finally, I want to thank my supervisors and teachers, Sjaak van der Geest and Ria Reis, for their guidance and enthusiasm. This article is based on my master thesis (Van Reeuwijk 2001) in Medical Anthropology at the University of Amsterdam. It is a slightly updated version of an earlier publication in Medische Antropologie 15 (2): 537-50 (2003).
view, children are transformed over time into mature, rational adults, but until then children are seen as culturally incomplete. As a consequence, research about children mainly focussed on child-adult interaction while child thoughts and social behaviour were interpreted in adult terms (see for example Caputo 1996, Christensen 1998, 2000). Furthermore, children were and still are commonly believed to lack the communicative, cognitive and social skills that are the prerequisite of good respondents (Christensen et al. 1999). In addition, there are the practical and methodological problems in conducting interviews with children, such as the problem with language use, literacy and different stages of cognitive development. There is a concern about the quality and reliability of the data obtained because children might have a rich imagination and thus embellish accounts, or might be influenced by the power relation between the researcher and the child. In addition, the issues of confidentiality and ethics are important when interviewing minors (Christensen et al. 1999).

Only recently has a shift in the ideas about children taken place and anthropologists have become aware of the fact that the aforementioned perspective leaves the understanding of children as social persons with their own experiences, perceptions and actions in the social and cultural world, more or less, unaddressed (Christensen 1998). Focusing on children’s constitution of knowledge, some studies have concluded that children do contribute to the development of their own identity and are actively engaged in the production of their own social world (Caputo 1996, Helman 2000). Their ideas do not necessarily reflect early development of adult culture (Hardman 1973). Also, with regard to ideas and understandings of illness, what causes it and how it should be treated, these studies made it more plausible that children have their own unique ideas and that, like adults, their ideas often have a very clear internal logic, even if they are not scientific (Helman 2000). Furthermore, modern psychological and medical evidence suggests that children are more reliable as witnesses than previously thought and reliability can be increased by skilful interviewing (Christensen et al. 1999). Because of the recent onset of child-centred research, data and literature about children’s perceptions of health, illness and related topics are scarce.

This paper is a first attempt to explore the ideas and practices of a group of children in a West-African community concerning the topics of dirt, hygiene, disease transmission, diarrhoea and other (gastro-intestinal) diseases. The importance of focussing on these topics is that these ideas might influence children’s hygienic behaviour and practices which, in turn, have consequences for the transmission of diarrhoeal diseases, one of the most prevalent childhood diseases in Sub-Saharan Africa and one with a high mortality rate. Having knowledge about the ideas and practices of children might prove to be important for hygiene promotion programmes. If programmes can develop hygiene-improving education, which is focused on children and built on children’s ideas,
they could have a direct positive effect on the health of the children themselves and an indirect positive effect on the health of others.

The emphasis of this research is on the biomedical construction of hygiene, with hygiene defined as the practice of keeping oneself and the environment clean in order to prevent diseases. However, one should be aware of the anthropological perspective on hygiene, which takes the social and cultural foundations into consideration. After all, motives of hygienic behaviour not only lie within the avoidance of diseases, but also in complex social rules of cleanliness and dirt avoidance, which influence the practice of hygiene, whether people believe in germs and microbes or not. Unfortunately, research constraints did not provide adequate time and resources to include a specific focus on the social and cultural aspects of hygiene and could only briefly be touched upon.

The main objective of this study is to record children’s ideas on the topics of dirt, hygiene, disease transmission, diarrhoea and other (gastro-intestinal) diseases and the observed practices that influence the transmission of diarrhoea. The documented ideas are analyzed on their construction and how they relate to the relevant practices. Because of the limited time and resources, the study was designed and executed as an exploratory and mainly descriptive study.

**Research strategy**

This article is based on anthropological fieldwork in Tchetti, a rural town in the southwest of Benin, on the border with Togo, during a period of seven weeks. Most data was collected through the techniques of participant-observation and ethnographic interviewing. More than forty children were interviewed and most interviews were in-depth in nature with either individual children or with small groups of children (up to four children per group). At the end of the research a focus group discussion took place with approximately twelve children. The informants were kept anonymous. The focus group discussion and all except one interviews were taped and transcribed. The research was conducted with the help of an interpreter.

**Interviewing children and the advantages and disadvantages of being a white stranger**

The name of my interpreter was Hugues, a 30-year-old who was one of the broadcasters of the local radio station. Although I was apprehensive that my interviewees would be intimidated by Hugues due to his occupation and age, the children overall responded well to him. In the beginning they were a bit hesitant

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and suspicious, but then they quickly appreciated the situation and attention
given by two ‘important’ persons, the radio broadcaster and a white researcher.
They seemed eager to give their opinion about inquired issues and liked showing
off to their friends that they were important enough to be interviewed to assist us
in an important research project. At one point, children even started to approach
us in the community or at home to ask if they could help us. The fact that I gave
away balloons and pens, that I liked to play soccer and organised water balloon
games, might have something to do with their motivation.

Being a white stranger in the community helped me to attract children
because the foreigner status made me intriguing for them from the start. I had no
problems whatsoever coming in contact with them. From the moment we
entered our new house in Tchetti, we were surrounded by children. The
neighbour kids helped us with sweeping the rooms, fetching water and buying
kerosene for the lanterns. When I unpacked my soccer ball and asked them if
they wanted to play a game with me, they were very happy to do so. The
neighbour children brought friends to play along and this marked the beginning
of my initial contact with my first informants (snowball method). Other
informants were encountered on the street, while we were walking through the
different areas of Tchetti. We would start an informal conversation and naturally
progress to reaching topics of research interest. If the child or children were
relatively comfortable and talkative, I asked them for their permission to tape the
conversation to be able to listen to it again more carefully. Most of the time I
showed how the tape recorder worked and let them play with it for a while.

When the interview commenced, I attempted to keep the questions simple so
that they were easy comprehensible to the children. On the whole, they were
very capable of answering even the more difficult questions, did not appear to
mind probing their responses, and were willing to explain things to me
repeatedly if necessary. Being an ignorant stranger in their eyes made it easier for
me to ask for detailed explanations and have ‘weird’ questions. For example, they
did not mind informing me about how and where they defecated and what they
used to wipe their bottoms. I could ask them why they were embarrassed if they
saw someone else defecate, or why they considered dirty things dirty. I heard
Hugues using the word yovo when he translated my questions for the children,
thereby emphasising that the ‘white stranger’ wanted to know how things were
with them. Sometimes they had to laugh since I, the foreigner, did not know
why things were dirty which were obvious through their eyes. Although, they
shared that they could imagine that things were different in my country
(sometimes they even asked about that) and therefore explained things to me in
detail, trying to make me understand ‘their ways’. Moreover, using ‘real life’
examples, made it easier to talk about certain things. For instance, I used to tell
them that I had become sick myself in Tchetti and if they could tell me how I
got diarrhoea. It seemed they liked to hypothesise about the causes and also liked
to ‘be consulted by the yovo about things she is ignorant of and they have knowledge about’.

Along with the advantages of being a white stranger came the few disadvantages as well, of which the biggest was that I could never become ‘invisible’. If I wanted to participate in something, like fetching water or even games, they would always notice my presence and start to ‘show off’. Even if the children did not notice or forgot about my presence, which was rare, there was always somebody else who would point me out again. So in that sense, I could not fully conduct much participant observation since their behaviour was noticeably influenced by my presence. Another problem was the fact that the girls were by far not as talkative as the boys. Especially when we interviewed girls in the presence of boys, they did not share as willingly and could not answer the more difficult questions, as did the boys. They were also more intimidated by Hugues than were the boys. To be able to acquire information from girls, I had to make sure that during the interview, there were no males around other than Hugues. Then we had to slowly and carefully try to make the girl(s) feel comfortable to talk freely, which most of the time took considerable effort and did not always work out. It became obvious that most girls in the culture were not encouraged to express their thoughts and ideas, even more than children in general, especially in the presence of males.

The final problem was that the presents that I gave to the children to thank them for their co-operation, were regarded by adults as too valuable for them. A few times I saw parents or an older brother take away the pen from the child I had just interviewed. I had not foreseen this problem and felt bad for these children whose token of appreciation it was intended for.

**Tchetti and its childhood diseases**

Tchetti is a rural border town with approximately 14000 inhabitants and growing. The inhabitants of Tchetti have many different ethnic and religious backgrounds. Most of the people are involved in agriculture or small business like petty trade.

According to many inhabitants Tchetti has two major problems; it has no running water or fresh water sources and there is no electricity. The people in Tchetti are dependent on wells and the three water pumps in town for their water supply. Because Tchetti is situated on an elevated plain and on rocky ground it is difficult to bore for groundwater. Due to the lack of a fresh water source most people are dependent on rainwater. If it does not rain for a few weeks the water in most of the wells starts to become turbid.

Besides the lack of electricity and water, a major problem, at least for health, is the lack of sanitation. There are only a few latrines in Tchetti. The vast majority of the inhabitants does not have access to a latrine and defecates in
certain areas near the mountains or in the bush. The poor water and sanitation situation contributes to a considerable number of health problems in Tchetti. The major childhood diseases seen by the local doctor were diarrhoea, malaria and respiratory infections. The main causes of diarrhoea in children he diagnosed, were Candida Albicans, an opportunistic yeast infection, and Giardia Lambia, an intestinal parasite of the protozoa type. In Tchetti, the food and water is often populated with Candida yeast. Because many children suffer from immune depression, caused by the low quality of the food and by the fact that they suffer from repeated illnesses, they become more susceptible for opportunistic infections such as Candida.1

The Giardia parasite is spread through water and food contaminated with the cyst of the parasite. Because there is no running water in Tchetti and people drink water from stagnant water sources without treating the water with disinfecting chemicals or boiling it, many people in Tchetti get infected. They often become asymptomatic carriers, but many also get diarrhoea, especially the children. The poor sanitary situation in Tchetti is a facilitating factor for diarrhoea causing agents to spread easily. People have to defecate in the bush where they have more of a chance of coming into contact with other people’s and their own defecation, spreading diseases by way of the faecal-oral route. The defecation sites are nurseries for flies that bring and spread diseases to the people. There is also a problem of parasites that are transmitted by means of the feet of people who step into infected faeces. In addition, amoebas are transferred from the stagnant water in the foliage, to the anus of people using leaves to wipe their bottom.

According to Tchetti’s doctor an important reason many children die of diarrhoea is because of parent negligence. According to him, the parents think diarrhoea is caused by bad food, try to treat the child themselves at home and often do not bring the child to a doctor or a hospital until the situation worsens to where the child is suffering from dehydration, anaemia or even convulsions. Many parents use decoctions of boiled plants and leaves to treat their children’s diarrhoea. If that does not work they go to the market to buy medicine, often an antibiotic or antihelminthic drug, depending on the advise of the market salesman or saleswoman and not on the results of a lab test or on the advise of a health worker.2 If these drugs fail to work, and the situation becomes worse, the parents finally seek the help of a modern or traditional healer. If the modern or traditional healer cannot find a cure either then they refer the patient to the

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1 Candida and Giardia were the most diagnosed causes of diarrhoea, but this does not mean that these were the main causes of diarrhoea. Through microscopic examination, yeast and parasites are relatively easy to diagnose. However, it is more likely that most cases of diarrhoea are caused by bacteria and viruses, like campylobacter, E.coli, rotavirus and Salmonella, which mostly go undiagnosed.

2 The antibiotic most often bought at the market and named by the children, concerned red and black capsules. Those capsules are most likely the antibiotic Amoxycilline.
other, or to the hospital. Biomedical doctors and health workers then are often confronted with the problem of resistance against antibiotics, the most serious consequence of people buying antibiotics at the market without the advice or a prescription of a knowledgeable specialist.

**Children's ideas about the causes and contagiousness of diarrhoea: the concept of kokoro**

All the children interviewed, without any exceptions, thought that diarrhoea was caused by ‘bad’ food (spoiled food, food not cooked well, unfamiliar food, mixed foods and too much food). These types of ‘bad’ foods did not ‘fit’ the stomach or could not be ‘accepted’ by the stomach. In the case of dirt, defecation or bad smells entering the stomach (by dirty hands or contaminated food or water), ‘other’ sicknesses were said to arise like vomiting, constipation, stomach-ache; only in a few cases was diarrhoea mentioned as a consequence.

To the inquiry of why one becomes sick when dirt enters the stomach or when one smells the dirt, the children explained that the dirt and its smell, ‘disturbs’ the stomach; the stomach cannot ‘accept’ the dirt or the smell and would ‘fight’ it. This resistance causes stomachache, constipation and vomiting and was also given as a reason to not share food with a dirty person in addition to stressing the importance of washing your hands. The smell of dirt seemed to be perceived as a very important cause of diseases including diarrhoea and was mentioned by the majority of the children. Although I argued that smell is an element which functions in the air and therefore enters the lungs and not the stomach, they persistently tried to convince me that smell enters and upsets the stomach.

The children stated that you have to wash your hands after defecation because while wiping your bottom, your hand could have touched the defecation. Then, if you eat with that hand, the defecation can enter your stomach along with the food. For the same reason that the stomach cannot accept ‘bad food’, ‘bad smell’ and dirt, it cannot accept faecal material either. I asked them why the stomach cannot accept defecation, even though it originates from there. Some of them said it was because of the “bad smell of the defecation,” others said, “defecation is something that you send away from your stomach and when you send it back, it will cause you problems.” During the Focus Group Discussion, a child stated “defecation is all those things that are not good for the body. You defecate to get rid of them. If such a thing gets into your stomach, surely it will cause you sickness.”

One of the first informants shared that the defecation that enters your stomach due to a failure of washing your hands or due to flies transferring it onto food, will turn into invisible worms inside your stomach. It is these worms that cause stomach pain and make one sick. The boy used the Ifè word *kokoro* (local
language) when he talked about the worms. In later interviews the word *kokoro* returned many times, but its exact meaning remained uncertain in the beginning. It mainly came up during conversations about flies, being another route through which defecation could enter the stomach. Flies, children explained, sit on defecation and then fly to food and land on the food or on plates and transfer the defecation from their legs to the food. One of the children revealed that if the defecation came from a sick person, then the sickness could also stay alive inside the defecation of that person. If you swallow a bit of this defecation, you ingest that sickness as well and you would become sick too. Yet, as he explained, this was only applicable for ‘other sicknesses’ like stomachache, not for diarrhoea. Some children told me it was not only human defecation the flies brought to the food, but once the flies make contact with the food, they defecate on it themselves as well, causing the same problems for the stomach, as human defecation would do.

In two separate interviews there were two children (a ten-year-old boy and an eight-year-old girl) who mentioned microbes as an agent that could be causing diseases. They told me that microbes are inside dirty things, that they are invisible and could be carried to food by flies or hands, causing diseases like cholera and stomachache. At a later point in the interview with the boy I became confused because he was using the words microbe and worm interchangeably. When I asked my interpreter for an explanation, he said the boy was talking about *kokoro*, something he translated with the English word ‘worm’, while the boy himself at the same time was using the French word ‘microbe’, which was translated by my interpreter with the English word ‘microbe’. He told me the boy was using these two words as synonyms. In the other interview with the girl, she was using the French word ‘microbe’ and I asked her to explain the definition of microbes. She told me microbes give diseases to people, they are everywhere, mainly in dirty things and that “if there is sand somewhere and you pour water on it, it becomes microbes.” A minute later she described microbes in a somewhat biomedical sense, but then used the Ifè word *bibi*, which was translated by my interpreter with the word ‘worms’ (which I had thought was *kokoro* in Ifè). I asked her what the difference was between *bibi*, microbes and worms and she told me those were all dirty things, but could cause different diseases. She could not explain the exact differences or similarities, so I turned to my interpreter for an explanation. He told me that *bibi* means small ants and that it was, as he said, Ifè ‘slang’ for *kokoro*. According to him, both the girl and the boy made the mistake to translate it with the French word ‘microbe’, while they were really talking about worms. In a later interview with an adult, the adult used the word *kokoro* and translated it himself with the French word *insect*. It was then that I understood that *kokoro* actually means insects that cannot fly, insects without wings, thus including ants and worms.
Several children told me flies carry *kokoro* from defecation to food. The following transcription is an excerpt of one of the interviews with the children. The M in front of the sentence represents my question or remark, the H stands for Hugues, my interpreter, translating the child’s answer. Because it is a literal transcription, we are talking about the child or children in the third person.

**H** There are some worms (*kokoro*) inside the flies. By the time they sit on the defecation of somebody else, they carry those worms and sit on the food in somebody’s house. That will cause sickness.

**M** Exactly how do they cause sickness?

**H** The worms will get inside the food and they get in your body and they can cause pain and diseases.

**M** Can you see these worms?

**H** The worms inside the flies are white and you can see them.

**M** But then you can see that they are in your food and you will not eat it?

**H** If they are on top of the defecation you can see them. But by the time the flies bring them to the food, you cannot see them.

In other interviews I learned that several children thought that defecation, after being excreted in the bush or the latrine, becomes sand or worms (again the word *kokoro* was used). This might explain the ideas of the boy quoted earlier, that defecation inside the stomach turns into worms. They described the worms on the defecation as white, visible worms that are brought there by flies or come out of the mud and turn into flies themselves, after they have eaten the defecation.

Again, it should be emphasized that most children, when they were talking about diseases caused by dirt, defecation, smell or *kokoro* entering the stomach, they were talking about ‘other’ diseases like stomachache, constipation and vomiting. Only a few children added diarrhoea to this list, but that was only after they were questioned directly if it could also cause diarrhoea.

Although the children were quite cognisant of the faecal-oral route of disease transmission all the children, without exception, said that diarrhoea is not contagious. Initially I found that very confusing, as the next quote of one of the interviews shows:

**M** If, let’s say, his brother has diarrhoea, and that brother did not wash his hands after defecation and with that hand he touches things in the house and then he (the interviewee) will come and touch the same things in the house, can he get diarrhoea then?

**H** It might not give you diarrhoea, but it might cause another sickness.

**M** What other sickness?
H  Constipation
M  Why?
H  By the time you eat together with such a person, that food will not fit you and will give you another sickness like constipation and you feel like throwing up.
M  Is it always that all the next times that you eat that particular food, it makes you ill?
H  Only for the first time, you will throw up, after eating with such a person you will throw up, but if it goes on like that, after some time eating with such a person it will give you another illness, like constipation.
M  But only if you eat with the person who is sick?
H  ha… ask it again (my interpreter is confused).
M  He said, that if you eat with someone who has diarrhoea, you will not get diarrhoea, but you will get other sicknesses. I asked why and he said it was because of the food, that the food did not fit him well. But that has nothing to do with the guy he is eating the food with, the guy who is sick. So I wonder, if the sick person is not around and you eat that particular food that does not fit you, you become ill, that is what he said before. But how, what, what does that person do that you share your food with, how does that make you sick, because that has nothing to do with fitting food or whatever.
H  It’s because the person who is sick with whom you eat, his hands are dirty. By the time you eat, even if the food fits you and the food is good for you, you don’t have any problems with the food. But for the part that you eat with such a person, a person who’s hands are dirty, it is for that reason you become ill.
M  But if that person has diarrhoea, and he has dirt on his hands, and you get that dirt inside you, why do you get another disease and not diarrhoea?
H  What causes the diarrhoea for him, you don’t know. You don’t eat that…if that is the food, you don’t eat that food, so it cannot cause you diarrhoea. Because you don’t eat the same food. You don’t know what food caused him diarrhoea. So by eating with him, without washing his hands, that one cannot give you diarrhoea, it can give you another illness.
M  Aha! Because it is two separate things. There is the dirt, it does not matter if the person is sick or not, that can cause the illness.
H  (after translating for verification) Yes.

It took some time before I understood that swallowing a bit of diarrhoea does not give one diarrhoea because it contains noxious agents of some kind, but that
it gives other diseases like stomach ache, vomiting and constipation, because diarrhoea is defecation and defecation causes ‘other diseases’. The only thing that can cause diarrhoea is ‘bad’ food and therefore diarrhoea itself is not contagious. The ‘other diseases’ on the other hand can be transmitted from person to person by means of flies, worms (kokoro), hands, dirt, defecation and smell.

**Preventive practices and motives for hygienic behaviour**

Since the children I interviewed perceive diarrhoea to be caused by ‘bad’ food, it is not hard to understand that they said diarrhoea is preventable by the avoidance of eating the food that caused diarrhoea in earlier episodes. If the diarrhoea was caused by eating too much, then you simply had to eat less, they said. Furthermore, you should take care not to mix your food, not to eat food that is not well cooked or that is left over for more than a day. It was also said to not drink water that has been stored for more than four days.

The children told me you could prevent diseases by washing your hands after defecation, before eating and by covering food and water. You should take care not to touch somebody else’s defecation, which is why you should always wear flip-flops when you go to the bush to defecate. This was also one of the reasons why the children did not like to go to the bush at night; at night you cannot see the other defecation. They explained that it is better to stay at the border of the bush, dig a hole and cover the hole again after you have defecated. Some children said they defecated near the house at night, if they really had to go, but made sure that they threw the defecation in the bush first thing the next morning. All the children, whom I asked which was more preferable, the bush or the latrine, said the latrine was better because there was less of a smell, fewer flies and a smaller chance of touching somebody else’s defecation. Besides, in the latrine you did not see the defecation like in the bush, which was also better. Finally, you should keep an eye on little children and prevent them from defecating near the house or on the street.

Avoiding sickness by cleaning up dirt and avoiding faeces is not the only motive for hygienic behaviour. As said before, smell, although rationalised as causing diseases, is a motive too, probably stimulating hygienic behaviour by triggering the feeling of aversion or the emotion of disgust. Furthermore, as stated a couple of sentences above, it is also better not to see defecation, probably for the same reasons. Yet another motive could be found in the socio-cultural foundations of dirt and hygiene. The children fervently described the social consequences of not cleaning and being dirty or having a dirty house: people would run away from you, yell at you or start to insult you. You would feel embarrassed and they might start to gossip about you. Children would react the same way if they would enter a dirty house or encounter a dirty or defecating person. It is interesting to notice that encountering a defecating person or being
encountered while defecating leads to embarrassment not only because of the situation, but mainly because of the embarrassment for the smell.

The ideas children have about the causes and transmission of diseases and the fear of punishment or shame for not being clean have important consequences for practices regarding dirt and hygiene. Although diarrhoea was not conceived of as being contagious, the aversion of faeces, the ideas about smell as causing diseases and the notion of other (gastro-intestinal) diseases as being contagious, resulted in several beneficial preventive practices.

Household tasks and the importance of knowledge of the ideas of children concerning diarrhoea and disease transmission

In low-income countries children start to participate in social and economic roles at an early age and often serve as a source of income for their families. This is an important reason why the concept of childhood in developing countries differs from that in developed countries, where the leading opinion about children is that they should have a protected and untroubled childhood with the opportunity to go to school and play. Children in developing countries, on the other hand, resemble young adults and often have important responsibilities in the household, which include fetching water, preparing food, looking after younger siblings, but also helping to care for the ill. Because of these tasks and responsibilities, children can have an important influence on the transmission of diseases, negatively as well as positively.

Therefore, it is beneficial to obtain knowledge about the ideas of children concerning diarrhoea and disease transmission because children might form a risk group in the transmission of diseases and diarrhoea, but they could also help to prevent diseases if they themselves have knowledge about preventive practices. If we look at the household tasks that are named and performed by the children, e.g. sweeping rooms, fetching water, washing dishes and clothes, helping to prepare food, working in the fields and assisting in the care-taking of younger siblings and sick people, it seems that children are directly linked through these tasks with the routes of transmission of contagious diseases, especially diarrhoea. Many children are involved in cleaning chores, getting rid of dirt, washing, sweeping etc. and therefore they also directly come into contact with disease causing agents and help to prevent these agents from spreading at the same time. If children are unaware of the risks and of good hygienic practices, they could unintentionally contribute to the spreading of diseases like diarrhoea to themselves and to others. This also applies to tasks like fetching water and helping to prepare food; sources that, once they become infected, could spread diseases to whole families. Farming (through which children come into contact with manure of animals and humans) and helping younger siblings with going to the bush to defecate to help them wipe, might influence disease transmission as well; positively if the child is aware of the
risks and preventive measures, negatively if the child is unaware or indifferent about them. In the case of the children with whom I spoke, the children were pretty much aware of risky behaviour, ways of transmission and ways of preventing transmission. Although the details about the agent that causes the diseases varied a bit between the children, and from biomedical explanations, the main ideas about ways of transmission were similar to biomedical notions and therefore hygiene practices made sense to the children and were practiced accordingly. The fact that diarrhoea was not perceived to be contagious did not negatively influence their practices, because prevention and hygienic behaviour were carried out to prevent ‘other’ diseases, thereby forming a barrier for the transmission of diarrhoea as well.

Like adults in their own society and in other societies the children rationalised their hygienic behaviour, saying it was practised to avoid dirt since dirt can cause diseases. They did not only try to avoid touching dirt, they also tried to avoid smelling and seeing it. In whatever way hygiene behaviour is rationalised as disease prevention, the emotion of disgust and the aversion related to dirt, plus the social forces and consequences related to cleanliness and dirtiness, form powerful motivations for hygienic behaviour as well.

These examples show how important it is to have knowledge about the ideas of children concerning disease causation and transmission and their ideas about the social consequences of being dirty or lacking hygienic behaviour. If their ideas do not lead to hygienic behaviour or if they are indifferent about it, then children could form a serious (and large) risk group in transmitting diseases to themselves, each other and others. It seems that it would therefore be worthwhile for prevention programmes to focus on this group of the population and adapt their programmes to the ideas, knowledge and already existing beneficial practices of children.

**Conclusion**

This research was performed with the aim to take the children’s point of view, with the assumption that children do not simply reproduce adult information, but are actively involved in the production and formation of knowledge and ideas. Considering the information described above one could see that the information given by the children has an internal logic and is coherent. As respondents they have provided reliable, meaningful and useful information.

The children perceive diarrhoea to be caused by ‘bad’ food, and is therefore not understood as being transmittable per se. Other gastro-intestinal diseases, like vomiting, stomach-ache and constipation, are in contrast seen to be caused by invisible worms (kokoro), microbes and smell, originating from dirt and defecation and reaching people directly or indirectly via hands, flies and food. These other diseases are therefore thought to be contagious.
Several hygienic practices were mentioned and executed by the children. These included hand washing, cleaning up dirt and avoiding faeces. Reasons for this hygienic behaviour were to avoid sickness and smell (which was thought to cause diseases), the aversion of dirt, defecation and the emotion of disgust that was triggered by it, and because of the social consequences of not cleaning (the negative reactions of others and the feeling of embarrassment). Although diarrhoea was not conceived to be contagious per se, the hygienic behaviour practiced to prevent the other diseases, and the socio-cultural forces, formed a barrier to the spread and transmission of diarrhoea as well.

Considering the household tasks in which the children were involved, the children formed an important factor influencing the transmission of diseases. Because they were fairly aware of risky behaviour and ways of transmission, the children behaved hygienically and therefore helped in preventing disease transmission. If the children were unaware or indifferent about these practices, then they would form a large risk group in the transmission of diseases and diarrhoea to themselves and the community at large.

Because children can form a large risk group in the transmission of diseases but can just the same be beneficial, active agents in disease prevention, they form an important group to focus on in prevention programmes. For such programmes to be effective they should understand the ideas and practices of children concerning disease transmission, diarrhoea, dirt and hygiene.

In the case of Tchetti, the high prevalence and mortality of childhood diarrhoea is more likely to be a result of the lack of sanitation, the lack of safe drinking water, the moderate health condition of the children (weakened immune systems), the antibiotic resistance and the therapy seeking behaviour of the parents than as a result of a lack of knowledge and performance of hygienic behaviour. The ideas children had about disease causation and transmission, the aversion of dirt, defecation and the smell of it, and the social motivation for hygienic behaviour together with the inconvenience of having to defecate in the bush, made latrines popular with these children. There seems to be sufficient grounds to believe that latrine programmes in Tchetti would be successful and would form an important factor in improving health and preventing diseases like diarrhoea.

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Body and Subjectivity
The body as a mediator of intersubjectivity in children with autism

A qualitative phenomenological study in Sarajevo, Bosnia

Selma Tanovic Rujanac

According to biomedicine, autism is a neurodevelopmental disorder that occurs in the first three years of life and is characterized by impairment in social interaction, a delay in language development and problems in behaviour. As a distinct psychiatric category, autism has been constructed through a complex and ambiguous interplay between biomedical institutions and cultural practices. In this study, intersubjectivity in children with autism was investigated using a phenomenological approach. Thus, intersubjectivity is defined as the interpersonal relationship accomplished through shared symbolic faculty and bodily presence, and situated in space/material environments. The body has been largely neglected in anthropological studies with autistic people. Self-advocating autobiographies illustrate the peculiarities of the sensory experience of people with autism. In this qualitative exploratory study, the everyday social worlds of children with autism in Sarajevo are explored with primary attention to the bodily dimension of interaction with the environment. Post-conflict political instability, demographic changes and economic uncertainty create a specific environment in which spatial and material elements are distinct and sometimes extreme and their meaning in the construction of categories of difference are particularly visible. Sarajevo is a rather novel site in medical anthropological literature, which makes it interesting to explore and to relate this post-conflict space to health and disease and their conceptions.

