



UvA-DARE (Digital Academic Repository)

TB truths

Patients' experience with tuberculosis and healthcare in sub-Saharan Africa

Cremers, A.L.

Publication date

2018

Document Version

Other version

License

Other

[Link to publication](#)

Citation for published version (APA):

Cremers, A. L. (2018). *TB truths: Patients' experience with tuberculosis and healthcare in sub-Saharan Africa*.

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

Abbreviations, Contributing
Authors, PhD Portofolio,
Publications, Words of Thanks
& Curriculum Vitae

ABBREVIATIONS

ACF	Active case finding
AIDS	Acquired immunodeficiency syndrome
AMC	Academic Medical Center, Amsterdam
ART	Antiretroviral Therapy
ARV	Antiretroviral Drugs
ASH	Albert Schweitzer Hospital
CCW	Community Care Worker
CERMEL	Centre de Recherches Médicales de Lambaréné
CHC	Community Health Clinic
CSO	Civil Society Organization
DOT	Directly observed treatment
DOTS	Directly observed treatment, short-course
DS	Drug Susceptibility
DR	Drug Resistant
ECDC	European Centre of Disease Prevention and Control
EEA	European Economic Area
EU	European Union
FGD	Focus Group Discussion
GAHC	the governmental ambulatory health care centre for HIV and TB
HBC	Home Based Care
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
HTR	Hard To Reach
IPHAMETRA	l'Institut de Pharmacopée et de Médecine Traditionnelles
IPT	Isoniazide Preventive Therapy
KAP	Knowledge, Attitudes, and Practices
LMIC	Low and middle income countries
LTBI	Latent TB Infection
LTFU	Lost To Follow Up
MDR TB	Multi-Drug Resistant Tuberculosis
MSF	Médecins Sans Frontières
MTB	Mycobacterium tuberculosis
NICE	National Institute for Health and Clinical Excellence
NTP	National Tuberculosis Program
OECD	Organisation for Economic Co-operation and Development
PCC	Patient Centered Care
PH	Public Health
PLHIV	People living with HIV
PV	Pharmacovigilance

TAC	Treatment Action Campaign
TB	Tuberculosis
TBAC	TB Patients Adherence and Compliance
UK	United Kingdom
UNZAREC	the University of Zambia Biomedical Research Ethics Committee
UNZA-UCL	University of Zambia – University College London
USA	United States of America
UvA	University of Amsterdam
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
XDR TB	Extensively Drug Resistant TB

CONTRIBUTING AUTHORS

Alimuddin Zumla, Division of Infection and Immunity, University College London, London, UK; National Institute for Health Research University College London Hospitals Biomedical Research Centre, London, UK

Andreas Sandgren, European Centre for Disease Prevention and Control, Solna, Sweden

Austin Kabika, Department of Psychology, School of Humanities and Social Sciences, University of Zambia, Lusaka, Zambia

Benjamin J. Visser, Center of Tropical Medicine and Travel Medicine, Department of Infectious Diseases, Division of Internal Medicine, Academic Medical Center, University of Amsterdam, the Netherlands

Beth Shaw, National Institute for Health and Care Excellence, Piccadilly Plaza, Manchester, UK

Charlotte C. Heuvelings, Center of Tropical Medicine and Travel Medicine, Department of Infectious Diseases, Division of Internal Medicine, Academic Medical Center, University of Amsterdam, the Netherlands

Christopher J. Colvin, Division of Social and Behavioural Sciences, School of Public Health and Family Medicine, University of Cape Town, Cape Town, South Africa

Emma Birnie, Center of Tropical Medicine and Travel Medicine, Department of Infectious Diseases, Division of Internal Medicine, Academic Medical Center, University of Amsterdam, the Netherlands

Grace Bikene, Centre de Recherches Médicales de Lambaréné, Lambaréné, Gabon

Kerstin Klipstein-Grobusch, Julius Global Health, Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Utrecht, The Netherlands, Division of Epidemiology, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa

Marieke J. van der Werf, European Centre for Disease Prevention and Control, Solna, Sweden

