Daily Trials

Lay engagement in transnational medical research in Lusaka, Zambia

Bruun, Birgitte

Publication date:
2014

Document version
Early version, also known as pre-print

Citation for published version (APA):
Bruun, B. (2014). *Daily Trials: Lay engagement in transnational medical research in Lusaka, Zambia*.

DAILY TRIALS

Lay engagement in transnational medical research projects in Lusaka, Zambia

Birgitte Bruun

Thesis submitted for the degree of Doctor of Philosophy of the University of London

February 2014

Department of Public Health and Policy

London School of Hygiene and Tropical Medicine

Declaration

I, Birgitte Bruun, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed: Date:

Declaration of third party involvement

I, Birgitte Bruun, declare that this thesis has been proof read by a professional proof reader, Jonathan Ingoldby. I confirm that this process has not introduced changes to the content or substance of the thesis.

Signed: Date:

Abstract

This anthropological thesis explores dimensions of lay people's trajectories of engagement in donor-funded transnational medical research projects for public health purposes in Lusaka.

The thesis offers an ethnographic contribution to debates about transnational medical research in less privileged settings that are otherwise often framed as a matter of research ethics or political economy. Rather than looking at transnational medical research projects in terms of their purpose and the ethics, politics and economics of their transnational character, transnational medical research projects are explored as part of a wider landscape of health and social development projects and interventions in Lusaka. Lay people variously engage in this landscape of projects as research subjects, recruiters, peer educators, outreach workers and community representatives. Depending on experience and relations, the same lay people may shift pragmatically between engaging in transnational medical research projects as sources of health care, as development projects and as medical research projects.

Furthermore, exploring trajectories of engagement in transnational medical research and other projects by lay people with situated concerns and aspirations the thesis argues that lay engagement is about learning a pragmatic attentiveness to possibilities and dangers in such projects that may stretch beyond both the purpose and the timeframe of the individual medical research project. Both the process of learning how to be in such projects, and the realisation of possibilities and dangers associated with them, are deeply embedded in – sometimes precarious – relations, not only with project staff, but also with partners, relatives, friends, neighbours and peers, that are animated by the virtue and obligation of sharing.

The thesis closes by proposing how attention to obligations could become a more explicit element in the implementation of transnational medical research.

Acknowledgements

This thesis was made possible by the patient engagement of many people and institutions. My main supervisor, Paul Wenzel Geissler, first agreed to the idea and later the Danish Research School for Anthropology and Ethnography granted me the internationalisation stipend that was made available by the Danish Research Council. This grant allowed me to enrol in what is now the Department of Global Health & Development at the London School of Hygiene and Tropical Medicine, while being employed at the Institute of Anthropology, University of Copenhagen and affiliated to what was then the DBL – Centre for Health Research and Development in Copenhagen.

During my stays at LSHTM in London I enjoyed the always inspiring company of members of the Martin Okonji Research Group for Anthropologies of African Biosciences (now at Cambridge) and the kind support by Linda Amarfio. James Fairhead, member of my advisory committee, provided important input to my project before my upgrading that was completed with constructive ideas by my upgrading committee that consisted of Melissa Parker and Karina Kielmann.

In Lusaka many people must be acknowledged for their professional and personal engagement. Member of the Martin Okonji Research Group for Anthropologies of African Biosciences, Bornwell Sikateyo, offered indispensable advice about how to settle as a researcher in Lusaka and my family and I enjoyed his hospitality very much. Virginia Bond, who is probably contacted by most Britain-based researchers hoping to work on health in Lusaka took time to also welcome me. She helped me with many first contacts and her kind attention quickly made Lusaka feel familiar. Philimon Ndubani agreed to supervise me in my affiliation with INESOR at the University of Zambia and he offered many useful suggestions about how to cut my field. I enjoyed inspiring conversations with Walima Kalusa, and I was very happy to work with his daughter, Hope, as one of my transcribers. Olivious, whom I met through Virginia Bond, was the other transcriber. A travel scholarship from the Nordic Africa Institute in Uppsala contributed to covering fieldwork expenses in Lusaka.

To protect the anonymity of my interlocutors and guides, I cannot name the people that I owe the most in Lusaka. While we were together I made efforts to share, but for many, I have surely been just another researcher passing through. For others, I hope I opened possibilities that were relevant for them – at least for a while. Being together with the people that I call Tabita, Albetina, Emelda, Estina, Lukonde, Linda, Brenda, Rose, Mr Lungu, Richard, Chibuye, Joyce, Joanna, Auntie Loveness, Elisabeth, Charles, and Precious in Lusaka remains a learning experience in so many more ways than this thesis can reflect.

In Copenhagen, at the Institute of Anthropology, University of Copenhagen, Karen Fog Olwig was my patient grant holder. Jørgen Pedersen and later Tine

Faghtman managed the administration of my file. During write up I received a grant to stay at Løgumkloster Refugium for a week.

My supervisors have kept opening both my field and the discipline for me. My main supervisor, Paul Wenzel Geissler, at LSHTM, stimulated my curiosity for different analytical landscapes that the ones I came from and kept asking me the necessary questions. His encouragement never faltered and his patient engagement continued after he moved to Oslo University. My other supervisor, Susan Reynolds Whyte, has set both a professional and personal example for me since I first enrolled at the Institute of Anthropology in Copenhagen. Her ways of listening and being attentive, and her apparently simple questions, have been deeply inspiring. Jens Aagaard Hansen, whose advice I have also been privileged to enjoy over many years, provided supportive, and once again, very patient feed-back on the final (and once again delayed) draft.

Clare Chandler, at LSHTM, took me in towards the end of writing up. Her suggestions, help and encouragement in the last hectic months were just great. Jon Ingoldby took very professional care of the proof-reading. Remaining errors are due to last minute editing by myself.

Colleagues at the Institute of Anthropology in Copenhagen were discerning readers, careful critics, and fellow explorers of what is at all knowable, and how, in the terrain of anthropology as a discipline. They included Astrid Oberborbeck Andersen, Ditte Marie Nissen Storgaard, Kristina Grünenberg, Lise Rosendal Østergaard, Sara Lei Sparre, Sidsel Busch, Tamta Khalvasi, and Trine Brinkmann. I have thoroughly enjoyed how both creativity and friendship has grown out of our shared situation.

My friend and fellow anthropologist, Grete Brorholt, helped me stay on track during the long period where I explored analytical possibilities. Meeting her every Monday evening for months kept me on track. Janne Bjerre Christensen offered the most invigorating pep-talks during the last tough month.

My parents, my brothers, their families, and my friends have all surrounded me with very sensitively dosed inquiries into my work and diversions from it. I particularly thank my parents and my cousin Mette who was with us for a while in Lusaka, my friend Mette and my goddaughter Cora, for staying close to my husband and children when I was away to work.

I was on the PhD track before I met my husband, Hazim, who had never imagined that he would be obliged to move to London and Lusaka as part of his marital relationship. Luckily, he accepted these movements as part of the package, and he is still around – two daughters and too many single Dad Saturdays later.

Needless to say, I stay responsible for the choices and arguments in this thesis. All gaps, errors and inaccuracies are my own.

To the institutions and to all the individuals who engaged in this project, whether mentioned here or included in my memory, I give my deepest, most respectful and heartfelt thanks.

Table of Contents

CHAPTER 1: INTRODUCTION

CHAPTER 2: A JOURNEY THROUGH THE HISTORY AND LANDSCAPE OF INTERVENTIONS IN LUSAKA

CHAPTER 3: THE FIELD-SITES, THE FIELDWORK AND THE ANALYSIS

CHAPTER 4: LEARNING HOW TO ENGAGE

CHAPTER 5: REALISING POSSIBILITIES

CHAPTER 6: MAKING A CAREER

CHAPTER 7: SHARING POSSIBILITIES

Maps

Figures

Tables

List of abbreviations

ART	Antiretroviral Therapy
AZT	Zidovudine (retrovir) for treatment of HIV infection
BCG	Vaccine against Tuberculosis (Bacillus Calmette-Guérin)
CAB	Community Advisory Board
CCF	Christian Children's Fund of Ireland
CDC	Centers for Disease Control and Prevention
CHAZ	Churches Health Association of Zambia
CHD	Community for Human Development
CHP	Child Health Promoter
CIDRZ	Centre for Infectious Disease Research in Zambia
DHMT	District Health Management Team
ECDTP	European & Developing Countries Clinical Trials Partnership
EU	European Union
FHI	Family Health International
GDP	gross domestic product
GFATM	Global Fund to fight AIDS, Tuberculosis and Malaria
HPTN	HIV Prevention Trial Network
IBFAN	International Baby Food Action Network
INA	Influential Network Agent
INESOR	Institute of Economic and Social Research
JICA	Japanese International Cooperation Agency
KARA	KARA Counselling and Training Trust
LSHTM	London School of Hygiene and Tropical Medicine
MCH	Mother and Child Health
MMD	Movement for Multiparty Democracy
MRC	Medical Research Council

NGO	non-governmental organisation
NGOCC	Non-Governmental Organisation Coordinating Council
NHC	Neighbourhood Health Committee
NIH	National Institutes of Health
PCR	Polymerase chain reaction test that can test for HIV and viral load of HIV
PEPFAR	President’s Emergency Plan For AIDS Relief
PF	Patriotic Front
PMCTC	Prevention of Mother the Child Transmission
PPP	public-private partnership
RAPIDS	Reaching HIV/AIDS Affected People with Integrated Development and Support
RLI	Rhodes-Livingstone Institute (now INESOR)
UCZ	United Church of Zambia
UNIP	United National Independence Party
UNZA	University of Zambia
UTH	University Teaching Hospital
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation
ZAMBART	Zambia AIDS Related Tuberculosis Project
ZAMSTAR	Zambia/South Africa TB and AIDS Reduction Project
ZEHRP	Zambia-Emory HIV Research
ZMK	Zambian kwacha (before 1 January 2013)
ZMW	Zambian kwacha (after 1 January 2013)

List of interlocutors (all names are pseudonyms)

Albetina	Tabitas’ friend, in her early 20s, had completed grade 9, lived with her husband and had three children. Albetina was in the CIDRZ microbicide trial.
Auntie Loveness	in her mid-50s, widow, member of the “Top 10” of the Neighbourhood Health Committee at a district clinic, outreach worker for CIDRZ.
Brenda	Tabita’s friend, in her late teens, had completed grade 9, lived with husband and their young child.
Charles	about 30 years old. Member of the Community Advisory Board (CAB) of the CIDRZ microbicide trial.
Elisabeth	in her late 40s, member of the Community Advisory Board of the CIDRZ microbicide trial, VCT counsellor at the clinic and volunteers to teach the Bible in community schools. Volunteer at a district clinic.
Emelda	Tabita’s friend, 21 years old, had a 4 year old child, was in the CIDRZ microbicide trial.
Estina	19 years old, Tabita’s friend, completed grade 8, lived with mother, brother and two children of a late sister. Estina was in the CIDRZ microbicide trial.
Linda	22 years old, Tabita’s cousin, has an infant, completed grade 7, lived with her mother, five brothers, four sisters and her mother’s sister. Linda was in the CIDRZ microbicide trial.
Lukonde	Tabita’s friend, about 25 years old. Lukonde had completed grade 5, she had three children and made a living from selling groundnuts in the market. Her husband had recently left her.
Joanna	in her late 20s, close friend of Joyce, recruiter for ZEHRP, study subject and peer-educator in the CIDRZ microbicide study.
Joyce	in her early 20s, close friend of Joanna, recruiter for ZEHRP, study subject and peer-educator in the CIDRZ microbicide study.
Malala	in her late 20s. Lived with her husband and their four children. Was in two studies on HIV and nutrition.
Mr Lungu	Rose’s husband.

Mr Chishimba	in his late 50s. Member of the “Top 10” of the Neighbourhood Health Committee.
Mrs Mwale	in her 50s. Member of the “Top 10” of the Neighbourhood Health Committee. Outreach worker for CIDRZ.
Precious	in her late 20s, my guide, volunteer at the clinic, former study subject, recruiter for ZEHRP and CIDRZ, leader of a women’s group, volunteered in three different nutrition programmes at one of the clinics.
Richard	about 40, founder and finance officer of NGO to assist orphans and grandparents outside Lusaka.
Rose	about 35, completed grade 9, six children, member of Precious’ women’s group, trained in home-based care by CARE International, recruiter for ZEHRP.
Tabita	in her early 20s, Auntie Loveness’ granddaughter, completed grade 9, lived with mother, three brothers, two sisters, an uncle and a cousin. Tabita was in the CIDRZ microbicide trial.
Vainess	in her 30s, member of Precious women’s group, became a widow during my stay.

List of organisations

CARE	Care International, international humanitarian organisation working on development issues in both rural and urban Zambia since 1992.
CCF	Christian Children's Fund of Ireland working in Zambia since 1983.
CHAZ	Churches Health Association of Zambia, established in 1970. CHAZ provides 30% of health care services in Zambia.
CHD	Community for Human Development, a Zambian NGO established in 1999. Programmes include home based care for the chronically ill, rural development, education and child survival, and micro-enterprise.
CIDRZ	Centre for Infectious Disease Research in Zambia, an NGO established in 2001 in collaboration with the University of Alabama at Birmingham (UAB), USA. CIDRZ conducts research, training and service delivery in the area of HIV/AIDS prevention and treatment, and maternal-child health.
FHI	Family Health International, international development organisation working in Zambia since the early 2000s.
KARA	KARA Counselling and Training Trust was established in 1989 as one of the first Zambian NGOs to address HIV and AIDS. KARA used to train, hire and pay VCT counsellors. At the time of my fieldwork the NGO operated both from its own facilities and from district clinics in Lusaka. Its ART clinic in Lusaka was funded by CIDRZ.
NEW START	HIV counselling and testing services run as a private (for fees, but not for profit) social franchise by Society for Family Health, a local NGO established in 1992 and affiliated to the international NGO Population Services International, funded by USAID/PEPFAR. New Start opened its first facility in Lusaka in 2002.
NGOCC	Non-Governmental Organisation Coordinating Council, umbrella organisations formed in 1985 for Zambian NGOs working with women and development.
RAPIDS	Reaching HIV/AIDS Affected People with Integrated Development and Support, a project by a consortium running from 2004-2010 and led by World Vision International in partnership with Africare, Catholic Relief Services (CRS), Expanded Church Response (ECR), Salvation Army, World Vision Zambia, and the Population Council. RAPIDS provided home- and community-based care for people living with AIDS, care and support for

	Orphans and vulnerable children, youth livelihood and promotion of abstinence among youth, and household resilience and improved food security for those affected by HIV/AIDS.
UCZ	United Church of Zambia, founded in 1965 by the merging of four protestant mission societies.
ZEHRP	Zambia-Emory HIV Research Project was established in 1994 in collaboration with Emory University, USA, with a focus on couple's VCT and HIV prevention and treatment. ZEHRP conducts research, training and service delivery in the area of HIV prevention and treatment.