[autism, intersubjectivity, intercorporeality, touch, communication, everyday social world, Bosnia]

When she decided to apply for AMMA, Selma Tanovic was a paediatric resident at University Clinical Centre in Sarajevo, Bosnia and Herzegovina, struggling with sleep-deprivation during nightshifts, coping with the huge responsibilities young doctors were given without preparation, largely unhappy with the harsh surrounding world of medicine. Since she had been an activist in associations taking care of autistic children and their parents for a very long time, she decided to focus her anthropological research on this vulnerable group of people. Her AMMA experience not only gave her a perspective that she had been missing, but it also made her medical work more meaningful. Email: selmatan2003@yahoo.com.

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Introduction

The first time I personally met a child with autism was during my undergraduate studies in Bosnia and Herzegovina when the mother of a pre-school autistic child was seeking volunteers for a home-based intensive educational program. Although I already had some (exclusively theoretical) knowledge of autism, I soon realized that my perceptions had been significantly influenced by my biomedical training and popular stereotypes. Spending months engaged in everyday interactions with Uma, a beautiful and cheerful five-year-old girl, I started to doubt the definition of social impairments I had encountered in the literature. My friendship with Uma and her mother remarkably influenced my perspective on persons with autism and their families.

During this period, I also became politically engaged in establishing the first parent advocacy organization for children with autism. I spent long hours solving complicated bureaucratic issues and participating in passionate debates on how to make a change in Bosnia and Herzegovina, a post-conflict country in economic transition. However, when I started my paediatric residency, my relationship with other association members changed dramatically—the parents acted cold and distant towards me, leaving me profoundly sad and bitter. After consulting the literature, I began to realize that I was probably not experiencing an expression of personal antagonism and hostility, but rather an embodiment of the more complex tensions that exist between biomedical and social models of autism.

In 2012, as a member of the last AMMA class, I was privileged to conduct my fieldwork in my home country of Bosnia and explore the bodily experiences of six children with autism in their everyday settings (school and home).

Autism, body and intersubjectivity

According to biomedicine, autism is defined as a neurodevelopmental disorder that occurs in the first three years of life and is characterized by impairment in social interaction, a delay in language development and problems in behaviour. Children generally lack symbolic and imaginative play. They have repetitive and stereotypic behaviour, express rigidity when routines are changed and have atypical interest in objects. Hypersensitivity (to sounds or lights), hyposensitivity (to painful stimuli), abnormalities in sleeping patterns, eating problems, difficulties in mood regulation or self-injurious behaviour are common. There is heterogeneity in symptoms and communication abilities, making autism a spectrum ranging from non-verbal children with serious behavioural problems to ‘high-functioning’ language-fluent children, and sometimes autism is accompanied by exceptional mathematical or artistic abilities (Volkmar 2008). As a distinct psychiatric category, autism has been constructed through a complex and ambiguous interplay of psychiatric institutions and cultural practices.
Nadesan (2005:2) argues that “…although there is a biological aspect of the condition named autism, the social factors involved in its identification, representation, interpretation, remediation and performance are the most important factors in the determination of what it means to be autistic, for individuals, families and societies.”

As a condition characterized by differences in social interaction and language development, autism is challenging for scholars interested in intersubjectivity. “To understand autism is to understand what it means to have relationships with people and material objects and the role of cultural and situational contexts in achieving joint attention, attunement, intersubjectivity, and social coordination of feelings and actions” (Ochs & Solomon 2010:70). Furthermore, bodies are not isolated – they are situated in material environments with various tools and artefacts facilitating intersubjective relations (Crossley 1996, Duranti 2010). On the basis of the notion that interaction and communication between humans is possible without verbal or non-verbal language, Duranti (2010:2) poses the theoretical question whether scholars should “…distinguish among different ways or degrees of sociality.” Most scholarly work that addresses intersubjectivity in autistic persons stems from a linguistic tradition and concentrates on personal narratives. Ochs and Capps (2001) claim that personal narratives are not only constructed in the form of plotted stories, but also through everyday conversation. Furthermore, this mundane, taken-for-granted conversation offers a site for intersubjectivity, because it develops “the boundary between two consciousnesses, two subjects” (Bakhtin 1986:106 cited in Ochs & Capps 2001:3), thus having a pivotal role in the relational construction of meaning.

Although children with autism are regarded as unable to create narratives, several studies in linguistic anthropology have demonstrated autistic children’s participation in everyday conversation and their ability to navigate social worlds in everyday settings such as home and school (Ochs et al. 2004, Solomon 2004, Solomon 2008, Sirota 2010). Ochs et al. (2004) advocate for a socio-cultural perspective that presumes that autistic children are a part of the group (family, school, wider society), and the social competence of autistic children depends not only on their own biologically induced inabilities, but also on the values, understanding and expectations of the other members of the social group.

Focusing on language, the bodies of autistic persons have been largely neglected in anthropological studies. Recently published autobiographical narratives of autistic persons reveal the peculiarities of a lived body and perception, giving valuable insight into the unique autistic experience (Williams 1998, Grandin 2006, Hacking 2009a, 2009b, 2009c). Furthermore, there is little scientific data on autism in cultures across the world. Daley (2002) reviewed studies on autism that have been performed in non-Western countries – most focused on the definition of the concept of autism, help-seeking behaviour, process of diagnosis, treatment options and family functioning, thus emphasizing
the need for further studies in developing countries. On the other hand, more detailed ethnographic data comes from researchers such as Grinker (2008), who explored the parental experience with autism in South Africa, India, South Korea and USA. Grinker (2008) claims that although autism is a universal phenomenon in terms of symptoms, the way families experience and make autism meaningful differs significantly across cultures. To my knowledge, no anthropological studies outside North America to date have specifically focused on the social interaction of children with autism.

Most studies on autism have been performed with ‘high-functioning’ verbal children, and only a few include children with more severe forms of autism (Silverman 2008). Bearing in mind the phenomenological definition of intersubjectivity, I explored the everyday social worlds of children with autism in Sarajevo – not focusing on how they engage in verbal (conversational) interaction, but rather their bodily interactions and the role of material objects and environment in social interaction in everyday settings such as home and school. By exploring the peculiar ways autistic children engage bodily with their environment, I aspired to give a modest contribution, not only to the social science literature on autism, but also to the scholarly work on the somatically felt body (Blackman 2008:52) and the role of embodiment in social and communicative processes.

Setting: Bosnia and Herzegovina

Since space plays an important role in intersubjectivity, it is important to emphasize the specificities of the context where this study was done. Sarajevo is the city well known for a four-year-long siege that ended with many civilian victims, significant demographic changes and a ruined infrastructure that is only now slowly recovering. Moreover, the economic transition from communism to free-market capitalism brought a period of unemployment, existential uncertainty and new social values (Malcolm 1996, Donia 2006, Bougarel et al. 2007, Markovitz 2010). Political instability, rural-urban displacement, constant ethnic tensions and economic unpredictability imbue the everyday lives of families and may impact their beliefs, values and attitudes as well as how categories of difference and autism are constructed. Sarajevo is also a city with intensive and deliberate bodily communication, exchanges of affection and vivid social interaction (Sorabji 2008, Markovitz 2010), all of which make it ideal to study intersubjectivity.²

² I would like to explain specific terminology that I employ throughout the thesis. The terms ‘children with autism’ and ‘autistic children’ are utilized interchangeably. Although ‘children with autism’ is more politically correct and the way parents address their children, self-advocates claim that autism is an inseparable part of their identity and prefer to be called ‘autistic individuals’. Similar to Hacking (2009a, 2009b, 2009c), in my study I designate non-autistic people as ‘neurotypicals’.
Methodology

To study intersubjectivity and explore the everyday life-worlds of children with autism in the short fieldwork period of six weeks (May-June 2012), I chose to concentrate on six children: Dario, Ogi, Faris, Mak, Emil and Muhamed (pseudonyms). I lived at home in Sarajevo and visited the children’s families during the day according to their daily routines and preferences. My research activities varied from day to day, but averaged 4-15 hours per day. Three families were recruited through the URDAS, or Udruženje roditelja djece i osoba u autističnom spektru (Association of Parents of Children and Adults in the Autistic Spectrum) parental advocacy association. Two families were recruited through personal acquaintances. I followed Gillespie and Cornish’s (2010) use of combined methods of ethnographic engagement and behaviour observation to investigate intersubjectivity. Since a key concern of my research was how intersubjectivity was bodily mediated, conducting my fieldwork required not only the visual acuity of my observations and participation in daily activities, but a complete bodily participation and awareness of everything that I sensed and felt as well. To grasp these tiny moments of bodily communication, I had to first broaden my definition of fieldwork to include not only data gathered by observation, but also to note what I perceived and felt with my body. In this sense, I was inspired by the methodology proposed by scholars of sensuous anthropology tradition, such as Stoller (1997) and Okely (2007).

Details of the study were explained and parents were requested to sign an informed consent for participation in the study. All the names and places in the study were given pseudonyms and efforts were made to preserve confidentiality and make families unrecognizable (Green & Thorogood 2009). Families were encouraged to abandon the study if they felt that the research affected their emotional state or everyday functioning. However, most of the children accepted me eagerly and we made very strong emotional bonds. During my research, I followed the Code of Ethics of American Anthropological Association (2009). Although procedural ethical approval was not necessary, ‘ethics in practice’ was respected (Guillemin & Gillam 2004). During my research, data were discussed with families to assure adequate interpretation.

My field-notes were transcribed and rewritten in the form of stories, coded and analysed using a pragmatic combination of thematic content analysis and grounded theory analysis. All interviews were transcribed using transcript conventions, coded manually and analysed using the method of narrative analysis. Transparency was ensured by explicitly describing the methods used. Reliability was maximized by accurate field-notes and precision in data transcription and coding. Validity was enhanced by respondent validation and discussion of my observations with parents and caretakers.
Findings

**Touch as a socially meaningful act**

Children with autism are described in literature (almost by definition) as disembodied beings who avoid touch and physical contact, or use only certain forms of touch, such as striking, pinching or pulling to express frustration and negative feelings (Volkmar 2008, Tanguay 2010). Touching, rinsing, rubbing, fiddling, brushing, striking, fingering, twiddling or licking are usually regarded not as socially meaningful acts, but rather as purposeless and unwanted stereotypic movements. However, my findings suggest that these forms of touch and movements, together with familiar forms such as hugging, cuddling or tickling play a role in mediating the personal relationships of some children with autism. Since touch is expressed through motion, it is not possible to engage in touch without including the sense of kinaesthesia.

Observing the social interactions of six children with autism and their parents, siblings, and caregivers in an everyday setting, I found that many of the children use touch as a socially meaningful act to establish contact, communicate feelings (such as love, amiability, fear) or simply to maintain a connection with the environment. Since the significance of this action is distinct for each child, it is not surprising that the meaning of the movements are usually first understood by those people who spend the most time with the child, such as parents or caregivers.

Touch is the first sense developed in a human foetus. It is the first ‘language’ used to experience and communicate with an external world – the uterus, a mother’s tissues during birth, the hands of a midwife or obstetrician. Newborns and infants communicate with the mother through touch during breastfeeding, diaper changing, bathing, cuddling, petting, etc. Over time, touching is replaced with verbal language, and becomes a ‘second-order sense’ in most Western countries (Barnet 1972). In *The Book of Touch* (2005) edited by Constance Classen, the authors highlight how touch (and sensory experience in general) has lost importance in Western societies due to a cultural representation of touch as ‘animalistic’ and ‘lower’ (together with smell and taste). Western culture is predominantly visual and textual, while a tactile culture has been largely unrecognized in the academic world. “Like the air we breathe, it [touch] has been taken for granted as a fundamental fact of life, a medium for the production of meaningful acts, rather than meaningful in itself” (Classen 2005:2). Classen illuminates how the sense of touch has been socially and historically constructed, not only among cultures, but also within gender, class and healthcare, thus explaining the role of touch in communication, nursing or social control. One chapter in *The Book of Touch*, written by autistic scholar Temple Grandin, is devoted to the importance of touch for autistic persons. Grandin (2005) describes her ambiguous tactile childhood experiences – she craved deep-pressed touch.
although rejected being hugged. Grandin emphasizes the importance of touch, referring to Therese Joliffe, an autistic person who experienced the world by touching it with her fingers the way blind people do.

Exploring the experiences and meanings of touch between parents and children with autism, Cullen and Barlow (2002) argue that Touch Therapy, a form of alternative therapy based on a massage and tactile stimulation, not only benefits children in terms of anxiety relief and relaxation, but also enhances bonding between parents and children and provides a mode of alternative communication.

_Tiny velvety moments of bonding_

Among the children in my study, Ogi had the most prominently expressed sense of touch. He used touch to communicate with the world. By touching, he explored his environment, expressed his feelings and bonded with people. Many times while we were sitting on a floor, a sofa at home or a bench in a park, Ogi nestled in his mother’s lap. He was usually the one who initiated this contact, but occasionally his mother Lejla took him in her arms when he was frightened, frustrated or squalling inconsolably. Ogi generally relaxed in her lap, his fragile body leaning on her body with his cheeks pressed on her shoulder. Once, when we were in a playroom, Ogi saw a swing hidden in the labyrinth of equipment, but didn’t know how to reach it. “Do you want us to help you?” asked Lejla. Instead of requesting help, he started crying bitterly. Lejla lifted him, comforting him tightly in her arms. He stopped crying, while leaning on her shoulder and pressing his cheek on the smooth texture of her leather jacket. When Ogi spontaneously came to sit on his mother’s lap, he sat so that he turned his face to her, touching her chin, cheeks, lips, nose, eyebrows, and eyelashes with his little fingers, inspecting every detail of her skin, smiling and cuddling in her arms. These were little moments of love and intimacy for a mother and son. Lejla felt privileged, as she was the only person in the world that Ogi would touch in this way. Ogi not only bonded with people by touching them, he also communicated tactiley with non-human environments: cars, plants, and horses. He even admired street art with touch, passing his hand over the colours on uneven wall surfaces.

Field Note: Ogi suddenly stopped: he saw a parked car, an old and ragged abandoned VW Golf 2. His eyes sparkled in amusement. He approached it slowly, walked several times around it, as it was a precious art piece in a museum. He touched the half blown tires on its wheels, its rusted bumpers, and its broken door handles. Then he pressed his nose and his cheek to a dirty window, inspecting the interior. This was what he did every time he saw a car that he liked.
Mindful hugging

While Ogi expressed his affection with a light, shy, barely perceptible touch, Dario’s touch was much stronger, daring and self-confident. Dario didn’t hesitate to ask for a hug or to touch unknown people in the street. I had the impression that hugging sincerely made him happy, since he usually smiled or even laughed, eyes sparkling with joy, and blond hair bouncing up and down in amusement. When he hugged me for the first time, Ana and Janko, his mother and father, said in one voice “Oh, it seems that he likes you a lot!” However, they expressed slight scepticism about the extent to which his hugging was a purposeful exchange of affection or just another of his stereotypes. The last evening of my fieldwork at their home, he was especially keen on hugging me. He sat in my lap, hugging me endlessly, touching my hair, laughing, saying, “Kiss-kiss.” His father filmed the two of us interacting.

Dario’s contagious laughter cheered all of us. When I got up to go, for the first time during my fieldwork he waved ‘good-bye’ to me. The following field note illustrates Dario’s bodily interaction with his parents, unknown passers-by and me.
It was a day with special offers in the DP supermarket, so Ana proposed going out for her weekly shopping at a store situated along Dario’s everyday walking route. Changing a route meant frustration both for Dario and his parents, frequently leading to a temper tantrum in the middle of the street. Ana and I were talking about his routines while Dario was half walking and half running in front of us. From time to time, he stopped waiting for us, saying “kiss-kiiiiiss” – that meant that we had to hug him, cuddle him for a while and kiss him on his cheek (in Dario’s vocabulary ‘kiss’ referred to everything that he liked: a kiss, a hug, or chips). Happy with his ‘dose’ of hugging, he continued walking. As he walked, he occasionally bumped into other people while laughing, although they looked at him angrily. But what was more interesting was
that from time to time, he approached young, beautiful and nicely dressed girls touching their arms and looking at them with significant interest and smiling. Some of them reacted by patting him and smiling, but some were really annoyed saying, “What an odd boy!”

‘Hopeful’ romantic

A family’s and a researcher’s body must be sensitive when receiving specific bodily signifiers from children with autism (usually taken for granted), as well as bringing these signifiers into their consciousness to decipher and appreciate fragile moments of bonding. Engagement in relationships demands not only awareness, but also openness in interpretation and a willingness to reciprocate. Sometimes, as seen in the following fieldnote excerpts, the child’s touching was so subtle and brief that it required a special bodily awareness to notice it at all.

Mak and Emil smiled when they saw me, sitting in their baby car seats, wearing a raincoat with a hood and colourful rubber rain boots. I was talking to Irma about my studies when I felt a small hand on my face: Emil touched my cheek with his little hand, then took my hand in his, held it for a while and touched his cheek with my hand, smiling. I was overwhelmed with joy, interpreting his action as a sign of closeness and friendship. He accepted me, I thought. Later on, he took my arm, pinched me slightly on its inner side, then patted it gently, drawing close, smelling my skin and smiling. It made me feel happy and honoured, because this was a gesture he awarded only few people: his brother, mother, teacher and his kindergarten mates Emina, Haris and Sanja.
During my home visits, he used to take my hand, bringing it close to his nose, touching and smelling it, crawling into my lap, touching my face and hair with his little fingertips, smiling. This was his way to show closeness. Irma used to watch him lovingly. “He is so cuddly, isn’t he?” she would say.

**Interacting acrobat**

Frequently, it is not only touch that mediates interaction – it can be a posture or movement, too. Philosopher and dancer Maxine Sheets-Johnstone (2009) writes about thinking and feeling in movement and rediscovering the mindful motion of our body. As seen from the following excerpts, Faris often communicated emotions through his idiosyncratic postures.

As I came into Faris’ room, he seemed quite tired, since he had been interacting with volunteers since early morning. Coming into his room meant that I must behave according to the rules of his program. “To go out, Selma, to go out” he said when I came in, trying to push me out of his room. It was very warm day and I felt drops of sweat rolling down my back. Everything that I said or did seemed to irritate him. He didn’t want to eat his lunch, protesting and spilling it from his bottle. “Soup”, he said grimacing, spitting it out immediately after he sipped a small mouthful. I felt rejected and helpless, wanting to scream for Maja’s help (his mother).

“Go out, go out” he pushed me again. This time Maja came in, wiped spilled food, rearranged the toys and opened the window. Although it was very warm and wet, opening the window brought a touch of freshness.

Kai, a playful adolescent golden retriever, recently adopted by Maja, followed her, waving his tail cheerfully. Faris felt relieved and sat on the windowsill gazing outside at Maja’s beautiful garden and road on the hill.

After several minutes, Maja closed the window, took Kai, and left us alone. Faris lay on the colourful comfortable cushions, arranged in a corner, touching their surface with his hand. I sat next to him. He didn’t want me to talk or sing (I really had a feeling that my voice irritated him so much!), but he wanted me to be near him – he leaned on my legs, and put my hand on his back. I tapped him gently and he seemed to enjoy it a lot, from time to time looking at me with his deep turquoise eyes, smiling. During my time in his room, he repeated this ‘game’ several times, every time enjoying it a lot. I offered him his lunch again. This time he ate it at once. Then he sat on the storage heater again, with his legs stretched on a huge Pilates ball, rolling it. I took another Pilates ball and sat on it. He put his legs on my lap, and I tickled him on his feet. He
giggled. Then he sat on a Pilates ball, still holding his feet in my lap, his body stretched, balancing. “You are such an acrobat” I said impressed with postures that he was able to make. Then we sat on the same ball bouncing, supporting each other by our backs. He laughed and giggled. I felt that we were friends now. Tomorrow, our friendship was confirmed; while driving back from the nearby mountain, he put his head into my lap and fell asleep while I tapped his hair.

Discussion

“You can’t measure the mutual affection of two human beings by the number of words they exchange,” wrote Milan Kundera (1999:78). My findings suggest that intersubjectivity in children with autism (especially those children who rarely use language) is mediated predominantly through the senses. Emil’s delicate touch, Ogi’s explorative caressing, and Dario’s extroverted hugs all have a rich bonding, affection or joy. Furthermore, postures and movements do converse deep thoughts and feelings. It seems that young children, still unspoiled by language, engage in fruitful bodily interaction. Personal relationships can also be strengthened by sharing passions, interests and material objects, such as toys. Sometimes, being with people means simply inhabiting the same space, being two living, feeling bodies in the same room.

In this light, Bagatell (2010) gives inspiring insights into the social interaction of autistic people referring to ‘autistic socializing’, a term coined by autistic self-advocates. Participating in the meetings and gatherings of a self-advocacy group, Bagatell (2010) observed specific kinds of verbal interaction, often without eye contact and back-and-forth conversation, but rich in humour. A peculiarity of this interaction was so-called ‘interactive stimming’ (Sinclair 2005:4 cited in Bagatell 2010:39) - the synchronization of self-stimulating stereotypic movements such as hand-flapping, body spinning or rocking. As one of Bagatell’s informants said, “We do not have to talk. We can just share energy to be social” (Bagatell 2010:40).

From my fieldwork excerpts, it is clear that there is significantly more in human relationships than just verbal language. Although affection and thoughts were not always expressed symbolically, it was actually possible to decipher the meaning of the communication of the children with autism by feeling it in the body, or experiencing bodily dispositions, postures or movements.

Merleau-Ponty presumed that intersubjectivity is “lived as intercorporeity and through the five senses as introceptivity” (Merleau-Ponty 1968:114-115 cited in Jackson 1998). In the absence of language, it is the ‘mindful’ body that communicates, understands and negotiates meaning. The subjective body is always there, but the presence of language makes the body invisible, taken for granted, and discarded in the background. Autism is a condition that makes
neurotypical symbolic language incomprehensible, but at the same time, it enriches the possibilities of social interaction, unveiling the forgotten potential of the body to communicate.

Recent scholarly work in philosophy and social theory largely criticizes the dominant role assigned to language within the dominant linguistic paradigm, arguing for the need for the ‘corporeal turn’ while acknowledging the lived ‘feeling’ body and its legitimate role in epistemology (Blackman 2008). According to Sheets-Johnstone (2009) “…corporeal affections and movements have no immediate meaning: we have to transform and translate them into another language of scientific and social objectivity” (cited in Vermes 2011:259). Cartesian dualism of mind and body and later a focus on language and semiotics in humanities and social sciences drove attention away from the corporeal dimension. However, the revival of phenomenology returned the body to the centre of scientific enquiry, emphasizing lived bodies. Sheets-Johnstone argues: “Language is not experience and does not create experience” (2009:49), but the lived, moving, feeling body does.

Thrift claims that language is certainly not the only mode of communication, and that “much of what passes as communication inheres within a realm that is difficult to see, understand and articulate” (Blackman 2008:138). Political theorist Tamborinino presumes the existence of ‘corporeality of thought’, the so-called ‘gut feeling’ as an important condition for human interaction. According to Tamborinino, acknowledging the intentionality of the body and its ability to feel certain situations that cannot be articulated in verbal language implies recognition of the body as a legitimate epistemological source. He emphasizes the importance of an ‘atunement’ of the lived body as the main premise for connecting people the body’s human and non-human environment. Moreover, challenging Cartesian dualism, Tamborinino advocates for a revival of corporeality within social theory (cited in Blackman 2008:52-53).

Concluding remarks

As a condition that affects social interaction, autism has recently come into the focus of social sciences’ enquiry, especially for scholars interested in intersubjectivity. Recent studies in linguistic anthropology provide a valuable insight into language-mediated intersubjectivity and the way children with autism navigate their everyday social worlds. Autistic narratives, especially autobiographies written by autistic self-advocates, emphasize peculiar sensory experiences as well as the idiosyncratic ways in which autistic people socially interact. However, bodily communicated intersubjectivity has not yet received adequate attention. Literature on social interaction in children with autism in non-Western cultures is largely lacking.
My explorative qualitative study, conducted with six children diagnosed with autism and their families over the six-week period in Sarajevo suggests that intersubjectivity in children with autism is predominantly mediated by the senses: touch and kinesthesia, smell, hearing and vision. I conducted my fieldwork bearing in mind Merleau-Ponty’s (2002a, 2002b) notion that the body is the subject of perception. It is through our senses that our environment is experienced, given meaning and enacted upon. As a neurotypical person, I was not able to decipher the system of meanings of autistic children’s perception; I could only interpret what I, as an embodied researcher, felt to be a relationship between children and their parents, siblings, researcher, caregivers or material environment.

I hope that my study contributes not only to the corpus of social science literature on autism, but also to the scholarly work on the importance of the lived mindful body in social and communicative processes. My research illustrates how specific cultural and historical circumstances might influence interaction between children with autism and their parents. Despite unfavourable conditions, the family, especially mothers, who love and care for children unselfishly and unconditionally, remains the strongest cornerstone for children with autism since they are the first to recognize their value and needs. Although my study was limited (in terms of the short period of fieldwork and small number of children), it opens up a space for further studies on bodily-mediated intersubjectivity in children with autism.

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Inside out

Some thoughts on issues related to self-harm and young people’s experience of their bodies

Zoe Goldstein

In recent years self-harm – for this paper taken to indicate the act of a person deliberately and non-fatally physically hurting or injuring their body, and distinct from suicidal activities – has become an increasingly observed phenomenon in the West. It is noted to occur predominantly among young people, with reported acts of self-harm occurring with children as young as eight, and has been represented as a frightening new ‘epidemic’ by the media. It is primarily viewed as a means of coping with mental health and emotional problems, and accordingly it has received most attention – in the way of conceptualising the phenomenon, and researching it – from the psychological and psychiatric professions. Anthropology, and more broadly the social sciences, have thus far contributed little to what is still a relatively unknown, and misunderstood, range of behaviours. This paper thus acts as a call for attention to this important topic, with a specific emphasis on an alternative conceptualisation from an embodiment perspective, investigating the very bodily nature of what is a very physical act done by the body, to the body. Drawing on several authors, and using specific examples, I aim to present a case for the value of an embodied understanding of self-harm as it relates to young people, and hope to inspire further social science research into this still little known issue.

This paper is a reflection on young people and self-harm. It is not based on field research, and does not present findings, but was inspired by a perceived gap in our understanding of the meanings of this behaviour for young people in relation to their understandings of – and relationship with – their bodies. The idea for the paper emerged during background research for my master’s thesis on non-mainstream body modification (Goldstein 2007), where I observed a tendency – both in public discourse as well as in psychiatric and social science literature – to rather uncritically associate practices of body modification with self-harm. The

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distinction – as I understand it – between the two inspired me to delve further into questions of the nature and perceptions of self-harm, and coupled with my interests in embodiment and children/youth, the theme for this paper emerged.

Self-harm – in the form of a person deliberately cutting, hitting, scratching, burning, or otherwise non-fatally hurting or injuring their body, and distinct from suicidal activities – is a phenomenon which has been brought increasingly to the public consciousness in recent years, receiving attention from the media, in popular culture, and from the health professions. This is particularly so in Britain, where one in twelve young people report deliberately harming themselves, the highest recorded rate in Europe (Hill 2006). Self-harm is also referred to as self-mutilation, self-injurious behaviour, deliberate self-harm, parasuicide, and self-wounding (Ross & Heath 2002), and the many terms and definitions for the behaviour pose difficulties in coming to a more comprehensive understanding of the phenomenon, particularly in evaluating clinical research. Such behaviour is most common in young people, with the greatest prevalence occurring in adolescence; however, recent reports suggest that many children start as young as eight years old (Revill 2005). In the media it is largely portrayed as a worrying and frightening phenomenon affecting today’s youth, with the rising prevalence being called an ‘epidemic’; but despite growing awareness about the issue, it is still poorly understood, and the reasons for its increased prevalence are merely speculated about.

In dealing with, explaining, and ‘treating’ self-harm, most approaches focus on mental health and emotional issues; for example, the experience of childhood sexual abuse is often cited as a predating factor, as well as emotional abuse, bullying, isolation, and mental health problems such as depression and personality disorders. The issue has therefore received a considerable amount of attention within the fields of psychology and psychiatry. While these approaches give valuable insight into certain aspects of this sensitive and evocative topic, I argue that most studies or theories fail to account for the very physical and bodily nature of self-harm: it is about the body, of the body, done unto the body, by the body. People who self-harm live with sometimes permanently altered, even ‘disfigured’ or ‘imperfect’, bodies. Thus more attention should be focused on how people who self-harm conceptualise, view, feel, relate to, and live with their bodies. Given that it appears to be especially pertinent for children and adolescents, I believe there are issues particular to their experiences – and their experiential relationship between body and emotions – which warrant further exploration. I argue that by looking at some of the issues from an anthropological and embodiment perspective – which have had a minimal contribution to the field thus far – it may suggest fresh ways of viewing self-harm that take into account issues such as childhood, the experience and expression of wellness and illness, and notions of the body and emotions.

In order to come to an understanding of what self-harm means for children and young people, we need to grasp it from their perspective rather than imposing an external model based on adult assumptions. I would also argue that given the wide
age range for the phenomenon, and the increasing prevalence among younger children, self-harm may appear the same from the outside – physical harm/hurt done to the body – yet it could have different meanings for people of different ages, and for a single person at different stages in their life. Just as it has been shown that the category of ‘child’ is neither homogenous over time, nor universal (Caputo 1995), so too are there differences between the ‘culture’ of eight year olds and the ‘culture’ of fifteen year olds in the same environment, in terms of their development, their expectations, the expectations others have of them, etc. For example, children of eight are still believed, in the Euro-American sense, to be ‘innocent’ and ‘vulnerable’, while teenagers are seen to have largely lost their innocence (Christensen 2000).