Martin P. Grobusch, Center of Tropical Medicine and Travel Medicine, Department of Infectious Diseases, Division of Internal Medicine, Academic Medical Center, University of Amsterdam, the Netherlands

Mischa A. H. Huson, Center of Tropical Medicine and Travel Medicine, Department of Infectious Diseases, Division of Internal Medicine, Academic Medical Center, University of Amsterdam, the Netherlands

Monwabisi Maqogi, Division of Social and Behavioural Sciences, School of Public Health and Family Medicine, University of Cape Town, Cape Town, South Africa

Myrthe M. de Laat, Center of Tropical Medicine and Travel Medicine, Department of Infectious Diseases, Division of Internal Medicine, Academic Medical Center, University of Amsterdam, The Netherlands

Nathan Kapata, The National TB/Leprosy Control Programme, Lusaka, Zambia, University of Zambia—University College London program, Lusaka, Zambia

Patrick F. Greve, Center of Tropical Medicine and Travel Medicine, Department of Infectious Diseases, Division of Internal Medicine, Academic Medical Center, University of Amsterdam, the Netherlands

René P.M. Gerrets, Faculty of Social and Behavioural Science, Department of Sociology and Anthropology, University of Amsterdam, Amsterdam, The Netherlands

René Spijker, Medical Library, Academic Medical Center, University of Amsterdam, Amsterdam, the Netherlands

Ruaraidh A. Hill, National Institute for Health and Care Excellence, Piccadilly Plaza, Manchester, UK; Health Services Research, University of Liverpool, Liverpool, UK

Sabine Bélard, Department of Pediatric Pneumology and Immunology, Charité Universitätsmedizin Berlin, Berlin, Germany

Saskia Janssen, Center of Tropical Medicine and Travel Medicine, Department of Infectious Diseases, Division of Internal Medicine, Academic Medical Center, University of Amsterdam, the Netherlands

Sophia G. de Vries, Center of Tropical Medicine and Travel Medicine, Department of Infectious Diseases, Division of Internal Medicine, Academic Medical Center, University of Amsterdam, The Netherlands

PHD PORTOFOLIO

Name PhD candidate: A.L. Cremers

PhD period: 2012 – 2018

Name PhD supervisors: Prof. M.P. Grobusch, Prof. A.P. Hardon, Dr. R.P.M. Gerrets

Courses

Theory course, UvA	2013
Methods course, UvA	2013
English Presentation, UvA	2015
French language course, Maison Descartes	2013
Human Rights & Medicine, UvA	2013
SIC Visual Methods, UvA	2014
Visual Methods, Manchester School of Media	2014
Xhosa language course, Cape Town	2014
Creative Writing, University of Cambridge	2015
Final Cut Pro edit course, UvA	2015

Presentations

Perceptions, health care seeking behaviour and implementation of a tuberculosis control programme in Lambaréné, Gabon. 16th International Congress on Infectious Disease, Cape Town, South Africa (poster)	2014
Tuberculosis patients' pre-hospital delay and non-compliance with a longstanding DOT programme: a mixed methods study in urban Zambia. 16th International Congress on Infectious Disease, Cape Town, South Africa (poster)	2014
Traditional Healers, Medical Doctors, and E-health. Dutch Albert Schweitzer Foundation (oral)	2014
Visual Methods in Health Research. University of Cape Town, Cape Town, South Africa (oral and visual)	2015
Panel Debate: the pros and cons of stories, images, personal narratives and messaging for reducing TB stigma at the community-level. Getting to Zero TB stigma, The Hague, the Netherlands (oral)	2017

Film screening 'TB in Town 2. A Visual Ethnography.'