Chapter 1

Introduction

> *Okay, the thing was I heard he was helping people if you have any problem you go there, you explain your problem then he will assist you. Not really that I went there for trials, no. So when I went there I told them where I live and they wrote it down. Okay, then for me to know that this doctor was conducting a study, it was later when the doctor said he wanted me to go for endoscopy. So, at first in my mind there was nothing like I am supposed to go for… Let me just say that I was ignorant by that time.*

This was how Malala, a woman in her early 30s, recalled her first encounter with transnational medical research run by a foreign doctor in Lusaka, Zambia. This encounter turned into a longer trajectory of engagement in transnational medical research projects for her in various capacities. Such trajectories are the empirical and analytical starting point for this anthropological thesis that explores dimensions of lay people's engagement in transnational medical research projects. What follows is a condensed account of what happened next in Malala's trajectory, as she told it to me:

> *But I joined, so that's how I went there. Then we went for the endoscopy. I was afraid, it is good that they kill us a bit. He did whatever he was supposed to do. Then we came back here. Before we went, he said "I will come and tell you the results" […] Then he said there was an issue of asking me "if you want to go for HIV test. It is voluntary, so it is up to you to decide whether to go for it or refuse." "I refuse," I said, "I think I am not ready." He came here to tell me the results. He never told me anything about the HIV because I refused. Then he told me that I was anaemic. He said, "I think you have to take some tablets so that at least you gain." Then he gave me some tablets, it was a prescription. I went to his assistants and they went in town, bought those medicines for me. I took them, then I went again for the second endoscopy. When I went there, he said "At least now you are much better, but I can advise you at least take a test of HIV, you have to free your mind," but I still said "No, for this time I am not ready." Okay, now by that time I had a baby, my last born, this child was very sick. The doctor was the one who helped me to take this child to UTH. I took him there, but first he gave me a note to give to a certain doctor. By the time I was going to the township clinic they never used to do anything, so in that way the doctor helped me a lot when I took*

that paper to the other doctor at UTH. He said the child will get ok. The child was found with TB and he got on drugs.

Now we continued with that study until it ended and then in the second study we were […] in the first study we were about 500 families, so in the second study I was told that "Malala, I think they let you be in the study because they are just choosing people, they won't get the whole group. We will just choose about 100 people." So this is when I got the knowledge, because they called us to have a meeting about his next study. So when we went there, that's when my brain opened. In the first study we were given some tablets, some vitamin tablets. We were given those tablets, taking them once a day. Now, we were taking them, but not fully aware about what we were doing, just taking them. We thought maybe us people in these shanty compounds sometimes we lack some fruits, so we were told that in those tablets there is everything. Some used to take them. Now, when you take those tablets you feel very hungry and the heart beat pumping a lot, you have a lot of appetite. We used to take them if there is food. But we were told these tablets they are very healthy and I remember the time the project finished we were called for a celebration there at Mike's Car Wash and at least we never had much cholera as we are having this year. It helped a lot.

We are now in this study. They said "for this study we are not going to give some tablets, it will be through a vaccine. We will see how this drug will work in a human being." I said "Now suppose the drug does not work, I mean the vaccine does not work well in a human being, have you ever tried this in some other countries?" Then they said, "Yes, we have tried this, except that in other countries the only reports were that they just experienced some silly noise in the womb […] But there is nothing harmful," so mainly I joined because sometimes we do fail, maybe, to buy medicine when we are sick, so again I was thinking: "Now suppose the medicine does not work well in me, what will happen if I die?" Because for me to join any programme I have to sign, meaning that I have accepted what someone wants. But again I was thinking that when you go to UTH when you are sick, what they do is that they will try different medicine to see which one will work. They will try this and that, that's the University Teaching Hospital. The doctor can easily […] he is also a human being, he can't kill us. This is the main reason, why […] because the child is sick and he is there for me if you cannot afford. Sometimes others pay for endoscopy if there is a problem in the womb, but him, he is just sacrificing: "let me help this person", although he is also studying. We are helping him and he is also helping us."

The interview continued and turned to the topic of the way she had checked with others whether the doctor was a Satanist, and how her husband had also been enrolled, but that he dropped out because he was too busy. Malala and her husband ran a relatively large grocery store in a high-density area on the south-

> western fringe of Lusaka, where they lived. The interview gradually turned into conversation about other things, but Malala returned to talking about the HIV test, asking me whether I thought she should take it. She had heard about the Well Woman study, another medical research project at one of the public clinics, but when she heard that it involved an HIV test she decided not to go. Later in the conversation she returned to the issue again. She said that she did not want to be laughed at.
>
> Towards the end of my fieldwork period in Lusaka, Malala was called to work as a recruiter for a project on moderately malnourished children run by a colleague of the doctor. I met her walking on the main gravel thoroughfare in the compound where she worked, carrying an alcoholic hand cleaner in her belt to use after touching children with edema. She had agreed to the job offer, she told me, because the doctor had once helped her when her own child had been seriously sick. It was sometimes difficult to recruit mothers, however, so they often had to go many times to the same mother. The children were referred to UTH where they were given Plumpy'nut (a ready-to-use therapeutic food) to get better. Malala was paid ZMK 750,000 pr. month (GBP 108) for the job and she enjoyed it. I asked her a bit more about the purpose of the project but she had not heard anything about the project being a research project. I can't tell whether she, in fact, did not know, or would rather not tell me, but I did not pursue the topic.

Rather than characterizing the typical, this account of Malala's trajectory of engagement in transnational medical research is meant to describe the particular that gives occasion to illuminate more general dimensions in the way lay people weave transnational medical research projects into their daily lives in contemporary Lusaka. How do lay people engage in these projects? What does lay people's engagement make transnational medical research? Who do lay people become themselves as they engage? These are the overall questions that this anthropological thesis will address.

The problem

During the 1990s there was a massive expansion of industry-funded transnational medical research in less resourceful countries, mainly in Eastern Europe, Latin America and Asia. In the critical anthropological debates that followed this expansion was often framed as a matter of research ethics or of structural inequalities on a global scale (Petryna, 2005; 2009; Rajan, 2005; 2007). In the middle of the subsequent decade, the 2000s, another expansion of transnational medical research, or global health science, began - this time in Africa and funded by state and philanthropic donors for public health purposes. This expansion has paradoxically both generated and relied upon the inequalities between the implied countries, organisations and human resources that it seeks to end (Crane, 2013).

I will review the important and timely studies of these developments in more detail below, but here I will point to an aspect of transnational medical research – whether industry funded or funded by state and philanthropic donors – that many of these studies left largely unaddressed, namely the expectations, hopes and concerns of the lay people that were involved in such transnational medical research studies in various capacities as study subjects, peer educators, outreach workers and community representatives.

Lay expectations, hopes and concerns have already attracted academic attention, but studies have tended to situate them either in the context of the particular procedures of medical research projects, such as blood-taking and informed consent, which were then fed back into wider critical debates about the ethics and politics of transnational medical research (e.g. Geissler et al., 2008; Molyneux et al., 2004), or they were addressed as a matter of new biopolitical subject positions made available by the expansion of transnational medical research. With a focus on industry-funded research, Sunder Rajan, for example, has suggested that the technoscientific co-emergence of market and life-sciences in India configures a particular type of subject, i.e. the experimental subject of global genomics research (Rajan, 2005). With a focus on state and donor-funded research for public health purposes in Africa, others have noted how new relationships and collectives emerge around transnational medical research interventions, such as trial or cohort membership and community advisory board membership that may foster a sense of belonging to research organisations, rather than to the state, thus influencing subjectivities and identities (Fairhead et al., 2006a; Geissler, In press).

In sum, previous studies of both industry-funded, and state and donor-funded transnational medical research have addressed issues of inequality and subjectivity within the context of the ethics, political economy and procedures of globalizing health science. In this thesis I will explore similar issues, but situated within a different context.

This thesis explores dimensions in lay engagement in donor-funded transnational medical research for public health purposes in Lusaka in the context of how lay people engaged in other health and social development projects. Suspending pertinent issues of ethics and political economy for a while, I will show how lay people engaged in transnational medical research projects and what they meant to my interlocutors. Unlike other contemporary studies of transnational medical research, I have followed my interlocutors' trajectories through research projects and other interventions in one location, instead of focusing on one aspect of research procedures (e.g. informed consent); on one particular project (e.g. prevention of mother to child transmission of HIV); or on one research organisation (e.g. Medical Research Council (MRC)). Rather than studying the practices and organisation of transnational medical research, I have explored how people move between medical research projects in a wider landscape of projects and interventions. This ethnographic insight not only illuminates how lay people come to see a wide variety of possibilities in these projects and how they go about handling these possibilities, but it also has the potential to offer new input to academic reflections about inequalities and selves in transnational medical research and to debates about what is important in the conduct of such research.

Towards the end of this introduction I will try to specify in more detail how my ethnographic approach might contribute to studies of transnational medical research, but first I will offer a brief history of medical research in Africa, followed by a presentation of my analytical approach and how it figures among previous studies of transnational medical research.

Transnational medical research in sub-Saharan Africa

Since the early 1990s, industry-funded clinical trials initiated by pharmaceutical companies based in Europe and the USA have been outsourced to private companies operating in middle- and low income countries, including countries in Africa. The commercial logic and problematic ethics of this new and rather massive off-shoring or globalisation of industry-funded clinical trials have been documented and discussed fairly extensively (Glickman et al., 2009; Leger, 2008; Petryna, 2006; 2009). Meanwhile, trends in the volume of clinical trials and other medical research that have been funded by state and philanthropic donors for public health purposes in other, often poorer countries, has mobilised relatively less academic attention until recently (e.g. Geissler and Molyneux, 2011). There is no doubt, however, that transnational medical research for improving public health in sub-Saharan Africa also expanded since the early 1990s. Particularly the HIV epidemic has sent prestigious American universities scrambling for Africa in search for hospitals where they can base their international HIV and global health research (Crane, 2011). Within a decade this has made Africa a key locus of knowledge production in HIV and global health research. In principle, the contributions from participating countries may be similar, but for medical research in sub-Saharan Africa and many other places, expertise, funding and leadership have tended to come from wealthier countries, whereas lower income countries have generally contributed labour and study participants.[1] Paradoxically, global health research partnerships across scales of privilege/economic resources not only benefit from the inequalities that they hope to redress, but may also reproduce them (Crane, 2013).

The expansion of transnational medical research since the 1990s is a new development, but the fact that publicly funded medical research in Africa is transnational is not new. Following independence, many new countries developed national medical research programmes, but such programmes were often extensively funded and planned by foreign research institutions (the American Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH); the British MRC; The British Wellcome Trust), sometimes channelled through multilateral agencies, such as the World Health Organisation (WHO), and conducted in

---

[1] In many state and philanthropically funded research projects it is an explicit aim to transfer authority, expertise and the building of capacity for research and leadership to the participating lower income countries. However, where leadership has been formally transferred to African institutions, the vast majority of funding still comes from abroad with the complexities that this entails in terms of priority-setting. Besides, much planning and analysis of data are still conducted outside Africa (Binka, 2005; Geissler, 2011b).

collaboration with large American and national university hospitals or health research institutions (Geissler, In press).

Transnational ties regarding medical research in post-independence Africa were of course often rooted in colonial history as medical research has taken place practically since the first colonisers established themselves on the continent (Arnold, 1996). The very history of biomedicine becoming a modern science is closely tied to medical research being carried out by more privileged institutions in less privileged populations, often in colonial territories (see Tilley, 2011). In Africa, the relationship was not a simple matter of biomedicine being instrumental for the purposes of the colonial state. Jean Comaroff has suggested that biomedicine and imperialism – in all their internal variations and self-contradictions – evolved by continuously justifying each other in a process that led to great authority for both science and empire (Comaroff, 1993:306; see also MacLeod, 2000).

Historians have not only highlighted how colonial medical research was a matter of the relation between politics and science, or authority and knowledge, but also a matter of identities and aspirations. The issue of difference between Europeans and Africans, for example, has been illuminated as a constant theme with different articulations in health and research policies, including the objectification of Africans by colonial medical discourses (Vaughan, 1991). By referring to “nature”, medical experiments and arguments were used in support of racial segregation and to reduce mortality of the so-called “tropical workers” in the Northern Rhodesian (now Zambian) mines until around the 1930s (Packard, 1993). Gradually, medical research and disease control programmes became components in more complex colonial ideologies of social concern for workers’ health and welfare (Hoppe, 2003). In the Zambian Copperbelt, this vision was mixed with economic and moral ambitions of regulating (or controlling) labourers into becoming modern and moderate members of a new working class (or consumers) – a vision that to a certain extent came to resonate with workers’ images of themselves as modern and urban (Schumaker, Forthcoming). Indeed, locals reshaped and translated artefacts and opportunities created by colonial medicine according to their various aspirations (Hunt, 1999) and fears (White, 1995). Particularly "middle-figures" or translators, such as African teachers, nurses and midwives (Hunt, 1999), and research assistants (Geissler, 2011a), played a crucial role in the workings of colonial medical research as "central to processes of translation in colonial therapeutic economy" (Hunt, 1999:2).[2] I will return to the notion of middle-figures in the presentation of my analytical approach below.