Children’s views are currently being considered more important within anthropology, however the process of involving children in research about issues that affect their lives remains sporadic and tricky (Van der Geest 1996, Hardman 2001). Furthermore, while there are qualitative studies on self-harm (Adams et al. 2005), many studies focus on people within clinical settings, and the greater number who self-harm in the community without ever accessing services are largely under-investigated (Ross & Heath 2002). There are obvious difficulties in undergoing participant observation research for this topic, particularly as it involves children – a group protected by many levels of ‘gatekeepers’ (Hood et al. 1996) – but I believe that ethnographic, qualitative study would prove helpful in increasing awareness of the many dimensions of the issue. Material that could enable such an endeavour might include first-hand narratives; diary-type documents; internet resources such as self-harm related websites, blogs, and chat forums; as well as interviews or focus groups.

Looking at literature that does exist about children and their experiences of their bodies, some very interesting insights begin to emerge which could have relevance for a deeper understanding of self-harm among children. In particular, Pia Christensen’s (2000) exploration of the cultural construction of children’s vulnerable bodies in the West offers some fascinating theoretical starting points, which deserve to be addressed here in some depth. While Christensen does not challenge the idea that children may be vulnerable, she does suggest that the vulnerability attributed to childhood in general, and children’s bodies in particular, is culturally constructed from a Euro-American perspective, and obscures the ways in which this construct renders unimportant children’s own understandings of themselves and their bodies. Furthermore, Christensen argues that adults have a vested interest in maintaining children’s innocence and vulnerability because they act as symbolic conceptual counter-balances to the perceived ‘dark-side’ of adulthood.

Christensen proposes that this conceptualisation of children as vulnerable, in need of protecting, leads to an interesting paradox whereby children are seen as precious, yet their perceptions are not necessarily regarded as valuable in their own right but only in relation to the adult world. Children’s own experiences and
understandings are devalued, while adult experiences/understandings are imposed upon them. This is particularly visible in adults’ and children’s contrasting notions of the body, differentiated between the former’s ‘somatic body’ – the body objectified beyond subjective experience – and the child’s ‘incarnate body’ – a unified, subjective experience of the body in time and space. During minor illnesses or day-to-day accidents, “this experience of the permeability, fluidity and extensibility of the body is transformed for children when adults attempt to translate the body incarnate into the somatic body” (Christensen 2000:45).

Christensen takes this notion further in her observation of the adult distinction between the exterior and the interior of the child: the child’s outer body is visible and deemed indicative of their wellbeing; the internal body is hidden, and is the site of emotions, motivations, and bodily processes. Adults work on controlling the external body in various ways in order to discipline and control the ‘inner’ child, seen as immature and incompetent. This leads to a belief in the need to develop a ‘hardened’ exterior skin in order to deal with the complexities of adult life and maintain emotional control and resilience. Thus adolescence, when a child moves into adulthood, is a period characterised by conflict between the inner and outer body, visibly manifested through bodily and behavioural changes due to their not yet fully hardened exterior. It is the “inside leaking out” (Christensen 2000:50).

What Christensen refers to here as the ‘incarnate body’ is also addressed by Csordas (1994) when he speaks of the preobjective character of our bodily being-in-the-world. Our lives are not, he argues, always lived in objective bodies but instead they are the grounds of perceptual processes that end in objectification, the individuation of the psychological self and dualism in the concept of the human being. While Christensen observed that the children in her studies, particularly the older ones (ten to twelve year olds), were “engaged in creating conceptual linkages between ‘the incarnate body’ and ‘the somatic body’” (2000:55), Csordas argues that embodiment as lived experience is the continual and lifelong play between preobjective and objectified bodies. If an important reason for studying children and childhood is because it “can enable us to understand how we come to hold the ideas we hold” (Toren 1990:28), then understanding when and how children begin translating the experiences of their preobjective bodies into ‘adult’ objectified bodies could be very illuminating.

In relation to self-harm, I believe Christensen points to some interesting concepts. The idea of a hard, external barrier to keep emotions in has been observed by Lupton among adults in Australia, whereby the “body is conceptualized as an inner, fluid or gaseous mass of emotions that are held back by the external skin and the will” (Lupton 1998:90). Lupton goes on to express how emotions bring about a heightened awareness of the body and embodiment, and that the emotional body is often represented as grotesque, transgressive, and polluting in Western society, unable to maintain its boundaries. The significance adults give to children’s external surfaces as markers for wellbeing establishes early
in life the message that the external body should be kept hard and intact, but also that external suffering or markers are valid, while internal suffering is not, and must be contained. Self-harm represents on one level, I argue, a breakdown of this barrier between inside and outside. Emotions and feelings contained on the inside build up to such a degree that they need to be released, and by cutting the skin, not only is the ‘hardened’ skin barrier temporarily broken down, but the (invalid) emotions, which are meant to be hidden and are hard to articulate, are translated into a (valid) physical marker, understandable as ‘pain’. Taken further, self-harm could be seen as an ‘extreme’ method of translation between the invisible subjective, embodied experience – pain, anguish, emotions – and the visible objectification of this experience – bruises, cuts, blood.

In this sense, a young person’s self-harm may also be perceived as a threat to, or failure of, the adult’s role as protector, and an exposure of both adult and child vulnerability through the *dys-appearance* (Leder 1990) of the child’s ‘inner’ self. Christensen demonstrates that adults pay a great deal of attention to maintaining the external appearance of children – their ‘social skin’, from Turner (1980) – as this demonstrates their competencies as protectors/providers. Yet self-harm subverts this by damaging – often permanently – the surface of the body. Following Foucault, much social science literature makes “references to the body as a kind of readable text upon which social reality is “inscribed”’ (Csordas 1994:12); self-harm is literal ‘inscription’. This may explain why it is so often reported by young people who self-harm that the reactions they receive from adults or carers have been ones of anger, dismissal, and stigma rather than empathy, support, and understanding (Hill 2006).

Self-harm, I argue, can also be seen as a form of embodied language. Children, as a social category, are muted in terms of their ability to speak, act, and be recognised as agents in their own right. In certain circumstances where children, and their ability to communicate or articulate, become extremely restricted, self-harm can be a way to ‘speak’ when their actual voice is denied. For example, the policy of mandatory detention for asylum seekers entering Australia has led to a highly publicised debate over the self-harm of child detainees (Parr 2005). In the camps, “children, in particular, suffer from a double silencing – unable to speak English, traumatized and often too young to speak for themselves” (Parr 2005:281, emphasis added), and there have been highly controversial reports of children slashing their arms and faces on the razor wire fencing them in, and sewing their mouths shut in protest. One child reportedly cut the word ‘freedom’ into his arm. Parr argues that the actions of the child detainees “could be viewed as a form of pragmatic writing: embodied graffiti” (2005:289), a means of communication when other means have been denied.

What I believe this final example reveals is the fact that there are many dimensions to this phenomenon. The child in the detention centre is, on one level, trying to communicate his or her situation to others through self-harm, and the
‘public’ nature of the act attests to this. On the other hand, in Britain, the majority of self-harm reportedly takes place not only in private, but in great secrecy, in contrast to the common yet false assumption that its primary purpose is ‘attention-seeking’ (Sutton, 2007). Therefore, while it may still be considered a form of communication, it is not directed outwards to others but inwards to the self. This difference is critical, demonstrating that there is not one single phenomenon of self-harm, nor one way of understanding it; rather it is multi-dimensional, related to persons, space, and time, thus trying to understand how it is reaching ‘epidemic’ proportions in Britain and elsewhere will need closer attention to the particular circumstances – socio-cultural, age-related, emotional, embodied, or otherwise – in which it takes place.

This is but a brief assessment of some of the issues related to self-harm among children and young people in Britain and elsewhere in the ‘West’. The issues I have focused on – principally Euro-American notions of childhood, the body, and wellness/illness – are broadly culture-specific, and do not necessarily account for self-harm observed in non-Western countries, or among immigrant communities in the West. Furthermore, the question of agency in the act of self-harm – for example, is the child victim or perpetrator, active or passive – has barely been addressed here. The issue is complex and multi-dimensional, and without hearing the voices of those affected the points raised above are largely theoretical. However, I believe anthropology can make a valuable contribution towards a greater understanding of the ‘self-harm epidemic’, particularly through an embodiment perspective which focuses on the very physical and embodied nature of what has previously been looked at as largely psychological and emotional. I hope this paper provides food for thought for future research into self-harm, drawing on the embodied experiences of young people expressing intense emotional feelings in visceral, physical ways; inscribing ‘pain’ onto the surface of their bodies; and translating this pain from the inside out.

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What does sitting have to do with the self?

Body techniques, personhood and well-being in Vipassana meditation

Nasima Selim

Sitting is a common ‘technique of the body’. Sitting can also be special, as a body practice in Vipassana meditation and thus become a metonym for it. What does this kind of sitting have to do with the self? This article attempts to answer that with empirical research on the sitting practice known as Vipassana meditation. These sittings are organized globally in isolated retreats of silence and in the middle of everyday noise with the promise to alleviate universal suffering: in Myanmar and India, North America and Israel, South America, Africa, Australia and in Europe. Field research for this article was conducted in Amsterdam with participants coming from different places around the world. The objective was to follow the everyday practices, lived experiences and perceived effects of Vipassana sittings based on interactive in-depth interviews, informal conversations, participant observation, content analysis of audio-visual materials/publications and auto-ethnographic narratives. The study findings revealed the reflexive techniques of Vipassana in practice: interrupting the flow of thought with focused breathing, cultivating attention with the systematic scanning of body sensations, and generating compassion with notes of forgiveness and wellness prayers. These techniques seemed to involve a reconfiguration of the self. The narratives offered a clue to how people from different parts of the world, facing life crises at various points of their lives, chose Vipassana and continued/discontinued with it. How sitting as a practice can be linked to the self, illustrates one possible way of reconciling embodied and discursive acts in their respective sites, the body-mind and the social zone of self-making narratives. Vipassana, the sitting and the talking about sitting combine various modes of self-reflexivity that make the construction and articulation of transcendence from suffering, or, well-being possible.

A young business executive sits to mend his broken heart (Oscar). A married German woman sits and comes to terms with her impending divorce (Andrea). A Dutch man sits to find direction in a life of

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2 I used pseudonyms to protect the identity of the participants.
confusions (Hans). A young woman from Africa sits after suffering sexual violence (Angel). An atheist sits to seek relief from depression in a practice of equanimity (Paul). A woman leaves her country to sit in the other hemisphere and fights the urge to smoke (Annelies). A young man sits to mourn the loss of a close friend (Marten). A Bangladeshi researcher sits to struggle with thinking/writing versus doing Vipassana.

Vipassana meditation is one of the many different kinds of meditation practices in Theravada Buddhism. However, in this article, what I call Vipassana is a secularized and standardized form of sitting meditation taught by S.N. Goenka (1924-2013) in the tradition of Sayagyi U Ba Khin, a Burmese lay teacher. This meditation practice spread worldwide since the 1980s. Presently more than 100 centres organize regular Vipassana retreats globally. Most practitioners do not identify themselves as Buddhists (Pagis 2008). Beyond regular sittings (twice daily for an hour) and preferably longer retreats in a Vipassana centre, practitioners are advised to adopt life-style modifications with five moral/health-related instructions (*sila*): abstinence from lying, stealing, killing, sexual misconduct and intoxicants. Through these practices, it is expected that he or she will be relieved of the ‘universal suffering’ (Hart 1987).

In 2011, I conducted six weeks of focused ethnographic research on Vipassana meditation in Amsterdam preceded by engagements in the field for six months. I explored the everyday practices, lived experiences and perceived effects based on interactive in-depth interviews, informal conversations with twelve practitioners, two key informant interviews, participant observation of group sittings, content analysis of audio-visual materials/publications and my auto-ethnographic narratives. The informants and I practiced sitting in our daily life. We had earlier participated in the initiation ritual, a ten-day silent retreat of sitting meditation as well as follow-up group sittings, at various points of our lives, in different places around the world (Bangladesh, Belgium, Germany, India, Myanmar, South Africa, Spain, the Netherlands, and New Zealand). That made us ‘old students’ of Vipassana. Most of us were driven by a recent (or impending) loss of intimate relationships, death of dear ones, suffering from sadness and worries of life, lack of direction, or, general dissatisfaction. For some the first sitting was situated in their quest for well-being in silence and a no-nonsense (‘non-cultic, non-Hippie’) ‘spiritual’ practice from the East.

In this article, I (re) present the narratives of seven Vipassana practitioners to illustrate how the sitting is mobilized, as a body practice and as a metonym for the experiential process of Vipassana meditation, to deconstruct the notion of a former ‘self’, not into the ‘not-self’ (as claimed by Buddhism or Vipassana pedagogy) but into the reconfiguration of personhood and articulation of its

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3 See Selim (2011) for the full thesis submitted in partial fulfilment of the Amsterdam Master’s in Medical Anthropology at the University of Amsterdam, the Netherlands.
well-being effects. In that, Vipassana combines two different modes of reflexivity, the embodied (sitting) and the discursive (talking about sitting).

**Following the sitting body**

The Vipassana Stichting\(^4\) (Foundation) in the Netherlands organizes daylong sittings for ‘old students’ in the city of Amsterdam. On the first Sunday of each month, from ten in the morning until five in the evening, women and men come together to sit in silence. I joined them in the spring of 2011 and became part of the core group that helped in the set-up. Group sittings also happened during the week, on Mondays and Wednesdays, in two neighbourhoods of Amsterdam, the first in a big apartment in the middle of a busy shopping area and the other in a quiet suburban flat. In 2009, the monthly daylong courses started in Amsterdam. The sites of group sittings shifted along the movement pattern of the practitioners who organized them. It was often difficult to find a permanent place in the city to sit through a full day. What follows is a brief description of one of the daylong sittings in the city of Amsterdam:

Along the river IJ,\(^5\) a wide road goes from the East to the West. It is drizzling lightly since daybreak. I arrive at eight in the morning. Annelies is directing the organization. Together we prepare the hall for silence. Sitting begins at ten. More women than men come to sit. I steal a long, sharp glance at the list of on-site registration to find out what is happening here. From the list, it is difficult to say where they are coming from and who is who. They are coming from all over the Netherlands: Amsterdam, Flevoland, Gelderland, Noord Holland, Utrecht, Zeeland, and Zuid Holland. I do not even know where some of these places are. It is also difficult to say if they are all Dutch citizens or simply visitors to Amsterdam or the Netherlands. I notice two women of colour, Neela and a Thai woman as visible Asians. In their twenties, thirties, forties and fifties. One woman has snow-white hair. She must be in her seventies. She needs a chair to sit. One woman is pregnant but she prefers to sit on a flat cushion on the floor. The men are mostly Dutch. I begin to draw conclusion from their last names. They are younger, most in their

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\(^4\) In 1996, a critical mass of ‘old students’ in the Netherlands, many of them Amsterdammers, joined together to establish the Vipassana Stichting. It is a non-profit organization that organizes group sittings in Amsterdam and other cities, as well as residential courses twice a year in a rented location within the Netherlands. In 2000, the Dutch practitioners joined the Belgians to build a residential centre in Belgium close to the border with the Netherlands, within three hours of commuting by train from Amsterdam. The centre, DhAMMA Pajjota, runs ten-day courses and shorter or longer versions for about 90–100 practitioners per course throughout the year. The rented location in the Netherlands runs 10-day courses only during the summer and winter holidays.

\(^5\) The river IJ (formerly a bay, now partly reclaimed from the sea) is Amsterdam’s waterfront (Mak 2001).
twenties and a few in their forties and fifties. I am familiar with some of the women (especially the organizers).

The men and women now separate and take their seats in the ‘resting room’. The organizers provide tea and coffee. The practitioners bring their own vegetarian lunch and meditation accessories, e.g., smaller cushions, blankets, shawls, kneeling stools etc. Some are already quiet and the others engage in hushed chats. The silence will soon take over. A minute before ten o’clock the gong rings. Slowly the men stand in a file and enter the meditation hall. The instructor is already there, sitting with her eyes closed. The women also stand in a file and one by one take their place in the hall on the right side. The snow-white haired woman sits quietly on a chair. The rest of us use the smaller cushions and blankets.

Sitting begins.

[As soon as the instructor (known as ‘assistant teacher’ in the Vipassana circle) turns on the audio CD there is a moment of silence. Then comes a voice. Goenka chants in Pali before instructing the students in English followed by Dutch translations. The voices continue:]

[anapana]
Start with the awareness of respiration. Awareness of incoming breath, outgoing breath. The awareness of sensation on the area below the nostrils, above the upper lip. To calm down the mind, practice anapana…

[vippassana]
Now start practicing vipassana. Keep moving your attention. From head to feet, from feet to head. Whatever sensations you may experience on the way, keep on understanding the characteristic of every sensation. anicca, impermanence…

[metta bhavana]
We shall now practice metta bhavana for a few minutes. You may relax yourself and practice. May all beings be happy…May all beings be liberated from all their miseries, all their bondages…Be happy, be peaceful, be liberated.”

The sitting techniques vary. Many sit cross-legged (known as the Burmese position) or on their knees (the kneeling position), followed by the half-lotus position. I shift from the cross-legged to the half-lotus position. I wonder if anyone in the hall is sitting in a full-lotus position (Figure 1). It is difficult without training (as in yoga asana, the specific body postures). There is a clear instruction about sitting in a comfortable position and
focusing on meditation rather than worrying about the postures one must adopt. That explains the many variations in sitting positions as well as the use of chairs, stools and cushions to make sitting easier.” [Daylong Vipassana group sitting in Amsterdam in a rented meditation hall by the river IJ, Field note excerpts, June 5, 2011]

This is a glimpse of the sitting, or rather, the context – of what is exterior to it. What happens after we sit in a particular posture, when silence falls and eyes close? What sense do we make of the sitting and the self that we carry? Sitting is a ‘technique of the body’ (Mauss 1973). What does sitting in Vipassana have to do with the Self?

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In an earlier comment on the draft version, a reviewer asked me to explain why individuals would be torturing themselves to sit in an uncomfortable position for a prolonged period. The long term practitioners rarely complained about that. What they consistently mentioned that in the beginning it was always difficult to sit for an hour but with time and practice it was easy and beneficial. It is difficult to say if sitting for prolonged periods is any more torture than other physical acts that people willingly take upon themselves, for example, going to a gym, to jog or exercise, to name a few.
Doing the self: Stories of personhood and well-being in Vipassana

In Vipassana, the practitioners sit and listen to the teacher’s voice, who chants in Pali language before giving the instructions. They follow the breath (anapana), observe the body sensations (vipassa na) and cultivate compassion through forgiveness (metta-bhavana). To different degrees, they practice the life-style modifications. However, one has to move away from the sitting body to the way these bodies talk about these sittings and situate them in their stories of personhood. These moving, personal tales illustrate how sitting in Vipassana is transferred to the self making narratives and create the well-being effects, the perceived ‘benefits’ of Vipassana.

‘De rode draad’

Paul was a 38-year-old Belgian studying Biological sciences in a university in Amsterdam at the time we met. I saw him a few times in the weekly group sittings and we had brief chats about his work and mine, before I approached him for an interview. We were of the same age and both interested in mind-body connections. We had a lot to talk. Paul was a serious practitioner of Vipassana, doing daily meditation for the last eight years. So one spring morning in 2011, he agreed to come to my student dormitory and we sat together, first for the Vipassana meditation and then for the interview. During our conversation, Paul used the Dutch idiom rode draad (red thread) when he talked about the effects of Vipassana in his life. The rode draad connotes a central theme, a plot that runs throughout the life, connecting all the parts. Paul had suffered from depression and questioned the meaning of life. He was raised as an atheist and he missed a belief-system to guide him in times of distress. Organized world religions did not interest him in his search for purpose in life (that included a formal comparative study of religion). Since 2003, Vipassana meditation became a ‘red thread’ that provided his self with a sense of purpose, a tool to guide his self in the ‘right path’, as illustrated in the following interview excerpt:

Nasima (N): You mentioned that Vipassana had some effects? How do you know the technique caused these changes?
Paul (P): How do I connect it? Before I did it [sitting in Vipassana] I was depressed. I did not have a real purpose in life. Vipassana is like… there is a Dutch expression, rode draad. When you translate this is the red thread.

N: What does it mean?
P: It is an expression. If I use a metaphor for the body, [for example] a complete artery system or vein system connects all parts of the body. It is feeding your body with oxygen and other nutrition and take out the filth. It is connecting everything. This is like the red thread.
Something that connects all the aspects of your life, gives you direction and purpose. I was like a ship in the ocean and I was floating. There was no direction. Because of Vipassana I have some direction. What it means to me is well apart from the final goal. That [the goal] is not the main thing. Main thing is the direction, the right path. It [sitting in Vipassana] has given me the right path.

N: Do you consider yourself Buddhist?
P: No. Buddhism is a religion. Certain mythical figures, all kinds of rituals...Philosophically I tend to connect to Buddhist philosophy. They don’t see a soul or self something somewhere...I think it is an important belief. If you want to practice this...You need to de-condition yourself. All this conditioning with education...with this conditioning you build a self, life, I am Paul. I have this history. It becomes your Self. It is constructed. With Vipassana you try to deconstruct it. [Excerpts from in-depth interview, May 13, 2011, 9.30 in the morning, student dormitory, Amsterdam]

Paul did not consider himself a Buddhist but he said he could relate to some of the Buddhist concepts. None of my informants expressed an affiliation with Buddhism as a religion. Neubert (2008) argued that the contemporary Vipassana movement rejected the label ‘religion’ and ‘ritual’ to protect itself from the negative associations with these terms, for example, extreme rigidity and sectarianism. Pagis (2008) finds similar emphasis by Vipassana students in the post-industrial settings of Israel and North America. For Paul, the ‘not-self’ notion in Buddhism made philosophical sense and he recognized that it was a belief-system that provided him the rationale for the practice.

He emphasized the effect of the sittings on his mental health. Sitting in Vipassana helped him in dealing with his depressive thoughts, and provided him with a sense of purpose. Although a Vipassana instructor in Amsterdam insisted on Vipassana as a practice for ‘healthy people’ (probably to stay clear of any medico-legal responsibility), Paul was unequivocal on its therapeutic benefits. In addition, he said that ‘mindfulness’ therapy “takes inspiration from Vipassana,” and, “it would be better...instead of giving people Prozac [anti-depressant] maybe try mindfulness or something [Vipassana].”

‘Durchhalten’ and ‘Houvast’

Andrea was a close friend who visited me in Amsterdam during my stay in the city. I had known her from Dhaka (Bangladesh) and shared with her my own

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7 Later Andrea became a very important person in my life. That is another story and not relevant for this paper. I am a regular witness to her continued engagement with Vipassana and her persistent struggles with smoking.
experiences of the sittings back in 2010, months before I decided to write my master’s thesis on the subject. According to Andrea, she was quite impressed with the before-after effects of my Vipassana experience. She found that I came back from my first ten-day retreat filled with insights, for example, accepting my past mistakes and forgiving myself for separating from my long-term partner. This was instrumental in her decision to try sitting in Vipassana as a remedy for her own life situation. Andrea was 50 years old when we met again in Amsterdam. Two months before the interview, she sat through her first ten-day Vipassana retreat in a centre near Kolkata (India), where I had been earlier. Andrea had been politically engaged in the anti-racist movements of Germany and development work in Bangladesh. She was always weary of what she called the esoterik (spiritual) stuff, but this was the first time she tried the sitting meditation as a self-help tool. Andrea was on her way to return to Germany, having decided to divorce her husband of fifteen years. She had been a smoker for almost 30 years and a significant effect of the first ten-day-retreat was that she stopped smoking. During our conversation in Amsterdam (followed by conversations in Berlin), she often used a German word, ‘durchhalten’ (to hold on), to express what smoking used to mean in her life and what the new practice of sitting every day meant to her now. According to her, she replaced a negative habit (smoking) with a positive practice (sitting) of ‘time-out’, a procedure of durchhalten so that she could survive by holding on to the sittings, through the storms and floods of life:

Nasima (N): It’s almost 2 month now [that you stopped smoking]? In these 2 months, you didn’t feel like smoking?
Andrea (A): I felt like smoking! But I didn’t smoke.
N: Do you think Vipassana has something to do with it?
A: I think so. I mean it helped me to stop...I don’t really know. What it [sitting in Vipassana] has done is that my attitude changed. I feel that smoking doesn’t help...Sometimes I felt like: I need to smoke a cigarette and everything will be fine. All my problems will be less. When I was very nervous, very desperate, when I was having a fight, I felt like: When I smoke everything will be ok. But even when I was smoking I felt like I wanted to smoke a cigarette. Also when I finished the cigarette I felt like I wanted to smoke a cigarette as if I hadn’t done it. It is not that I actually want to smoke a cigarette. It is the function. I want the relief from the sensation...I know now that if I want to smoke a cigarette it is not that I want to smoke a cigarette. It is a replacement of something else.
N: How is it linked to Vipassana?
A: I stopped because of Vipassana.
N: Yes, but this new idea that smoking doesn’t help, how do you link it to Vipassana?
A: I think it is indirectly linked. It is linked with the reason why I am doing Vipassana. With the focus on looking at things seriously, looking at myself, having the place with myself, having the space for myself. Where I am, where I am with myself and not let the world intrude [inside] me. [From] there this understanding of ‘smoking doesn’t help’ comes. Because smoking is also this kind of outside intrusion kind of thing. I take something from outside, which [I think] will help me to overcome in a crisis. My new realization is: It doesn’t work. I have to find a way to overcome my inner crisis with myself. I have enough. It is the same kind of principle like when I am doing Vipassana, because it gives me space to be myself, to be in tune with myself, to shut off the intrusion from outside. This intrusion from outside are also these cigarettes...

N: Once [in our previous conversation about Vipassana] you mentioned a word, durchhalten. Please, tell me a bit more about that.

A: *Durchhalten* is a German word and I don’t really know what it is in English. It means something like ‘to bear’, ‘to go through with something’. Literally it means ‘to hold through’, ‘to hold on’, ‘to hold on while going through’. And I felt like smoking was the medium for ‘durchhalten’ for me, the medium to bear unbearable situations, to stay in situations which are unbearable.

N: So, it [smoking] did help.

A: It helped, because I felt like drowning and that was like a post to hold. While the floods were flooding me, I could maintain my position...When I feel like I want a *durchhalten* then I want to smoke. When I feel it now I know it doesn’t fulfil its function. Even when I was smoking I wanted a *durchhalten*. It didn’t work anymore...This [life] is not a ‘flood’, it is actually life happening. It is not that there is an outside storm happening and I need a post so that I can hold myself. It is not about bearing things. It is about designing things, to take control over things, to take things into my hands, to be aware of the things that are happening in my life and to be in charge of them. That is the basic difference.

N: And after coming from Vipassana you wanted to smoke, but you didn’t.

A: Ja.

N: And why did you not smoke?

A: Why didn’t I smoke? Because I know that I don’t need to. When I was in Vipassana [ten-day retreat] I didn’t feel like smoking. Why should I do something which I neither need nor does it help just because I did it and because there is an illusion attached that it would help?

[Excerpts from the in-depth interview transcript, dated 7th May, 2013, student dormitory in Amsterdam]
Hans was a 52-year-old Dutch man working in a local NGO. He was a quiet person and spoke slowly with a friendly nod of the head. He had been a serious meditator for fifteen years when I met him in a group sitting in Amsterdam. He travelled to India in his youth and learned to sit there for the first time. That was also when he separated from his wife. This led to a long period of depression. Back in the Netherlands, he had to be hospitalised and went through therapy for many years. He practiced Yoga for some time but finally continued with the Vipassana sittings as his daily practice. He had participated in regular ten-day retreats annually and recently in longer sittings (30 days of silent meditation). Hans was curious about my research project and assisted me in finding out various documents related to Vipassana. Our conversation took place in his house, which he shared with his girlfriend and two dogs, in a suburb of Amsterdam:

Nasima (N): What did it [sitting in Vipassana] give you? Or what does it give you?
Hans (H): During courses there are moments you feel [pause] very difficult to put it in words...some kind of happiness, or realization, or some kind of [hmm] being in the here and now and experiencing things without all the...I don’t know how to say: moments that give you some glimpse into what meditation is all about.
N: Do you also practice in daily life?
H: Every day two hours. There have been periods I was less confident, less sure about the effects. Your life continues, you meet people, things go right, things go wrong, sometimes small crisis, big crisis. I have discovered that it [sitting in Vipassana] prevents me from falling back too deep.
N: Falling back?
H: It [sitting in Vipassana] helps me not to glide back to some kind of crisis. It gives me some holdfast
N: Is there a Dutch word for it?
[Hans smiles and continues talking as I write down the Dutch word in my notebook]
H: Houwast ('holdfast'). It [sitting in Vipassana] keeps me a bit on the road, on the path. Life is very distracting. You can choose so many directions. What to read, what to see, which people to meet. Life can be quite confusing.
N: Coming back to this holdfast. Give me a concrete example.
H: Sometimes I focus too much on very unimportant things. Do I want to buy this thing, musical equipment, etc...I am a bit neurotic. Meditation seems to control that a bit. I know how to stop that. It still happens. But it [sitting in Vipassana] helps me to control that kind of neurotic behaviour. [Interview in Hans' house, May 27, 2011]
I noticed that Hans used the Dutch term *Houvast* (grip; ‘holdfast’), which sounded quite similar to Andrea’s *durchhalten* or Paul’s *rode draad* to describe the symbolic role of the Vipassana sittings in holding their sense of self together or keeping them on the path. In that, their expressions resonate to the idea that sitting silently in Vipassana provided a direction in the ‘distracting’, ‘confusing’ and often distressing life.

