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Coping with cancer and adversity : Hospital ethnography in Kenya

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Preface

This monograph is the result of an ethnographic study in a cancer ward in Kenya. I carried out the fieldwork in Kenyatta National Hospital between August 2005 and July 2006. The study sets out to examine the experiences of cancer in-patients and suggests ways to improve their condition. It explores how cancer patients feel about and make sense of their conditions and treatment, and describing and analysing healthcare issues that emerge from patients' narratives and experiences. The description situates these experiences in the context of healthcare interactions among actors in the ward, and highlights the role of patients in negotiating their own care. The study also draws attention to patients' circumstances outside the hospital in order to describe the wider social and economic implications of their hospitalisation. My work is a contribution to hospital ethnography as a research approach in low-income societies, in particular in Kenya.

The analysis is patient-centred and focuses on sufferer experiences of disease and hospital treatment. It differs from the usual 'hospital study': gauging patient satisfaction, for instance, based on data collected outside the hospital or through post-discharge interviews. The present study contextualises patients' distress, dissatisfaction and satisfaction in the realities of the ward and their socio-economic backgrounds.

Cancer patients, their relatives and staff members at Kenyatta National Hospital were consistently supportive during my research. I am indebted to all the patients and their relatives who participated directly in this study through either brief or in-depth conversations with me. The patients who participated in this study fought bravely to cope with cancer and arduous hospital treatment. Only a few pulled through to the end of my fieldwork and the conclusion of this book. May God rest the souls of those who passed on to eternal peace.

I wish to express my special gratitude to the hospital's Ethics and Research Clearance Committee for approving this study. Special thanks go to the then Deputy Director, Clinical Services Dr. Jotham N. Micheni who confirmed approval of the ethnography in the adult cancer ward. He welcomed my supervision team and me at the beginning of the study, which further legitimised and facilitated my position in the hospital and ward as a social science researcher. I am grateful to the ward and Radiotherapy Clinic staff who allowed me to hang around to observe and learn from their work. Special thanks go to Dr. Henry Abwao, then head of the Radiotherapy Department, Mrs Roselyne Opindi, the

nurse-in-charge of the Radiotherapy Clinic, and Mr. Caesar Barare for their gracious support during my observation at the cancer treatment centre. Many nurses, support staff and doctors in the cancer ward provided me with welcome encouragement and friendship. I fondly remember the tea and regular chats in the staff and ward rooms. I am particularly grateful to Mrs. Elizabeth Mbeti Owino, the then matron of the cancer ward, and Dr. Ndung'u, who welcomed me to the ward and encouraged me to feel at home 'like one of us.'

I could not have completed this dissertation without the unrelenting support of my supervisors and advisors. My principal promoter, Prof. Dr Sjaak van der Geest, has played an invaluable role since the inception of my PhD project. My interaction with him dates back several years to when I was seeking admission to the University of Amsterdam. He accepted my request to be my first supervisor and guided me through the application processes and PhD research as a mentor, philosopher, friend and many times like a father. His encouragement to maintain my patience, consistency and resilience contributed a great deal to my personal growth. He was the first to encourage me to embark on this project as a study area that is consistent with my interests and my desire for higher professional and career training. I would also like to express my heartfelt gratitude to my second supervisor, Dr. Fred Zaal, who has worked for many years in Kenya and has a wide range of experience in the country. He often made me aware of the significance of many aspects of local livelihood which I was tempted to take for granted as a 'native anthropologist'. His critical comments and enthusiasm for my work since the stages of proposal development helped me better organise the arguments in this book and in oral presentations related to my PhD training. Sjaak and Fred helped me at every step, from preparing applications for funding to finalising this dissertation. I am also grateful to them and their families for contributing to my orientation in the relatively new environment of the Netherlands.

Dr. Diana Gibson of the Department of Anthropology and Sociology, University of the Western Cape, South Africa, provided significant support as my day-to-day tutor during the first year of my PhD trajectory.

I acknowledge with sincere gratitude the role played by Prof. Dr. Anastasia Nkatha Guantai of the Department of Pharmacology and Pharmacognosy in the School of Pharmacy, University of Nairobi. As my local adviser and hospital supervisor, Dr. Guantai facilitated my entrée in the hospital, arranging for my introduction, orientation and working space in her department within the hospital. This eased the feeling of being a 'professional stranger' as most social science researchers in clinical settings see themselves. I am also indebted to Prof. Dr. Isaac K. Nyamongo, the director of the Institute of African Studies at the University of Nairobi, my other local supervisor and adviser. He was supportive and committed to providing useful guidance, making time for me from the

beginning of my application for admission to the PhD programme and funding to pursue this study at the University of Amsterdam. He consistently encouraged me whenever we talked and corresponded.