Contemporary transnational medical research in Zambia

The information in this section is based on interviews conducted in Lusaka with medical and other researchers. Before the 1990s, medical research was mainly carried out by a few doctors at the University Teaching Hospital in Lusaka, who had often studied abroad and succeeded in raising funds through personal contacts outside Zambia. Smaller research projects funded by WHO focusing on malaria and other parasitic infections were carried out in different parts of Zambia. With the massive international attention and funding to HIV and AIDS in the late 1990s there was a leap in scale and complexity of studies as new collaborators approached the University Teaching Hospital in Lusaka. As I will describe in more detail in the next chapter a significant amount of research also took place within the district clinics, or in stand-alone research clinics, run by transnational research organisations. Today a few larger transnational research organisations have established themselves firmly in Lusaka, funded by American or British state and philanthropic donors as well as the European Union (EU).

Some research organisations have evolved from pure research organisations into organisations that also provide health services in collaboration with the Zambian Ministry of Health, such as ARV distribution, HIV testing, prevention of mother to child transmission, and cervical cancer screening. They have invested heavily in infrastructure, such as laboratories, clinics and a hospital wing, as well as data management systems and the upgrading of various human resources. Most studies are related to HIV, AIDS, TB and related conditions. Depending on the set-up of the studies, these research organisations engage non-professional locals as study subjects,

---

[2] Schumaker has described how research assistants were, of course, also crucial "'middle-figures" in anthropological research at the Rhodes Livingstone Institute (Schumaker, 2001, esp. chapter 7).

peer educators, outreach workers, recruiters, research assistants or community advisory board members.

As NGOs providing services, building infrastructure and hiring local people to work on HIV and other health issues, transnational medical research projects can appear quite similar to other transnational and national NGOs working in health and social development in Lusaka. This is an observation that I will elaborate considerably in the coming chapters, but here I will present my approach to studying how people move in this landscape of projects with a particular emphasis on their engagement in medical research projects.

Trajectories of lay engagement in a wider landscape of projects

As this thesis will show, there are many projects and organisations in Lusaka that engage lay people. Key to my exploration of their engagement are the two notions of ‘trajectories of engagement’ and ‘landscape of projects’. In this section I will present some theoretical underpinnings of these two notions. I begin from the end of the headline above and explain how I look at *projects*, before I describe in more detail how I approach the *landscape* of projects. I will define my use of the term *engagement* and then present the explanatory value of *trajectories* as an analytical term.

Projects

Medical research projects have a particular purpose, i.e. to produce new scientific knowledge, which can be seen as their defining feature. However, as I will emphasise in this thesis, medical research projects are also facilities and infrastructure in particular places and for particular periods. They are organisations that involve many kinds of staff, both lay and professional, and they are linked to other organisations in Lusaka and beyond. They involve activities that include appointments, meetings and transport, and they include things, such as certificates, medicines and cars. Looking at medical research projects from this perspective they may not appear very different from other health and development projects that are carried out in Lusaka.

Looking at medical research projects and other projects in this way, as organisation, bureaucracy and technologies, they can be understood as expressions of biopolitics that express particular ideas about life and knowledge and that forge particular subjectivities. Drawing from Foucault,[3] Nicolas Rose applies the term "biopolitics" to highlight strategies that involve *"contestations over the ways in which human vitality, morbidity, and mortality should be problematized, over the desirable level and form of the interventions required, over the knowledge, regimes of authority, and practices of intervention that are desirable, legitimate and efficacious"* (Rose, 2007:54). Particularly relevant in the case of transnational medical research, Rose applies the concept to describe changes in a politics of "life itself" that derive from shifts in rationalities of government in advanced liberal democracies, but even more from new technological developments in life sciences, such as genetics and reproductive technologies.[4]

Studies that revolve around questions of sovereignty, science and biopolitics focus on the ways that biopolitical forms, expressed in bureaucracy, medical technologies, regimes and projects condition life, people and populations. It is, indeed, possible to extend this approach to transnational medical research projects in Africa and explore them as manifestations of biopolitics – but emerging and incomplete (cf. Geissler, 2012; Marsland and Prince, 2012). Recognising that some people's lives and survival may be conditioned by the biopolitics manifest in transnational medical research projects in Africa, the sphere of life that is governed by biopolitics is not all-encompassing – not in the global North and neither elsewhere (e.g. Marsland and Prince, 2012; Petryna, 2002; Whyte, 2009).[5]

Besides, transformations that take place within the realm and reach of biopolitics through the application of new technologies or the implementation of projects may not only condition life and living, but also open alternative spaces for social relations,

---

[3] Foucault did not apply his concept of biopolitics very consistently. Fassin (2009) shows how Foucault occasionally used the term to refer to life as the object of power with reference to state racism and Nazi concentration camps. This use of the term inspired Agamben's theories mentioned in Note 10. Foucault's other use of the term, which inspired Rose, to denote discourses, technologies and projects exerted through the modern state and other modern authorities to discipline bodies and normalise populations is more developed and more well-known .

[4] See also Franklin (2000), who developed a theory of "life itself" based on developments in reproductive technologies around the same time as Rose.

[5] See Redfield (2005) who discusses the explanatory power of Foucault's theory of biopower in locations where elements of European modernity co-exist with other conditions for governance.

solidarity and claims-making in the global North (e.g. Rabinow, 1996) and in Africa (Comaroff, 2007; see also Kesby, 2005; McKay, 2012; Prince, 2012; Robins, 2004).

With an ethnographic starting point in people's homes and neighbourhoods (cf. Meinert et al., 2009) my study differs from analyses that explore the way projects unfold in institutions and as biopolitical interventions. I explore transnational medical research projects with a starting point in my interlocutor's engagement in them. This means that I approach them in terms of three different aspects, i.e. their purpose of producing scientific knowledge; their association with health and health care provision; and finally their organisation as transnational and time-limited projects *per se*. I explore how their purpose and their organisational, material and relational elements were variously actualised and downplayed when lay people moving in a wider landscape of projects tried to turn the medical research projects into possibilities or matters of concern.

Landscape

Medical research projects take place in a wider landscape of health and social development projects that unfold in the clinics, schools, churches, compounds,[6] NGO offices, government offices, neighbourhoods, streets and homes.

This project landscape is characterised by particular features, such as transnational resource flows and connections, bureaucratic structures with specified goals, tasks and procedures, limited and formalised outputs, etc. Three features of this project landscape are particularly relevant for this thesis: one is that individual projects and programmes always end. A second feature is that whereas individual projects always have an end, the mode of operating through projects and programmes does not show signs of going away. In fact, the number and variety of transnational interventions in the form of programmes and projects within health, education and environment, have increased in number and volume since the years of Structural Adjustment Programmes in Zambia, as they have in many other sub-Saharan African countries. A major factor in this regard is the spread of the HIV epidemic on the

---

[6] A common term throughout the southern African region, a compound originally referred to a designated African housing area within a colonial settlement. Today, a compound in Lusaka refers to all so-called "high-density", low income areas that are often unauthorised squatters' settlements

continent that has led to massive foreign donations unprecedented in volume to alleviate its consequences. Efforts have included funding of medical research on treatment of the HIV infection and its associated conditions through bilateral programmes, such as President's Emergency Plan For AIDS Relief (PEPFAR), and multilateral programmes, such as The Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM), but also through private philanthropic actors, such as the Bill & Melinda Gates Foundation, that dwarfed earlier and concurrent public health research on malaria and other ‘classic’ public health problems in scope and organisational complexity. A final relevant feature of this landscape of time-limited and proliferating projects is that the institutional ‘owners’ and the exact purposes of the projects – and connections between them – can be quite difficult to trace for lay people and for professionals alike.

These three features of the landscape situate medical research in a rather diffuse context of projects that has implications for the way people engage in them. For example, people may not always ascribe much importance to the difference between medical research projects and health care projects. Building on this observation, some studies situate medical research projects as part of wider therapeutic landscapes (e.g. Greenhough, 2012; Leach and Fairhead, 2011), but in this thesis I show how transnational medical research projects also figure in landscapes of piecework and employment opportunities and how they may invoke landscapes of unequal relations between poor Zambians and elite Zambians and the wider world. Rather than studying landscapes my main intention, however, is to study how people engage in the landscape of projects. It is the inhabitants of the landscape and the way they engage in it, that are the pivot of this thesis.

Engagement

In dictionaries, the term ‘engagement’ first and foremost denotes a pledge, but also an appointment, a promise, an obligation or another condition that binds.[7] Such meanings of the term often, but not always, connote positive value. The term can also refer to a hostile (military) encounter, or the neutral state of interlocking (mechanics).

---

[7] Collins English Dictionary, Random House Kernerman Webster's College Dictionary.

In this thesis the term engagement refers to involvement that people can enact and articulate in many ways and that may be attributed both positive and negative value. With this analytical perspective, acts of criticising or disengaging in medical research can also be understood as acts of engagement. An offhand critical remark about medical research could be seen as engaging in medical research for a moment, but I am primarily interested in enactments of engagement that stretch out in time. Engagement is a matter of duration (Whyte, 2013), and studying trajectories of engagement means studying engagement over time.

Trajectories

Trajectories extend in time and space. Applied as an analytical concept, they highlight connections and movement rather than interfaces (e.g. Long and Long, 1992; Rossi, 2006). This capacity of the term is particularly useful for my purpose of exploring how engagement develops over time. Through accounts, like Malala's above, I follow trajectories of engagement in the wider landscape of health and social development projects in Lusaka and how various aspects of daily life in Lusaka, including learning how to engage and to see possibilities in projects, gender performance, the virtue of sharing, and images of exploitation, are animated and refracted along the way.

Trajectories unfold in relations. I trace how trajectories take shape in relation to projects and project staff, but also in relation to partners, relatives, friends, neighbours and peers that are often overlapping categories. Adapting Hunt's notion of the "middle-figure" I will look at lay people who engage in transnational medical research projects as central to processes of mediating and transforming such projects into possibilities and dangers of various scopes.

Trajectories may have an intended destination, but it may not be clear how to get there, and other things may happen on the way. The thesis is not so much about *why* people engage in research and other projects, i.e. what do they give and (want to) gain, as it is about *how* they engage over time, about what people might learn, the processes they might undergo, and the relationships and images of the world – and themselves in this world – that this process involves (cf. Haski-Leventhal, 2009:293).

I will follow particular trajectories of engagement over time within and between projects, and particularly medical research projects, from the point of view of the lay people who engage in them. At the basis of my inquiry is a view of lay people as actors with situated hopes, intentions and concerns who, in a subjunctive mode, engage in trying to steer through profoundly uncertain daily lives (Long, 2001; Whyte, 2002). I show how engagement in medical research projects become part of this trying to steer as people learn to realise possibilities in the projects and as they relate to the dangers that they may imply.

Staying close to lay people's experiences and accounts, I follow a strong tradition in medical anthropology of taking a broad phenomenological approach to inquiry into health and well-being in Africa (Janzen, 1978; Livingston, 2005; Simpson, 2009; Whyte, 1997). This tradition, in combination with an interest in science and its political, economic and material aspects, has been the basis of a new cluster of historical, sociological and anthropological studies on medical research and trial communities in Africa. These studies have dealt with specific aspects of medical research, such as rumours and informed consent (Geissler, 2005; Leach and Fairhead, 2011; Molyneux et al., 2005a), but also broader issues of knowledge, technologies and political economy (Geissler, 2011b; 2013; Kelly, 2011; Kelly et al., 2010; Tousignant, 2013). The present study hopes to contribute to this new body of studies, both by drawing from them, but also by making some different analytical choices than them. Below, I will present these studies and how they relate to more general framings of transnational medical research, and I will specify how the present study is positioned in relation to them.

Framing transnational medical research

The recent shift in scale and organisational complexity of transnational medical research in Africa has attracted the attention of scholars, who have focused on quite different aspects of this shift and its significance. Here, I offer an overview of approaches and observations in these studies that I have grouped into three clusters around research ethics, political economy and science studies, respectively.

Research ethics

In 1997, the coming together of increased foreign funded medical research and the HIV epidemic in sub-Saharan Africa became the focus of a heated debate among physicians and ethicists (e.g. Angell, 1997; see also de la Gorgendière, 2005) that spilled into the general public sphere; that led to changes in several sets of international standards for research ethics (Idänpään-Heikkilä and Fluss, 2004); and that spurred the development of international guidelines specifically for medical research in developing countries (NCOB, 2002; 2005). The controversy focused on a randomised clinical trial of a short-course (and cheaper) AZT regimen that was initiated in 15 countries, nine in sub-Saharan Africa. The trial had been initiated at a point in time when a course of treatment with AZT was the only option known to prevent HIV infection from mother to child and far too expensive to be available in the public sector of African countries. The trial was designed to include a placebo control group. Among various concerns with the trial, this was the most contentious, since the effect of the short-term course was compared to no treatment, and not to the positive results of the longer course regimen that had been tested in the USA and France and published the same year that the short-course trial was initiated (Wendland, 2008:4).

The core of the controversy was the question of standards of care. As Claire Wendland has pointed out, the interpretation of the passus in most international human-subjects research guidelines that every research subject is required to receive the best proven medical care available turned on a fine point of emphasis: should research subjects receive the *best* available medical care (globally) or the best *available* medical care (in a given setting) (Wendland, 2008:5)? This question spurred an intense debate for several years both in academia and in the general public about research ethics in general and in poorer countries in particular. Wendland observes how African researchers and study subjects were conspicuously absent or made Other in this debate (ibid.:9), thus somehow reproducing the distinctions of colonial times discussed by both Vaughan (1991) and Packard (1993) that I referred to above.

This rather detailed account of the peri-natal AZT trial is not meant to open a debate about research ethics, or their historical and philosophical foundations. Instead

I wish to point to the powerful way that this controversy contributed to the *framing* of transnational medical research in low-income settings primarily as a matter of research ethics. This framing, rooted in Euro-American sensibilities and a long, sometimes scandalous, history of medical research on humans (e.g. Beecher, 1966; Jonsen, 1998; Katz, (cop. 1972); Reverby, 2009), is not only powerful among medical researchers and practitioners, but also in the general public in the global North. Many times when people have asked me about the topic of my research they have been reminded of John Le Carre’s novel *The Constant Gardener* that describes the involvement of very diverse and powerful economic and political interests in the conduct of medical research that ends up exploiting poor patients in an African country. This thesis, however, will not reveal foreign medical experiments in a powerless population of Others, but explore how people, like Malala above, engage in the fairly undramatic manifestations of medical research projects in a community where the uncertainties, insecurities and contingencies of everyday life hold all the drama.