University of Cape Town	2015
University of Leiden	2016
Academic Medical Center	2017
Camerawise, Documentary Institute Amsterdam	2017
Anthro screening, University of Amsterdam	2017
KNCV Tuberculosis Foundation, the Hague	2017
Amsterdam Institute for Global Health and Development	2018

49th Union World Conference on Lung Health, the Hague	2018
Conferences	
International Congress on Infectious Disease, Cape Town, South Africa	2014
Annual Meeting Amsterdam Public Health, Amsterdam	2017
Getting to Zero TB stigma, the Hague	2017
49th Union World Conference on Lung Health, the Hague	2018
Coordinator, Lecturer & Supervisor	
Course Global Health, Care & Society, UvA	2015–18
Course Medical Anthropology, AUC	2016
Minor Health, General Social Science, UvA	2016–17
Scientific internship, AMC	2014
Bachelor thesis, AMC	2015
Bachelor theses (18x), UvA	2015–17
Other	
Weekly meetings Tropical Centre, AMC	2013–18
Reviewer for BMC International Health & Human Rights	2014
Ethnographic Film screening, UvA	2014–15
Visual Anthropological group Camerawise, various universities	2015–16
Editor Innovation Document, KNCV Tuberculosis Foundation	2015–16
Reviewer for Journal of Tuberculosis and Lung Disease	2015–18
Anthroscreening, UvA	2015–18
TB stigma working group, KNCV TB Foundation	2016–18
Grants & Prizes	
Scholten-Cordes fonds	2013
KNCV Tuberculosis foundation	2013
AUF-Spinoza fonds	2013
European Center of Disease Prevention and Control	2014
Dutch Albert Schweitzer Price	2014, 2016
Price for best short story, University of Cambridge	2015
Diplomas	
Diplôme d'études en langue française (DELF) B2	2013
Filming for Fieldwork Certificate	2014
Creative Writing Certificate	2015

Publications included in the thesis

- Cremers AL, de Vries SG, Heuvelings CC, Greve PF, Visser BJ, B elard S, Janssen S, Spijker R, Shaw B, Hill RA, Zumla A, van der Werf MJ, Sandgren A, Grobusch MP. Barriers and facilitators for the uptake of tuberculosis diagnostic and treatment services by hard-to-reach populations in low and medium-incidence countries: A systematic review of qualitative literature. *Lancet Infectious disease* 2017; 17 (5): e128-e143.
- Cremers AL, Gerrets R, Grobusch MP. Visual ethnography: bridging anthropology and public health. *Practicing Anthropology* 2016; 38 (4): 7-11.
- Cremers AL. TB in Town 2: a visual ethnography. *49th Union World Conference on Lung Health 2018, The Hague*.
- Cremers AL, Gerrets RPM, Maqogi M, Colvin C, Grobusch MP. Resilience and survival: a visual ethnographic health study of patients with tuberculosis in Cape Town. *Under review*.
- Cremers AL, Gerrets R, Kapata N, Kabika A, Birnie E, Klipstein-Grobusch K, & Grobusch MP. Tuberculosis patients' pre-hospital delay and non-compliance with a longstanding DOT programme: a mixed methods study in urban Zambia. *BMC Public Health* 2016; 16 (1): 1130.
- Cremers AL, de Laat MM, Kapata N, Gerrets R, Klipstein-Grobusch K, Grobusch MP. Assessing the consequences of stigma for tuberculosis patients in urban Zambia. *PloS One* 2015; 10 (3): e0119861
- Cremers AL, Janssen S, Huson M, et al. Perceptions, health care seeking behaviour and implementation of a tuberculosis control programme in Lambar en , Gabon. *Public Health Action* 2013; 3 (4): 328-32.
- Cremers AL. Exploring processes of boundary-making and the concept of medical pluralism in Lambar en , Gabon. *Submitted*.