The University of Amsterdam generously funded my entire PhD study and fieldwork through the Amsterdam Institute for Metropolitan and International Development Studies (AMIDSt). I am very grateful for the comprehensive support I received from AMIDSt and its entire staff during my whole PhD study period in the Netherlands and Kenya. I extend special gratitude to the manager, Drs. Gert van der Meer for his support and encouragement. Members of the AMIDSt secretariat also played an invaluable role in facilitating my study and stay in the Netherlands. Special thanks to Guida, Marianne and Puikang Chan for their generosity each time I sought their assistance. Numerous informal interactions with Prof. dr Ton Dietz, Dr. Mario Novelli and Dr. Valentina Mazzucato who always spared time for me, enriched my social and academic experience. I am also indebted to the research group Livelihoods, Environment and Governance (LEG), directed by Prof. dr. Isa Baud, for offering an important environment for academic and social interaction that contributed in a special way to my PhD trajectory and apprenticeship. My first and second supervisor were both great assets as they facilitated the academic connection between AMIDSt and the Medical Anthropology Unit, ASSR and the CERES programme. I benefited immensely from the PhD orientation and coursework that these institutions facilitated. I also thank my employer, the Catholic University of Eastern Africa, for granting me study leave and a stipend for basic family support during the challenging PhD research journey.

I wish to thank all my friends and colleagues in Kenya and the Netherlands who contributed to the successful conclusion of my study in one way or another. I can mention only a few of the colleagues and friends in Kenya by name. Dr. Maurice M. Sakwa sustained his supportive friendship when I arrived in the Netherlands as he completed his PhD study at Radboud University, Nijmegen. Dr. Ekisa Anyara, Mr. Bethwell Owuor, and Mr. Peterson Mwangi also provided constant moral support, and their interest in my work encouraged me. Fellow PhD students and staff at AMIDSt, ASSR, Medical Anthropology Unit and the CERES were invaluable companions throughout my stay in the Netherlands. Just to mention a few of my colleagues in the Netherlands, I appreciated the companionship and support of Josien de Klerk, Christine Dedding, Miranda van Reeuwijk, Christine Böhmig, Anna Laven, Kees van der Geest, Edith van Ewijk, Marloes Kraan, Johan Roest, Inge van der Welle, Babak Rezvani, Grace Akello-Ayebare, Dr. Getnet Tadele, Dr. Adano Wario, Emmanuel Nyankweli, Dr. Francis Obeng, Ruya Gökhan Koçer, and Jacob Boersema. During my final year at

UvA, my successive housemates at Sondastraat, Mounir, Stefan Minica and Bart, were great companions with whom to share my experiences.

Members of the PhD promotion and Hospital Ethnography reading clubs provided both social and academic forums. I was privileged to be part of these working groups, and am indebted to them for their constructive criticisms and comments. Similarly, the CERES working group on Health, Population and Well-being in which I was a PhD representative provided an important audience for discussion. I am grateful for the comments of participants in the Second AEGIS European Conference on African Studies at African Studies Centre in Leiden in July 2007, as well as suggestions from participants in the Symposium on Methodological and Theoretical Aspects of Hospital Ethnography, May 1-2 2006, at the Medical Anthropology Unit, University of Amsterdam.

I owe a special debt of gratitude to Cate Newsom who carefully read and edited the manuscript at a critical moment in its revision and to Edith van Ewijk who translated the English summary into Dutch. Similarly, I would like to express my earnest indebtedness to Dr. Dick Foeken of the African Studies Centre in Leiden for facilitating the publication of this dissertation in the African Studies Collection. I also wish to thank the members of my promotion committee for their evaluation and recommendations on this dissertation. While it is true that I benefited from advice and encouragement from many sources, any errors of fact or of interpretation in this book are my sole responsibility.

I wish to thank my larger family for their continued support and solidarity during the challenging times of my study. Thanks to my late father, Ezekiel Mulemi Munyasa, and my late mother, Mary Nyagoha Mulemi. My parents gave me an invaluable foundation for education, patience and life as my first mentors and role models. Just as many of my respondents did not live to see this book, my mother passed away as she awaited my “party in August”. I thank her for her unrelenting inspiration. I also give my special thanks to my brothers and sisters for their constant moral support.

This research entailed one year of coursework followed by one year of fieldwork. I was away from my family for the first year and rejoined them during the fieldwork period. I was away from them again in the third and fourth year of my PhD programme. During the long period of my absence from home, my wife, Prisca, bore the burden of taking care of our lovely daughters, Lillian Nyagoha (Lillie) and Sidney Kathomi (Sidi). I wish to express my deepest gratitude to her for her patience. Her support during the fieldwork was a source of great inspiration. My heartfelt thanks are also due to Lillie and Sidi who had to miss the company of their father for such a long time, but bonded with me fast when I returned. I am indebted to those relatives and neighbours who reached out to com-

fort my children at the height of post-election violence in Nairobi when neither my wife nor I were with them in Kenya at the time.

Benson A Mulemi
Nairobi, March 2009