The research ethics framing has been a prominent sounding board in many anthropological studies of transnational medical research in low-income settings during the first decade of the 2000s. By observing and discussing various ‘aberrations’ from the kind of autonomous, and perhaps altruist, participation by informed volunteers that is implied as the ideal in international codes of conduct for research on human subjects (e.g. CIOMS, 2002; WMA, 2008) these studies questioned and qualified the assumptions in such codes (Geissler et al., 2008; Marsh et al., 2010; Molyneux et al., 2005b; Mulder et al., 2000; Sariola and Simpson, 2011) and thereby highlighted the broader ethos of medical science in Africa (Geissler, 2011b).

In this thesis, I will continue these studies’ close ethnographic attention to practices, but I will not frame my observations as a matter of research ethics and the ethos of medical research as such. It is not my intention to disregard the important and ever-relevant questions that arise from a research ethics framing, or from attention to medical research as a diverse practice, but I wish to set aside these interests for a while, as I follow the unfolding of perspectives and framings that people in Lusaka articulate when they engage in transnational medical research projects. I will return to issues of research ethics and social justice by resourceful research organisations that work in less affluent settings in the conclusion.

The political economy of transnational medical research

Another dominant analytical frame for transnational medical research in low-income settings has co-evolved with the concern for research ethics, and particularly the issue of standards of care, into a broader concern with inequalities and social justice. Studies drawing from this framing often question the political economy of medical research drawing from both theories of the postcolonial (Anderson, 2009; Seth, 2009) and of globalisation (e.g. Craddock, 2004). Notable studies include Adriana Petryna's study of the globalisation of industry-funded human subjects research where accountability and transparency is compromised in the competitive logic that drives global clinical trials (Petryna, 2006; 2011). Kaushik Sunder Rajan illuminates the inherent structural violence of conducting clinical trials in India where the promise of a new market (paradoxically) stimulates the development of standards for research ethics and regulation of clinical practice. The same promise, however, also overdetermines standards and regulations (Rajan, 2007) as the confluence of neoliberal policies and pharmaceutical markets puts a market value to life (Rajan, 2006), and turns people into experimental subjects (Rajan, 2005).[8]

Critique along these lines has mainly been directed at industry-funded medical research in less privileged settings where products are developed for other, more affluent consumers and markets. Concerns about inequalities, however, are valid whether research is funded by "Big Pharma" and carried out on populations in the global South for the benefit of rich consumers with lifestyle problems, or funded by state donors and philanthropists to address diseases that afflict the same poor populations that the research enrols. Besides, it is possible that distinctions between commercial or industry-funded research vs research funded by state donors and philanthropists have become increasingly blurred in Africa, since the early 1990s when medical research projects, often multi-country studies, to an increasing extent became

---

[8] See also Melinda Cooper, who explores the political economy not of medical research, but of post-Fordist innovation and experiment in itself, and who proposes to understand trial participation as labour or "experimental body work" (Cooper, 2008).

planned and carried out in large conglomerates of foreign and national universities (e.g. Crane, 2011), pharmaceutical companies, foreign governments, philanthropic donors and more or less local NGOs.

In the global North it is often – but not exclusively – the comparatively poor, marginalised, or disadvantaged who join medical research as (healthy) study subjects (Epstein, 2007:42; Fisher, 2013; Stones and McMillan, 2010), or people who try to make an extra income (Abadie, 2010; Ondrusek, 2010; Zink, 2001). There are no similar studies on the social position and distribution of study subjects in the global South. Still, it is possible to maintain that human research subjects in the global South are, indeed, exploited in both a direct and a structural sense by transnational medical research, whether it is funded by industry or by state and philanthropic donors from the global North (Anderson, 2009). Without downplaying the pertinent political issues that come with such an acknowledgement, ethnographic curiosity should not end with such an assertion. How do people living at the unfortunate ends of multiple structural inequalities relate to the presence of transnational medical research and how do they engage and disengage in it? I am less interested in the ways that power structures emerge or are maintained in these research endeavours than in the ways people act in – and on – medical research in a world of unequal relations and how they make such research interventions 'inhabitable'.

The question could also be turned around and phrased as a matter of what spaces medical research in an unequal world offers for people to 'inhabit' (cf. Geissler, Forthcoming)? In sub-Saharan Africa, the expansion of transnational medical research happened at a time when state financed health services had been in decline for decades in many countries (Masquelier, 2001) and in many cases simultaneously with multiple transformations related to the state that are often summarised as 'neoliberal' (e.g. Comaroff and Comaroff, 2000). The complex implications of these wider changes, and particularly the way they reconfigure the relation between state, life science, and different 'publics' has once again made the relation between power, politics and science in Africa a productive question. Geissler has observed how health research around the middle of the twentieth century was imagined as a tool for governments to improve the lives of the general public in African nation-states, whereas contemporary transnational bioscience has become enclaved and loosened from the nation-state and the territory where it takes place. This loosening entails that people who used to relate to science as the 'public' or as citizens of a state, now relate to science in more fleeting collectives, such as belonging to a cohort or being a member of a community advisory board (Geissler, In press).[9]

These observations about the operation of transnational medical research resonate with what other scholars have characterised as a new humanitarian governmentality (Fassin, 2007b). A characteristic of this trend is that NGOs operating across national borders come to figure prominently (de Waal, 2007; Fassin, 2007a; Redfield, 2006) and that the urgency of emergency precedes evidence as the basis for interventions to save (biological) lives.[10] This kind of intervention has been characterised as a form of experimentality that mirrors colonial "governing as an experimental activity" since the 1930s when science became seen as the basis for efforts to ”develop” Africa (Bonneuil, 2000:280), but with an inverted sequence between what is perceived as exploration or evidence of effect, and what is perceived as intervention for improvement (Nguyen, 2009a; Rottenburg, 2009). These studies discuss important changes in forms of governance and science, but they do not explore how lay people may relate to these changes in very different ways, or the diverse ways that they may be turned into (new) possibilities and dangers.

This study will explore just that. Transnational medical research is, of course, very deeply embedded in contemporary global political economy, and it is possible that it is loosening from the places where it takes place, but it is important to acknowledge that it still takes place – in the literal sense – in particular locations with

---

[9] A similar observation has been made in Uganda where the "projectification" of ART can be regarded as turning citizens of the state, or "the public", into clients in time-limited transnational projects that introduce new inequalities (Meinert, 2009b; Whyte et al., 2013)

[10] The state of emergency and its relation to biological lives, or "bare life", are also at the centre of the Italian philosopher Agamben's work on modern sovereignty (Agamben, 1998). "Bare life" exists outside law and can be killed without the killer being seen as having committed a crime – as opposed to "qualified life" or a citizen embraced by law. Agamben's ideas allow theorising of how people can be left to their own means (to die), which has inspired much anthropological work on (global) inequalities and exclusion (e.g. Biehl, 2001; Lucht, 2012; Nguyen, 2009a). See Comaroff (2007) and Rottenburg (2009) for a critique of Agamben's theories.

particular histories and as particular projects. In Lusaka, people's engagement in such projects is constantly mediated in relations, where limited and gendered opportunities for making a living, norms for sharing, hopes of learning and concerns about being used, are at stake. These aspects condition lay engagement in a way that should not be underestimated as part of the scientific production of knowledge.

The anthropology of science and technology

Medical research, and particularly clinical trials, can be seen as scientific experiments to improve knowledge, but since the mid-1970s they have also been regarded as a particular social practice to produce a specific kind of authority called science. Looking at science and its authority as a social process, often associated with Latour in France in the 1980s,[11] and Wynne and Irvin in Britain in the 1990s,[12] has been very productive. Particularly Latour's work has inspired the large and amorphous field of science and technology studies, although not so many in Africa (but see Brives, 2013). Feminist studies of medical research and life sciences have emphasised how the production and implementation of scientific knowledge is both predicated upon gender inequalities and producing such inequalities (e.g. Booth, 2004; Waldby and Cooper, 2008).

I am also interested in social aspects of transnational medical research, but not with the purpose of examining the production and authority of scientific knowledge. Instead, my ethnographic attention to actors with intentions and situated concerns in a particular place and time will take me in a different direction, where transnational medical research projects are less about the production of science and more about the

---

[11] In 1979 Latour and Woolgar published their book *Laboratory Life. The Construction of Scientific Facts* (1979) and in 1987 Latour published his much cited book *Science in Action* (1987) where he applies ethnographic methods to show how scientific knowledge is a social and cultural construct.

[12] Brian Wynne and Alan Irwin were less interested in the 'internal' workings of science and authority. Instead they explored the relationships between the public and science that changed with the development of new technologies, such as bio- and gene-technologies. Throughout the 1990s Wynne and Irwin defined the field with their publications on the ways that the public made sense of science and technology. Wynne suggested that the designation of the field as one of public 'understanding' and 'uptake' of science was really a about a crisis in the 'credibility' and 'legitimacy' of science (Wynne, 1996:39-44). Following this thinking, examples of good public understanding of science should instead be seen as examples of public *identification* with science (Irwin and Wynne, 1996:219). Furthermore, Irwin and Wynne suggested that the very framing of something called 'public understanding of science' was constructed to project onto 'the public' the uncertainties about legitimisation, identification and identity that pervade scientific institutions, but that are given no legitimate space for reflection (Irwin and Wynne, 1996:214).

exploration of possibilities. With this approach I not only take seriously what people try to do (Whyte, 2002:175), but I also hope to illuminate some lay framings of medical research and the social processes that underlie them (cf. Leach and Fairhead, 2011) that may be useful in thinking about transnational medical research and in its implementation.

The contribution of this thesis

This thesis offers an ethnographic perspective on lay engagement in transnational medical research in low-resource settings that acknowledges the complex research-related ethical issues and structural inequalities that have been described in earlier studies of transnational medical research, but mainly explores how people then 'inhabit' the issues and inequalities that are manifest in contemporary medical research projects in Lusaka.

Inspired by my interlocutors' trajectories of engagement I have approached transnational medical research projects not as *a priori* research projects, but as part of a wider landscape of projects that people learn to engage in and that mediate relations, positions, and images of oneself and the wider world. From this perspective transnational medical research projects are about a variety of possibilities mediated in precarious relations and realised from a range of historically contingent positions that I will specify in the coming chapters.

Besides, the thesis can contribute to a language for capturing what might be at stake in the ongoing dialogue, interaction and negotiation with lay people that many research project staff engage in across Africa (Gikonyo et al., 2008) and beyond, but that is not so often made explicit as an element in the process of producing medical knowledge.

Apart from being an ethnography of lay engagement, this thesis opens a vista of life and lives in an urban African neighbourhood. The spatial and social particularities of urban life in Lusaka will, however, remain an unaddressed ethnographic potential in my thesis as I focus on my interlocutors' lives and engagement in relation to the particular landscape of projects and interventions that stretch across neighbourhood, city, nation-state and continents.

Organisation of the thesis

Following this introduction, **Chapter 2** offers an account of the history and landscape of projects in Lusaka and Zambia that draws from the wider history of colonial and transnational interventions in Africa. **Chapter 3** discusses the formation of my field as it was shaped before, during and after my fieldwork. In the subsequent five chapters I explore nine trajectories of engagement to illuminate how possibilities and dangers associated with transnational medical research unfold in various relations across the spheres of home, neighbourhood, clinic and project.

Vignettes between chapters illuminate aspects of my protagonists' daily lives in Lusaka that may not be directly related to their engagement in projects. Instead, they are meant to offer glimpses of the contingencies that saturate my interlocutors' lives outside the project context that I focus on in this thesis, and thereby to serve as a sounding board for an overall observation in this thesis that engagement in projects is about attentiveness to possibilities.

In **Chapter 4** I begin by making a distinction between 'knowing about' medical research projects and 'knowing how to' be in medical research projects as different kinds of knowing. Then, I follow Tabita and her friends' trajectory of engagement through their first research project. The young women's trajectory illuminates how lay people learn about medical research projects that can appear quite ambiguous, but more importantly it illuminates a different kind of learning, namely 'how to be' in these ambiguous medical research projects, which is embedded in caring relations.

Chapter 5 introduces a distinction between predefined benefits in projects and the possibilities that people may see in the same projects. Such possibilities may change over the course of engagement and possibilities in research projects may not differ much from possibilities in other kinds of projects. In this landscape of (rare) project possibilities Rose and her husband Mr Lungu engaged very differently in research and other projects. First she regards the project as piecework, but later she comes to see other possibilities in it – similar to Richard, whose trajectory of engagement I will also briefly discuss – contrary to her husband, who does not see any possibilities for himself in the project or in any other interventions. I discuss how gender and other aspects of self may be animated by engagement in research and other projects.

Chapter 6 operates with an analytical differentiation between trajectories and careers in order to explore the story of Joyce and Joanna, who were among the few that managed to make a career out of their engagement in research projects. Building on the discussion of kinds of knowledge in Chapter 4, this chapter explores elements in their specialisation and how this includes knowledge of how to move in the wider landscape of time-limited projects that was laid out in Chapter 5, but how it is no guarantee against uncertainty.

Chapter 7 opens with a brief introduction to sharing as a concept in anthropological exchange theory and as a local term and virtue. The main protagonists in the chapter are Auntie Loveness, who was an outreach worker, and Elisabeth, who was a community representative for a research organisation. They both had many years of experience in volunteering and working for development projects at the clinic and they both took up a patron position in relation to others. The chapter explores how they and others shared project possibilities, as defined in Chapter 5, in relations and positions that overlapped and sometimes conflicted. The chapter also shows how a research organisation may be incorporated into such overlapping relations.

Up to this point in the thesis it has been a premise, and indeed a point, to explore lay engagement across transnational medical research projects and other projects. In the context of the precarious relations and positions described in Chapter 7, **Chapter 8** explores how transnational medical research projects are set apart from other kinds of projects when my interlocutors doubt the projects in various idioms of concern. The chapter closes with some observations about the way such doubts are handled pragmatically.

The concluding observations in **Chapter 9** summarise analyses and discuss the contribution to understanding lay engagement in transnational medical research via the particular perspective that this thesis has offered.