**Where is the craving? Vipassana sittings as de-toxification**

Annelies was a 48-year-old Dutch social worker who organized group sittings regularly in Amsterdam. We met at the daylong sitting by the river IJ where she was among the main organisers. Later we met quite regularly at her place, often sitting together for an hour in the evening. I met many informants in her house and had long, informal talks over herbal tea. Annelies was a serious practitioner sitting twice every day with at least one, if not more, ten-day-retreats a year. She gave up smoking after her first ten-day sitting more than twelve years ago and now continued as a non-smoker. Spending ten days in abstinence from tobacco helped Andrea to go through the initial difficulties and strengthened her volition to stop smoking. For Annelies, the technique of body scan while sitting still, made her question the craving itself. Instead of going for a cigarette, she searched in her body (mind): “Where is the craving? Where is it?” Sitting without movement for long hours and practising a sustained focus on her breath and body sensations distracted her and the initial craving would always pass. Since her first ten-day course twelve years ago, Annelies never smoked a single cigarette. Returning to daily life, both Annelies and Andrea practiced regular sitting and maintained *sila* in varying degrees to maintain their non-smoking status.

Marten was a 28-year-old clinical psychologist and an experimenter who tried many different practices, for example, yoga, energy healing as well as cognitive-behaviour therapies and meditation techniques other than the Vipassana sittings. He labelled Vipassana as a ‘behavioural de-tox’ (detoxification for addictive behaviour). His description of effects referred to the daily meditation as an effective tool for focusing the mind, increasing the willpower and helping the self to literally “sit through the impulses”:

Marten: [sitting in] Vipassana is...like brushing your teeth. Meditation daily gives me focus and it works against the habit formation of craving and aversion...staying in the present moment...

Nasima: [Referring to an earlier remark] How were you able to let go [in Vipassana]? Marten: You observe the emotions and feelings without reacting to them...You prevent the automatic reaction pattern of your

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* Paul, Hans, Oscar, Annelies and Marten – the serious practitioners have continued with the sitting every day. Andrea returned to smoking after six months of Vipassana but she still sits occasionally. I myself sit irregularly, a few times in the week.
mind or of your brain. In that way, you dissolve the link between the emotion or the memory and the automatic reaction pattern. That for me was the point to be able to let go and experience the moment: Passing away of the body [sensations], passage of time, feeling that nothing is permanent.

Like Hans, Marten also assisted me in finding research informants. Through him, I met Oscar, a 28-year-old successful business executive who recently returned from his first ten-day-retreat. We met at his sunny apartment to sit and eat together before we engaged in a long conversation. Oscar considered himself a novice of the technique, having recently experienced Vipassana for the first time following a distressing separation from his girlfriend after nine years. He described ‘relaxation’ and ‘focused attention’ as the main effects of the sittings in his life. Since returning from the retreat, he continued to sit daily to maintain the relaxation he experienced during those ten days. He jogged regularly and told me that the sittings also affected his running activity. With an increased focus on sitting still, concentrating on breath and body sensations, Oscar could breathe deeper, and run longer with an increased focus. He also learned to accept the separation with greater equanimity by literally sitting through his distressing thoughts and emotions. Sitting mended his broken heart.

The Vipassana drop-out

Angel was a 44-year-old woman from a country in Africa, currently a Dutch citizen, a freelance filmmaker and meditation teacher. She considered sitting in Vipassana a ‘therapy’. Her life story was replete with tragic episodes. She had experienced abuse as an adopted child and later sexual assaults as an adult in Africa and the Netherlands. In her home country in Africa, she was helped by a local church and one of her church friends guided her to the sittings. Angel said, “It [sitting in Vipassana] confronted me a lot with my sadness and my sad life. I questioned where I come from and where I was going...It made me see the essence of beauty again”.

Twenty-two years later however, Angel was ambivalent about the particular effects of Vipassana. In fact, she considered the compulsory sittings and the life-style modifications as a regimented way of meditation. Although Vipassana was ‘therapy’ for her for many years, she decided to give it up for a more flexible meditation technique she named as “Universal Meditation”. Doing meditation in general had healing effects on her wounded self. But the effects, according to her, were not specifically the results of Vipassana. Angel’s comments made me reflect: “Are these effects the general effects of doing meditation, or, are they specific to Vipassana?”

In the end, how can we ever find the answer to this question through ethnography? My research was not an experiment or an attempt to attribute cause-
effect relationships. I have tried to retell the stories of what sitting in Vipassana does in the lives of its practitioners. If there is any attribution, it is how the practitioners formulated it with a ‘before-and-after Vipassana story’. None of the practitioners did only Vipassana. They did not just sit. They talked, they sometimes ran, did Yoga or other forms of meditation, spent time socialising or pursuing creative work. Some wrote books, some were political activists and researchers. Some were in an intimate relationship, some not. Many were clients of different models of psychotherapy. There is no way to know for sure if and how the sittings created the effects they claimed it did. One can reflect endlessly on the question: Why do they sit? How could sitting possibly work? There could be so many different answers. Maybe the techniques of Vipassana really work, as systematic reviews and practitioners’ narratives claim, that sitting still in silence facilitates the inner practices, reduces stress and cultivates ‘mindfulness’, a ‘nonjudgmental awareness of the present’ which leads to its therapeutic benefits (Chiesa 2010; Germer, Siegel & Fulton 2005). Maybe the Vipassana discourse of remedying the ‘universal suffering’ disciplines the body-mind of its practitioners to administer such effects. Maybe it is simply the fact that Vipassana sitting costs little (or, does it? One must consider the opportunity cost of taking two hours off every day, ten days or more each year) and combines with the lifestyle modifications and daily rituals that provide a routine that might work for those who continue with the sittings for a longer duration. I am not sure I could ever find a convincing answer from the limited ethnographic study I conducted in Amsterdam. What was evident nevertheless, even with few months of engagement with the practitioners, is that most of them converted the body technique of sitting into narratives of well-being, and almost always a ‘new’, perhaps ‘purified’, self was evoked.

What does sitting in Vipassana have to do with the self?

The sitting in Vipassana involves the visible body postures, closure of eyelids, the silent breathing, as well as the invisible/internalized process of interrupting the flow of thought with focused breathing, cultivating attention with the systematic scanning of body sensations, and generating compassion with notes of forgiveness and wellness prayers. In addition to the body practice, sitting also became a metonym for Vipassana meditation. Sitting was a constantly evoked term in the Vipassana field. Before and after group sittings, one would hear people uttering phrases, for example, “when did you do your first sitting”, “do you sit every day”, “shall we sit”, “do you go for longer sittings”, or, “when do you plan to sit the next time”, with emphasis on the word ‘sitting’. In that they were talking about Vipassana and not just any other/usual sitting.

The multiple ‘body (and mind) techniques’ of focused breathing, body scan and forgiveness in Vipassana all together comprise the synecdoche of sitting. The non-visible and non-recordable body-mind techniques of Vipassana begin from and
anchor on the visible bodily practice of sitting. These non-visible techniques - the body practice and the metonym of sitting evoked in the before-after stories and the attribution of beneficial effects to them - can perhaps be better understood as a set of ‘technologies of the self’ that the informants use. Sitting is practiced within the ‘matrix of practical reason’, “which permits individuals to effect by their own means or with the help of others a certain number of operations on their own bodies, ... thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection” (Foucault 1988: 18). Vipassana meditation mobilises the bodies (and minds), manages thoughts and living situations. In conjunction to the immediate techniques (sitting in silence, breathing in anapana, scanning the body for identifying sensations and generating compassion in metta alone/together) there are other life-practices involved in Vipassana (sīla). The immediate body practices and these corresponding life-style practices are not separate. Together they comprise Vipassana, designated as the ‘art of living’ (Hart 1991). Or, simply as sitting.

Stories of Vipassana are not focused on finding the truth about one’s self, or ‘being who you are’ but rather on becoming, and attributing this becoming to a particular technique, even though there is no way of telling how that happens. The self that the newcomer carries and brings to the residential courses is destabilized of course. Through the various processes of maintaining disciplines and following the techniques in sitting the practitioner is initiated into novel considerations of what the self is or can be. The Vipassana discourses provide a framework for the ‘not-self’ but what the practitioners return with is a sense of ‘self’ different from the ‘self’ they brought to the retreat. Once they practiced the techniques and experienced the doing of their body and mind, they incorporate these new ‘ways of being’ in their personhood. The Vipassana discourses provide a framework for the ‘not-self’ but what the practitioners return with is a sense of ‘self’ different from the ‘self’ they brought to the retreat. Once they practiced the techniques and experienced the doing of their body and mind, they incorporate these new ‘ways of being’ in their personhood. The concept of self was not annihilated but an embodied “self-made self” (Pagis 2008) emerged from the practice. This new self is maintained through the continuation of techniques in everyday life, as well as in maintaining sīla to varying degrees. For many, attending the group sittings during the week, in addition to daily sittings alone, added to such disciplining (and making) of a new personhood.

This still does not explain how the sitting body connects to the enterprise of self-making. Existing literature provides us with little insight. Sitting is documented in anthropology as a common technique of the body (Mauss 1973), or, as a unit of behaviour (seating oneself) in ergonomics (Branton & Grayson 1967). Hewes (1955) attempted a world distribution of culturally determined sitting postures. He recommended engineers and designers to make use of “postural patterns borrowed from outside [one’s] cultural tradition” (p. 232). Following the more recent literature on the anthropology of body and embodiment, sitting in Vipassana can perhaps be conceptualised as a particular ‘somatic mode of attention’ (Csordas 1993). Do such formulations help us adequately to understand the connection between the sitting body and the self?
Mauss (1973) considered sitting among the ‘techniques of rest’ as opposed to the ‘techniques of activity’. He wrote, “Rest can be perfect rest or a mere suspension of activity: lying down, sitting, squatting etc” (1973: 81). The empirical materials in this article direct our attention to other kinds of sitting, and to conceive sitting as a ‘technique of intense activity’, which turns it into a ‘reflexive technique of the body’ (Crossley 2005). Are there better ways of opening this ‘black box’ containing secrets of sitting and the self in Vipassana? We can talk about the quality of practice. What is considered a good sitting, can perhaps act as an index of the sitting self. Pagis (2010) described the sitting arrangements in Vipassana meditation halls as a practice of producing not only ‘inter-subjectivity in silence’ but also an education in non-movement. In the beginning of the sitting training, participants were told that the postures did not matter as long as they kept their back and neck straight. However, the newcomers soon learned that a good sitting meant non-movement. In an auto-ethnography on Alexander technique, Tarr (2008: 490) explains how “the self is understood to be firmly located in the body, through consciousness, and is not separate from it. The ‘good’ or ‘bad’ use of the self is defined not only by the positioning of the head, neck and the back but by the degree of conscious control which is exercised over their relationship.” These are only a few indicators I could mobilise from existing literature on the sitting body and its connection to the self.

Access to my own sitting experience will not necessarily fill up this gap but in this instance, may come in handy. Similar and/or different experiences of sitting are of course equally possible. In a discussion, Andrea and I explored how sitting could be connected to the self. We both agree that the sitting posture is a pragmatic compromise between two other postures, standing and lying down, because standing is too exhausting and lying down makes us fall asleep easily. The sitting posture facilitates the internal practices of attention to the breath on the upper lip. Sitting still also helps us concentrate in following sensations in the body. When we sit without moving for an hour, the stillness and calm sensation in the body-mind, make formulating notes of forgiveness easy. The sitting posture therefore becomes an axis, a point of entry into the set of inner practices. Sitting also requires managing time, space and intention. For example, time, two hours must be set aside every day, which means cutting out time for other preferred activities. Space, quiet and undisturbed location in shared households. Above all, intention and motivation of the self - that not only drive us to sit but are also generated by the continued sitting every day. Sitting operates in in the time-place-intentionality dimension to create the necessary ambience for Vipassana meditation and in the process becomes a metonym for the meditation itself.

Sitting is the last visible, recordable practice we do, before we close our eyes in silence and non-movement. The self that we ‘carry with us’ in everyday life remembers these sittings and the internal practices that we follow each time. For Andrea, sitting as a routine helps her return to it. When she can sit twice a day, it
transforms the whole day into a totalising rhythm of two points in time, space and intentionality that provide her a direction in life (resonating Hans’ narrative?). It creates a thread (Paul’s red thread?) that connects other practices, thoughts, intentions and movements she carries out during the day. When she does not sit for more than a few days, she loses the thread. The beneficial effects on the self diminish and it takes a long time before the sitting can establish itself again. In my case, I mix my sitting with other practices that I learned in the past years. I contaminate my Vipassana sittings with the practices of Zen sitting, known as shihkhon taza, which means just sitting and waiting for my thoughts to slow down or stop. Sometimes right after seating myself in a comfortable posture (usually the Burmese position) I do concentration exercises, focusing on particular thoughts or a specific life-problem that requires persistent attention.

In Vipassana, the sense of self is constructed through the embodied practice of sitting as well as the discursive practices, the narratives of the self (Kirmayer 2006). Through these sitting and talking, we illustrate both ‘embodied’ and ‘discursive’ self-reflexivity. We not only sit but also talk about sitting, linking the sittings to the rest of our lives, before and after. That is how sitting becomes a condensed repository of meanings and practices. A particular body practice (sitting) mobilises other sets of body-mind practices (breathing, body scan, forgiveness etc.). Sitting relieves the body-mind of the sitter of the burden of all other activities. It provides repose as well as a set of intense activities, producing the meanings of continuity, relaxation, concentration, forgiveness and equanimity. The body-mind of the sitter retains in memory these meanings and transfers them to other kinds of movement and practices of the self in everyday life. The practice of sitting becomes an ‘embodiment’ of the self.

During Vipassana, Pagis (2009) argued that, “bodily sensations [acted] as indexes to psychological states, emotions and past experiences” (p. 265). In this article, instead of the bodily sensations, I argue for the sitting body as the starting point, the index to the self. This body posture is adopted prior to the bodily sensations and is sustained to enact the Vipassana experience. Sitting anchors the non-discursive body awareness that Pagis calls ‘embodied self-reflexivity’. This is followed by talking about the experiences of sitting, the ‘discursive self-reflexivity’. Now, whether it is the sitting or the awareness of bodily sensation performed by the sitting, the self-making narratives seem to emerge as a result of the interaction between these two self-reflexivities, the embodied and the discursive (Pagis 2009). In that, the reconfiguration of self and the sitting body mind come together. Sitting is no longer separated from the self; it becomes the self.

Concluding remarks

For medical anthropology, a discipline traditionally focused on narratives of ‘suffering’, the discussion of embodiment in well-being practices adds different
stories, where actors focus less on suffering and more on ‘transcendence’. Embodiment is only one of the many standpoints to examine human action but it can be utilised in relation to understand this pursuit of ‘well-being’, as well as the more abstract fields of psychic activity, in this case the ‘making of the self’ aimed towards achieving well-being (Csordas 2011; Mathews & Izquierdo 2009). Reflections on the probable ways of linking the sitting in Vipassana to the self illustrates that the reconciliation of embodied (sitting and attending to the body-mind) and discursive acts (self-making narratives) is possible. Sitting as a practice and as a metonym in the self-making narratives, combine the apparently opposing modes of self-reflexivities (embodied and discursive) into an articulated experience of transcendence from suffering, or, well-being. Vipassana sitting also throws us into the conundrum of responding to old questions. Doing versus being. Effects versus talking about effects. To be able to respond to all that one must address the on-going debate between ‘experience’ and ‘enactment of experience’. In case of attribution, one needs to engage with the concepts of ritual efficacy and placebo effect. This essay is not about that. It is an illustration how one technique (sitting) travels from the site of embodied practice to the discursive acts of narratives, and, what kinds of stories are told to attribute benefits in the remaking of who we are (self). I sit to write it, and when this article is over, I shall sit again.

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Research and Theory
Teacher / paediatric nurse becomes medical anthropologist

Outsider and mistrusted

Julia Challinor

My AMMA research was with children with a visual impairment and studying how they understood friendship. The children I spoke with and observed attended the only school for children with a visual impairment in Ireland. During my time at the school, I found that the teachers and staff viewed me as a distinct outsider. My participant observations in the classrooms and around the school, and particularly note taking, raised their suspicions that I was an evaluator. Here, I address how I learned to negotiate this unexpected situation and was successful at learning from the children as they told and showed me how they ‘do friendship’. Ultimately, I was left to use my experience as a teacher and a paediatric nurse, which I had erroneously thought would position me as someone with insider status, to negotiate my solitary daily transition into a medical anthropologist.

The loci along which we are aligned with or set apart from those whom we study are multiple and in flux. Factors such as education, gender, sexual orientation, class, race, or sheer duration of contacts may at different times outweigh the cultural identity we associate with insider or outsider status (Narayan 1993: 671-672). (Narayan, an anthropologist, writing about being the son of a German American mother and Indian father and his ‘hybridity’)

1 A former teacher with an MA in Education, I earned a PhD in nursing and served as the Educational Liaison for children with cancer and survivors at the University of California, San Francisco from 1993-2003. In 2007 I studied at the University of Amsterdam in the AMMA program. Email: jmchallinor@gmail.com. Acknowledgments: I am grateful for the careful guidance and support throughout the program from Ria Reis and Sjaak van der Geest. Without their constant gentle pressure to rethink and reframe what I saw and heard, I’d never have made the transition to a fledgling medical anthropologist. I am indebted to my Irish landlady during my fieldwork for her perspicacious insights into Irish character. I also thank the children who so easily spoke with me and included me in their lives. As an international nursing consultant for oncology with an anthropological perspective, I seek to strengthen nursing resources and opportunities in countries with limited resources. I advocate for nurses to be recognized as critical and essential members of any multidisciplinary team attempting to improve cancer care across the globe.
Introduction

In 2004, I emigrated with my family from the US to the Netherlands and continued working as a paediatric oncology nursing consultant in Latin America and other countries with limited resources. In 2007, I entered the AMMA program at the University of Amsterdam to learn to be a medical anthropologist, which I thought would help me answer some of the questions I had in my work overseas. However, when I came to decide on a topic for my thesis, I was influenced by my work over ten years with children with cancer in a hospital in the US. There I had met children who told me they had no friends and I could hear the pain in their voices as they usually looked at the floor or their hands when they told me this. During AMMA, I began thinking about children who had had retinoblastoma (cancer of the retina of the eye) and I wondered if children who were visually impaired also had difficulty making and keeping friends given the social and physical restrictions they might have in school or the community. I had intended to do my fieldwork in the Netherlands, but at the last moment that was not possible and I went to Ireland. My goal was to investigate what children with a visual impairment said about current friends and making new friends. I also intended to explore the teachers’ understanding of the children’s abilities to make and maintain friendships and how they viewed friendships in general in the student population.

When I first told people that I was going to Ireland, they immediately responded, “Oh that’s great! They speak English and this will make it much easier for you!” The presumption was that the Irish had so much more in common with me, an American, than the Dutch did, starting with language. At first, I thought I would be perceived as an insider, a native English speaker, a kindergarten teacher and a paediatric nurse used to working with children with disabilities. However, I soon was made acutely aware of my outsider status in a myriad of ways some of which were overt and some covert. Merriam et al. (2001:405–6) state,

In particular, the reconstruing of insider/outsider status in terms of one’s positionality vis-à-vis race, class, gender, culture and other factors, offer us better tools for understanding the dynamics of researching within and across one’s culture. There is a growing body of literature around issues of positionality, power, knowledge construction and representation in qualitative research. However, as all researchers have discovered, there is no substitute for actual fieldwork where these issues are personally encountered in sometimes unanticipated, and oftentimes subtle ways.

In my work with children with cancer in California, I had had limited exposure to children who were visually impaired with retinoblastoma (a childhood cancer of the eye) since these children were treated in the eye clinic and not in paediatric oncology.
In this article, I describe my fieldwork in the Primary School as I struggled mightily with positionality — the teacher and paediatric nurse who I was, and the medical anthropologist I was trying to become. I could not rely on an instrument to gather my data such as a survey or behavioural checklists as I had done in the past for research. I could not use my old approach as a paediatric nurse — look for variation from the norm, explore the reasons for the difference and take nursing action. Now I had to listen, watch, consider, and write it all down while hoping it would make sense in the end. Unfortunately, it never occurred to me that I would have to work hard to be even grudgingly accepted by the teachers to have adequate access to the children to gather ‘data’. Although I had official permission from the school to conduct my research, ultimately, the individual teachers could decide whether or not I would be allowed in their classrooms. In addition, I discovered that in Ireland, as in most high-income countries, many children who are visually impaired have an additional difference such as autism, cerebral palsy, or developmental disabilities. This complicated my interaction with the children as some were non-verbal and others struggled when answering my questions. I did not know much about Ireland or Irish schools, and although I had read literature about children with visual impairments, nothing I had read discussed concomitant disabilities. The one saving grace was that I did know how to talk with children and observe their behaviour, since I had spent many years doing this.

Initially, I intended to represent myself to the staff at the school as a former teacher and paediatric nurse and someone who would be empathetic to the challenges of teaching children with a disability; and I intended to emphasize my new role as a medical anthropological researcher in the school for fieldwork on children’s friendships and engage their support and interest. Despite this plan, it became clear over time that the teachers saw me as principally a teacher, a Californian, possibly an auditor, and definitely an outsider — plain and simple. This is my story.

The Primary School

The gatekeeper to the school was the principal. He was not Irish, but British and had only been at the school for one year. I believe the principal was also perceived as an outsider by the staff, despite the fact that he’d had extensive experience working in a school for the blind in the UK. The former principal had been quite beloved and several long-time teachers told me that the old school that had served children whose only disability was vision impairment was changing. Now the children had multiple disabilities and they were worried that this was going to be the way of the future since there were so few students who met the vision-impairment only criteria. The teachers were not happy about this.
When I arrived at the school near the end of the year, I was grateful to hear that the principal had planned for me to be based in one classroom for most of my fieldwork, but with the option to also spend time in other classrooms and activities. Unfortunately, some teachers were not happy with all the visitors in the school and grumbled that the principal had not ‘asked for their input’ or permission to accept another visitor. For this reason, I felt it was particularly necessary for me to be flexible and effusively display my gratitude for access to each classroom.

The children were taught the regular Irish curriculum and expected to learn Irish. In addition, they had multiple activities such as art, music, swimming, and in some cases, braille. I was to be in the assigned classroom all day with the students, on the playground during recess, and could go with them to other activities. I could also eat in the teachers’ lounge for lunch, which I did frequently.

In practice, after a few days in the originally assigned classroom, the principal told me that the teacher had had many visitors and that I should spend time in other classrooms and go with children to some of their other activities, such as swimming and art. I would have to request entrée into other classrooms myself, which was difficult, and it was challenging to establish a rhythm with the children I was initially observing. It became awkward when the children in the first classroom where I had been assigned asked each day if I would come back to their classroom when I knew I might not be welcomed by the teacher, who I suspected had requested that I go out of her classroom.

Minor differences

In an article on the “narcissism of minor differences”, Blok wrote, “The theoretical purport of the narcissism of minor differences suggests that identity — who you are, what you represent or stand for, whence you derive self-esteem — is based on subtle distinctions that are emphasized, defended, and reinforced against what is closest because that is what poses the greatest threat” (1998:48). I believe that in my time in the Primary School, the closeness of my background — compared to the teacher’s identity — as a native English speaker, trained teacher, and nursing experience with children with a disability became a situation that led to antagonism. My presence appeared to be threatening to several teachers at the school whose reaction was to push me into an outsider status. To do that required focussing on how I differed from them and establishing my social identity based on those characteristics to diminish the threat that I posed as a possible evaluator. The first question I had from most teachers was, “What is a

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3 Since the school is the only school for the visually impaired in Ireland, they have many visiting education students, researchers, and outside observers. While I was there, there were two student teachers in residence.
medical anthropologist?” I’d explain that it was someone who studied how people understand and experience illness and health. Then the teachers would say, “But you are a teacher, right?” I’d confirm, yes, I had been a teacher, and then a paediatric oncology nurse, but my role now was as a researcher learning to be a medical anthropologist. This did not seem to convince them; I was firmly positioned as a teacher in their minds; no one ever mentioned my being a nurse or medical anthropologist.

Once I was established as being a teacher, our commonality appeared to cause an underlying friction as the staff searched for the “subtle distinctions” that Blok mentioned, which separated us. Well into the second week of my fieldwork, one teacher asked me “Where are you living?” in the lunchroom one day. I said I was living with the elderly mother of a friend. “Yes, but where does she live?” she asked. I said I didn’t know the city very well, but I took two buses to get to the school. The teacher continued to press, “What busses do you take to get here?” I told her, but I was not happy to do so, because I knew that she would know where I was living and I suspected that it was a fairly affluent neighbourhood. She immediately said, “Oh, that’s Black Rock, that’s very posh!” My heart fell because I felt the divide between the teachers and me widening. Indeed, where I lived was mentioned throughout my fieldwork off and on by several teachers in the lunchroom. Now I was positioned as ‘rich’, which the teachers were certainly not, while in truth, I only had a friend who had benefited from the former booming economy.

Suspicion

Unfortunately, it soon became apparent that many of the teachers and staff were convinced that I was there to evaluate their work. The first day, when I was observing in the classroom where I had been assigned, I was drawing a diagram of how the room was set up. The teacher came up and asked me what I was writing. I showed her my notebook and the diagram. She asked what the other writing was about. I showed her that I was taking down notes of the conversation I’d heard two children have on the playground a few minutes earlier. She was satisfied and walked away, but she continually glanced at my notebook. I took pains never to leave my notebook anywhere and was cautious about what I wrote in it. I became quite paranoid about someone finding the notebook and misinterpreting what I had written. I believed the teachers were certain that I was noting negative impressions or critical comments about their

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1 Despite numerous explanations during the early days of fieldwork of what a medical anthropologist was and discussions of my work as a nurse for children with cancer trying to return to school, I was never able to satisfactorily convey the purpose of my research or the work I had done as an educational liaison for children with cancer.
performance, despite having reassured them several times that I was there to study the children and their friendships.

Every week, the teacher whose classroom I had originally been assigned to asked me out loud in front of other teachers, “When are you going home?” I told her the same answer every time, but apparently, she either didn’t believe me, or she wanted confirmation. Her behaviour was quite standoffish. At one point she asked me to work with one child on her reading. I agreed, although I thought it was a test to see if I would agree or say no or to see if I really was a teacher. I always wondered if she thought that I had a hidden agenda that she would not come out looking well on and she was going to protect herself from that threat. I was not comfortable in this teacher’s classroom because I always felt as though she mistrusted my intentions.

The day after the principal told me that I must pick a new classroom to visit, I asked two other teachers if I could visit their classrooms; one said no, she already had a visitor and the second one was going on a field trip, so no. I finally asked a teacher whose class I had visited (youngest children) the week before and she said okay but that it would be a repeat of Friday before (when I had been in the classroom) and said, “We’re not going to put on a show for you today.” I said, “Don’t worry, I’ve taught kindergarten and I’m not looking for a show.” She said they were winding down for the year and also they were more flexible on Fridays. I said that that was to be expected. I was quite taken aback that she thought I was looking for “a show.” She was a woman of approximately my age (54) and obviously had spent years teaching. I surmised that she too was convinced that I might be there to audit her teaching and could tell the principal about any deficiencies in her approach which I had no intention of doing. Here seemed to be confirmation of what I had suspected — I was positioned as a potential spy. This feeling continued as I got the distinct feeling in the lunchroom that I was not welcome when I was ignored or asked when I was leaving or tried to get a teacher to agree to allow me in her classroom.

**The outsider: A ‘Californian teacher’**

All the teachers in the school were female and Caucasian, and so was I. There were several teachers who were approximately my age, but there were more new teachers with less than five years of teaching experience. All but one of the teachers was Irish; there was one American teacher from California who was married to an Irishman. The American teacher spoke often about her Irish life and she did not ask me about my background in the US.

The teachers told me early in my fieldwork that in Ireland there is no teacher training for special education. All but one of the teachers was Irish; there was one American teacher from California who was married to an Irishman. The American teacher spoke often about her Irish life and she did not ask me about my background in the US.

The teachers told me early in my fieldwork that in Ireland there is no teacher training for special education. If the teachers want to learn braille they have to pay for it themselves. There are no free continuing education programs for teachers. In the US training for a Special Education Certificate is quite rigorous
and the teachers at the Primary School made it clear they were aware of this. There are programs for US teachers to specialize within sub-disciplines (e.g., severe/multiple disabilities, early childhood special education, behaviour disorders, blind and visually impaired) and these are often supported by the school district since continuing education is mandatory to maintain licensure. Although I had never trained as a special education teacher, I had extensive experience collaborating with them for children with cancer and knew both the law, options, and support available to these children. It became apparent that the teachers and I had disparate educational and professional experiences. Therefore, I made it clear to the teachers who had these conversations with me that I was not trained as a special education teacher and more importantly knew very little about teaching children with a visual impairment.

An example of how the teachers saw me is as follows. In a conversation with a teacher about potential future careers for two students, I suggested that one girl who was obsessed with cartoons could be a cartoon critic. The teacher said, “See that’s it about the Irish. I’d never have thought of that. Californians have such good ideas. Irish just think about what folks are already doing.” I was surprised that she positioned me as a Californian, since I had told her that I’d been living in Amsterdam for five years. I had never considered myself to be a Californian nor presented myself as such; I actually consider myself to be a New Englander since that is where I grew up.