Publications not included in this thesis

- European Centre for Disease Prevention and Control. Guidance on tuberculosis control in vulnerable and hard-to-reach populations. 2016; DOI: 10.2900/72431
- Macintyre K, Bakker MI, Bergson S, Bhavaraju R, Bond V, Chikovore J, Colvin C, Craig GM, Cremers AL, Daftary A, and Engel N. Defining the research agenda to measure and reduce tuberculosis stigmas. *The international journal of tuberculosis and lung disease* 2017; 21 (11): S87-S96.
- Heuvelings CC, de Vries SG, Greve PF, Visser BJ, B elard S, Janssen S, Cremers AL, Spijker R, Shaw B, Hill RA, Zumla A, Sandgren A, van der Werf MJ, Grobusch MP. Effectiveness of interventions aiming at identifying and managing tuberculosis among hard-to-reach populations: A systematic review. *Lancet Infectious disease* 2017.
- Janssen S, Wieten RW, Stolp S, Cremers AL, Rossatanga EG, Klipstein-Grobusch

- K, Belard S, Grobusch MP. Factors Associated with Retention to Care in an HIV Clinic in Gabon, Central Africa. *PLoS One* 2015; 10 (10):e0140746.
- KNCV Tuberculosis Foundation. Innovation Document 2016-2020. The Hague, KNCV Tuberculosis Foundation, 2016. Internal document.
- Owusu E, Cremers AL, Brown C, Mens P, Grobusch MP. Knowledge, attitudes and practices regarding malaria in people living with HIV in rural and urban Ghana. *Acta Tropica* 2018; 181: 16-20.
- Heuvelings CBC, Greve PF, De Vries SG, Visser BJ, Janssen S, B elard S, Cremers AL, Spijker R, van der Werf MJ, Sandgren A, Grobusch MP. The effectiveness and cost-effectiveness of service models and organisational structures supporting TB identification and management of hard-to-reach groups in low incidence countries: a systematic review. *BMJ Open*, in press.
- Cremers AL, Gerrets RPM, Alege A, Osibogun A, Okwor T, van t Hoog A. Patients' and healthcare providers' perceptions and practices regarding hypertension, pharmacy-based care, and e-monitoring in Lagos, Nigeria - a mixed method study. *Submitted*.
- Nelissen HE, Cremers AL, Alege A, Van Leth F, Brewster L, Osibogun A, Okwor T, Van T Hoog A. Feasibility of a pharmacy-based hypertension care pilot using e-monitoring of patients in Lagos, Nigeria – a mixed-methods study. *Submitted*.

I WOULD LIKE TO THANK THE FOLLOWING PEOPLE

Martin, thank you for being so enthusiastic about my work. I am happy I could be the first anthropologist that you offered a PhD position. Thanks for your supervision and positive pep talks when I was struggling with this (interdisciplinary) research. For being open-minded about all my initiatives during this PhD and approving this dissertation to constitute both articles and a documentary. And much more important: thank you that you *koepelt* me to Emma.

Anita, thank you for being my second promotor and for connecting me to René. Hayley, thank you for all the communication.

René, your very sharp critical reflection on my research first discouraged me, but I soon realised this was the most fantastic and inspiring way of learning. You are the first one who made me reflect on every single word I wrote and who showed me the importance to choose these words carefully. Thank you for introducing me to the AIGHD. It was wonderful working with you, Anja, and Heleen on the research project about hypertension and e-health in Nigeria.

Martin and René, thanks for our meetings that were motivating and additionally showed me how different disciplines can be. Thank you for all the freedom you gave me during my PhD to choose my own path, methods, and topics. This made my research very interesting, creative, and exciting.

Thanks to the members of the committee for examining this dissertation.

My research respondents. Without you there would be no research. I wish you and your families a healthy life.

Saskia, my good friend and cousin, who informed me about the call for an anthropologist for a project in Gabon. If it wasn't for this, my PhD position wouldn't have been created. It was fantastic to live together in Gabon, South Africa, and now in the Sanderijnstraat. Thanks to your boyfriend Gys for all his help and foremost for his braai.

Grace, my research assistant and good friend in Gabon. You taught me a lot about your country, the variety of existing cultures, initiation rites, *veillées*, healers, and local medicines. Thanks for inviting me over to your family's house. Thanks to your mother for her openness, for her invitations to her healing rituals, for sharing how she worked as a traditional healer. Thank you Judith for introducing me to the various churches in Lambaréné and explaining the role of Christianity in your community.

Austin, my research assistant and good friend in Zambia. Thank you for venturing

in the townships even though you were not very familiar with these areas. For your endless curiosity and enthusiasm for your own country and all its churches, sub-cultures, and people.