Chapter 2

A journey through the history and landscape of interventions in Lusaka

This chapter takes the reader on an imagined journey from Lusaka's Kenneth Kaunda International Airport to the 'high density' residential areas south-west of the city centre, where most of my interlocutors lived. Along the way we pass the Institute of Economic and Social Research (INESOR), i.e. the former Rhodes-Livingstone Institute, and the University of Zambia (UNZA). We pass new shopping malls, the old business district, a new cathedral, some district clinics and some medical research facilities. I have selected these particular sites to make 'detours' into accounts of elements in the political and economic history of Lusaka and Zambia, with a particular focus on interventions of consequence for education, livelihoods and health, that are relevant as context for the observations about lay engagement in transnational medical research and other projects that this thesis addresses in the coming chapters. The journey is imagined, but its elements are compiled of actual places, people, events and stories.

Coming to Lusaka

Leaving the grey concrete lattice and the artificial lights of the airport building, we move into the bright sun over the pick-up zone and parking lot in front of the airport. We agree to one of the taxi drivers' offers and begin our 40-minute journey – depending on the traffic – towards our destination, the peri-urban compounds south of Lusaka's city centre. As the car gets moving, the taxi driver, Mr Phiri, asks me what project I am in. I am used to people assuming that I work for an NGO, so I explain that I am in Lusaka to do research on the way people join health and health research projects. He hasn't heard of any health research projects, but he knows of other projects. In fact he is currently on a one-month unpaid leave from a network organisation to reduce poverty, so to make ends meet he is driving for the taxi company, where he used to work before he was hired by his current employer. A woman working for this organisation used to call him when she needed transport and she encouraged him to apply for the job as a driver when it became vacant. We can assume that he got the job because she knew him already.

We continue chatting as we quickly drive westwards on very good roads, passing wide stretches of flat savannah with a few dispersed trees under an infinite dome of blue sky. We are up on the southern tip of Africa's central plateau where the wind is dry and dusty, and where the temperature can drop to around 10°C in the cold months of June and July.

Early urban order

The cool, and presumably healthier, climate was among the reasons for the two British architects hired by the British colonial administration to select the location and plan the layout of Lusaka as a future capital during the early 1930s (Curtin, 1992; Hobson, 1996:186-188) when Zambia was known as Northern Rhodesia.[13] Apart from the healthier climate, Lusaka was much more centrally located for the territory and the recently discovered and promising copper deposits further north in the Luanshya area (then known as Broken Hill). Lusaka was located at a spot where major roads to the north, south, east and west intersected with the north-south axis of the railway line that had been established around 1905 to connect the rich copper mines of the Katanga region of Belgian Congo with South African ports (Mulenga, 2003).

The British architect, Professor Adshead, developed a plan for a purely administrative capital to accommodate about 5,000 inhabitants, implicitly non-African.[14] The plan mixed earlier colonial ideas of sanitation that would exclude Africans on health grounds and the British-based Garden City movement that promoted the spatial layout of an idealised English village as a norm for healthy living (See Schumaker, 2011:413-14 on housing at the Roan mine and nearby Luanshya town

---

[13] Until 1935, Livingstone, a town further south by Victoria Falls, had been the administrative headquarters of Northern Rhodesia.

[14] The government's town planning engineer, J.T. Bowling, however, added areas for industries to service the town and increased the planned population to 20,000 inhabitants (again excluding Africans) (Makasa, 2012).

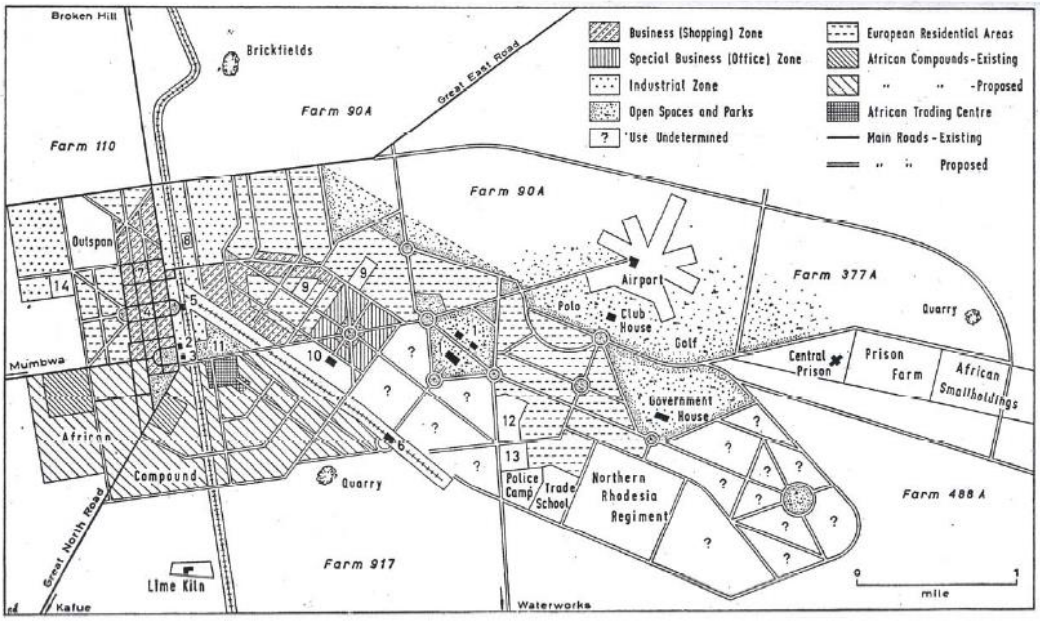
in the Copperbelt that was also planned and built in the 1930s along the same lines).[15] The result was a city divided into separate spaces for trade, public administration and residence, with spacious building plots, wide avenues, a golf course and a polo club. European residential housing areas were again subdivided into classes: first class in the Ridgeway area; second class[16] in Luburma, where most Asians, who mainly traded, also resided; and third class near the railway (Hansen, 1997:22-29).

Africans were not supposed to reside in Lusaka unless they had a work permit, usually as personal servants, where they could stay on their employer’s plot, but housing for married Africans was, nevertheless and pragmatically , supplied in Kabwata compound, south of the European first-class area. Although interwar concerns of health and welfare had begun to intersect with earlier and more rigid segregationist ideas for managing the populations in the colonies (Schumaker, 2011) the layout of Lusaka envisioned an order that tidily separated function, class and race. It also ordered the gender of Africans, as women, i.e. wives, were not formally allowed to settle in urban areas at all until 1948 when the African Urban Housing Ordinance was passed (Hansen 1997:28).

---

[15] Lusaka should be regarded as quite distinct from mining towns, however, not only in terms of demography and labour history, but because of its diversity in ethnic composition, of wage-labour, and especially in terms of the proliferation of its squatter settlements and its growing informal economy (Hansen 1997:31)

[16] The Kamwala market near the Luburma area is still sometimes referred to simply as “second class”.



Map 1: Town plan of colonial Lusaka.

Source: http://cpdafricablog.blogspot.dk/2010/12/final-paper.html[17]

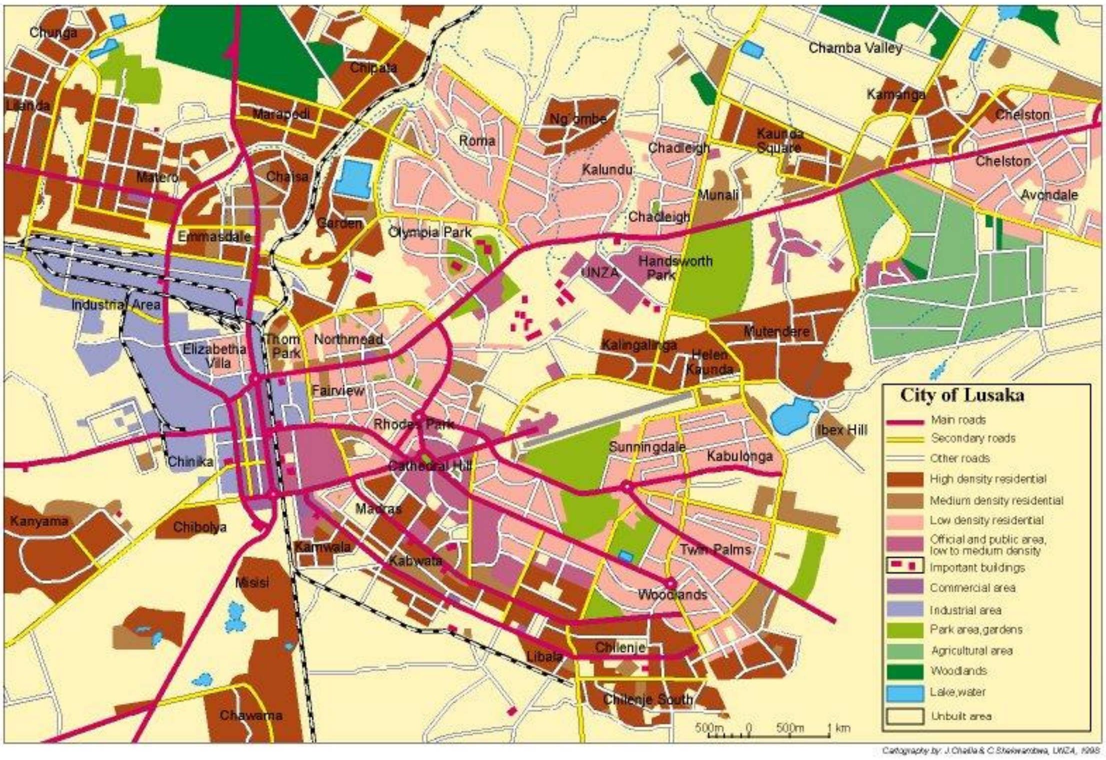
Before the British architects arrived with their particularly powerful kind of 'beginning', there was, of course, already a Lusaka. A village named after its headman, Lusaakas,[18] is said to have been located near the place where Zambia's National Assembly is located today. The British came through with the railway around 1905 and in 1913 an elected Village Management Board composed of white settler farmers, mostly of Afrikaaner descent, formally established a trading centre and town in a narrow strip along the railway loop lines where the present-day central business district and Emmasdale is to be found. They had been granted authority to manage their own affairs by the British South Africa Company (Mulenga, 2003), established in 1889 by the very entrepreneurial businessman and controversial politician, Cecil Rhodes, in whose honour the area territory was named, that administered the area until 1923–24, when Northern Rhodesia became an official British protectorate.

---

[17] The image is taken from John Collins 1969, 'Lusaka: Myth of the Garden City' that appeared in *Zambian Urban Studies*, edited by Professor D. Hywel Davies, University of Zambia Institute for Social Research, 1969, 2. The original source with information about when the map was produced could not be located from Copenhagen.

[18] Lusaakas means "thorn bush" in Lenje (Hansen 1997:23).

Today, nothing is left of chief Lusaakas' village, except the name, but the grid of streets in the Central Business District established by the Afrikaaner farmers is still there. It forms the clogged backdrop for politicians, town planners, street vendors and other citizens to recurrently blame each other and colonial town planning for the disorder that is found there (Hansen, 2004). Likewise, the professor's segregationist plan still reverberates in the layout of Lusaka's boulevards and streets east of the railway line, where many government offices, embassies and expensive residential areas are still located today. His vision of order by separation that was common at the time continues in the way contemporary city planners think in terms of zones.



***Map 2: Recent map of Lusaka that maintains a 'zoned' representation of the city in terms of function and density of residential areas*.**

Source: http://www.rzhrg.org/Pictures/Lusaka%20City%20Map.jpg

On Great East Road, passing INESOR – the Institute of Economic and Social Research

Back on the road from the airport, about halfway on our way towards the city, we pass the materialisation of a much more recent layer of order: depending on the season, the dusty browns and dark greens of the savannah may suddenly be interrupted by the vibrant greens of crops that are irrigated by central pivot systems on wheels that form huge, perfect circles in the middle of an otherwise irregular topography. Farmers, once known as Afrikaaners, now Zambians of European descent, have developed their farming methods, especially on the more fertile soils east of Lusaka. Their agro-industry dwarfs the small patches of greenish-brown maize around the huts that can be discerned in the distance as we speed on.

We gradually reduce our speed as we enter newer residential areas, many behind long, low walls. We pass through two roundabouts and just north of the third, the Munali Roundabout, we reach the gate in front of the low white buildings of INESOR. The Institute has had several titles since its foundation in Livingstone in 1937 when it was named the Rhodes-Livingstone Institute (RLI) and after it moved to Lusaka in 1952. It was at this institute, so closely associated with its second director, Max Gluckman, that distinct and hugely influential methods and theories for studying (urban) social fields in Africa and elsewhere were first developed (see Schumaker, 2001). Later they became known as the approach of the Manchester School, named after the university in the UK where Gluckman settled (following a stint in Oxford) after his years in Africa.

Social change in urban Africa

With a focus on the Copperbelt cities that came out of mining activities, Godfrey Wilson, the first director of the RLI (1938–42), observed how a way of life in British Central Africa almost contained by kinship relations had been transformed since its incorporation into a world community during the preceding few decades. In the first part of one of his main publications: “An Essay on the Economics and Detribalization in Northern Rhodesia” from 1941 Wilson characterised this new community as:

> *a community in which impersonal relations are all-important; where business, law and religion make men dependent on millions of other men whom they have never met; a community articulated into races, nations and classes; in which the tribes, no longer almost worlds in themselves, now take their place as small administrative units, a world of writing, of specialized knowledge and of elaborate technical skill.*
> (cited in Hannerz, 1980:124)

Wilson's characteristic of the new world in Zambia foregrounds an image of modernity that has since been discussed (e.g. Ferguson, 1999), but his overall observations of radical social change remain unchallenged. Scholars at the RLI continued exploring this major change with a focus on rural-urban ties and tribalism.

Their approach challenged colonial ideas of separating different functions, classes and races, as was expressed in city planning as described above. They insisted on seeing society and defining the social field as a whole, epitomised in the second director Max Gluckman's famous pronoucement: "An African Townsman is a townsman, an African miner is a miner". They disregarded *a priori* distinctions such as tribesman/townsman and refuted the notion of bounded tribes in their attention to social processes and situations (Macmillan, 1995:48-49; Werbner, 1984).