**Medical diagnoses: Trying not to think like a nurse**

Once at the Primary School, I was never told the extent of a child’s visual impairment unless the child was completely blind. I very much wanted to ask someone about the diagnoses of specific children who obviously had multiple medical differences. However, I knew myself well enough to realize that had I been told any child’s diagnosis, I would have immediately looked it up on the internet and the results would have coloured my opinion, attitude and approach to that child when speaking to them about friendships. I was afraid of having biased assumptions, such as children with disabilities have trouble with friendships, and also succumbing to my nursing inclination to categorize children based on diagnoses. In this setting, my ignorance helped me to focus on what the children told me and showed me and not to focus on who they were by biomedical criteria. So I resisted asking about the children’s diagnoses; this was an on-going and constant resistance in the background of my work every day.

While I was constantly struggling not to think and act like a nurse, the teachers – to the contrary – were not inclined at all to regard me as a paediatric nurse. There was a school nurse who came occasionally to the school, yet I was not introduced to her. The children’s health issues were rarely discussed by the teachers. In only one instance did I actually inquire about the rash on a child’s
face, however, the teacher had little information about its origin. Ultimately, I realized that while I was quite busy trying not to think like a nurse, the staff never actually perceived me as such.

The children

As the days went by, I saw and heard how the children functioned within this quite special environment where to have a visual impairment was ‘normal’. The children spoke freely with me and were enthusiastic about having me observe them and spend time with them both in and out of the classroom. Many were quite eager to talk about friends and friendship, even if their conversations on the subject were sometimes difficult to follow due to cognitive or speech impairments.

I observed a definitive hierarchy in the school with children who functioned at a higher social and intellectual level at the top and those with severe language impairment and multiple disabilities at the bottom and negative language used towards those children. I learned about how they approached one another in friendship (although some never initiated contact with other children or had only an adult they considered as a friend — usually a teacher’s aide) and the meaning of friendship for them. Many times the children told me about an imagined friendship, wishing for a friend, or what they might do if they had a friend. Those who could identify friends told me about the activities they engaged in including conflict resolution with friends. In my thesis I called this ‘doing friendship’.

Conclusion

So, in the end, it was obvious that my sharing a language, gender, age, and profession with many of the teachers at the Primary School was not going to ‘buy’ me insider status or help me to create a bridge to make accessing the children for time to discuss friendship more streamlined. The fact that the teachers had been told (not consulted) that I was coming by the principal, an outsider himself, was not a good start. My position as a student medical anthropologist and this exotic and unfamiliar role was also difficult to navigate. The suspicion that I was an outside researcher looking to evaluate the teachers was an on-going subtext during my fieldwork. The teachers’ attitude about my lodgings did not help.

To my surprise, as the days went by, I discovered that instead of ‘feeling insulted (e.g., by being asked regularly when I was leaving), I was intrigued by what had generated these behaviours and statements/queries. The staff’s efforts to establish me as an outsider struck me as an expression of “narcissism of minor differences” (Blok 1998); subtle differences between us were highlighted,
commented upon and reiterated. Observing the teachers’ behaviour and answering their questions became a sort of anthropological exercise for me although not the subject of my research.

Unravelling the teachers’ behaviour and comments by discussing them with my landlady was most helpful. She often laughed and said, “But oh, that is so Irish!” and then she would go on to explain starting with an anecdote about Irish history. I began to see that even though I was not functioning as a teacher or a nurse, all that I had learned and experienced in those roles was helping me to navigate a complicated situation. Relying on my two professional roles and knowledge about working with others, allowed me to avoid confrontation when provoked both overtly and covertly and to focus on the children and what they told me and showed me about friendship.

Ultimately, I learned that I could metamorphose into a medical anthropologist, but would never lose the awareness and knowledge of my former training and experience. My bias about measuring children by quantitative instruments and scales in teaching and categorizing them by diagnosis in nursing was muted by my deliberate decision not to ask about these details for the children. Thus, I used my experience as both a former teacher and paediatric nurse, which I had erroneously thought would position me as an insider, to negotiate my solitary daily transition into a medical anthropologist in a context of the staff’s on-going suspicion and continual highlighting of our differences. I carefully asked only a few specific staff to occasionally elucidate their understanding of the children’s behaviour or conversations. In general, I relied on what I knew about children, both as students in a classroom and those managing a disability to focus on the goal of my research, which was to explore the meaning of friendship for children with a visual disability.

How to write about the students, teachers and staff in the only school for children with a visual impairment in Ireland? It would have be impossible to disguise the school, or create new student characters as a blend of the children I studied, as Bluebond-Langer did in *Private Worlds of Dying Children* (1978). Instead, I decided to use pseudonyms for everyone I wrote about. Of course, that meant that anyone from the school who read my work could easily identify the student or teacher (such as the principal who requested a report from my thesis). Referring to her use of pseudonyms in 1978, and on reflection twenty years later of what she had written in *Saints, Scholars and Schizophrenics*, Scheper-Hughes (2000) said that she would not have made the same decision. She wrote, “the question then becomes an ethical one; What are the proper relations between the anthropologist and her subjects? To whom does she owe her loyalties, and how can these be met in the course of ethnographic field work and writing?” (p. 127).

Probably I could have written about the children without using pseudonyms, but for the teachers? I do not think I could have named the teachers in my thesis knowing the principal was going to read a redacted edition. Despite the staff’s
mistrust, I thought I owed them the benefit of the doubt and freedom from retribution even it was my imagined retribution.

Thus, ultimately and rather painfully, despite my best efforts, I became a fledgling medical anthropologist and a mistrusted outsider. As I now see it, I could not ignore my awareness of the mistrust and exaggeration of minor differences that I experienced during my fieldwork. As a medical anthropologist, I have grown significantly in my ability to see children and adults in a new less linear and categorical way. How this affects my on-going consultation work in paediatric oncology in countries with limited resources is yet to be fully realized. That is another chapter in the tortuous life I am leading.

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Merriam, S.B. et al.

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Scheper-Hughes, N.
Critical ecological medical anthropology

Selecting and applying theory to anaemia during pregnancy on Pemba, Zanzibar

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A novel theoretical framework is presented that is an amalgamation of seemingly discordant theoretical stances: critical (medical) anthropology and (medical) ecological anthropology. Yet the significance of this article does not lie in the theoretical framework as much as it does in its elucidation of the process of picking and choosing aspects from various theoretical frameworks. This contribution is important primarily because it demonstrates how theories can be combined and what the implications thereof are for analysis. In the first section, some brief ethnographic notes about anemia during pregnancy on Pemba, the second largest island of the archipelago of Zanzibar, are presented. Next, the virtues and weaknesses in the bodies of work of critical (medical) anthropology and ecological (medical) anthropology are discussed. I then explain how and why I have selected components from each to create a bricolage theory I fondly (if not imaginatively) call ‘critical ecological medical anthropology’ (CEMA). Finally, I illustrate how ethnographic flesh can hang on these conglomerated theoretical bones by showing how the model can be applied to the ethnographic observations.

It does not take an anthropologist to observe that comprehending both the underlying and overarching meanings of that which we notice and are told is not easy. Yet, the analysis of the remarkable things we see and hear is often both the most nebulous and the most valuable part of anthropological research. Noticing

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particularities and juicy cultural tidbits is fascinating, but what can we learn about culture or human nature in the larger scale of things from the assorted details? Often, to make sense of those, we need theory, and strong, clear, usable, realistic theory at that. Medical anthropologists do not suffer from a dearth of theory; we can choose from structural-functionalist, transactionalist, ecological, cognitive-symbolic, political-economic, and critical approaches to analysis. Some of us work within one or more of these frameworks simultaneously, with varying degrees of awareness of which perspective(s) we have chosen, why we have chosen them, and what the implications of such decisions are.

In this article I present a theoretical framework that I fashioned out of several existing ones. This was done of necessity, in order to help me to organize and analyse lively ethnographic data about anemia during pregnancy collected between late May and early July 2002 in Zanzibar, Tanzania (Young 2002). Although the resulting framework is novel in the sense that its components and orientation are slightly different than those of other theoretical orientations, it is far from unique in its effort to combine several existing frameworks. Other examples of scholars integrating the two fields include Armelagos et al. (1992), Baer (1996), and Leatherman et al. (1993). Thus, it is the elucidation of the process of picking and choosing aspects from various theoretical frameworks that is the more interesting and more primary goal. In short, this article is an exercise in making explicit how theories can be combined and what the implications of those choices are for analysis.

In the first section, I present an abbreviated ethnographic description of anemia during pregnancy on Pemba, one of the islands of Zanzibar. The middle portion is more theoretical in nature. I first discuss two important commonalities of critical (medical) anthropology and ecological (medical) anthropology. Then, I highlight what I (with the invaluable insight of many scholars’ critical analyses) have come to perceive as the virtues and weaknesses, and similarities and differences in both bodies of work. I then explain how I have selected morsels from each to create a cut-and-pasted theory that I have termed ‘critical ecological medical anthropology’ (CEMA). In conclusion, I illustrate how ethnographic flesh can hang on this amalgamated theoretical skeleton by applying the critical ecological model to the ethnographic observations.

**Ethnography**

Anaemia is one of the most pressing health problems for women of reproductive age on Pemba. Mild anaemia was found to be as high as 72% in non-pregnant Pemban women; the prevalence of mild anaemia in pregnant women is expected to be much higher (Stoltzfus 1997). On Pemba the prevalence of severe anaemia

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1 Severe anemia is defined as levels of hemoglobin (Hb) less than 70g/L, mild anemia as Hb between 110g/L and 70 g/L.
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in pregnant women was established at 20.2% (Stoltzfus et al. 2001: 7). The consequences of anaemia can be very serious. Severe anaemia during pregnancy can impair immune function, cause reproductive failure (miscarriage, still birth, prematurity, low birth weight, and perinatal mortality), and maternal death during childbirth (Levin et al. 1993 in Galloway and McGuire 1994). Mild anaemia can increase a person’s susceptibility to other infections and cause a range of non-specific complaints such as fatigue, headache, faintness, anorexia, and bowel disturbances (Eddleston & Peirini 1999: 510).

In an effort to reduce anaemia in Zanzibar, the United Nations made ferrous folate supplements available to pregnant women in early 2002. My research in Pemba began as an investigation of how these iron supplements were perceived and used by mothers and mothers-to-be, and broadened to encompass all of the treatments for anaemia available on Pemba and the understandings of the illness itself. In the middle of the study, I felt compelled to expand the study further, beyond the variety of treatments, as I realized that neither the illness nor the treatments could be understood outside of their topographical, historical, political, social, ideational and economic contexts. Thus, the study concluded with an etic as well as an emic description of anaemia during pregnancy. Due to space limitations, I have heavily abridged much of the ethnographic description. I have limited my discussion to portions of the aforementioned contexts; I have included just enough to illustrate how the model helped me to analyze the information that I gathered. (For more discussion of perceptions of pregnancy and perceptions of anaemia during pregnancy, see Young 2002).

‘Zanzibar’ is the name of an entire archipelago anchored down in the glimmering turquoise East African part of the Indian Ocean with about 880,000 residents (Zanzibar & UNICEF 2001). Unguja is the biggest island, 1464 km², and the one most often (mistakenly) called Zanzibar, on which about 550,000 residents live. Pemba is the second biggest island, with 864 km² and about 330,000 inhabitants. The two islands are about 50 km apart, separated by the 700-meter deep Pemba channel. In addition to these two islands, there are a slew of other islands and islets, some inhabited, most not, which also comprise Zanzibar. The entire archipelago is situated about 50 kilometers off the coast of mainland Tanzania, five degrees south of the equator (Garssen 1993a).

Because of its strategic location off the coast of East Africa, Zanzibar has had contact with traders from as far away as India, China, and Greece for hundreds, even thousands of years. After periods of Persian and Portuguese influences in the 1500’s and 1600’s, it became part of the Sultanate of Oman and Muscat in 1784. After a dream about his own assassination Sultan Seyyid Said decided to move the headquarters of the sultanate from Oman to Zanzibar. During his rule, he introduced clove production to the island, and facilitated their large-scale cultivation in plantations. In doing so, he made two important contributions to the conditions in present-day Zanzibar. Zanzibar became very wealthy from
cloves until Indonesia began producing cloves, more bountifully and cheaply than Zanzibar did. Because of its dependence on cloves, Zanzibar now suffers much financial hardship due to dwindling revenues. Secondly, Seyyid Said laid the roots for the later racial miscegenation between Arabs and Africans by insuring the plantations were owned by Arabs and worked by Africans.

The Sultanate did little in the way of health care for its people. While Livingstone was in Zanzibar in 1865 preparing for his final expedition, he proposed the name ‘Stinkibar’ as a more apt name than Zanzibar (Livingstone in Garssen 1993a: 9). Inspired by Livingstone’s writings of the appalling health and social conditions on Zanzibar, late 19th century missionaries tried to exploit the powers of hospital medicine in order to gain influence over the indigenous populations. “Curative care in the first hospital on Zanzibar, Nôtre dame des Anges, was a distant second concern to the mission’s true objective: to baptize children and old people prior to their deaths” (Garssen 1993a). Few natives attended; the Mission attributed this to awe, “The Blacks are somewhat afraid of the Whites, whose superiority often inspires them with as much fear as admiration” (de Courmont in Garssen 1993a: 13).

By the late 1800’s several European countries had competing interests in the region. In their rush to keep the Germans out of East Africa, the British forced the Sultan to formally separate from Oman and declare Zanzibar a protectorate of Great Britain in 1862. Though the Sultan remained a figurehead, the British took over financial control of the government, including the Sultan’s accounts, and appointed British ministers to all key positions. Arabs remained part of the elite class, with Indians below them, and Africans, who comprised two-thirds of the population (half of whom were of slave origins) were the lowest ranking citizens (Nisula 1999: 34).

The British played a more active role in public health than the Sultanate had, but it was not a necessarily welcome one. The British colonial government opened a hospital for colonized subjects in Zanzibar Town, known as ‘The Native and Subordinate Hospital of Government.’ ‘Native’ referred to Africans and ‘Subordinate’ to Asians: Arabs, Indians, and Comorans. Health services were arranged according to the alleged needs of diverse races and offered care according to the medical standards thought appropriate for each group, thus racial differences were naturalized through curative medicine (Nisula 1999: 235). It is noteworthy that one (if not the prime) motivation for the improvement of living conditions and disease prevention was concern about the decline of the native population who were the workforce of the island.

Preventative public health measures, coordinated by the newly established Health Department, began only when the island was faced with a major plague epidemic, which lasted from 1899 until 1905. Health officials often resembled the paternalistic, autocratic and outdated ‘Medical Police’ who had once been important authorities in Western Europe. ‘Mosquito Brigades’ were one such
example of these medical police. They made weekly visits to inspect potential mosquito breeding sites. When larvae were found, notices were served to householders and legal action was taken against repeat offenders. The Protectorate also worked to expand and improve vaccinations, general sanitation, health education in schools, collection of vital statistics, and dispensary facilities. Mother and Child Health services on the island were first offered around this time. However, the care that was offered was of such low quality that many of the posts were closed soon after opening.

The depression of the 1930’s caused the government to curb public health expenditure, but the Rockefeller Foundation stepped in to fund the construction of thousands of latrines and boreholes. The population remained suspicious of receiving something for nothing, and rumors that the government would levy some sort of hut tax as soon as a building was erected caused most of the new latrines to remain unused. Village Health Boards were started in the hope that villagers would accept from their own leaders what they refused to accept from the government, but to no avail.

In 1957, the British allowed the first political elections in Zanzibar. During these elections considerable social tensions, especially racial tensions, surfaced. Three political parties emerged: the primarily African Afro-Shirazi Party (ASP); the Zanzibar and Pemba People’s Party (ZPPP) another, more conservative, predominantly African party; and the Arab-dominated Zanzibar Nationalist Party (ZNPP) who wanted Zanzibar to preserve its independence from the mainland. The Arab-dominated ZNP, the largest single political party, and heavily favored by the British, came to power when Zanzibar became independent from Britain in 1963. Political dissatisfaction among the other two parties led to the overthrow of the freshly independent, mostly Arab, government, just 33 days after independence, on April 12, 1964. At least 5,000 Arabs were killed during this uprising, and large numbers of Indians and all Europeans, were expelled from the islands.

Three months after the Revolution, the governments of mainland Tanzania (Tanganika) and Zanzibar merged to form the United Republic of Tanzania. No popular referendum was held. This union was motivated in great part by the protection the mainland could offer in case of a second uprising. Zanzibar, with its revenues from cloves and shipping, represented an economic boon for the mainland. The union was resented by many Zanzibaris from the outset.

Abeid Karume, a semi-literate revolutionary ASP party member became the post independence leader of Zanzibar. He declared the ASP to be the only lawful political party, and forbade elections for the next sixty years. Africans were appointed to positions of responsibility that had previously been held by Indians, Arabs, and Europeans who had been forced to leave the country. For Karume, revolutionary zeal was a more important qualifier for these jobs than formal training was; he distrusted intellectuals and took pride in the fact that none of his ministers had been educated beyond the elementary level. With such an attitude,
Educational institutions were not given priority and suffered greatly. Even the legal system was abolished in 1970, replaced by a system of People’s Courts, staffed by loyal ASP party members. In the eight years of Karume’s increasingly despotic rule, approximately 35,000 educated and skilled people fled the country, and Zanzibar became virtually closed to Western visitors.

Under the ASP, all land was nationalized; land from 743 plantations (537 in Pemba and 181 in Unguja) was redistributed in three-acre sized plots. While it was intended to improve the plight of the poor landless, many argue that the fragmentation of land holding ultimately led to lower productivity. When land redistribution stopped in 1974 a significant proportion of the land on Pemba had not been redistributed, and there were still people in rural areas who had not received any. About 5.4% of rural households remain landless today (Zanzibar & UNICEF 2001).

Pemba has suffered under the ASP/CCM government. Arnold and McKim write, “Pemba has been the object of state repression and systematic underdevelopment ever since the CCM government took power” (2001). Because Pembans did not much participate in, nor generally support, the Revolution, they have since been regarded by the Zanzibari and Tanzanian governments as dangerous, disloyal citizens, and have been treated as such. “Since the 1960’s, military forces in Pemba have engaged in public beatings, humiliation, torture, rapes and the looting of property with full state support, as part of a campaign aimed at cowing the population and suppressing any potential opposition” (Arnold & McKim 2001). Recent elections have further crystallized this marginalization.

Zanzibar returned to a multi-party democracy in 1992, but the last two elections are alleged to have been scandalously undemocratic. The Zanzibar elections on October 22, 1995, the islands’ first multi-party elections since the 1964 Revolution, are widely believed to have been manipulated by the ruling party. Because of the circumstances of the election, the international donor community cancelled most aid to Zanzibar.

Since the 1995 election, friction between CCM and CUF has been rife. Discriminatory practices carried out in the wake of the elections removed most Pembans from Unguja and further exacerbated Pemba’s marginalization. Residents of Pemba, from where CUF primarily draws its support, were particularly targeted. Hundreds of Pembans were fired from the civil service and others lost their homes as the Revolutionary government razed several of Unguja’s Pemban-populated neighborhoods with neither notice nor compensation. A dozen CUF leaders were imprisoned on spurious accusations of treason.

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1 In 1977, ASP merged with the mainland’s sole political party, TANU, to form the Chama cha Mapinduzi (the Revolutionary Party, or CCM). By this time ZPPP and ZNP had united to become Civic United Front, or CUF.

2 The whole of this section draws heavily from Arnold and McKim’s report (2001).
The second multiparty election was held on October 29th, 2000. This election was alleged to be filled with more manipulation, e.g. army and police were deployed across both islands to seize all ballot boxes, counted and uncounted, and beat opposition party agents who had been present in the polling stations to monitor the votes. In protest, a broad-based movement in Tanzania prepared to hold a nation-wide, peaceful demonstration on January 27th, 2001, to call for a re-run of the Zanzibar elections and constitutional reform of the Union between Tanganyika and Zanzibar. Police and military, acting under orders from the Tanzanian government, reacted with an extraordinary show of force. In mainland towns, demonstrators were harassed and beaten, and many were arrested. Yet the reactions of security forces to the mainland demonstrations were mild in comparison to the state-sanctioned campaign of reprisals that has been carried out in Zanzibar, and especially in Pemba.

Hundreds of police from the mainland were deployed in the islands, where they committed acts of intimidation prior to the start of the demonstrations. Demonstrations in the three main towns of Pemba were met by violence on the part of the security forces, which, far from ensuring the security of citizens (the stated purpose of their presence), placed it in jeopardy. Police detachments fired tear gas pellets and live ammunition into the crowd both from the street and from the top of nearby apartment buildings. A police helicopter, reportedly carrying the Tanzanian Chief of Police swooped in over the crowd, dropping tear gas canisters and, some say, bullets. As protesters fled, police gave chase, arrested at least fifty people, and began to undertake violent house-to-house searches. The police and army prevented ambulances and private cars from carrying the injured to the hospital by beating the drivers. At least one doctor was arrested for simply attending to a patient. Relatives coming to the hospital to claim bodies or to inquire about the wounded were subjected to harassment and beatings, and in one instance, death. When patients were discharged from the hospital they were not sent home but taken immediately into police custody, and charged with participation in an illegal gathering – though many of the dead and wounded were not involved in the demonstration at all.

January 27th looms large in the consciousness of Pembans. Few discussed it with me outright, though there were daily allusions to the violence committed against Pembans by the government. One close friend spoke openly with me about it. His mother was shot in the leg, and her neighbor, with whom she had been talking, was shot fatally. Police had thought the man shot fatally was her husband, a prominent CUF member.

Zanzibar is no longer the rich, prosperous island it once was. Because of ASP (now CCM) policies like the government’s right to confiscate any property at any time, the ban on mortgage charges, and its virtual closure to the West, little external investment was made in Zanzibar until recently. Additionally, because of international support for Nyerere’s Socialist experiments, little reform in
spending was encouraged. A severe drop in the price of cloves has also contributed to economic hardship. In 1982 one ton of cloves was worth 9000 USD, in 1998 one ton of cloves fetched only 1000 USD. Zanzibar's present economic mess can also be attributed to gross mismanagement of funds, failed attempts at industrialization, inflation, and too much borrowing. Of late, it has become heavily dependent on foreign aid (Zanzibar & UNICEF 2001). As a result, Zanzibar has a very unstable economy.

In an effort to reign in the budget that was spiraling out of control, a policy of economic liberalization was initiated in the 1980's. This was disastrous for the living standards of 33,000 government employees (who then comprised 95% of all employed persons on the islands). Consequently, absenteeism, lack of motivation, and the augmentation of income through dubious means have all become widespread practices. Wages are not the only things that have suffered; the entire infrastructure of Tanzania has been compromised as well.

The faltering economy has impacted all of the government-provided services; the quality of utilities like electricity and water, roads, and health care are all deteriorating, and seemingly more quickly on Pemba then in Zanzibar (Zanzibar & UNICEF 2001). The supply of water is a good case in point. Public access to clean water has deteriorated during the past decades, and like the drought in Nancy Scheper-Hughes' Bom Jesus, its origins lie in history and political economy and not cruel geography (1992: 69). Ironically, the ground water supply is plentiful, but leaking pipes cause so much water to be lost in the process of pumping it that it cannot satisfy the demands. The water system dates back to the Protectorate; it has not been significantly improved since before the Revolution. In 1978, 41% of Pemba used piped water, while today only about 16% of Pemba gets piped water (Zanzibar & UNICEF 2001). The supply of water on Unguja is better than on Pemba; on Unguja, 45% of homes have piped water. The situation is actually worse than these statistics convey, for they do not reflect the fact that piped water is often only available at irregular intervals. Though as promised by the revolutionary government, the water is free.

The roads are another good example of public services that are deteriorating asymmetrically on the islands. Pemba has only one major road, which runs from the north to the south of the island, and connects the three major population centers. The condition of long sections of the road is atrocious. I estimate the beating that a body takes in the course of the three hour ride from the north to the south of the island is equal to about one moderate car crash. The appalling state is in part attributable to the doubling of the number of cars in Zanzibar in the last five years (Zanzibar & UNICEF 2001). Heavy rainfall also erodes and damages the road, a problem particularly noticeable on Pemba (Zanzibar & UNICEF 2001). However, the primary reason for the bad conditions is that the government has done little to rebuild or repair any of the roads in Pemba. I was told that in the last five years, five new roads have been built in Unguja, and in
that time, none have been built or significantly repaired in Pemba. The consequences of such poor roads are numerous: wear on vehicles, increased cost of transport of goods, impossibility of transporting very sick people to a more adequate health center.

The condition of the water supply and roads is bad, but health care is probably the gravest part of the crumbling infrastructure. Equity in health care has been espoused as an explicit principle of Zanzibar’s health policy since the overthrow of the Sultanate in 1964. Equitable healthcare for all stood in welcome contrast to the miscegenation so prominent in the British health care system. Socialist principles motivated the government to find methods to improve access to health services and concerned both affordability and availability, (though improving acceptability was never given much attention) (Garsen 1993b: 50). Yet the quality of services suffered greatly under the Socialist government because of their neglect of education in favor of revolutionary zeal, and the murder or exodus of skilled personnel.

Accessibility was improved by the construction of health facilities called primary health care units (PHCU’s). Clinics are more numerous than they ever were; today there are three types of health care facilities: hospitals (3 in Unguja, 3 in Pemba), cottage hospitals (2 in Pemba), and primary health care units (39 in Unguja, 44 in Pemba) (Zanzibar 2002). Now, approximately 89% of Zanzibar’s population lives within 5 kilometres of a health facility, and nowhere does the distance of a primary health care unit exceed 10 kilometres (Garsen 1993b). Affordability was improved by declaring all treatment free. Charges for health services were abolished after the revolution, and visits to the hospitals and clinics remain free to this day. Yet a free consultation is not to be confused with totally cost-free health care; though some medicines are sometimes available free of charge, patients must usually purchase all of the necessary medical equipment and medicines required for their treatment. For example, it is free for women to deliver in the hospital, but they must spend at least 10,000 TSH (about 11 USD) to buy gloves, plastic sheets, needles, syringes and intravenous infusions needed (Lees-Mlanga 1998: 59). Serious health problems cannot be treated at clinics, thus one must also pay for transportation over very bad roads in order to get to the hospital.

Quantity cannot compensate for quality. While it is indisputable that Pembans have access to health care, the care that is available is often not worth the visit. The PHCU’s are often under-equipped, undersupplied, and understaffed (Zanzibar 2002). The workers at the PHCU’s are usually health aides, which means they have had only two years of training, which is insufficient to evaluate the broad substantial range of patients. At one of the cottage hospitals I visited, the ‘doctor’ who was responsible for running the entire hospital had had only

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5 The Bamako initiatives have not been introduced in Zanzibar.
four years of training. In addition to, or perhaps because of, their insufficient training and low pay, many health care workers are unmotivated and spend their shifts chatting and snoozing instead of working.

The political properties of medicines and health care must also be understood; medicines have become a metonym for the government, and a rather oppressive, manipulative one at that. On Pemba, medicines have become perceived as symbols of the government’s (dis)regard, and used as political weapons, both offensively and defensively. Shortages are a generative theme in Pemban life. One of the first ‘Pemban’ words I learned was kivunge, and I was always congratulated on my proficient Swahili when I used it. Literally, kivunge means small bunches, (ki- is a diminutive and vunge means bunch) and is used, for example, when someone buys small amounts of sugar or tea at the market. The second use of kivunge refers to shortages in supplies; electricity and water are most commonly referred to with this word, but petrol and medicines are as well. Greetings usually include inquiries or predictions about kivunge, such as when the water will come back on, or if the electricity will be working that night. Shortages are numerous in type and frequency, and they are surprising in their far-reaching effects. They affect evening get-togethers; social calls are generally only made on nights when there is electricity. Sometimes there isn’t enough petrol, so dala dala, local buses, can’t travel as expected. Sometimes there is no water to bathe the children.

Shortages (whether real or perceived) of medical supplies (both medicines and staff) have come to symbolize the government’s manipulation and neglect of Pemba. During lunch of green bananas boiled in coconut milk, a friend said to me, “Sera, do you want to know why Pembans don’t like the government? Because of what the workers at the hospital were saying yesterday. They don’t give us medicines or other medical equipment.” She went on, “Medicines are only supplied during the honeymoon period of the presidency, when the government needs some credit from the people, or when DANIDA or UNICEF remember us.” She went on to discuss the state of the roads, the electricity, and the water.

I was given many other examples of party politics spilling over into the world of health care. After the violence and murders on January 27th 2001, two 40-foot containers of aid were packed up and ready to be delivered to Pemba, pending the signature of the Director of Red Cross Tanzania. As he was also a CCM member running for Minister of Parliament, he refused, and the supplies languished. This is widely cited as proof that CCM punishes CUF (and by extension, the whole of Pemba) by blocking the passage of medicines to Pemba. In return, CUF has asked donor organizations to stop all non-humanitarian aid to Tanzania. Another friend explained to me that giving money to CCM is the same thing as squeezing CUF. “We are just a political party, CCM is the government. So CUF doesn’t get aid from outside, only CCM does.” For CCM members, CUF attempts to stop aid to Tanzania are proof that CUF “wants people here to die.”
During a visit with a high-ranking health official on Zanzibar, the conversation turned to the political climate of medicine use. The following quotations are a synopsis of the discussion about why people aren’t using the drugs that are provided for them; he feels ‘his people’ need help, but accuses them of not accepting any.