Monwa, my research assistant and good friend in South Africa. I admire you for your history of resistance against Apartheid regime. And for your fight for a better life for the people in Khayelitsha. I always felt very safe around you, despite being in one of the most violent townships of South Africa. Thanks for connecting me to all your community members and making me feel at home in your house. I believe your work is invaluable to your people and wish you all the best in future.

Nokubonga, wife of Monwa, thank you for being there for me every morning during my fieldwork in Khayelitsha. For making me feel at home, for being my respondent and a good friend. When you passed away during one of our lengthy and warm conversations, I felt devastated. Because you are one of the main characters in my documentary, I hope everyone will remember you as the strong woman you were. I wish your eight children all the best.

Chumisa, George, Khulish, Tamtam, Nokuzola, Vuyelwa, Siyabonga, and Monwa, thank you for starring in my documentary *TB in Town 2*. For sharing your stories and putting a human face on the hardship of having TB. You have become friends and I hope we will keep in touch. George, you passed away just after my research, I will not forget you.

Chris and Alison, for being a huge support in South Africa. Without you, I would never had the courage and the network to plan the research that I was able to conduct in the end.

Thanks to every one of the Holland House in Gabon: Saskia, Mischa, Sebastiaan, and Astrid. (And Emma who was always visiting us.) Thanks to Lisa and of course Remy. I will not forget dancing with the mermaids in the Ogoouéguini, driving our car to the market (and avoiding gigantic speakers), and eating lots of mangos and piment.

Rosanne, Sophie, Lotje, Jimmy, Fred, Ewurama, Alinune, Marielle, Cornelis, and Nathan, it was great to do my PhD in your team of medical PhD-ers, for giving me a good time during the breaks (or during work time). For inspiring me, working together on a wide variety of projects, and to broaden my mind. Thank you Myrthe for figuring out SPSS and writing an article together. Jelle, thank you for all your entertaining stories and your fascinating ideas. You know I am still waiting for this AMC elephant trip.

Dorith, I think you have had the most intense experience with me and Emma. I hope you enjoyed this as much as we did! Thanks for all the fun, and of course your

PhD and life advice. Also thanks to Marieke and Jasmin, with whom we had a lot of feestlunches at the Voetenplein and in the sun.

Tine, you have been so involved with your PhD students. Thank you for answering all my questions, your management, and support during this PhD.

Michèle, thank you for all your advice regarding my career choices. Also thanks to the other staff from the Tropical Center of the AMC: Cees, Bram, and Pieter. Thank you all for the interesting, very medical, meetings on the Wednesday afternoons. You showed me how enthusiast medical doctors can be when they see a tropical worm pulled out of someone's eye. I am happy you can help these patients. Thanks to Ines, Bjorna, Beatrix, Loan, Moniek, Ingrid for making the Tropical Center such a lively place to work.

Janine en Ildiko, thank you for encouraging me to develop my first version of *TB in Town 2* in a documentary and for giving me valuable feedback. Thanks to the visual anthropologists involved in the inspiring group Camerawise and the monthly anthroscreening. Special thanks to Ildiko, Hilbert, Matthijs, Fien, Marijn, Ronja, and Anja. Daniel, you have become a very good friend. The conversations with you always led to new ways of doing, seeing, or filming!

Nastasha, Natashe, Lianne, Mark, Carola, and all other colleagues at the UvA, thanks for being friends, the spontaneous lunches, the revision of each other's work.

Danny, for teaching Global Health together and giving me the opportunity to screen many versions of my documentary to the students. Thank you also for pulling me on board of all the various Global Health projects that enabled me to wrap up this PhD.

Hilbert, thank you for welcoming me at DIA: a fantastic place where not a single corner is left unutilized and funny texts spice up your thoughts. Thank you for helping me with editing my documentary and for all your advice. Also thanks to Jennifer for her advice.