On Great East Road, passing UNZA – the University of Zambia

In the taxi we continue chatting, as we move on to Great East Road. To the right are older and newer residential areas, with spacious houses and gardens. More cars are on the road with us now. Mr Phiri, our driver, makes ZMK 1.6 million a month (GBP 230)[19] which is not really enough for supporting his wife, five children and one dependant. Two of his children are in private schools and two are in (nominally free) government schools. His wife has very little schooling, so she is not working, not even doing business (often meaning informal trade), so he considers himself lucky to work for the organisation and he has learned a lot. English and computer skills, for example. He wants to further his education and also his wife's, but he has to think of the children first.

To the left we pass the expansive lawns, the lakes and the tall trees at the entrance of the University of Zambia (UNZA). Its long, low buildings of reinforced concrete were erected around independence in 1964 and its mission was closely associated with ideas of nation-building and the need for education at all levels that

---

[19] On 1 January 2013 the Zambian Kwacha was debased, so that 1,000 old Kwacha (ZMK) equalled 1 new Kwacha (ZMW). All amounts in this thesis are stated in the old ZMK and converted into GBP as per the rate of 1 January 2009 (GBP 1 equalled ZMK 6,935). The value of ZMW to GBP has since fallen.

became urgent at the time.[20] If we had turned to enter the university grounds, we would have seen how some of the buildings are slowly crumbling from lack of maintenance.

Independence and decline

Colonial Northern Rhodesia became independent Zambia in 1964 after a relatively non-violent process and Zambia was one of the leading young nations in the period of decolonisation around the late 1950s and early 1960s. This was the time when the budding modernity observed by Gluckman and colleagues was hoped and expected to come to its fulfilment. The economy, based on mining in the Copperbelt, was very strong and growing. Measured by per capita gross domestic product (GDP) on a global scale Zambia was considered a "middle-income country" throughout the 1960s and most of the 1970s (Ferguson, 1999:6).

As in many other post-independence governments in Africa, the provision of schooling was given very high priority by the Zambian government headed by left-wing and egalitarian President Kenneth Kaunda of the United National Independence Party (UNIP). The good foreign exchange earnings from copper exports made it possible to rapidly expand the public school system and offer education for free (Musambachime, 1990).

With a secondary school certificate or a degree, coupled with a comparatively low population density, it was relatively easy to get formal sector employment. This was particularly easy in Lusaka, because the new government decided that all government ministries and departments, major embassies and the headquarters of all major companies should be located in Lusaka. This created many jobs, and assumptions about jobs, which attracted many migrants both from the Copperbelt and from the rural areas. The urbanisation that began in the industrialising Copperbelt long before independence increased exponentially after independence. With 40% of the population living in towns by 1980 Zambia became known as one of the most urbanised countries in Africa (Hansen, 1997). Mulenga cites sources that state the

---

[20] See Lachenal (2013) on the stories and histories told by modernist concrete in colonial Belgian Congo.

population in Lusaka at independence as 123,146 and five years later it had more than doubled at 262,425 (Mulenga, 2003).

Only 10 years after independence, in 1974, Zambia’s position and development changed dramatically. Falling prices for copper on the world market and a growing external debt resulted in a radical decline in living standards – extraordinarily steep, even for Africa – which made former hopes for a bright future fade (Ferguson, 1999:7-9). This development took Zambia on a slide from being one of the richest countries in Africa (measured by GDP), and a shining example of post-colonial, modern Africa, to becoming one among the poorest on the continent.

Around the same time, in 1973, the first stability measures and later Structural Adjustment Programmes were introduced (Rakner, 2003). These interventions put pressure particularly on urban livelihoods. Ferguson cites a study that shows how the cost of a family food budget rose more than 650% between 1980 and 1988. In the same period, monthly supplies that cost 64% of an unskilled worker’s wages in 1980 cost 88% of it in 1988 (Ferguson, 1999:10). Fees for education and health care, that was otherwise made free for all after independence, were introduced in 1988 (Phiri, 1999). Kenneth Kaunda, now head of a one-party government since 1974, tended to abandon more radical economic reforms when protests escalated in “food riots”, that later turned against the political system as such (Rakner, 2003:12, 63).

In 1991 Kaunda was forced to step down and at the same time Zambia became a multiparty democracy. The international donor community wanted to reward the peaceful transition to multiparty democracy and the economic liberalisation policies that were promoted by the winner of the election, the Movement for Multiparty Democracy (MMD), headed by Frederick Chiluba. Hoping to make Zambia a ‘model for Africa’ (once again), Zambia experienced a substantial growth in development assistance in the years after 1991 (Rakner, 2003:12). With MMD, Zambia eagerly complied with new Structural Adjustment Programmes (Englund, 2013:671) and several radical economic reforms were implemented during the 1990s. Among them was the privatisation of the vast para-statal agencies, that consisted of major companies that had previously been nationalised, or “Zambianised”, by Kaunda between 1968 and 1971 with a focus on the public sector, rather than the foreign-dominated private sector (Rakner, 2003:45-46). The period after 1991 is associated with many economic reforms and also with rampant corruption in the Zambian elite.

Education

With rising oil prices, falling prices for copper, and the rapidly growing population, the link between education and employment changed drastically during the 1970s and onwards, but the association between schooling and getting a formal job is still very strong in many people's minds. The general value ascribed to European-style education as the path to social mobility, formal sector employment and as a sign of being "civilised" (Serpell, 1993; Simpson, 2003), which has also been observed elsewhere in Africa (Englund, 2006:89-90; Stambach, 2000), has not diminished. The landscape of learning has changed character, however.

In colonial and postcolonial Zambia there were a few well-defined avenues to certificates and degrees in a few public and mission schools that the few could access. The relevant types of knowledge were the classic education topics and there was not much choice. Today, there is a great and differentiated market for education and training, spanning Government, private, NGO-sponsored training institutions, colleges, and vocational training centers that offer various forms of certificates and diplomas. Selling shorter courses has developed into a very diverse market in Lusaka (Hansen, 2005:9). In spite of meagre possibilities, people at all levels of education dream, hope and strive to add to the formal education that they or their close relatives have (see also Gough, 2008). It is not uncommon to leave parents, spouses and children for extended periods of time to move across the country (often where it is possible to stay with relatives) to take a course or a degree in a school with a tuition fee that is more manageable than the ones in Lusaka. Possibilities have diversified, but it has also become more difficult to assess what is the relevant and marketable course, training or education possibility. Whereas training and education still holds value as a desirable marker of individual progress (usually based on pooled funds), it has become more difficult to translate proof of completed courses, training and education into employment and social mobility.

On Great East Road, passing the big malls

Continuing along Great East Road, we go through another roundabout and suddenly traffic is very dense and much more differentiated. Pick-ups, ordinary cars, large four-wheel drives, licensed and unlicensed taxis in all possible states of maintenance jam the road together with blue minibuses picking up passengers along the way. We have reached the two large malls, Arcades (opened in December 2003) and Manda Hill (established in the late 1990s), that are located on either side of Great East Road with just a kilometre between them. We pass the malls slowly enough to take in the atmosphere of modern cosmopolitan consumer heaven that emanates from them. Behind large parking areas lined with palm trees, South African supermarket, fashion, bank and restaurant chains spread out, interspersed with cinemas, cafes, cutting-edge health shops and bars that are often run by white or Indian Zambians. In 2009 Manda Hill began further expanding its facilities to become even more attuned to satisfying the needs of the wealthy and stirring the dreams of the less wealthy.

Recent upturn?

In 2002, Zambia elected Levy Mwanawasa (MMD) as its third president, who became known for his anti-corruption measures. Zambia received debt-relief[21] and American, Brazilian, British and Chinese investments have revived many copper mines, as copper now commands prices higher than any previous peak on the global market. During my fieldwork there was a shared sense that wealth was again flowing in the country. In Lusaka, people noted the shiny, new tarmac on paved roads that previously had been left to turn into dust over many, many years; the many huge, new SUVs that had worsened the congestion on the roads in the city centre; the new malls with South African supermarkets and shopping chains; and the older malls expanding. In 2011 Zambia was classified as a lower middle-income country by the World Bank.

This wealth is not evenly distributed, however. With a Gini coefficient of 0.65, Zambia is among the most unequal countries of the world today, with the poorest

---

[21] In 2005 Zambia's $7.2 billion external debt was reduced to $500 million after reaching benchmarks for fiscal discipline and good governance set by the International Monetary Fund (IMF) and the World Bank.

living in the rural areas (UNDP, 2013). In Lusaka, prices for everyday items have kept rising. Olivia, my young transcriber, told me how 11 years ago she could get a small notebook, a pen and a pencil for ZMK 500 (GBP 0.07), but that now a notebook alone costs ZMK 2,500 (GBP 0,36).

From January to December 2008 the price of mealie meal[22] almost doubled from ZMK 36,100 (GBP 5.23) to ZMK 61,000 (GBP 8.79) per bag of 25kg. When I arrived in August 2008 the Basic Needs Basket cost ZMK 1,828,100 (GBP 263) per month for a family of six, and by the time I left in July 2009 it cost ZMK 2,226,930 (GBP 321).[23]

Table 1: Prices of selected food items in a township market in early 2009 (as negotiated by Joyce, Chapter 6)

Items	ZMK
A handful of green vegetables	1,500
Five medium onion	1,000 (or 1 "pin")[24]
Six medium tomatoes	1,000
Offals	10,000 for 1 kg
Offals (heart or liver)	20,000 for 1 kg
One dressed chicken	23–28,000

Salaries have not risen accordingly. In June 2009 the nurses held a month-long strike demanding a 25% increase in salary[25] (coinciding with the unfolding of a major corruption case involving ZMK 10 billion (GPB 144,179) in the Ministry of Health).[26] The

---

[22] A coarse maize flour for making *nshima*, a porridge that is the staple food in many parts of southern Africa.

[23] Since 2002 The Jesuit Centre for Theological Reflection in Lusaka has carried out monthly surveys of cost of basic food items for a family of six in Lusaka, known as the Basic Needs Basket. In addition, the survey registers selected costs in relation to education, health services, transport and fuel, as well as the range of monthly salaries for teachers (from ZMK 1,145,300 – GBP 165 in July 2009), guards (from ZMK 300,000 – GBP 43), and for piecework on a farm (from ZMK 3,000 – GBP 0.43 per day). There is an interesting line from the "poverty datum line" surveys done by human geographer, Edward Batson in southern Africa in the late 1930s and early 1940s, that were continued by other human geographers at RLI in the late 1950s (Schumaker, 2001:157) to today's Jesuits publishing this Basic Needs Basket in major Zambian newspapers every month.

[24] "Pin" is common slang for ZMK 1000 and can be used as a denomination so that "50 pin" means ZMK 50,000. I was told that the expression stems from when wage labourers received their salaries in bank notes kept together in piles of ZMK 1000 by a pin.

[25] In June 2009, junior nurses earned about ZMK 1,121,000 (GBP 161) and senior nurses ZMK 2,624,000 (GBP 378). JCTR Basic Needs Basket, http://www.jctr.org.zm/.

[26] In 2008 Mwanawasa passed away and Rupiah Banda (MMD) was elected president. He was known as less tough on corruption. In 2011 Michael Sata of the Patriotic Front (PF) was elected president.

government offered only a 15% increase with reference to the global credit crunch (*Lusaka Times*).[27] Here, it is relevant to add that only 29% of the employed population in urban areas are engaged in formal employment (Central Statistical Office, 2008).

The landscape of development interventions

The Structural Adjustment Programmes that were rolled out in many sub-Saharan countries in the 1980s and 1990s were aimed at the macro-economic level, but they often had detrimental consequences at household level for a number of reasons, including layoffs and removal of subsidies in the education and health sectors. Well-established Christian missions that had operated in Zambia for many decades expanded their social development activities, backed by their Churches abroad, and new Christian and Muslim national and international organisations joined to provide health services and education (Gordon, 2012). In the same period, international NGOs established programmes and projects to assist in the alleviation of the poverty that deepened at the time. This development marked a shift in the landscape of service providers with mixed implications for state-citizen relations (Fisher, 1997; Stewart, 1997) and the vision of public health (Pfeiffer, 2003; Reich, 2002) in a globalising context.

With the massive funding that came in the 1990s to address the HIV pandemic in Africa the NGO landscape was transformed yet again, and even distorted towards focusing on HIV and AIDS. In many parts of Africa, there are now more NGOs working on HIV and AIDS than on any other issue, and work on HIV and AIDS possesses great legitimacy (Morfit, 2011; see also Swidler, 2007; and Swidler, 2009b). In Zambia, cooperating partners fund approximately 87% of HIV and AIDS interventions (UNDP, 2013).

In Zambia today, large and small international and national organisations, religious and secular, form programmes and networks. They work in various forms of partnerships with government agencies for short or longer periods of time. Offices open and close or move and logos painted on walls are left to wither in the sun, or

---

[27] http://www.lusakatimes.com/2009/06/19/strike-by-uth-nurses-illegal-labour-minister/.

they are freshened up or changed. The organisational landscape of health and social development interventions is complicated and ever-changing.

Walking along Cairo Road

We pass a flyover, looking down on the railway loop lines that played a central role in colonial Lusaka's origins, and immediately reach Northern Roundabout, the end of Great East Road. We turn south onto Cairo Road, the central street in Lusaka's business district. The name of the road is often said to be a remnant of Cecil Rhodes and others' ambitions of connecting the British Empire all the way from Cape Town to Cairo and to join the two cities by a railway line, but it is also said to have been suggested by a local farmer in the mid-1920s commenting on the route that adventurous motorcar drivers on the same mission would invariably choose (Hobson, 1996:166). Although the vision did not come true, the road retained its name,[28] with a low fenced strip of grass, nicely cut hedges, and trees dividing the avenue down the middle (that used to be a deep ditch).

This is where we feel the 1.7 million people living in the city today. Cars often jam the road and although Cairo Road is less than two kilometres long with several lanes in each direction it can take an hour to move from one end to the other by car. Cars stop more than they move and it is often faster to walk, so that is what many people do. Cairo Road is lined on both sides with small and large shops with bright and bold signboards. We pass through the smells and hisses of frying oil coming out of the local and very popular fast food restaurants, past the loud pastel colours of the ice cream parlours, the smaller hotels, filling stations, a few supermarkets, the Central Post Office, and the towering silos that bear witness to light industry in the middle of the city.