After the political changes, [an allusion to the elections] people were nervous about using certain drugs. There have been some misbeliefs in medicine provided by the hospital. There are particular Pemban particularities, misleading campaigns carried out by malicious political leader to disrupt the policies of the Ministry of Health. It isn’t politics in the right sense of the word. The opposition is strong here. It’s supposed to be constructive, but it isn’t. Some completely refuse to accept them. The failure of compliance with taking the drugs that are distributed to combat X,Y, and Z is their [the opposition party’s] fault. These [messages] are engineered by ill-willed population, while the government is trying to marshal support. The political climate was heavily polluted.

He then turned the issue into a racial one:

The poor Arabs here on the island still believe an Arab sultan will one day come back and rule the islands. Relations with Arab communities in Oman and Saudia have influenced them to sow seeds of hostility here in our community. A number of people are not clever enough to see it. They [CUF] were saying that the cholera and polio vaccines were not pure, not holy, that Muslims are not supposed to take them.

He concluded by shaking his head sadly and yet knowingly, standing up and saying, “We need continuing education to raise awareness of our people.” The meeting was over.

Near the end of my stay, a neighbour shared with me his scepticism about the drugs that were being distributed for free. He saw merit in CUF’s message, “If they really are medicines that are good for us, they must be expensive. Why is something of value suddenly being given away for free?” What the health official saw as a lack of gratitude and unwillingness to be helped, (“They simply think that anything that is free is worthless”) Omar saw as a healthy dose of scepticism in the light of an abundance of animosity.

The Tanzanian government is not the only provider of medicines that Pembans are sceptical of. Some villagers felt that filariasis tablets distributed last year had many side effects, including reducing the sexual ability of men (Khalfan 2002). They believe that the supplements were intended to reduce their fertility rate because donor countries “are always complaining about overpopulation.”
They reasoned that the countries’ solution to this burden was the reduction of their fertility.

In addition to a shortage of medicines (due to either scepticism or misappropriation), there is not enough competent staff. To Pembans, staffing shortages seem to have been exacerbated by CCM. During the last campaign, CCM promised jobs to its party members. To fulfil the promise, room had to be made; many CUF affiliated hospital workers were fired, and replaced by CCM members. One of my informant’s sisters was a midwife at a PHCU, but was fired last year “for political reasons.” A very talented woman who had been a nurse coordinator, a midwife trainer, and worked closely with the German NGO had been demoted to a dispenser of medicines at one of the PHCU’s near my house. “Political issues caused me to drop,” she said.

The Tanzanian government remains in complete control of what the storage centres on each island receive. Even as the government provides fewer medicines in the hospital, they have been sure to maintain a measure of control over the increasing amount of medicines circulating in the private sector.6 Typically, the Tanzanian government sends all of the medicines for Zanzibar to the main island. This is not always done in a timely or regular manner, and there are never enough.7 Once medicines do arrive on Unguja, they are shipped over to the storage centre in Wete, and from there, distributed to the hospitals and the District Health Management Team who see that each of the PHCUs receive their fair share. To further complicate things, there are also smaller storage areas at the hospital in Chake Chake and Mkoani. The health care workers seem very concerned about the equal distribution of medicines to the different institutions once the medicines actually arrive on Pemba. This concern for equality was the reason given for why the remaining 26 tins of ferrous had not been distributed: there was not enough for each PHCU to have one. The allegations that I had heard that the government had held up medical supplies between the mainland and Unguja, and Unguja and Pemba were made more real by the UNFP cardboard boxes in the medical storage room stacked as tall as I am, brimming with tins of ferrous tablets. I estimated that there were at least 1200 tins, each containing 1000 tablets. Only they were of no use; they had all expired because they arrived on Pemba too late.

The health care situation continues to worsen. Spending in the health sector has declined from 10% of the total recurrent budget in 1995/6 fiscal year to 5% in 1999/2000 (Zanzibar & UNICEF 2001: 53 of 62). Because of the economic failure, the government can no longer sustain the formidable institutional

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6 Contrast this governmental control of medicines with Turshen’s assertion that the government has given up a measure of independence for the health care system because of its external financing and management (Turshen 1984: 204).

7 In 1981, a pharmaceutical plant began operation near the main hospital. Because of technical, financial, and administrative problems, it is no longer operational. But even when it was, the shortage of medicines was still severe (Nsula 1999: 200).
structures it had created. Compounding the economic strain is the growing population it must serve. The total fertility rate for the whole of the archipelago is 8.2, though for rural areas, it is thought to be higher (Garssen 1993b: 13). People younger than 15 years constitute half of the population. Intercensal growth in the last few decades has shown population to be increasing by more than 30% (Zanzibar & UNICEF 2001). The limited health care available is reflected in the life expectancy at birth; in 1988 it was only 48 years.

Public health control measures have suffered not only because of governmental economic strife, but also because of short-sighted management of these programs by NGO’s sometimes compounded by sudden withdrawal, as was the case in the mid-1990’s. Malaria control is one such example. In 1967, six years into a WHO campaign, the rate of malaria had dropped from a prevalence of 75% to only 7.8% in Unguja and 1.7% in Pemba (Schwartz et al. 1997: 37). Malaria was no longer considered a health problem, and so the program was discontinued. The prevalence then skyrocketed, and USAID interventions in the 1980’s were to no avail. At every clinic I visited during my research period, I was told that malaria was the biggest infectious problem which confirms the findings by any number of health researchers (cf. Matteelli et al. 1994; Nisula 1999: 208; Schwartz et al. 1997; Stoltzfus et al. 2001).

There is much to say about how Pembans think, and are thought of throughout East Africa. Here, I will include just two features of the ideational environment. The first is that of spirits. For centuries, Pemba has had a reputation as a centre of powerful traditional medicine, magic, and spirits. At the beginning of this century, Evelyn Waugh wrote that novices would come from as far as the Great Lakes and even Haiti to study “the witchcraft and voodoo” of Pemba (Waugh 2002). Even today, Pemba is known throughout East Africa as the heart of powerful cults of spirit worship. Many Ungujans think that everyone from Pemba is some sort of sorcerer. I have even heard it said that Ungujans and mainlanders avoid visiting there, for fear of becoming possessed. Spirits are not unique to Pemba - informants told O’Malley during her research that anywhere from 50-90% of women in Unguja have been possessed (2000: 192) - only they are thought to be more powerful there. Not only are they important as supernatural ideational landscape, they are important to that of health, “While the shetani can be read as many things by a visiting anthropologist, for their hosts, shetani are primarily understood as health problems” (Nisula in O’Malley 2000: 192). Because of the number of spirits on Pemba, one might surmise that there is a commensurate number of health problems.

The second is the connotations of physical appearance. The miscegenation that was so rampant during both colonial periods has been discussed, as has the ethnic composition of the political parties, but the effects thereof have not. The

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8 For more extensive discussions of spirits in Zanzibar, see Larsen 1998, McGruder 1998, and Nisula 1999.
skin colour and other physical features of Zanzibaris fall along a continuum, from very dark skinned, so-called ‘African’ features, to very light skinned, ‘Arab’ features. ‘Arab-looking’ people are assumed to be CUF members, and are usually harassed by CCM officials, the more ‘African’ party. More ‘Arab-looking’ people live on Pemba than anywhere else in Tanzania. The family with whom I lived on Unguja several years ago were more ‘Arab’ looking than ‘African.’ I was with them on several occasions when they were extra carefully scrutinized, simply because of their physical features.

Zanzibar is often thought, and even markets itself to tourists as a lush spice island. Rich stereotypes notwithstanding, Pembans do not even produce enough food for their own needs. In spite of a warm and humid climate and reasonably fertile soil, the production of essential food has fallen far behind local demand (Zanzibar & UNICEF 2001). Even though over 90% of arable land is cultivated, much of the staple food, e.g. rice wheat, flour and sugar, must be imported from the mainland. This is because much of the cultivation done is for cash crops, namely cloves. Secondly, as discussed above, not all of the land repossessed during the revolution has been redistributed, and is therefore left fallow. This brings an increase in the cost of food and a measure of dependency on the mainland.

Diet is limited not only by the production and cost of purchasing food; it is also dictated by social norms. Ideally severe nutrient deficiencies would be prevented through a diet adequate in quantity, quality, and diversity. Dietary change is, however, often constrained by limited access to food, either because of cultural beliefs about the appropriateness of certain foods (which become particularly predominant during pregnancy) (Jackson & Jackson 1987: 588) or because of economic limitations. For example, Pemban women’s postpartum abstinence from nutritious ‘blood-giving’ foods limits their ability to recuperate from the blood loss at birth. In addition, women may not be independent enough within their own household to implement the nutritional changes that would benefit their health.

Zanzibar’s traditional patriarchal society dictates the subordinate position of women which, historically, has been one of marginalization (Zanzibar & UNICEF 2001). Women rarely leave the house, and almost never without permission. Rarely are women employed outside of the home; when they are it is as nurses, teachers, and performing menial tasks within the tourist industry. When they do go out, they dress very modestly, with long dresses and head coverings. “The woman’s ideal behavior is kind, agreeable, quiet and helpful to her family and friends. She is supposed to demonstrate self-respect through her modest dress, in her quiet calm comportment, and in her respectful interactions with others” (O’Malley 2000: 202). Marriages are still polygynous, and residence is patrilocal. Men – fathers, older brothers, and husbands, have the last word in all matters. “Men are perceived to be more rational than women, who are said to be
saturated with emotional dispositions, and the contrasting codes of conduct —
self-control and respectability are often referred to as principles of male
demeanour, unlike chastity, shyness, and virginity which are commonly
attributed to women” (Nisula 1999: 31). Obedience is one of the most important
qualities for a female. Because women remain within the privacy of their own
home or that of their neighbours, men usually perform tasks in the public arena.
This includes going to the market to buy food. Because women do not do the
marketing, they rarely choose the food that is purchased. If they farm, they do
have a say over which food is grown. Rural women are responsible for planting,
weeding, and harvesting, and all the household activities, as well as the care of
the children (Zanzibar & UNICEF 2001). These activities cost a lot of energy,
energy that needs to be sustained by nourishing food, which is not available
frequently enough, nor in sufficient quantities. In return for the women’s
subservience, the men are supposed to bear responsibility for household
maintenance and leadership (Zanzibar & UNICEF 1995).

These nutritional limitations put pregnant women (along with small children)
at the highest risk for iron-deficiency anaemia in sub-Saharan Africa. Both
groups are prone because while they intake very little iron, they also have a very
high physiological demand for it. Typically, women’s and children’s meals are
the lowest in animal products and high in foods that inhibit iron absorption.
Women need it for tissue synthesis in their own bodies, of the placenta, and of
the fetus. Women also lose large amounts of iron completing a normal pregnancy
due to blood loss during delivery.

In Zanzibar (and throughout sub-Saharan Africa) nutritional causes of severe
anaemia are compounded by infectious causes such as HIV, malaria, and
deworming, or worms. On Pemba, two parasitic infections are most
important: hookworms and malaria (Stoltzfus et al. 2001: 7). Hookworms are
endemic along the entire east coast of Africa (Stoltzfus et al. 1997). Adult
hookworms live in the intestine of infected individuals and cause chronic
intestinal bleeding by feeding on the intestinal mucosa; they are the most
common infectious cause of anaemia worldwide (Eddleston & Peirini 1999). In
Pemba, transmission of hookworms and other geohelminths is intense (Stoltzfus
et al. 2001: 5). As such, presumptive treatment of hookworms is recommended
according to the World Health Organization’s Standard of Care in order to
prevent anaemia during pregnancy (Stoltzfus & Dreyfuss 1998). The crumbling
infrastructure means that more and more water is drawn from unclean sources,
sources that are often infected with these very parasites.

9 Animal products are the best sources of iron as they are both relatively high in iron and the iron
they contain has high bioavailability, such that about 20% is absorbed. The bioavailability of iron in
plant sources is only about 2 to 5%. Phytates, found in unprocessed grains are strong inhibitors of iron
absorption, as are polyphenols in legumes, tea, nuts and coffee, and oxalate in green leafy vegetables.
The incidence of malaria on Pemba is also very high. *Plasmodium falciparum* is the species of malaria endemic to east Africa and the species most pathogenic in terms of anaemia (Verhoef 2001). Malaria causes anaemia through a variety of mechanisms that include decreased iron absorption, suppression of erythropoiesis (productions of red blood cells) and hemolysis of infected red cells (Brabin 1992). Women in their first pregnancy experience compromised immunity to malaria and are therefore particularly vulnerable to malaria-related anaemia (Desowitz 1991). Chronic malaria often worsens during pregnancy, even for multigravidae, and this is often complicated by folate deficiency (Reuben 1993).

Even in this brief ethnographic passage, it becomes clear that there are a number of factors working concomitantly to exacerbate anaemia during pregnancy. In the next section, I discuss the theoretical decisions that I made to help manage this rich information.

**Hope in the commonalities**

My experiences working as a biological anthropology research assistant with the Dogon people in Mali have made it impossible for me to ignore the importance of our biological selves in the worlds in which we act and interact. But being part of a research team that was testing evolutionary theories without any ameliorative action planned, (and even expressly forbidden), in a place where 47% of children died by the age of 5 years, made me insistent that the consideration of politics and potential for action be a part of my own anthropological approach. For the former reason, I was drawn to ecological (medical) anthropology, the theoretical perspective that best remembers the biological human body. For the latter reason, I was drawn to critical (medical) anthropology. Yet at the outset, both academic literature and personal experiences made it seemingly impossible to utilize both bodies of theory. In a series of scathing critiques (e.g. Fabian 1982; Singer 1989b), proponents of each accuse each other of ignoring the power of culture to shape the body and its functions, or denying the relevance and variety of bodily phenomena to culture (Sperling & Beyene 1997: 137). Writing my Bachelor’s thesis under the tutelage of a biomedically-oriented anthropologist as well as a culturally-oriented one reinforced the impressions that I had drawn from the literature that the two were incompatible.

Yet I have become convinced of late that the two perspectives need not be irreconcilable, for they have two important points in common. Though they consider the origins of disease as different, both are similar in that disease is embedded in networks of multiple causation (Wiley 1992: 223). Secondly, both perspectives consider how individuals respond to threats to their well-being within the particular parameters of said environment; it is ‘only’ the networks of causation each considers that are different. These commonalities convinced me
that both perspectives could be utilized to examine how pregnant women on Pemba maintain their health within the many realms of their environment. But how broadly should the term environment be interpreted? Which actions should be regarded as health-motivated responses to the environment? How can one reconcile the two frameworks without lapsing into reductionism (for which traditional ecological anthropology has fallen out of vogue) or forgetting the biological body (as critical anthropologists have been wont to do)?

**Discordant bodies**

I was originally drawn to medical ecology because, through its consideration of the biotic, abiotic and social environments, it was the most comprehensive approach to culture. Such consideration “attempts to account for as many environmental variables as possible” (McElroy & Townsend 1998: 105). This is the strength of the ecological approach. It makes it possible to relate biological as well as cultural factors, and do so on the same level of analysis (Kandel et al. 1980). Biology and culture have been disparate for too long; ecology can offer a framework in which both biological and cultural anthropologists can work within (Alland 1972; Cronk 1991: 25; Wellin 1998: 21). Alland, one of the founding fathers of medical ecology felt that the adoption of such a perspective would enable medical anthropology to bridge the yawning chasm that divides the biological and sociocultural arms of the parent discipline (Alland 1966). An example of the commitment to the integration of the physical and the ideational is found in the opening lines of *Nutritional Anthropology*, “Differential nutritional status, by making some people more fit than others, has wide-sweeping social, political, and economic implications” (Jerome et al. 1980: 1) Thus, ecological medical anthropology can offer a holistic framework, if, when considering the environment, it does more than just pay ‘lip service’ to the importance of the political and economic effects upon it.

Yet some of the most important figures in ecological anthropology have been materialists like Marvin Harris, Andrew Vayda, and Roy Rappaport, who believed that cultural systems are adaptive responses to ecological variables. As those ecological variables are generally those of the physical ecosystem and not of the social world, this has often meant that non-physical environmental factors have been neglected (e.g. McElroy & Townsend 1998). As such, traditional ecological medical anthropology is accused of having failed “to consider fully or accurately the role of social relations in origins on health and disease” (Singer 1989b: 223).

In more recent work, the integration of social and cultural factors in ecological medical anthropology has often continued to be viewed as unsatisfactory (Wiley 1992, Van der Geest: pers. comm). “Typically, writings that adopt this [ecological] perspective abstain from analysis of critical relational
factors, such as ownership of the means of production, export of capital, extraction of profit, and racial and sexist oppression that underlie and ultimately determine human response to the physical environment” (Singer 1989a: 1194). Baer takes medical ecologists to task for not assessing the relative contribution of the diverse factors that they do consider (1996: 130). Due to the exclusion of social aspects of the environment, particularly the political and economic ones, ecologists have even been accused of “stopping short of real analysis” (Wiley 1992: 218). The self-titled political ecologist, Meredith Turshen, is another critic of traditional ecological analysis. She writes, “Although environmentalism [ecology] opens our eyes to factors such as diet, environmental exposure to toxic substances, the importance of workplace and occupational history, it is inadequate because it does not address the power relationships of race, class, and gender that dominate our everyday lives” (in Wiley 1992: 220). For Turshen, there is no wholly ‘natural’ disease, as evidenced by the title of the opening chapter in her book about disease in Tanzania, “The Unnatural History of Disease” (Turshen 1984).

The strength of critical medical anthropology is the weakness of ecological anthropology: the politicization of health. Critical medical anthropologists prefer to examine the social and historical forces of political economy as dominant determinants of health and disease; these are, of course, the very realm ecological anthropology is accused of having neglected. “Disease and health are products of the relationship between the producers of wealth and the owners of the means of production, as well as between producers and the distributors of goods and services, because the distribution of resources vital for health—such as housing, food, or leisure—is a function of the relative power of different groups.” (Turshen in Wiley 1992: 224). Political ecology emphasizes the need to consider the macro- and meso-level activities of society, i.e. the interaction and interdependence of political and economic factors, and their effects on cultural and social phenomenon. Singer, a proponent of critical medical anthropology, writes, “Because the restructuring of social relationships can have a radical impact on the health status and health care system of a society, understanding the nature and determinants of social transformation should be issues of central concern to medical anthropology” (Singer 1989b: 230). The assumption that defines this perspective is one shared with Crandon-Malamud, in her study of medical systems in Bolivia, “that medical systems, medical practitioners, and the population served operate and coexist within a political and economic context” (Crandon-Malamud 1993: 32).

Surprisingly, critical anthropologists often feel they must part ways with the political economy of health tradition (Singer 1989a: 1199). This is due to the latter’s tendency to “depersonalize the subject matter (…), by focusing on the

10 For a discussion of the place of history in ecological anthropology, see Headland 1997 and Turshen 1984: 18.
analysis of social systems and things, and (.), neglecting the particular, the
existential, the subjective content of illness, suffering, and healing as lived events
and experiences” (Scheper-Hughes & Lock 1986: 137). Turshen faults her
ecological anthropology colleagues for failing “to consider the relation of people
to their environment in all its complexity” (in Baer 1990), but she and her
political economy comrades forget to consider the individual person in the
context of all of their individual complexity.

Critical medical anthropologists remember the individual in the context of
their historical, political, and economic complexities, but on occasion, those have
been emphasized to the exclusion of the biological. Thus, they have been
accused of paying “scant attention to ecological factors” (Baer 1996: 129). In
critical medical anthropologists’ conception of the individual, as understood in
the phenomenological sense of the lived experience of the body-self, “there is no
biological organic body mentioned or allowed a reality or history” (Wiley 1992:
222). Critical anthropologists do not doubt that an individual’s mind can affect
the state of the body, but there is no opportunity to consider the reverse as
possible, that the body can affect the state of the mind (Wiley 1992: 222).
Critical medical anthropologists regard science skeptically and are often accused
of not having integrated relevant knowledge from the biological sciences into
their explanations of human behaviour (Steklis & Walter 1990: 137), but medical
ecologists have done this, and done it well.

Ecological medical anthropology embraces biological indices. The end goal of
ecological medical anthropology has tended to be scientific documentation,
model building, and the revision of hypotheses. For this, they are faulted by
critical medical anthropologists who often reject ecological medical anthropology
for being too closely allied with Western biomedical approaches to health and
disease (Singer 1989b; Turshen 1984) and for reinforcing the medical monopoly
over an individual’s suffering (Singer 1989a: 1194).

A further difference between the two perspectives is that ecological medical
anthropology has “no manifest political agenda” (Wiley 1992: 217). They may
observe that the environment was disrupted, but they do not explore why the
environment was disrupted, by whom, or for what reasons. Instead, they focus
only on the process of responding to those changes, i.e. adaptation\(^\text{11}\) (Wiley 1992:
223), and how balance, or homeostasis, is restored. Ecological anthropology
ignores social ills like misdistribution of resources and power differentials, or
couches them as ‘ills of modernization’ without examining the motivation or
sources (Singer 1989b). Thus, ecological medical anthropology may be vaguely
critical, but it is not explicitly political, nor is such a critique central to its
perspective.

\(^{11}\) Political change is not high on agenda, but change is central to the field as adaptation is central concept.
This distinctly apolitical agenda stands in sharp contrast to the centrality of the political agenda in critical medical anthropology. Social transformation is implicit and explicit in the research (Wiley 1992: 217). Given the improvement of unjust social relations as a primary objective, there can be no assumption of homeostasis.

**Harmony?**

In the last several years there have been attempts to resuscitate ecological anthropology. Sometimes, these attempts have come from scholars with a background in critical medical anthropology who see merit in a closer regard of the environment. Baer, for example, has written a very interesting article in which he examines how critical medical anthropology can most productively incorporate the environment into its theoretical model through the incorporation of political ecology (Baer 1996). He suggested the incorporation of political ecology into critical medical anthropology, but did so to the point of ignoring more traditional biocultural ecology in favor of emphasis on the political ecology.

In other instances, ecologists themselves have acknowledged weaknesses in their theoretical orientation. Kottak (1999) writes that “the older ecologies have been remiss in the narrowness of their spatial and temporal horizons, their functionalist assumptions, and their apolitical character.” He insists on the need “to recognize the importance of culture mediation in ecological processes rather than treating culture as epiphenomenal and as a mere adaptive tool.” Other ecological anthropologists have improved their analyses by simply adding political, historical, or symbolic dimensions to their ecological framework, without explicit reference to earlier ecological perspectives as remiss, or their work as ‘new.’ Some theorists have begun a more explicit discussion of the role of New Ecology in the social sciences (Botkin 1990; Lash et al. 1996; Scoones 1999; Vayda & McCay 1975) and anthropology in particular (Biersack 1999; Kottak 1999).

New Ecology is a perspective used in disciplines as disparate as environmentalism, economics, social geography and anthropology that “emphasizes the need to go beyond the restrictive nature-culture or natural and human-influenced divide and focus on the interaction between the socially constructed perceptions and representations and real process of biophysical change and ecological dynamics” (Scoones 1999, see especially 483, 490–496 for further explanation). New Ecology is characterized by three themes: environmental history; structure, agency, and scale; and complexity and uncertainty (Kottak 1999; Scoones 1999). It differs from the ‘old’ ecological

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12 The New Ecology may not be so new; note the article from 1970 that makes references to the New Ecology.
anthropology in many areas: policy and value orientation, application, analytical unit, scale, and method. More specifically, the new ecological anthropology blends theoretical and empirical research with applied, policy-directed and critical work, attuned to the political aspects and implications of ecological processes (Kottak 1999). Accordingly, new methodologies have been proposed, ones that study process, examine history (of people and their environmental and cultural change), consider the role of political and economic power, and systematically considers feedback among local, regional, and national institutions (Headland 1997: 608-9; Kottak 1999: 31).

Spurned by the criticism of the ‘old’ ecology, new subfields, sometimes called ‘new ecologies’ (Biersack 1999) have emerged. These new ecologies, all with a healthy dose of traditional ecology in their genealogies, include: historical ecology (e.g. Ferguson 1995; Goodman & et al. 1988; Headland 1997), political ecology (e.g. Escobar 1999; Leatherman & et al. 1986; Szurek 1997; Turshen 1984) and symbolic ecology (more a neologism than a new field, e.g. Descola 1994; 1996; MacCormack 1980). These new ecologies could be better termed refinements of previous ecologies, for they are not entirely new. Take, for example, Rappaport’s *Pigs for the Ancestors* (Rappaport 1968), a classic example of traditional ecological anthropological theory. It incorporated elements of history (albeit one that was only a decade long) as well as elements of symbolism. Yet these new ecologies are considered quite different in that they “radically depart from the reductions and elisions of the ecological anthropology of the past, and override the nature/culture, idealism/materialism dichotomies that informed and enlivened the debates of the past” (Biersack 1999).

The re-examination of the ecological anthropological perspective has been fruitful and a source of invigoration for much research; yet I remain unsatisfied with even the recent ecological anthropology metamorphosis for two reasons. The new ecological analyses still focus on the way the ecology (in the sense of the physical ecosphere) affects or has been affected by social forces (Brosius 1999; e.g. Gezon 1999; Kottak 1999). I propose to elevate the position of politics, economics, and symbolic systems a notch higher in the framework, and consider politics as part of the environment. I believe that these social forces in and of themselves contribute to our health or lack thereof; it is not necessary to consider the environment as a mediating factor through which politics works. Secondly, I do not wish to focus exclusively on the symbolic, or the political, or the economic, or the historical, in the way the new ecologies have tended to. As ambitious as it may be, I propose to consider all of these ideological components as equally important determinants of the individual’s environment (see too Brown et al. 1996: 217-8 and Wolf 1999: 22). After all, holism is one of the pillars of anthropology; we owe it to our discipline and our informants to at least attempt it.
I conclude this first section by touching on a contentious final concept for the two perspectives: adaptation. Medical anthropologists of many a theoretical persuasion have found the term ‘adaptation’ to be important (Brown et al. 1996), but critical medical anthropologists reject the concept as immaterial. Ecological medical anthropologists define adaptation as “changes and modifications that enable a group or a person to survive in a given environment” (McElroy & Townsend 1998: 96). While the ecological anthropologists McElroy and Townsend believe adaptation is a “core theoretical concept of the field [of medical anthropology],” Singer, a proponent of critical medical anthropology, critiqued adaptation as a “useless concept because it could not incorporate the role of social relations in explaining health-related behavior” (Singer in Wiley 1992: 216). Though I disagree with him that it is ‘useless’, there are certain weaknesses that must be acknowledged.

There is potential for tautology in the notion of adaptation, “what is adapted is there, and that which is there is adapted” unless there is an independent measure for adaptation. For ecological medical anthropologists, this measurement is defined as health. They posit that we constantly strive for homeostasis in our environment; the achievement of balance with our environment is reflected in good health. Disease, therefore, becomes an indication of lack of equilibrium or maladaptation. When we are ill, we are out of balance, or not at ease with the environment, hence, ‘dis-ease’ (Van der Geest: pers. comm.). It is, however, dubious whether ecological medical anthropology’s reliance on health status is an appropriate measure of adaptation. It is a short step to blaming the victim (i.e. the sick person) for failing to adapt, says Singer (1989b), with which I agree. Furthermore, adaptation needs to be rescued from the rather outdated, narrow individual moral basis (Van der Geest: pers. comm.).

I prefer the definition of adaptation put forth by Wiley, “the ability to respond to or seize opportunities, which in turn is circumscribed by the resources (material and biological) available to the individual or group” (1992: 228). Utilizing such a definition, we can examine what the limitations to their responses are, if people are able to ‘adapt’ at all, and, if so, we can examine how they manipulate their total (biological, social, political, etc.) environment to maximize their interests. Thus, illness is no longer a failure to adapt, but a product of a certain environment of pathogens, ideas, history, biases, and resources.

How does adaptation work? Is it conscious or unconscious? Is it planned, or do our behavior and phenotypes simply morph, or evolve, seemingly of their own volition? Does our environment change us, or is there an element of choice in how we react, i.e. do we change us? Adaptation exists at many levels, from the molecular to the behavioural; we need to specify the definition of adaptation for it to be a meaningful concept for critically- as well as ecologically-oriented medical anthropologists.
From a biological standpoint, changes to our physiological, morphological, and cultural characteristics to enhance survival in given habitats have been termed 'adaptive strategies' (McElroy 1990: 249). Yet as a functional concept, an adaptive strategy does not necessarily imply that human behavior and customs are the result of conscious planning, or trial and error, to reduce disease or to increase well being.

Social scientists have written of strategies as well. I quote at length from Scheper-Hughes’s discussion of the struggles and strategies of poor men and women living in the Alto, a hillside shantytown in Brazil (1992: 471-2).

Although I have occasionally used the word ‘strategy’ with reference to the daily practices of the women and men of the Alto, perhaps the time has now come to disown the term with all its biologic and militaristic overtones. For the people of the Alto do not really strategize.

She then turns to the treatment of the strategic metaphor by Michel de Certeau, [Strategy] implies that people are consciously organized or prepared for action. It suggests they have a clear-sighted vision of the lay of the land and a certain knowledge of the ‘enemy’ that they can look (optimistically) toward the future, and that they can plan toward an upset victory. But this is not the reality in which the moradores [residents] find themselves. Their daily lives are circumscribed by an immensely powerful state and by local economic and political interests that are openly hostile to them. A strategy implies a base, a starting point, a specific location, one that is also a locus of power.

Following Michel de Certeau, Scheper-Hughes substitutes ‘tactics’ for ‘strategies’ as a better description of the everyday, oppositional survival practices of the poor. “Tactics are defensive and individual, not aggressive and collective, practices. They should not be confused or conflated with the domain of ‘resistance’ that James Scott (1985) and his colleagues have done” (Scheper-Hughes 1992). Tactics are daily acts to better improve one’s existence, and are thus not so very different from the behavioral definitions of adaptation.