Michael, Monica, Ellen and all the others of KNCV Tuberculosis Foundation, thank you for our wonderful projects together in order to fight TB. Thank you Frank for introducing me. You all do wonderful work and I truly hope that one day the world will be free of this disease.

Bas, Astou, and Emma Lesuis, thanks for the many tips and tricks regarding documentary, story line, edit, special effects, sound, and music. Thank you Christian for doing the sound design and music composition and introducing me to the world of sound.

My friends, thank you for being there for me during this six years of work. Clara and Thom, for having a good time in Gabon and South Africa. David, for reading my work.

Jill, my good friend, thank you for making the cover of this dissertation. You have beautifully captured the pain and sadness of one my respondents, so illustrative for the majority of TB patients. This deeply touched me. Thanks for the drawings of every chapter, I am one of the biggest fans of your art. Thanks to your friend Bas Reijnen who created the lay out of this dissertation with a lot of patience, precision, and creativity. The result of your combined efforts are impressive.

The Birnies, thank you for being my new family and treating me like a daughter and sister. Liesbeth and Jeroen, thank you for all your support, for attending my film screening, and reading my work. Special thanks to Jeroen, who made me much more business-minded.

Gwen, my good friend and cousin, who often proofread my work, with whom I have had good discussions about the content of this work and about the important things in life. Who is always there for me and with whom I follow a similar life path regarding education, work, and love.

My family, I am unbelievable happy that we are so close. Papa, mama, thank you for supporting me, for always being proud, for attending my presentations, and reading my work. My brother, sisters and their families, Paul, Sanne, Nora, Lucas, Willemijn, Rolf, Elleke, Rozemarijn, and Julia, thank you for being there for me and for always being interested. For visiting me in almost every country I have lived.

Love of my life, Emma Birnie. I met you in Gabon, just at the start of this PhD. Thank you for hunting me down and showing me that life together is thrilling. You are one of the most curious, inspiring, and energetic people I know. I couldn't have done this PhD without you. You revised all my articles, made sure I corrected all my references, discussed the story line of my documentary endlessly, loved joining me during my fieldwork, and got to know all my research assistants and most of my respondents. You are one of the few people I know that feels at home anywhere in the world and quickly connects to people, and most important, you make me laugh a lot. Thank you for making me the happiest woman in the world.

CURRICULUM VITAE

Lianne Cremers was born in Leiden on Sunday 23rd of March, 1986. After secondary school at the Stedelijk Gymnasium Leiden, she lived in Oxford for one year and worked as an au pair. Inspired by the multicultural student environment, she returned to the Netherlands to study social and cultural anthropology at the VU University Amsterdam. She studied half a year in La Paz, Bolivia. In between her bachelor and master she worked in Pokhara, Nepal at a local NGO that aimed at improving education in rural areas. She decided to follow a second master in Governance at the VU University. Fascinated about medical anthropology, she started working as an anthropologist for a clinical study on TB in Lambaréné, Gabon. In this little village in the jungle, she met the love of her life. Additionally, she was offered to continue her research in the form of a PhD at the Academic Medical Center with a focus on patients' experience of tuberculosis and National TB Programmes in sub-Saharan Africa. She involved the anthropological department of the University of Amsterdam to give her research an interdisciplinary character. During her PhD, she conducted research in Zambia and South Africa using a variety of methods, such as ethnographic, qualitative, and quantitative methods. Fascinated by documentary as a medium for research, she got trained as a visual anthropologist in Manchester. She made an ethnographic documentary for her PhD thesis to not only write, but to additionally show what TB means for patients who are living in South Africa. In 2015, she started her own business and worked as a freelance anthropologist. She lectured the course Global Health, Care & Society at the University of Amsterdam and the course Medical Anthropology at the Amsterdam University College. Moreover, she conducted various research projects in the field of tuberculosis, hypertension, e-health, community preparedness, and HIV for a variety of organizations, such as the KNCV Tuberculosis foundation, the AIGHD, ECDC, and the AIDS foundation. Additionally, she works as a documentary maker. She lives with her fiancée Emma Birnie in Amsterdam.





ISBN 978-94-6332-362-8