Along the road there is the entrance to a New Start Centre for HIV testing which is not easy to find under the large Bata sign of the shoe shop next door, unless you know where to look. Everywhere pedestrians weave in and out between each other,

---

[28] This is unlike other roads that had their names changed with independence, and the original Saddam Hussein Road that was renamed Los Angeles Boulevard after the Gulf War in 1992 (Hansen, 1997:2).

traffic, self-appointed parking assistants and street vendors who have established instant shops on the pavements, selling newspapers, calendars featuring the Manchester United or Chelsea soccer teams, herbal medicines in attractively coloured carton boxes, socks, belts, etc.

The informal economy

Since wage-labour became increasingly rare in the 1970s many struggled in the informal sector, mainly through small-scale trading (Hansen, 2008) and street vending, although the government repeatedly and futilely tries to limit it (Hansen, 2004). The informal sector grew very quickly in Zambia in the 1990s. It has been estimated that in 2000 about 65% of Lusaka's workforce earned its livelihood from informal economic activities (unregistered, unregulated small-scale economic activities, mainly trading) (Mulenga, 2003). In Lusaka, small-scale trading has been the dominant mode of making an income for women since well back into colonial times, but as a result of changing factors over time (Hansen, 1984).

Southern Roundabout

We reach the Southern Roundabout of Cairo Road marked by the highest building in Lusaka and an emblem of the city, the Findeco office building with its characteristic crown, built of grey concrete and completed in 1974, standing 23 floors high. Since I left Lusaka plans have developed to refurbish and modernise the building in a new public-private partnership (PPP). Likewise, the tall Society House, that has stood burnt out since 1997, will be renovated and remodelled to house a 160-room four-star Holiday Inn hotel, clad in a copper metallic surface.

If we continue south onto Kafue Road we will pass The Great Wall Casino compound on the right, complete with a red gate and golden arched roofs, and further on Ben's Garage to the left, a very popular nightspot for music, dancing and bottled beer. Before that, however, we would pass the huge new Cathedral of the Brazilian Universal Church of the Kingdom of God that was built in 2005 and had its windows smashed by dozens of people the same year. There had been rumours of Satanist rituals taking place in the church and the government banned it from operating, as they had done once before, in 1999, following similar allegations. The Supreme Court nullified the ban, however, and so did the High Court in 2005.[29] People still talked about what was going on in the church and I will return to their concerns with Satanism in Chapter 8.

Religion

Since David Livingstone crossed the territory, Christian missionaries have settled in Zambia. The history of mission and the Christian Church in northern Rhodesia and in Zambia is rich and diverse. Apart from churches, schools and health services were established from the earliest settlements. Both Catholic and Protestant denominations worked in what became Zambia, but with a Protestant majority. Protestant values were a central part of Kenneth Kaunda's Christian humanism (also sometimes known as scientific socialism), introduced in 1967, as a philosophy that *"tried to marry basic ideas of Christianity and antiracism to egalitarian precepts of nineteenth century liberalism and Fabian socialism"* (Burdette, 1988:77). More than two-thirds of the Zambian population are Protestant and the United Church of Zambia is the largest protestant Church in the country.

As in many other parts of Africa, Pentecostalism is growing fast in Zambia and southern Africa. In Zambia, this development grew considerably after 1991, when the Pentecostalist Frederick Chiluba was elected president. Pentecostalism has received considerable academic attention, often analysed in the context of neoliberalism and free market ideology as prosperity gospels, where images of individual salvation are analysed in the light of such neoliberal economics that I described above (Gordon, 2012; Maxwell, 1998). Other studies of Pentecostalism and its particular form of sociality in small congregations point to the way it is about security and trust in peri-urban areas (Englund, 2007) and about middle-class hierarchies, images of graded social mobility through exchange, and thus about networks of social relations and dependence (Haynes, 2012; 2013).

---

[29] http://news.bbc.co.uk/2/hi/africa/4567430.stm

Independence Avenue and the townships

We turn left onto Independence Avenue reaching the flyover with a view of the rickety market stalls that people have put up along the railway. The stalls line all the footpaths that criss-cross the rail area between a smaller South African mall established sometime between 2000 and 2004 and the old Kamwala market, that was part of Prof. Adshead's plan. Kamwala market used to be run by Zambians of Indian descent but many of the shops have now been taken over by Chinese shopkeepers.

We continue south-east on Chilimbulu Road, passing Madras on the left-hand side, where many Zambians of Indian descent have resided since colonial times, and Kamwala township on the right-hand side. Kamwala was established in 1936 by the City Council, with African government employees in mind (Schlyter and Schlyter, 1979). After Chiluba was elected president, he decided to sell the council houses to the City Council around 1996, who then sold the houses to their tenants. This is a change that still rings in people's minds. The council houses are praised for their sturdiness. They are now middle class, and the owners have built walls around their plots. Many have filled their plot with housing, and they rent out rooms to others. We continue in a soft curve south-east, on narrow roads with speed bumps, or 'sleeping policemen', every few hundred metres. We pass the army barracks and the police compound (since colonial times, see Map 1 above).

We reach the row of seven grey and very worn-down four-storey apartment blocks that were built around independence on one side of the road and the always busy car washers' stations in front of the canal that separates the road from the houses on the other side. We are in Kabwata, the first planned African township for personal servants (established in 1935). We pass through Chilenje township (established in 1945), a busy middle-class residential area, before we connect to Leopard Hill Road near the vast and growing cemetery where graves seem to spill over the boundaries of the grounds, further and further away from the road and sideways into the neighbouring open plots (the filled up space assigned to the city's dead was a recurring issue in the newspapers, just as the filled up spaces assigned to receive the city's solid waste). If there is no funeral procession of cars followed by hired busses and trucks full of mourners we can now speed up again to reach Bauleni compound. From here onwards we pass the White Fathers' compound, the American International School, walled ex-pat residences, Adventure City (a leisure park for well-off families), several large farms owned by former or current Zambian politicians[30] or by Zambians of European descent, including a farm selling organically grown vegetables and very high quality handicrafts in African materials for 'western' tastes and wallets, and several training and teaching stables. There are some more walled residential areas under construction. At some point the tarmac thins out and the road becomes a dirt track that continues all the way to the Zambezi river.

Health and illness

The three townships that we have just passed through, Kamwala, Kabwata and Chilenje, each have a public clinic managed by the Lusaka District Health Management Team. I received permission from this office to work in the three clinics and their catchment areas. Kamwala and Chilenje clinics were quite large and busy, their catchment areas including several high-density residential areas, or compounds, whereas Kabwata clinic was smaller and less busy – presumably because the middle-class population around it sought private clinics. All three clinics had outpatient departments, an Environmental Health Office, a TB corner and a small laboratory. Chilenje clinic had capacity for a few inpatients, including delivery. All three clinics ran family planning, mother and child health programmes and offered VCT, ART and PMTCT programmes[31] as well as PCR for infants. The clinic programmes were supported by several national and international cooperating partners, including Care International, CIDRZ, CCF, ECDPT, JICA, KARA and ZAMBART.

In 1994 Neighbourhood Health Committees were established in all district clinics with the task of bringing problems from the community to the clinic and information from the clinic to the community. Catchment areas are divided into zones and in each zone 11 people are elected to membership of the Committee. Members of the Committee elect a leader that represents the zone for the subsequent three years in

---

[30] One rumoured to have a pair of lions given as a gift behind the high walls of the farmhouse area.

[31] In Chilenje PTMTC programmes began in 1997 and the ART clinic in 2004, both supported by CIDRZ.

the meetings of the Committee at the clinic. The 10 elected representatives, one from each zone, are known as “the Top 10”. Apart from the Neighbourhood Health Committee, lay people are engaged as community health promoters (in Chilenje 72 were trained, 15 were active), TB treatment supporters (10 trained, four active), peer educators for ART clinic (30 active), lay counsellors for PMTCT (three active) and supporters of mothers breastfeeding (four active, supposed to be 10).

As described above, much has changed since the 2000s, but some changes are not so visible. For example, the HIV/AIDS epidemic and its silences. In the only nationally representative population based sero-survey, the percentage among adults reduced from 15.6 in 2001–02 to 14.3 in 2007 (UNAIDS, 2012). When the prevalence was at its highest in the late 1990s the national prevalence was estimated at 22% and considerably higher in urban areas and among the relatively better educated (Fylkesnes et al., 1997). Translated into experience, these figures mean that most people in Lusaka have lived through the protracted illness and death of close relatives due to AIDS. Zambia is a recipient of PEPFAR funding and since 2004 ARVs have been available for free. This has changed much in terms of hopefulness (see Colson, 2010 on people living in Gwembe Valley), but people still fear illness and death, moral condemnation, being laughed at, being seen at a testing site, let alone telling others that one is positive – especially if one has a relatively higher socio-economic status (Bond, 2010). The Demographic Health Survey of 2007 found that 78% of men and 61% of women had never been tested and received their results (Central Statistical Office, 2007). Women get tested when they become pregnant and go for antenatal care, otherwise both men and women only go when they are already sick – in that case there can be quite substantial, often still indirect, pressure from spouses, relatives and neighbours to go and get tested.

HIV/AIDS in adults and children is a dominant health issue in Zambia, together with the conditions that may accompany it, such as TB and sexually transmitted infections. Many other health issues receive comparatively less attention by the organisations and agencies involved in interventions.

The history of medical research in Lusaka

Among the interventions in health are medical research projects. Several transnational research organisations have worked in Lusaka since the latter half of the 1990s.

Zambia Emory HIV Research Programme (ZEHRP) was established in 1994 and had its first small clinic in Chawama compound, where they recruited discordant couples. Later, the organisation moved to a large compound in Emmasdale for research activities, but, as an NGO working in partnership with the government and funded by the American CDC the organisation began rolling out couples' VCT services to cover all district clinics in Lusaka in the late 2000s.

Some time during the late 1990s a Director of Health, the late Dr Moses Sinkala, working from the Lusaka District Health Management Office, saw the establishment of transnational research projects in the public clinics at district level as an opportunity to upgrade both physical infrastructure and the capacities of human resources within the health sector in the city. His collaboration with the University of Alabama at Birmingham, where he had received his Master in Public Health, resulted in the establishment of a medical research organisation in Lusaka, the Centre for Infectious Disease Research in Zambia (CIDRZ) in 2001, that has since become the largest in Zambia, now also operating outside Lusaka. Working from the district clinics and not the University Teaching Hospital (UTH) was a break with the usual practice at the time. Basing its first studies in the district clinics made its activities blend into the many other activities that took place in the clinics.

Since then, CIDRZ has expanded and built offices, a large lab of highest international standards (in Kalingalinga compound, not at UTH), a hospital wing at UTH focusing on cancer research and treatment, and most recently a campus at Ibex Hill, but they still operate out of the district clinics. The organisation has become an NGO delivering health services and training, including a community department working with social development projects.

Other research organisations, like the British Zambia AIDS Related Tuberculosis Project (ZAMBART), formed as an NGO in 2004, building on relations between UNZA's School of Medicine and LSHTM spanning more than 20 years. ZAMBART mainly focuses on HIV and TB, and also works from the district clinics, as do visiting foreign researchers who collaborate – often over many years – with the same clinics. A British funded research group, TROPGAN, that has also worked in Zambia since the 1990s, focusing on nutrition, and is based at the School of Medicine and now collaborates with a mission clinic in one of the compounds. Towards the end of my stay in Lusaka the European & Developing Countries Clinical Trials Partnership (ECDTP) prepared a study in one of the three clinics that I had permission to work in. The ECDTP, created in 2003, is a partnership between 14 EU member countries plus Norway and Switzerland and 49 African countries.

It proved difficult to get exact figures on the volume of medical research in Lusaka[32] but it is possible to get an impression of the trend over time. A simple count of publications in medical research culled from a search on PubMed with the search word 'Lusaka' shows an increase in the number of publications per year:[33]

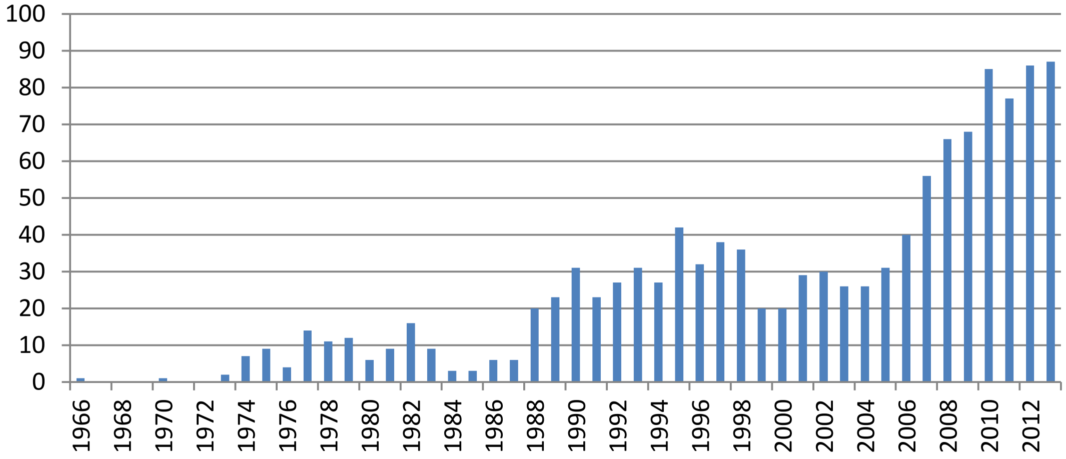


Figure 1: Distribution of publications on health research associated with Lusaka since 1966.

---

[32] Towards the end of my fieldwork, when I had planned to contact the Ministry of Health to obtain this information, a large corruption scandal began unfolding in the Ministry, which made it very difficult to establish contact with staff. Information from the UNZA Ethical Review Board was equally difficult to access. With regard to obtaining information directly from the research organisations, see Chapter 3 on methodological reflections.

[33] The table is the result of a search in PubMed on 29 December 2012 and 12 January 2014 with Lusaka as search word. It includes 1036 publications on health research since 1966 (manually excluding veterinary research)

Transnational medical research should be seen in the context of colonial, transnational and national interventions with intimate implications for lives and livelihoods through history, just like the segregation policy of colonial urban Zambia, the urbanisation following independence, the economic crisis in the 1980s and 1990s and the concurrent influx of NGOs.