Borrowing heavily from Scheper-Hughes’s discussion of tactics, (and flirting with some ideas of transactionalist medical anthropology) I have defined adaptation in a manner that is amenable to both perspectives. I can preserve the concept of ‘adaptation’, but will speak of tactical adaptations, actions and reactions to an environment in which and through which people seek the best life that they can. Tactic implies volition, even if it is a circumscribed one, while adaptation alone often entails passivity or unconscious motivations. Discussion of tactical adaptation entails consideration of the adaptations that are possible, the
factors that are too immense to struggle against and would only defeat health, and an analysis of which of these possible adaptations are most worth fighting for.

A second feature of such a tactical adaptation is that it must no longer be solely a physical one. Culture has long been considered our most powerful tool for adaptation; to speak of culture helping us to adapt to our environment is no revelation. As anthropologists, we have long ceased to marvel at mankind’s consummate adaptability, ever since we first learned about the warm, dry houses that culture has enabled us to learn to build in order to protect ourselves from the harsh environment during our introductory anthropology classes. The potential for this cognitive adaptability has only begun to be considered (Van der Geest: pers. comm.), and unexpectedly, it is critical medical anthropologists who have done so. “Emotions do not precede or stand outside of culture; they are part of culture and of strategic importance to our understanding of the ways in which people shape and are shaped by their world” (Scheper-Hughes 1992: 431, my emphasis). Cognitive adaptation means we can change the way we think about things, such as health, in order to put our selves at ease. The consideration of babies’ deaths in the favela as blessings could be considered one such example, albeit an extreme one, of cognitive adaptation (Scheper-Hughes 1992: 429-45).

Medicine is another such domain in which cognition plays an important role, “[medicine] is a domain in which meaning is created and negotiated and reformed” (Crandon-Malamud 1993: 205).

A critical ecological schematic

In summation, ecological medical anthropological perspectives are appealing because of their potential for holism, though the political and economic aspects of health are often neglected. Critical medical anthropology has a strong political and economic component, but, at times, emphasizes the historical, political, symbolic and economic dimensions of health to the exclusion of the biological body. While ecological medical anthropologists may succeed in remembering the biological body, they may perceive the causes of its illnesses uncritically or at least apolitically, while critical medical anthropologists have situated social transformation centrally in their research. The idea of adaptation, so vital to ecological medical anthropology, is avoided by critical medical anthropologists, but by adding tactical and cognitive dimensions to it, can be rescued and used in both perspectives.

In light of what I consider the merits and shortcomings of critical medical anthropology and ecological medical anthropology, I have fashioned a framework that gathers the best from both bodies of knowledge. The most salient characteristics are: 1. a broader definition of the environment to include historical, political, economic, biological and symbolic forces, 2. an expanded
definition of adaptation to include the notion of tactical adaptations, and 3. social transformation as a goal.

These characteristics can be depicted within a framework borrowed from ecological anthropology. Ecological anthropology often incorporates simple (perhaps overly so) diagrammatic models that can help to chart almost any setting. These diagrams are an excellent heuristic tool for both organizing important influences on health as well as visualizing how they interact. Such schematics can also facilitate comparison between environmental features of other settings. The graphic representation I have created for the CEMA framework borrows heavily from a diagram in *Nutritional Anthropology*, ‘An Ecological Model for Nutritional Anthropology’ (Jerome et al. 1980: 14), albeit with some significant adjustments.

Figure 1. An ecological model for nutritional anthropology (Jerome et al. 1980: 14)

Food is not at the center of my diagram, as it is in Jerome, Kandel, and Pelto’s diagram; the individual is. This model is meant to help us to understand the environment in which we live, not only the environment in which our food is produced and consumed. A second reason for the centrality of the individual is the importance of the concept of adaptation; it is as individuals that we act and react (though these actions are, of course, mediated by our social environments). This construction seems acceptable to both perspectives, as both are occupied with how individuals respond to threats directed at their well-being within the particular parameters of said environment.
In the *Nutritional Anthropology* diagram, ‘social environment’ is “the effects of other societies’ food production”; ‘social organization’ refers to the “economic and political structures, and micro-level features of household structure” (Jerome et al. 1980: 14-5). I have redefined what these are comprised of. In my diagram, ‘social environment’ is the meso- and macro-level social setting (which was absent from their diagram), i.e. the political, economic, and historical environments on a state and global scale. ‘Social organization’ in the *Nutritional Anthropology* diagram refers to the micro-level social setting; I have re-titled this in the CEMA perspective with a new title, but have not changed that which it refers to: household organization. What was, ‘culture and idea systems’ has been re-titled ‘ideational setting’. ‘Culture’ is no longer compartmentalized whatsoever; it is found throughout the whole diagram, as it permeates each individual life. Each sub-frame is an integral part of the entire environment a person lives in, and each constantly acts with and reacts to all of the other smaller boxes, a response to Frankenberg’s entreaty to “demonstrate clearly what effects are produced at the local level, by national and international social processes; and what is coming from the local level in return” (in Singer 1987: 1200). To draw this accurately, arrows would have to fly every which way. I have drawn no arrows, but have represented the environment, the space in which these small boxes interact, by drawing a large frame that encompasses the entire diagram. Thus, all components are equally open to change and to be changed by the other factors in the environment. Note that this too is a difference with the *Nutritional Anthropology* diagram, in which each peripheral box interacts only with certain other ones.
**Ethnographic flesh on theoretical bones**

As outlined above, the first of the three salient features of a critical ecological medical anthropology perspective was the inclusion of tangible and intangible settings at equal levels of importance to demonstrate how factors like history, politics, and household structure can and do affect one’s health as much as the topography and physical needs and limitations of the body do. It was important to present information about the environment that, at first glance, may seem immaterial to anaemia, such as information about who does the marketing or how the infrastructure has been crumbling, and why. But if I had only included discussion of aspects the physical environment, i.e. the ecological approach at its narrowest, the influence of politics and history would have gone unappreciated. If I had focused only on the political oppression and gender inequalities, i.e. critical medical anthropology at its narrowest, then information about the biological requirements during pregnancy and the contribution of infectious diseases to malaria would have gone unnoticed. Careful analysis reveals that all of this information is, in fact, germane.

Thus, a satisfactory ethnography of anaemia during pregnancy on Pemba must include a history of Omani and British colonialism in Zanzibar, with an emphasis on their policies towards health care, in order to demonstrate the distrust and miscegenation that have shadowed hospitals since the first one opened. It also includes some discussion of natural resources, e.g. the monocropping of the once-profitable cash crop, cloves, and the misdistribution of land after the 1964 revolution to explain why Pembans do not grow enough food to feed themselves. Poor sanitation, which exacerbates the spread of worms, and an untimely end of malaria control in a holoendemic area contribute to the prevalence of parasites which cause blood loss and red blood cell destruction, and in turn, anaemia. A discussion of recent politics, such as the violent elections in 1996 and 2001, in which Pembans were singled out for injury and murder, begins to explain why Pembans feel that medicines are another form of political oppression and are thus sceptical of their benefits. The economic strife due to the drop in clove prices, structural adjustment programs, and the withdrawal of NGO’s because of governmental corruption, sheds light on why the entire archipelago’s infrastructure is crumbling, with concentrated effects on Pemba. The dominant gender ideology on Pemba, which encourages women to be passive, stoic, and obedient, often translates into women suffering silently through very painful conditions. Beliefs about when it is appropriate to eat nutritious, ‘blood-giving’ foods during pregnancy and the postpartum period most certainly negatively influence women’s hemoglobin status. All of these environmental factors, and even more, are essential to understanding why anaemia is the problem that it is during pregnancy.
In Figure 3, my favourite heuristic device from ecological anthropology’s toolbox, I have recapitulated some (but not all) of the elements of the environment important to understanding anaemia during pregnancy. Not all that are included have been explained in the ethnography, but a sufficient number have for the reader to see the way in which the schema was used. Such a flexible tool helped me to orient my analysis as I learned of more and more aspects of Pemban culture that contribute to the prevalence of anaemia during pregnancy. The critical ecological medical anthropological framework is able to display and summarize the most important categories of data, though by no means is it exhaustive or subtle; nor is it meant to be. The emic perspectives of anaemia and pregnancy are arranged next to historical, political, economic, and ideational environments, in order to create an etic understanding of why anaemia poses the serious health risk that it does during pregnancy in Pemba. It should now be clear that it was impossible to study anaemia in Pemba without studying Pemban culture in its entirety, and that the critical and ecological perspectives were imperative to doing so.

The compartmentalization of the box renders the factors more separate than they actually are. One can become caught up worrying if sanitation goes under ‘physical setting’ or ‘social setting,’ or if the priority men are given when eating fits under the ‘micro-level social setting’ or ‘ideational setting.’ The answer is that those factors fit under both headings, but that in the end, it does not matter so much; this is not a literal representation but one with heuristic value. Another weakness of such a schematic is that it renders Pemban culture deceptively straightforward. It is not. Despite the potential for oversimplifying culture, I felt that it was edifying to include the diagram without the ethnographic description that normally accompanies it.

Understanding what is in the environment is one aspect of the CEMA model, and the first step to understanding how the individual acts and reacts within it. The second facet of the CEMA perspective was the broadening of the term adaptation such that it took on tactical and cognitive possibilities. When the environment is laid out for us, the areas of change, action and interaction, i.e. adaptation, become clear. “Until we fully realize that social process in the medical arena is shaped not by the unrestrained will and might of potent oppressors but by an ongoing clash between those best served and those least served by existing medical institutions and between those most in control of and those least in control of medical knowledge, procedures, and technology, we will misunderstand [clinical process]” (Singer 1987: 1199). Change is not unidirectional.
Figure 3. A critical ecological model for anaemia during pregnancy

**Micro-level Social Setting: The Household**

- Relatively greater workload/physiological demands on women: need more calories
- Control that husbands have over food purchasing and consumption
- Men as decision makers about health
- Recurrent (and often unwanted) pregnancies
- Rural women further from hospitals than urban ones
- Rural women less familiar with variety of cures
- Poverty

**Physical Setting**

- Worsening water supply: worms
- Little sanitation: worms
- Untimely end of malaria control in holoendemic area: malaria
- Cash crop monoculture: not enough staple foods
- Incomplete land redistribution after revolution: not enough arable land

**Mental and Physical Needs of Pregnant Anaemic Women**

**Macro- and Meso-level Social Setting: History, Economics, and Politics**

- Substandard health care: staff and supplies
- Political malevolence and/or disorganization: delay of medicines
- Colonial exploitation through the manipulation of medicines: history of resentment
- Drop in clove prices: bad economy
- Strapped governmental budget: no money to buy supplies
- Marginalization of Pembans: ethnically, politically & economically
- Infrastructure: cannot travel to main hospital over bad roads

**Medical Technology**

- Antenatal Clinic: unmotivated, unsympathetic workers, many mistakes, free medicines
- Traditional healers: women skeptical of most traditional medicine during pregnancy
- Private pharmacies: motivated though, some untrained workers, must pay for medicines, treatment of anemia seems correct, customer has bargaining power

**Ideational Setting**

- Identification of anemia-like symptoms as ujumbe, or normal signs of pregnancy
- Suspicion of medicine from intl. donors or government
- Inability to eat because of nausea
- Privacy of spirit-caused anemia
- Postpartum avoidance of blood-giving foods
- Gender ideology of women as weaker, more passive, uncomplaining
- Fear of “fat” baby

**Adaptation?**
In a model that considers all the constraints and possibilities within their environment, we can see how Pemban mothers-to-be accommodate or cause elements in their environment to adapt to meet their health needs. I believe that there are three realms within which a woman can tactically adapt to, or cause to adapt to her needs. These are denoted with the linkages ‘adaptation?’ in Figure 3 above. I am not convinced, however, that pregnant Pemban women can elicit much change at either the macro and meso-level social setting, or at the level of her physical setting. Perhaps she can negotiate a few adaptations in the household setting: she can figure out how to better get permission from her husband to go to the clinic, private pharmacy, or traditional healer. She could devise ways of having enough money to afford medicines and/or transportation to care. She can get this money either from her husband or through small enterprises she does on the side, such as selling foods or extra crops. Lastly, she can try to eat more nutritious food. She could do this by growing more food herself, convincing her husband to purchase more nutritious foods when he does the shopping, or persuading him to share more of the scant protein that they do have.

The second realm for potential adaptation is that of her ideational environment, e.g. what she considers as illness and what she considers as health. If she learns more about anaemia she can more easily distinguish between ujumbe and signs of anaemia. Additionally, her perceptions of what is acceptable behaviour for a woman may now keep her from insisting that her symptoms are unreasonably unhealthy. She may begin to consider treating spirit-caused anaemia with iron supplements as well as with traditional cures. She may come to realize the value of nutritious, ‘blood-giving’ foods during ujusi, the postpartum period lasting approximately forty days, instead of avoiding it as most women do now.

A final realm for adaptation is that which is labelled ‘medical technology’ in Figure 3. Pregnant Pemban women can make better or different use of the medical technology at hand, i.e. the antenatal clinics, non-hospital medicines, and the private pharmacies. She could become more of an active participant in her diagnosis, by clearly explaining her symptoms when asked, instead of answering the doctors’ and nurses’ questions with monosyllabic replies and embarrassed silence as is presently the norm. She could seek medical treatment earlier, which necessitates changing her ideational environment, i.e. learning to recognize when symptoms are grave enough to merit treatment. She could ask more questions when she is at the antenatal clinic, and she could be more assertive about knowing what her diagnosis is, i.e. comprehending what it means and understanding the proper treatment thereof. Alternatively, she could seek assistance from a place where she has more bargaining power as a paying customer, where she is served by those who she feels comfortable with, who can diagnose her on the spot, without long waits and excruciating interviews, i.e. the private pharmacy.
Adaptation, framed as such, brings us only a few short steps away from the third tenet of CEMA, that of social transformation. If we better understand how a Pemban woman perceives her health, constructs her health, and seeks health, and the tangible and intangible environment of ideas in which she does this, then we can better understand how to make tools better available to her, or help her to realize what tools are already at hand, to facilitate her maneuvering through the vulnerable time of pregnancy as an already marginalized citizen.

All of these suggested adaptations require a woman to recognize that she can empower herself. This shoots straight to the heart of critical theories: a critique of ideology and power. “Ideologies can mystify reality, obscure relations of power and domination, and prevent people from grasping their situation in the world… When institutional arrangements and practices reproduce inequality, domination, and human suffering, the aims of critical theory are emancipatory” (Scheper-Hughes 1992: 171).

In pointing out all that women can do to improve their health, there is a potential for an accusatory tone. I am not implying that Pemban women are anaemic because they have failed to adapt; shedding the moral overtones that can accompany more traditional ecological anthropology was one of the goals of reworking the term adaptation. There is a certain danger in assigning such control. “[I]n granting power, agency, choice and efficacy to the oppressed subject, one must begin to hold the oppressed morally accountable for their collusions, rationalizations, ‘false consciousness’ and more than occasional paralyses of will. With agency begin responsibility and accountability” (Scheper-Hughes 1992: 533). My intention is not to blame women for not trying hard enough; my intention is to acknowledge a degree of agency in women who do not necessarily think of themselves as having a say in their health, reproductive or otherwise.

In this final section, I hope to have demonstrated that the prevalence, perceptions, and treatment of anaemia during pregnancy are embedded in all facets of the environment of Pemba, thereby justifying my claims for the necessity of an all-encompassing environment. During the discussion of adaptation, I have made explicit the ways in which this environment changes and is changed. Finally, by suggesting a tactical adaptation or two in light of unsupportive governments and husbands, I have dabbled in social transformation.

In closing, I return to the original goal of this article: making transparent the process of selecting aspects from various theoretical frameworks, and then using those to analyze one’s fieldwork. I am curious if other scholars accept that I have indeed, as I have argued, fruitfully harmonized two seemingly discordant bodies, and if so, if that is sufficient for a successful analysis. I am even more interested to know how other medical anthropologists have selected the theories they use in their work. I invite other scholars to reveal their processes of theoretical bricolage, and their
justification for these choices. Such an exercise is guaranteed to make one’s analysis more comprehensive, lucid, and meet the anthropological priorities that we have set for ourselves no matter what our theoretical orientation.

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In memory of
In memory of Pieter Streefland (1946-2008)

Pieter Streefland, professor of Applied Development Sociology and core member of the Medical Anthropology and Sociology Unit of the University of Amsterdam, died on the 3rd of January 2008 after a long illness. He was only 61. He was a gifted teacher and writer and an excellent organizer who initiated several teaching and research programmes in the field of health and development. The focus of his work was always on the intertwining of poverty, politics and ill health, particularly in Southern Asia and Africa.

He studied sociology at the Free University of Amsterdam, specializing in the sociology of non-Western societies. In the early 1970s, he did research among sweepers and scavengers in Karachi, Pakistan, focusing on social conflicts within this outcast community. The study resulted in his PhD dissertation and later on in a book *The Sweepers of Slaughterhouse* (1979). Several articles on the social organization of urban sanitation followed. His description of the work of sweepers and cleaners is one of the first examples of sanitation ethnography. He discussed both the monetary aspect of the work, such as options for relative high income for private cleaners, and the stigmatization that accompanied the work.

After returning from Karachi, he joined the South and Southeast Asia sub-department of the University of Amsterdam to teach Sociology of South Asia. He went to Bangladesh to study the role of non-governmental organizations in the development process, which resulted in various articles about the plight of the rural poor. He continued to be involved in applied research in Bangladesh and in 1987, jointly with the Centre for Social Studies of the University of Dhaka, published *Different Ways to Support the Rural Poor*.

In 1978 he joined the Royal Tropical Institute (KIT) in Amsterdam where he headed the newly erected section of Primary Health Care, which consisted of public health doctors and social scientists. His focus was on problems of health,
health care and development, particularly in South Asia, and later also in Africa. He conducted related research in India, Bangladesh and Nepal and was involved in advisory work with regard to health development programmes. Among studies he conducted were those on the distribution of medicines at the village level in Thailand, on the socio-cultural background of the AIDS epidemic in Southern Africa, and on the revitalization of Primary Health Care in Uganda. He led a multi-centred study on Social Science and Immunization. His last research was a study of chronicity, poverty and care in a Zambian town.

In 1990 he became professor of Applied Development Sociology at the University of Amsterdam. In his inaugural lecture *Seeking a Balance*, he sketched the liminal position that health social scientists held between their sociological and anthropological colleagues on one side and epidemiologists and medical scientists on another. His lecture was a strong plea for interdisciplinary respect and collaboration. It was also an advice to social scientists to present the data of their research in clear and accessible language in order to attract the attention of policymakers and to convince them of the relevance of a social and cultural perspective on health and health care. His own writing was exemplary in that respect.


He held several positions outside the university such as chairman of the Dutch Society of South Asia scholars and member of the advisory committee of one of the main Dutch non-governmental development organizations.

He was one of the health social scientists who organized a six weeks introduction course in applied medical anthropology that was held in Thailand, The Philippines and Bangladesh. He also contributed to the design of the Amsterdam Master’s in Medical Anthropology (AMMA) in 1997, and the Dutch Master in Medical Anthropology and Sociology (MAS) in 2004. Until he became ill he headed the AMMA exam committee, designed and chaired the modules on ‘Social and Historical Meanings of Infectious Disease’ and on ‘Health and Health Care in Asia’, and supervised several students in the research and thesis writing. He also briefly functioned as MAS director.
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His contributions to the scientific quality and social relevance of the Unit’s research and educational programs have been invaluable. We will miss him for his loyalty, his insight and sharp analyses, his inspiring teaching and supervision of students and his unbending principles.

Sjaak van der Geest


In memory of Els van Dongen (1946-2009)

In the evening of the 4th of February 2009, Els van Dongen, anthropologist and colleague, died at the age of 62. Her death came after a long and painful illness, a period of hope and desperation, of gratefulness for a rich life mixed with stubborn resistance to the unfairness of that same life.

Els was a gifted anthropologist and an unusual colleague. Students loved her teaching - original, sharp, concerned and full of entertainment. Colleagues admired her for her unbridled energy and productivity and her many talents. She was fast in everything she undertook and impatient if things went too slowly. She deeply disliked bureaucracy and its meetings.

Her anthropological life started late, at the age of 35. She first trained as primary school teacher and from 1968 till 1978 she taught in two primary schools in the proximity of her beautiful house in the rural south of the Netherlands, near the Belgian border. In 1978, she decided to study geography. During that course she discovered anthropology, which she liked instantly. In 1982, she decided to join the new part-time evening course anthropology at the University of Utrecht and combined the role of student with the care of her family. She completed her master’s ‘cum laude’ in 1988 with a thesis on the semiotic approach in the study of illness. That approach revealed her later interest in illness as a social event and a metaphor of conflict.

Six years later, in 1994, she defended her PhD thesis based on conversations with psychotic people in a psychiatric hospital. The title of her thesis Zwervers, knutselaars, strategen (Tramps, handymen, strategists) betrayed her aversion to psychiatric labels. She regarded the people she met in her research first of all as people who were out of tune with the ‘normal’ society, but gifted with extraordinary skills and ideas. She experienced ‘kinship’ with them in their common ‘unusualness’. Provocative also was the quote from John L. Caughey that she chose as device for her book: “Schizophrenic’ is perhaps best kept in its traditional sense, as a pejorative label for deviants whose visions we do not like.” A few years later she would write that ‘madness’ showed: “that otherness is present in all of us. The otherness we fear.”
In her book, which ten years later was published in English in a slightly revised version (2004), she sought to describe and understand how psychiatric patients experienced their world. She did so from the patient’s point of view, focusing on the fears and hopes that characterise the life in a clinical mental ward. Dilemmas in that life are: How to express subjectivity in an atmosphere designed to restrain demonstrative emotion? And how to maintain personal integrity in a completely ordered regime? She portrayed the psychiatric patients as ‘wanderers’ – homeless people, as it were – in an alien and hostile country, creating a ‘bricolage’ reality from materials at hand. Although she often positioned the therapists and psychiatrists as representatives of an oppressive regime, she did not doubt their integrity either.

In 1996 she joined the staff of the Medical Anthropology Unit at the University of Amsterdam and began to play her key-role as teacher and researcher in our team. She taught both general courses in anthropology and specific medical anthropology modules in AMMA on themes such as ‘Critical Medical Anthropology’, ‘Anthropology and Psychiatry’, ‘Anthropology and Chronic Illness’ and ‘Medical Anthropological Ethnography in Europe’. She taught and supervised AMMA students in her typical flamboyant and sometime provocative style.

She published a collection of six narratives by people she met in the closed wards of the mental hospital during her PhD research. The personal stories are alternated by her observations and comments. The book, she wrote in her prologue, was her debt to these people: “I became indebted because the people shared with me what they had: their stories and (part of) their lives.” A little further she reflects: “When I went into the hospital, my aim was to study how people deal with mental illness and how mental illness could be understood from the perspective of the people themselves. Now I must admit that madness taught me more about the power of culture and the power of people than about madness.”

The power of culture…In 2000 she co-edited a volume with contributions about the way Europe treated migrants in need of health care. A central theme in that volume is exclusion. It proved a recurrent theme in all her work: exclusion and marginalization of ‘others’, such as psychiatric patients, migrant, refugees, victims of violence and older people.

When she turned her attention to older people in South Africa, she came home with touching stories about the beauty and warmth of old age, but also with horrifying data of older people being abused and maltreated by their own children and grandchildren. In one article she spoke of ‘social gerontocide’. Invisible dramas unfolded in poor households where the young generation despised and rejected their older relatives for their passive role in the Apartheid era and tried to ‘kill’ them socially. But, she stressed, the older people are not helpless victims. They fight back and develop strategies to survive.
Research among older people drew her attention to remembrance. Being old consists of having many memories. Rejecting or silencing those memories, however, implies a rejection of the older people themselves. “It is almost as if the past never happened,” one person tells her. In one of her last published articles she quotes a common saying of the young silencing the old: “That was your time...This time is ours!” In other words: Shut up. The ‘culture of silence’ in which they were forced to live during Apartheid is thus prolonged into the post-Apartheid era. That awareness of muted memories inspired her and Monica Ferreira, with whom she collaborated throughout the South Africa years, to bring out a collection of ‘untold stories’ to give voice to the lives of older people in the new South African society (2004).

Her last major publications were two edited books, one about lying and concealment in medical settings and one about distance and proximity during illness. The former, co-edited with her long-time friend and colleague Sylvie Fainzang, argued that lying is a way of dealing with major crises that people encounter, particularly during illness (2005). The theme connects with ideas she has been airing from the very beginning: health problems are not only about health; they are linked to shame, exclusion, suffering and social violence. Lying in such circumstances may be the most effective medicine to restore the damage. But lying is mutual; those with power in medical contexts may exploit the lie as well, to maintain their position in the medical hegemony.

Facing distress (2007), co-edited with Ruth Kutalek, brought together papers of a conference of the European Association of Social Anthropology in Vienna. Distance and proximity constitute the ambiguity of the illness experience. On the one hand, illness leads to loss of independence and need of help and care by others; on the other hand, illness makes one lonely as it isolates the patient from normal social encounters and may scare others away. The pain of the sick body will thus be aggravated or replaced by the distress of ostracism.

Between 1994 and 2009, Els was editor of the journal Medische Antropologie and published several articles in it on the themes that ‘haunted’ her. She also co-edited five special issues on ‘the senses’, ‘older people, well-being and care’, ‘defecation, culture and well-being’, ‘medical technology and the body’ and ‘violence and human rights’.

In 1998, Els co-organized the first conference on ‘Medical Anthropology at Home’ (MAAH). For Els doing fieldwork ‘at home’ was a personal experience. For about ten years she had been doing research ‘around the corner’ in a psychiatric hospital. The conference was an attempt to de-exoticise (medical) anthropology. The theme and format (small-scale / intensive discussions) proved successful and since 1998, the MAAH conference has been held every second year, in the Netherlands, Spain, Italy, Finland and Denmark. Els co-edited two voluminous special issues with conference proceedings (2001, 2002) and remained active as long as she could. She wrote a paper for the 2008 conference
in Denmark focusing on her personal sickness and suffering, but was unable to present it. We discussed her moving self-reflection in her absence.

Els was a person with many talents. She took lessons in drawing and painting and produced beautiful canvasses with symbolic objects and portraits of relatives, friends, and people she met during fieldwork. Many of her productions can still be viewed on her website. She was also a filmmaker and photographer. The topics she chose for her photographs and films were sometimes from her anthropological research, but often focused also on other things such as nature, everyday life and unexpected details such as the movements of hands during a conference.

Els has lived a very full life and accomplished more than most of us will be able to achieve in a life twice as long as hers. Even so, she was not always a happy scholar, perhaps feeling that her close colleagues did not fully understand or appreciate what she was doing. Close colleagues are sometimes more distant than those who are far away. Nevertheless, in this space, she carried on with her own strong and positive energy, becoming a popular guest lecturer in universities abroad and serving on various international scientific committees.

When her sickness grew more serious, about two months before her death, colleagues decided to make a book of friends for her. Thirty-eight people, colleagues from Amsterdam, from other Dutch universities and from abroad, plus students and friends contributed brief essays (and one poem) that dealt with the themes that had been prominent during her academic life.

The title of the book ‘Theory and Action,’ was the name of a famous core module that Els taught in the Master’s of Medical Anthropology and Sociology (MAS). In one of her papers she stressed that theory and action are closely connected in medical anthropology. Theory provides a way of finding pertinent meanings and making intelligent interpretations that open the door to relevant action. She then cited the famous line from Kurt Lewin that there is nothing so practical as a good theory because it enhances understanding and produces the questions that really matter.

The book was presented to her when her condition had become critical. She was almost too weak to open the paper wrapped around the book, but she read the essays and reacted personally to many of the authors. Ten days later she died.

Sjaak van der Geest

In memory of Lily Zakiyah Munir (1951-2011)

Each individual is unique, but Lily was more than unique. She was a kind of anomaly, a hybrid of a typical Javanese woman and a woman raised in the Islamic Pesantren (Islamic boarding school) tradition. Anthropologists generally portray Javanese women as patient, inward, accepting of what fate deals them, shy, sensitive and refined, with an emphasis on harmony in relationships. On the other hand, Javanese women are also like magma – hidden behind all that gentleness and patience, there is plenty of power that might erupt at any time. Women from the Pesantren culture embody a blending of this Javanese model with the role of women as commonly defined in Islamic tradition – again, subordinate, passive, inward, even ascetic. But, anyone who knew Lily Munir will agree that she did not conform to these models. Lily was a hard-working woman, energetic, active, full of enthusiasm, and very open. She always spoke her mind; she would share her ideas, her experiences and her dreams with anyone who would listen. In her AMMA thesis about ‘marital well-being and sexuality among elderly Javanese women’ she included her own marital experiences and autobiographical reflections. Once at a formal dinner, my friends from the office were shocked when she related a tragic event in her life. Such openness required courage. One time she asked to meet me just to share her anxiety because she thought she was falling in love!

When the news spread that Lily had died from breast cancer, people were stunned. Everybody knows that breast cancer is not a cause of sudden death; this type of cancer has very noticeable symptoms, and develops over a long time, usually years. Lily must have known about it; we had even discussed the topic in a class (AMMA), when we talked about ‘the meaning of a lump’ or when we examined the use of metaphors when describing a disease. Clearly, she must have known that there was something amiss with her breast.

When I visited her two months before her death, I expressed my shock and sorrow. What she said amazed me: “I felt it around four years ago, but I ignored it. I’ve never touched my breasts. I felt it was improper, especially since I’m a widow. And I was so busy with my work, and trying so hard to win the love of my children, who were probably upset by the death of their father.”

I first met Lily over 25 years ago when I was active in a women’s NGO and Lily was in the Nahdlatul Ulama N-affiliated Islamic women’s organization Muslimat. We met at a forum held by Canadian International Development Agency (CIDA) that had invited a gender expert from Canada. Lily’s educational background in English literature made her much more capable of using English than the other activists. I was impressed to see this middle-aged woman in traditional attire – a
pink kebaya and a long red kerudung covering her head – speaking English so fluently. We quickly became good friends.

Lily’s better-than-average English – compared to other Indonesians – made it much easier for her to travel abroad. She attended many seminars, short-term training programs and conferences all over the world. She had graduated from university with a degree in English, but she did not have a particular expertise in the field of development, other than being a chairperson for international relationships in the central board of the youth female wing of NU – Fatayat NU until 1990. She then continued these duties in a related organization, the women’s wing of NU- Muslimat NU, until 1995. In the run-up to the 1995 Beijing Women Conference, she led a working group of Indonesian NGOs. From that time on, Lily became deeply involved in gender, development and the role of Muslim women.

In 1998, with assistance from the Asia Foundation, she led a debate on violence against women, examining religious teachings as one basis of such violence. This activity was closely related to a then-recent political event – the major riots in Jakarta, which included mass rapes of Chinese women.

From that point onward, Lily was clearly deeply interested in violence against women and religion. But, she would not have been Lily if she had not also been interested in many other issues. As the 1999 election approached, she became a project coordinator in a voter education campaign for women, and focused especially on rural women living near Pesantren.

No matter how busy she was one of the most noticeable things about Lily was her desire to learn. This stimulated her to write articles in newspapers, and even books. It was especially at that level that Lily and I kept up our relationship, despite the fact that we were both too busy to meet.

One day in 1999, I told her that I had received funding from the Ford Foundation to continue my studies in AMMA, at the University of Amsterdam. Upon learning this, she immediately phoned Rosalia Sciortino, program officer for reproductive health at the Ford Foundation, and pleaded to allow her to go with me to the Netherlands. I thought this was a great idea, so I also tried to persuade Rosalia.

At AMMA we lived in the Meer en Vaart dormitory from the fall of 1999 to 2000. Lily had a constant thirst for knowledge. She studied until late at night, making orderly notes. We often visited each other’s rooms and shared food and stories, but the most important thing in those days was studying, studying, studying. That year, her eldest daughter Cici got married, so when there was a break between classes to do thesis research, she went home to Jakarta to do her research and also take part in her daughter’s wedding.

The test for module 1 put us both under a lot of stress, even Lily, who didn’t have any problems with the language. She invited me to join her in Islamic prayers; evidently she had noticed that I often neglected this religious obligation.
She was astonished when I said I’d already done my prayers in another form. “You are too liberal,” she said. I laughed.

Returning to Indonesia after completing AMMA, I worked at an international institution, The Asia Foundation. Through this job, we continued our professional relationship. Several times, Lily was invited to meet with our guests from Washington who wanted to discuss various issues in this country, especially related to Islam. The representatives of Islamic women were usually Lily and I.

Lily’s areas of interest developed into three main fields: sexuality, which was the topic of her thesis; Islamic shariah, as related to political developments in Indonesia; and the traditional organization of the Pesantren, where she was born and raised.

In 2001, she was a visiting researcher at the Institute of Southeast Asian Studies (ISEAS) in Singapore and produced a paper on Islam, Sexuality and Local Culture. On the invitation of Prof. Abdullahi an-Naim, an expert in Human Rights and Islam, she became a research fellow in the Islam and Human Rights Program at Emory University, Atlanta, Georgia for a full year (2003-2004). After that, she was a visiting lecturer on Islam and women’s rights under shariah at the University of South Carolina at Columbia for one semester.

During that time, she seemed to be neglecting medical anthropology. But then, in 2009, she came and told me she was going to do a doctorate at the State Islamic University (UIN) in Jakarta, and return to the world of anthropology by doing research on Javanese women, Islam and sexuality. She felt that sexuality was the most critical centre of a woman’s experience. We met several times to discuss her conceptual framework. She wanted to talk about “women’s desires and sexuality.”

Then we did not see each other for quite some time, until mid 2010 when our office asked her to serve as facilitator and resource person in training a group of women from the Afghanistan government, to be held in October 2010. But she suddenly withdrew and I heard she was having a series of tests for cancer. I regularly checked her status on Facebook to follow the progress of her treatment. As usual, she was always cheerful and optimistic. But starting in December 2010, there were no more reports on the progress of her treatment; apparently, she had had two chemotherapy treatments, but felt this was not the right approach.

January 2011, she tried various types of alternative medicine. She always said she was making rapid improvement. But, one day in April, I met a friend of hers at the airport, who said she had just come back from visiting Lily. I was shocked to hear that her condition had worsened. As soon as I got back, I went to visit her in her lovely home with its beautiful flower garden. She showed me the condition of her breast. One of my grandmothers died from the same condition, and I could see that there wasn’t much hope. But, I wanted to see a miracle, because I saw no signs of defeat in Lily herself; she was still so optimistic. As sick
as she was, she was still laughing out loudly, speaking stridently, eating a lot, drinking juice, and was still plump.

From then on, I visited her almost every week. Her daughter Cici told me that my visits meant a lot to Lily. Lily promised to write about her experience with her cancer. But she also wanted to complete her dissertation. I agreed.

During one of my visits, we talked about “different experiences that we don’t yet know about.” I told her about the diagnosis by my doctor in Singapore that sooner or later I would be totally blind. My optic nerves were getting weaker and I was already blind in one eye. “Are you scared?” she asked. “So far, no,” I replied, “in fact, I’m rather excited, because I’m going to discover new experiences through my blindness.” “Do you think death is also like that?” “I’m sure it is; we will discover a new experience that the living never have. Interesting, isn’t it?” I said jokingly. She laughed and took my hand. “You’re brave, Lies...”

Lily passed away on 27 May 2011. Just the day before, I visited her to read her a letter from Sjaak. She was no longer moving, her tears flowed, but I knew she could hear me. A week before she died, she had been taken to the hospital and was in a bed in the ICU. Her eyes were sad. I could hear the holy verses softly over her head. I stroked her gently. She asked me to come closer. “I miss mas Munir. Last night I dreamed about him. I’m ready.” I knew she was ready to go. When I held her to say goodbye she whispered, “Lies, I love you.” My tears dropped. I did not want her to go. Lily has gone to join her husband.

Lies Marcoes (AMMA, 1999-2000)
Appendices
Appendix 1

In addition to the alumni mentioned in this overview, some students participated in the AMMA course for just a few modules. Most of them were PhD candidates who used the AMMA modules to improve their proficiency in Medical Anthropology.

Participants with * did not write a thesis.

- Daniel Arhinful, Ghana
- Preeti Kirbat, India
- Maurice Kon’gon’go, Kenya
- David Kyaddondo, Uganda
- Frans Leppers, Netherlands*
- Lillian Mpabulungi, Uganda
- Tilaye Negewo, Ethiopia †
- Aryanti Radyowiyati, Indonesia
- Ma‘a Kamanathan, India
- Iris Shiripinda, Zimbabwe
- Shaduz Zaman, Bangladesh

AMMA 2 (1998/1999)
- Abebe Bekele, Ethiopia
- Andonovska Biljana, Macedonia
- Jacintha Bruin, Netherlands
- Paul Bukuluki, Uganda
- Riekje Elema, Netherlands
- Elisabetta El-Karimy, Egypt
- Guillermo González, Cuba*
- Andres Suarez González, Colombia
- Jorg Karlgard, Norway*
- Maricel Lim-Nalian, Philippines
- Anuma Mahbub, Bangladesh
- Alister Munthali, Malawi
- Papreen Nahar, Bangladesh
- Tyas Triningtyasasih, Indonesia
- Violette Yebei, Kenya
- Milka Gavrovksa, Macedonia
- Gunawan Ingkokusumo, Indonesia
- Lies Marcoes, Indonesia
- Tedros Menelik, Eritrea
- Lily Munir, Indonesia †
- Ava Nepaul, USA
- I Made Setiawan, Indonesia
- Ashild Stangeland, Norway
- Payyappalli Mana Unnikrishnan, India
- Marianne Vijana, Netherlands
- Budi Wahyuni, Indonesia

AMMA 3 (1999/2000)
- Ashraful Alam Neeloy, Bangladesh
- Laura Ciaffi, Italy
- Krista Coppoolse, Netherlands
- Asheburi Desalegn, Ethiopia
- Wies Dulfer, Netherlands
- Ashraful Alam Neeloy, Bangladesh
- Laura Ciaffi, Italy
- Krista Coppoolse, Netherlands
- Asheburi Desalegn, Ethiopia
- Wies Dulfer, Netherlands

AMMA 4 (2000/2001)
- Nurul Agustina, Indonesia
- Mohammed Alam, Bangladesh
- Kim Cowher, USA* †
- Maisie Dagpiiso, Philippines
- Dang Vu Trung, Vietnam
- Dao Quang Vinh, Vietnam
- Jennifer Fagan, USA
- Leanna Fries, USA
- Amina Gadri, Switzerland
- Victor Igreja, Mozambique
- Agnes Iswari, Indonesia
- Xiaoqing Mao, China
- Daniel Ngemera, Tanzania
- Miranda van Reeuwijk, Netherlands
- Marion Steentjes, Netherlands
- Stephen Alayemola, Nigeria
- Romeo Arca Jr., Philippines
- Carin Beijer, Netherlands
- Huub Beijers, Netherlands
- Shahanoor Chowdhury, Bangladesh
- Siti Darwisyah, Indonesia
Lori Evans, Canada  
Michael Golinko, USA  
Laufred Hernandez, Philippines  
Mirjanne Kessels, Netherlands  
Jeanne Medjeu, Cameroon  
Gail Meerschwan, USA  
Nguyen Thi Thu Nam, Vietnam  
Nguyen Tran Lam, Vietnam  
Bruce Powell, USA  
Astrinda Suryono, Indonesia  
Nancy Vinikoor, USA  
Margriet Wilbrink, Netherlands  
Kyung-Wha Yeo, South Korea*  
Sera Young, USA

Grace Akello, Kenya  
Liku Alemu, Ethiopia  
Francis Boakye Yiadom, Ghana*  
Carla Donoso, Chili  
Moumina Dorgabekova, Bangladesh  
Philip Felipe, Philippines  
Hien Phan Thi Thu, Vietnam  
Johanna Imelda, Indonesia  
Leelan Low, Malaysia  
Alicia Manlagnit, Philippines  
Gul-E-Rana Mufti, Pakistan  
Nike Speranza Nostra Nkwi, Cameroon  
Janus Oomen, Netherlands  
Rebekah Park, USA  
Vanessa VanSchoor, Canada  
Vu Phong Hong, Vietnam

AMMA 7 (2003/2004)
Chilanga Asmani, Tanzania  
Mumin Austiya, Indonesia  
Assefa Bidu, Ethiopia  
Bui Thi Thanh Thuy, Vietnam  
Maria Correos Fariza, Brazil  
Charmaine Cu-Unjieng, Philippines  
Jet Derwig, Netherlands  
Heinrich Dulan, Philippines  
Jirra Gidibo, Ethiopia  
Gemma Keijzer, Netherlands  
Astrid Koolde, Netherlands  
Kassa Mekuria, Ethiopia  
Catherine Newsom, USA  
Maria Olarte Sierra, Colombia  
Pham Hong Hau, Vietnam  
Erwin Rif’Ah, Indonesia  
Euan Sadler, UK  
Ingrid Sturkenboom, Netherlands  
Ursula Wagner, Austria

AMMA 8 (2004/2005)
Hindun Anishah, Indonesia  
Sasitorn Chaiprasitti, Thailand  
Ronald Gunawan, Indonesia  
Barbara Hahn, Canada  
Ai Juariah, Indonesia  
Ahmaddudin Maanj, Afghanistan  
Ana Maria Ochoa Hoyos, Colombia  
Juli Oktavia, Indonesia  
Emily Rosenberg, USA  
Silvana Rugolotto, Italy  
Allison Winer, USA

AMMA 9 (2005/2006)
Raihana Nadra Alkaff, Indonesia  
Kapil Babu Dahal, Nepal  
Alexander Hughes, USA  
Iveta Lazarashvili, Georgia  
Anthonie Millenaar, Netherlands  
Nipael Eliabu Mrutu, Tanzania  
Marjolein van Paridon, USA  
Georg Ruppe, Austria

AMMA 10 (2006/2007)
Payam Abrishami Shirazi, Iran  
Marleen Arends, Netherlands  
Kristen C. Blume, USA  
Adriana Diaz del Castillo, Colombia  
Daniya Lynn Fast, Canada  
Zoe Goldstein, U.K.  
Nino Gurginidze, Georgia  
Margaret Hartzler Hemel, USA  
Elisabeth Oey, Netherlands  
Tiiffany Tiara Pakasi, Indonesia  
Sahienshadebe Ramdas, Surinam  
Mariana Rios Sandoval, Mexico  
Peter Santos, USA  
Petra Tomlinson-Cox, U.K.  
Hikaru Ueki, Japan  
Mangeni James Wasike, Uganda
Michelle Allport, USA
Ina Asino, Namibia
Julia Challinor, USA
Svagita Elks, USA
Maria Erazo Pesantez, Ecuador
Shamindra Herat, Sri Lanka
Miladi Kurnisari, Indonesia
Rosa Persend, Namibia
Theoneste Rutayisire, Rwanda
Melisa Soto-LaFontaine, Puerto Rico
Tri Hayuning Tyas, Indonesia

AMMA 12 2008/2009
Sadia Chowdhury, Bangladesh
Mekonnen M. Debel, Ethiopia
Susanna Graham, UK
Ahmad Waqass Liaqat, Pakistan
Wycliffe O. Ochieng, Kenya
Ngoc Yen Pham, Vietnam
Karina Romo Medrano Mora, Mexico
Mesha Saeed, Pakistan
Malissa K. Shaw, USA
Henny P. Slegh, Netherlands
Clare Sproun-Bailey, UK
Hoe Ly Tjoeng, Netherlands

AMMA 13 2009/2010
Sanjay Aggarwal, Canada
Fasika Ferede Alemu, Ethiopia
Tania M. Algaba Masis, Nicaragua
Tiara Amelia, Indonesia
Ricky Andrian, Indonesia
Sara Elizabeth Brewer, USA
Shahab Daneshvar, Iran
La Kenya Houston, USA
Chantal Marie Ingabire, Rwanda
Andrea Faith Kalvesnaki, USA
Pimontipa Malahom, Thailand
Issac Tri (Kiki) Octaviatie, Indonesia
Emila Perujo Lavin, Mexico
Nuria Rossell Curco, El Salvador
Priya Pramod Satalkar, India

AMMA 14 2010/2011
Nicola De Martini Ugolotti, Italy
Hannah Hilda Ewoame, Ghana
Blessings Nyasilia Kaunda, Malawi
Mulembet Kiar Mothahem, Ethiopia
Patience Muchada, Zimbabwe
Nasime Selim, Bangladesh
Carola Patricia Titze, Canada
Nawaraj Upadhaya, Nepal

AMMA 15 2011/2012
Alfred K. Adams, Swaziland
Turinawe Benon Emmanuel, Uganda
Thandeka Dlamini-Simelane, Swaziland
Maren K. Jellef-Entscheff, Austria
Alice Larotonda, Italy
Ngoc, Lung-Bich, Vietnam
Laban Musinguzi Kashaja, Uganda
Agata Mazzeo, Italy
Swasti Mishra, India
Jude T. Rwemisasi, Uganda
Fortunate Shabalala, Swaziland
Selma Tanovic, Bosnia Herzegovina
Appendix 2
Group pictures (1997-2012)


AMMA 3 (1999–2000)

(front row, L-R) - Margriet Wilbrink; Laufred Hernandez. (standing, L-R) - Romeo Arca Jr.; Michael Golinko; Jeanne Medieu; Carin Beijer; Nguyen Thi Thu Nam; Lori Evans; Gall Meerschewam; Huub Beijers; Nguyen Tran Lam; Sera Young; Astriaanda Suryono; Mirjanne Kessels; Nancy Yinikoor; (not present) - Shahanoor Chowdhury (see photo AMMA 6); Siti Darwisayah; Marjan Mol; Bruce Powell; Kyung-Wha Yeo (see photo AMMA 6)
(front row, L-R): Vu Phong Hong; Leelan Low; Carla Donoso; Gul-E-Rana Mufti; Hien Phan Thi Thu; Kamaljit Parhar; Johanna Imelda; Liku Alemu; Shahanoor Chowdhury. (back row, L-R): Philip Felipe; Yasessa Van Schoor; Moumina Dorgabekova; Rebekah Park; Janus Oomen; Alicia Manlagnit; Nike Speranza Nostra Nkwi; Grace Akello; Kyung-Wha Yeo, (not present): Francis Boakye Yiadom.

AMMA 7 (2003 – 2004)
(front row, L-R): Jinna Gidibo; Bui Thi Thanh Thuy; Chilanga Asmani; Kassa Mekuria; Charmaine Cu-Unjeng; Ursula Wagner; Heinrich Dulay; Catherine Newsom; Erwin Rif'Ah. (back row, L-R): Assefa Bidu; Jet Derwig; Euan Sadler; Gemma Keijzer; Ingrid Sturkenboom; Minin Austiana; Pham Hong Hanh; Maria Olarte Sierra, (not present): Maria Correa Farias; Astrid Kodde (see photo AMMA 8)
(front row, L-R) - Ahmaddudin Maarij; Sasitorn Chaiprasitti; Silvana Rugolotto; Ai Juariah; Hindun Anisah; Juli Oktalia, (back row, L-R) - Ronald Gunawan; Emily Rosenberg; Barbara Hahn; Astrid Kodde; Allison Winer; Ana Maria Ochoa Hoyos

(L-R) - Raihana Nadra Alkaff; Nipael Eliabu Mrutu; Kapil Babu Dahal; Georg Ruppe; Alexander Hughes; Marjolein van Paridon; Iveta Lazarashvili, (not present) - Anthonie Millenaar (see photo AMMA 10)
AMMA 10 (2006 – 2007)
(front row, L-R): Mariana Rios Sandoval; Zoe Goldstein; Anthonie Millenaar; Payam Abrishami Shirazi; Mangeni James Wasike, (back row, L-R): Petra Tomlinson-Cox; Danya Lynn Fast; Adriana Diaz del Castillo; Kristen C. Blume; Peter Santos; Nino Gurgenidze; Sahienshadebe Ramdas; Elisabeth Oey; Tiffany Tiara Pakasi; (not present)- Marleen Arends (see photos AMMA 11 and 12); Margaret Hartzer Hermel; Hikaru Ueki

(From left to right)- Melisa Soto-LaFontaine; Marleen Arends; Svagita Elks; Rosa Persendt; Maria Erazo Pesantes; Ina Asino; Tri Hayuning Tyas; Theoneste Rutayisire; Miladi Kurnisari, (not present)- Michelle Allport; Julia Challinor; Shamindra Herat
(front row, L-R): Wycliffe O. Ochieng; Karina Romo Medrano Mora; Ngoc Yen Pham; Clare Spronk- Bailey; Henny P. Slegh; Sadia Chowdhury; Hoey L. Tjong; Mesha Saeed; Ahmad Waqass Liaqat,
(back row, L-R): Malissa K. Shaw; Mekonnen M. Debel; Susanna Graham; Marleen Arends

AMMA 13 (2009 – 2010)
(crouched, L-R): Andrea Faith Kalvesmaki; Pimontipa Malahom; La Kenya Houston, (Standing front row, L-R): Tiara Amelia; Priya Pramod Satalkar; Tania M. Algaba Masis; Issac Tri (Kiki) Octaviatie; Nuria Rossell Curco, (back row, L-R): Shahab Daneshvar; Fasika Ferede Alemu; Ricky Andriansyah; Emila Perujo Lavin; Sanjay Aggarwal; Sara Elizabeth Brewer; Chantal Marie Ingabire
AMMA 14 (2010-2011)
(Left to right)–Carola Tize; Hannah Hilda Ewoame; Patience Muchada; Misheck Nkhata; Nicola De Martini Ugolotti; Nawaraj Upadhaya; Nasima Selim; Blessings Khangamwa; Monica Rodriguez Garcia; Muluembet Kiar Mohhamed

AMMA 15 (2011-2012)
(Left to right) –Selma Tanovic; Laban Musinguzi Kashaija; Agata Mazzeo; Jude Tibemanya Rwemisisi; Ngoc Lung-Bich; Maren Kristen Jeleff-Entscheff; Swasti Mishra; Thandeka Dlamini-Simelane; Turinawe Benon Emmanuell; Fortunate S.S. Zwane; Alfred Khehla Adams; Alice Larotonda
### Appendix 3
#### Teachers AMMA 1997-2012

We have tried to compose a complete list of all teachers of the various AMMA modules and winter schools during the fifteen years of AMMA’s existence. We apologize if we overlooked someone.

<table>
<thead>
<tr>
<th>Teachers</th>
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<tbody>
<tr>
<td>Michiel Baas</td>
</tr>
<tr>
<td>Chris de Beer †</td>
</tr>
<tr>
<td>Stuart Blume</td>
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<tr>
<td>Gouke Bonsel</td>
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<tr>
<td>Han ten Brummelhuis</td>
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<tr>
<td>Pia Christensen</td>
</tr>
<tr>
<td>Walter Deville</td>
</tr>
<tr>
<td>Els van Dongen †</td>
</tr>
<tr>
<td>Nicolette van Duursen</td>
</tr>
<tr>
<td>Alex Edmonds</td>
</tr>
<tr>
<td>Sjaak van der Geest</td>
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<tr>
<td>René Gerrets</td>
</tr>
<tr>
<td>Trudie Gerrits</td>
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<tr>
<td>Diana Gibson</td>
</tr>
<tr>
<td>Roy Gigengack</td>
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<tr>
<td>Ton Haans</td>
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<tr>
<td>Anita Hardon</td>
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<tr>
<td>Tony Holslag</td>
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<tr>
<td>Lianne Holten</td>
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<tr>
<td>Oliver Human</td>
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<tr>
<td>Joop de Jong</td>
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<tr>
<td>John Kinsman</td>
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<td>Winny Koster</td>
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<tr>
<td>Marie Lindegaard</td>
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<tr>
<td>Eileen Moyer</td>
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<tr>
<td>Daan Mulder †</td>
</tr>
<tr>
<td>Janus Oomen</td>
</tr>
<tr>
<td>Fiona Parrott</td>
</tr>
<tr>
<td>Christopher Pell</td>
</tr>
<tr>
<td>Robert Pool</td>
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<tr>
<td>Annemiek Richters</td>
</tr>
<tr>
<td>Ria Reis</td>
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<tr>
<td>Rosalia Sciortino</td>
</tr>
<tr>
<td>Erica van der Sipt</td>
</tr>
<tr>
<td>Pieter Streifland †</td>
</tr>
<tr>
<td>Marian Tankink</td>
</tr>
<tr>
<td>Corlien Varkevisser</td>
</tr>
<tr>
<td>Peter Ventevogel</td>
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<tr>
<td>Leontine Visser</td>
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<tr>
<td>Shahaduz Zaman</td>
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<tr>
<td>Jarrett Zigon</td>
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</tbody>
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Appendix 4
AMMA theses 1998-2012

This is a complete overview of all master theses in the Amsterdam Master's in Medical Anthropology (AMMA), in alphabetical order by author. The theses can be downloaded from: scriptiesonline.uba.uva.nl or scriptiesonline.uba.uva.nl/AMMA. Sixteen theses cannot be downloaded because the authors did not give permission. Four theses could not be traced.

Abrishami Shirazi, Payam, Contribution, challenge, or threat? Dutch psychiatrists' attitudes toward pharmaceutical promotion (2007) [pharmaceuticals, psychiatrists, promotion, marketing, psychiatry, Netherlands]

Adams, Alfred Khehla Wayne, A Qualitative Study on the Low Utilization of Male Circumcision Services in Kwaluseni, Swaziland (2012) [male circumcision, masculinities, sexual pleasure, barriers, acceptability, adverse events, Swaziland]

Agarwal, Sanjay, Between Rejection and Belonging: Exploring mental health disparities between homosexual and heterosexual men in Amsterdam (2010) [homosexuality, mental health, social stress, minority stress, stigma, self-esteem, Netherlands]

Agustina, Nurul, Back to Childhood: A study on urinary incontinence perception among the female elderly in Jakarta (2001) [incontinence, elderly, women, urine, care, stigmatisation, dirt, Indonesia]

Akello Ayebare, Grace, Common diseases and medicine use at a primary boarding school in Uganda (2003) [common disease, primary school, ethnography, public healthcare, Uganda]

Alaiyemola, Stephen Oludare, We are family: Perspectives of male British Pakistanis on the persistence of first cousin marriage practice (2002) [first cousin marriage, Rishta, genetic testing, Pakistan, UK]

Alam, Ashraful, Care for the elderly poor: A case study of a Bangladeshi village (2000) [care, elderly, poor, geriatrics, Bangladesh]


Alemu, Engudaye Liku, From confrontation to castration: Sexual harassment and the young Dutch (2003) [sexual harassment, students, Netherlands]

Alemu, Fasika Ferede, Minors’ awareness about the new abortion law and access to safe abortion services in Ethiopia: The Case of Marie Stopes International Ethiopia Centers in Addis Ababa (2010) [abortion, liberalized abortion law, unintended pregnancy, minors, contraception, stigma, shame, Ethiopia]

Algaba Masis, Tania Maria, Discussing sexuality among Nicaraguan female adolescents: An anthropological study (2010) [risky sexual behaviour, cultural beliefs, sexual taboos,
early motherhood, machismo, gender inequality, lack of sexual education, poverty, religion, Nicaragua]

Alkaff, Raihana Nadra, Ambiguities around “Telat Bulan” A study of married women’s practices and perceptions of termination of (suspected) pregnancy, in Jakarta, Indonesia (2006) [pregnancy, married women, abortion, Indonesia]

Allport, Michelle Lynn, Suffering, Depression and the Freedom in Learning about Psychological Violence: a process of orientation for women in Mexico City (2008) [women, Mexico, violence, sex, gender, abuse]

Amelia, Tiara, Home birth care in the eyes of Indonesian women in Amsterdam, Netherlands (2010) [anthropology of birth, maternal health, neonatal health, home birth, childbirth, Indonesia, Netherlands]

Andriansyah, Ricky, “Money Talks” A study on the interaction between drug actors and non-drug actors within the community in Bures, Jakarta, Indonesia (2010) [drug scene, drug actors, addiction, inner-city street culture, underground drug economy, putaw, Indonesia]

Anisah, Hindun, “Deddik jen Nyaman” (It’s more pleasurable). The meanings of Madurese Muslim rituals prior to sexual intercourse (2005) [sex, rituals, sexual intercourse, gender, religion, Muslim, Indonesia]


Arends, Marleen, Drugs & penal pains (2009) [drug users, addiction, prison, recidivism, effects of imprisonment, perception of self, autonomy, Netherlands]

Arhinful, Daniel Kojo, Ghanaian migrants and social security assistance to relatives at home (1998) [immigrants, remittances, assistance, relatives, healthcare, Ghana, Netherlands]

Asmani, Chilanga Ambrose, Borstvoeding in Nederland: The meanings and experiences of breastfeeding among Dutch mothers (2004) [breastfeeding, motherhood, Netherlands]


Beijer, Carin, “Although 90% of the system is against us, we are able to survive”. An exploratory study of West-African Christian migrants living in Netherlands on healing practices and sources of empowerment in times of social distress (2006) [healing practices, spiritual healing, Pentecostalism, West-African Christians, migrants, depression, Netherlands]

Beijers, Huub, People with a mission. Meanings of psychosocial distress of Cape Verdean migrants in Netherlands (2004) [religion, distress, healthcare, immigrants, psychiatry, Cape Verde, Netherlands]


Bidu, Assefa Mulu, Perceptions of epilepsy among Ethiopian immigrants in Netherlands (2004) [immigrants, epilepsy, perception, stigma, Ethiopia, Netherlands]
Biljana, Andonovska, Relationship between health and healing subjectively interpreted among participants of a Zen Buddhist healing group in Amsterdam (1999) [Zen, Buddhist, healing, health, alternative therapy, new age, Netherlands]

Blinne, Kristen, Public relations - Depilation: disgust & desire (2007) [pubic hair, hair removal, sexuality, body hair]

Brewer, Sara, The Social Life of Iboagene: Meanings of medicine through Iboagene and its providers (2010) [Iboagene, evidence-based medicine, TCAM, addiction, efficacy, risk]

Bruin, Jacinta, It simply has to be commercial: perceptions of Dutch occupational health physicians on the consequences of the commercialisation of Dutch occupational health services (1999) [occupational health physicians, occupational diseases, commercialisation of health care, social medicine, Netherlands]

Bukuluki, Paul, Factors influencing low levels of teenage pregnancy in Netherlands. A case study in Amsterdam city (1999) [teenage, pregnancy, sex, adolescent, Amsterdam]

Chaiprasitti, Sasitorn, Fractured bone, fractured knowledge. The transmissions of Northern Thai bone healing in the time of khwam thansamai (2005) [traditional medicine, healing, bone healing, rituals, healer, Thailand]

Challinor, Julia, "She makes it better because she is my best friend": Friendship among children with a visual impairment in Ireland (2009) [children, visual impairment, friendship, Ireland]

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