Arriving in the compound

We have had a quick look up Leopard's Hill Road, but I ask Mr Phiri to turn around and go back all the way back towards town, so that we can get to the compound, where most of my interlocutors lived. From a certain point it is easier to walk, so we thank Mr Phiri and as we leave the taxi he gives us his card with his phone number, in case we need him again. We find one of the many paths that stretch across the ditch, the old railway tracks and the open limestone ground that separates the township from the compound. Although it is illegal, people dig the limestone for building material in the night, so the ground is full of rather wide and deep holes (that are sometimes filled with waste, which is also illegal). We avoid the holes and find a path between the low and close unplastered brick houses that takes us further into the busy compound.

The compound that we are heading for is one of the euphemistically classified 'high-density areas' (see Map 2 above), known as 'compounds' in local English. In Lusaka, the settlements are sometimes called by the names of the not-so-well-off white owners of the farms, who rented the land to the settlers – for example, Kuku (Cook), John Laing, Garden (probably not named after the garden city idea), George and John Howard (named after the owner of a construction company that had a site where construction workers settled). Lusaka is home to more than 10 such compounds that are very diverse in terms of history, population and infrastructure – both internally and between them.

The settlements began in the colonial period as homes for people whose short-term contract in the city had ended, and thereby removed the right to live within the city borders. The unauthorised compounds were situated outside the city borders, and technically outside the jurisdiction of municipal authorities. These settlements were never a formal part of colonial Lusaka, and they did not figure on formal maps of the city, although they were always there (Hansen, 1997). This ‘administrative blindness’ did not change with independence, when people migrated in even larger numbers to Lusaka (and the white settler farmers left, so people did not have to pay rent any more). Today, they are controlled by party cadres who allow the city and the compounds to expand and ‘densify’.

At the time of my fieldwork the compound had a population of approximately 70,000 people who shared water from about 50 wells and water taps, and who had limited access to legal electricity and no access to sewerage. Most houses were built of bricks and sometimes plastered, but size and maintenance varied considerably. So did people’s education levels, Church affiliation, place of birth, language, year of settling in the compound, etc. This diversity was partly a result of migrants coming in from rural areas and from the Copperbelt cities, but also due to the fact that many people living in Lusaka’s middle-class townships had been forced to move to these compounds since the decline in living standards that began in the 1970s and accelerated in the 1980s.

Class

As in many other urban areas in Africa, the contrast between privileged and less privileged is very visible in Lusaka in the way people transport themselves, how and where they shop, and how and where they live (Hansen, 2007: 7-8). Less visible, but just as important, is their level of schooling. A lot can be assumed about a family’s shifting access to resources by recording the children’s trajectories of schooling in community, public or private schools in Lusaka or in the provinces (where schooling is cheaper).

In public schools, primary level (grades 1–7) is nominally free, but students are charged for uniforms, books, reams of paper and Cobra (for polishing floors). Public schools also offer junior secondary level (grades 8–9), but not for free, which means that many children stop schooling after grade 7. Schools that teach grades 1–9 are known as “basic schools”, since nine years of schooling is considered very good for the majority of children. Private schools offer upper secondary level (grades 10–12) and their fees are about twice as much in Lusaka as in the rural areas.

Education is also a local measure of class that people link to place of living in the city. Joyce and Joanna, whom I will introduce in Chapter 6, distinguished between compounds and townships in terms of education: *"A compound is a lot of uneducated people, the houses are not all that ok […] townships are like Kabulonga. People there are educated, they boast as if they have knowledge."*

The line between living in the township and in the compound is porous – not only because of their geographical proximity. People living in the township, who are not able to manage because of illness or loss of jobs in the household may move to the compound and then have tenants in their house in the township (Gough, 2008: 251). There is a trend for higher income households to move to lower income residential areas, where housing is extensively subdivided, thereby increasing residential density (Gough, 2008: 253; Hansen, 2005:7)

The compounds are much differentiated places, both between compounds, but also inside each compound. People rank the compounds in terms of access to water, sanitation and electricity, how dirty they are and how flooded they get during the rainy season. The compounds are not just residential areas, but are complete – except for water, sewerage and other public facilities – with hair salons, bars, tailors, groceries, church halls, football fields and markets.

Today, earlier racial divisions have become socio-economic divisions. The geography of races that colonial Lusaka was founded on is replaced by a geography of class: what used to be areas for Asians, mixed race and coloureds are now middle-income areas and the areas that used to be for the African population are now low-income areas (Hansen, 1997).

The look of interventions from the compound

As mentioned earlier, there are many national and international NGOs in Lusaka, but they are not very visible in the compounds. Their head offices are in other parts of the city, where people from the compounds may rarely, if ever, come. What people from the compounds may see is the big cars with logos and letters that form acronyms. Sometimes they come into the compounds and erect a tent for VCT, for example, but this is far from a daily occurrence. Sometimes the cars with logos and letters come to visit the community schools in the compounds, or one of the churches, with various items for distribution, but this is also irregular. Some people, often mothers, may be visited by neighbours from the compound, who are known to work at the clinic, and they may receive mealie meal and oil, or special foods if their infant is sickly. If there is a sick person in the house, they may also be visited by someone who helps to care for the sick person. This can be someone from one's church or someone trained at the clinic. People hear about unspecified projects, and specific training – often aimed at women – such as tie-and-dye, hairdressing, soap-making, catering and tailoring, but also brick-making for men. They may have observed how some receive various food items and mosquito nets from the clinic and that some schools receive books and toys.

If people leave the compound they may see the big cars pass by or parked at the clinic. They see large new buildings with freshly painted logos next to the older and more worn buildings in the clinic compound and many people lining up outside the buildings. Sometimes there are foreigners in the cars and in the buildings. If people know staff at the clinic, they may see them working in one of the old buildings on one day and in one of the new buildings on another day. If people know staff or volunteers at the clinic, or someone from church, they might themselves get involved in these activities.

It is in this landscape of passing cars, projects and possibilities that research organisations carry out their studies in a city and a country that has been intervened in by foreign and national organisations in different constellations for more than a century.

Vignette I: Independence Avenue

On a warm afternoon in mid-February, I walk on the path along Independence Avenue towards the Southern Roundabout. I reach a woman, thin, well-combed, with very clean and ironed, but worn, clothes. Still walking, she says hello. I say hello and ask her where she is going. She says that she is on her way to Soweto market. We continue walking – her in front of me – on the narrow and uneven path where the grass has been worn off along the flyover. She says that she is looking for a job and asks whether I have a maid? I say yes, and sorry. She says that she doesn't know what to do. She just came from court – she lifts her right hand that holds a large white envelope, heavy with papers. Her husband has left her and he left her with HIV. We stop and she repeats, looking straight ahead of her, that she does not know what to do. I try to say something feeble like, 'One day at a time.' She says that she is on ART. I ask for how long. She responds since October last year. Her husband disappeared at the beginning of January this year and he went home to his mother where he remarried yesterday. The court has told her to go and buy reconciliation. She fixes her gaze somewhere on the horizon and says again that she doesn't know what to do – he just got married … She is now alone with two children in a rented house that costs her ZMK 300,000 (GBP 43.25) per month. I ask whether she wants to reconcile. She says she doesn't know but that is what the court tells her to do. I ask whether she can find a cheaper place to live and she says she can find a one-room apartment for 150,000 (GBP 21.63). She will sell her fridge and the stove. And she will send the children to live with her grandmother. She lifts her other hand to show me a thin plastic bag with three aluminium cooking pots. She will sell them at Soweto market. We part as she begins to cross through the chaotic traffic on Kafue Road and then disappears in the crowds.

Chapter 3

The field-sites, the fieldwork and the analysis

This chapter will lay out the choices and coincidences that settled the field-sites, influenced the process of conducting fieldwork, and formed the analysis in this thesis (cf. Sanjek, 1990). Although the spine of the thesis is records of stories and interactions produced in Lusaka, my inquiry did not begin and end with the fieldwork experience. Thus, this chapter not only describes the methods applied during fieldwork, but also offers an account of how the scope and argument of this thesis emerged, which is as much about what happened before and after fieldwork as it is about what happened during fieldwork.

The chapter is organised chronologically. I begin by discussing the initial orientations and questions that guided the development of my project proposal before I left for Lusaka, and that profoundly shaped my strategy for meeting interlocutors in a setting where I was not sure about the reception of my project. I continue with a description of the way contact with people and institutions in Lusaka unfolded by both directed effort and by coincidence, and how my initial questions were adjusted along the way. In this process I became very involved both in relations with my interlocutors and – sometimes reluctantly – in relations among my interlocutors. I end the section on my fieldwork with some considerations about the way the ethics of precarious relations have influenced my data production and my argument. I close the chapter with a few reflections on the way I have analysed my data and represented my interlocutors.

Initial orientations, questions and choices

In the light of recent critiques of transnational medical research, my initial interest was study subjects' experience of such research in Africa. How did they come to engage in this research? What did they see themselves engaging in? What was at stake for them in their engagement, and how might it change over time? Assuming that experience is intersubjective (Jackson, 1998), I address these empirical questions by applying a broad phenomenological approach to exploring situated, lived experience in combination with ethnographic attention to social processes and situations inspired by the Manchester School (Evens, 2006; Gluckman, 1964; Kapferer, 2005; van Velsen, 1967) in a particular time and place (Candea, 2007).[34] These broad theoretical orientations set the initial frame for my field and my fieldwork. I made two initial decisions about the geographical site of my fieldwork, and the kind of interlocutors I would try to meet, which also fundamentally conditioned my field and my fieldwork.

As a member of the Martin Okonji Research Group for Anthropologies of African Biosciences at the Global Health and Development Department at LSHTM (now at Cambridge), my focus was on an African fieldwork site and I explored possibilities for fieldwork in both Tanzania and Kenya, but – much in line with my observations about relations and possibilities in this thesis – I came to Lusaka as a result of a personal connection. Previously, my contact had informed me about the growing volume of medical research projects in Lusaka that were run by different conglomerates of foreign universities, foreign state and philanthropic donors, local research organisations and NGOs. This information gave rise to the idea, also suggested by my supervisors, of studying the way people might engage in and move between different medical research projects over time. Such a starting point would have the potential to open different avenues of inquiry than many existing studies of transnational medical research that tended to focus on issues related to one particular research procedure, one research project or one research organisation. My contact guided me through the application procedures for ethical clearance and made other useful practical and strategic suggestions along the way.

Given my primary interest in lay experience of transnational medical research I first and foremost wanted to learn from study subjects. I considered the possibility of contacting my prospective interlocutors through the research organisations that had

---

[34] Recent reflections about flows, mobilities and the fuzziness of the field can be seen as preceded by scholars of the Manchester School and their interest in social process and conflict (Coleman and Collins, 2006:11) as well as their reflections about how to delineate the field (Epstein, 1964 (written in 1957); Hannerz, 1980:144-147).

enrolled them, but I also knew how lengthy the process would be, if I was to inform research organisations operating in Lusaka about my project and apply for permission to speak to study participants. For pragmatic reasons, I chose to operate the other way around, and try to find study participants and others in their homes and neighbourhoods. I was unsure about how far into the clinics I could and should follow my interlocutors and to what extent I should inform research organisations about my project. I chose to let these questions be open until I came to Lusaka, together with the extent to which I would try to contact local research assistants and other local professional staff.

Before I departed for Lusaka I received ethical clearance from the LSHTM Research Ethics Committee and I submitted a project proposal for ethical clearance from the Ethics Review Committee at the Tropical Diseases Research Centre (TDRC) in Ndola, Zambia.

The fieldwork and the field-sites

An interest in transnational medical research could easily lead to multi-sited fieldwork, but given my main interest in study subjects' experience, I have conducted a 'classic' kind of fieldwork, living in one place for 12 months, where I established relations with people that I met and interacted with repeatedly. This made it possible to explore lay engagement in a transnational phenomenon as it unfolded in a particular location and in particular relations. This does not mean that I have disregarded the transnational aspect of medical research, but that my attention to transnational aspects of engagement was mainly activated when my interlocutors paid attention to them.

Access and timing

Upon arrival in Lusaka I received provisional ethical approval from TDRC and I proceeded to obtain research permissions from the Permanent Secretary at the Ministry of Health and the District Director of Health at the Lusaka District Health Management Team to work in the catchment areas of the three district clinics of Kamwala, Kabwata and Chilenje. While waiting for the permissions to come through I took a language course in ChiNyanja at the Faith and Encounter Centre Zambia (FENZA) for four weeks, which made me able to handle greetings, but with little lasting effect on my local language communication skills. The real benefit of my contact to the very able language teachers at FENZA was the opportunity to have my information sheet and informed consent form translated into both ChiBemba and ChiNyanja, the two most widely understood languages in Lusaka.

Having received my permissions I visited each of the three clinics to meet the sister-in-charge, to present my project, and to ask a few questions about health programmes and research activities in the particular clinic. I also met the chair of the Neighbourhood Health Committee in each clinic and several members of the "Top 10", who confirmed that they knew many people who had been or were involved in medical research projects. In fact several of them had been or were still outreach workers and recruiters for various projects.

Meeting these people and learning about their rich experience made me expand my original focus on study participants to also include others variously engaged in medical research projects. In fact most of my richest data come from being in the company of the Neighbourhood Health Committee members. They were used to researchers, they had a lot of experience, and research projects and other programmes took up more space in their lives than in the lives of most one-time study participants.

Members of the Neighbourhood Health Committee knew many people who were involved as study participants in research projects, but to contact these people without anyone breaking their promise of confidentiality I prepared a slip with a sentence about my interest in stories about engagement in health projects, my name and my contact details. I did not specify my particular interest in research projects for two reasons: first, based on observations from many other research sites in Africa and elsewhere I could not be certain that people distinguished clearly between health research and other health projects; secondly, I was interested in the way people engaged in different kinds of projects. I added space for people to fill in their name, what health projects they had been in, and how to contact them. I asked whether the

Neighbourhood Health Committee members would be interested in distributing the slips to people they knew and then return them to me.

I informed Committee members that I would pay ZMK 10,000 (GBP 1.44) for the first interview, but not in case of any follow-up interviews that people could, of course, decline to participate in. My decision to pay people and the particular amount to pay them was the perhaps controversial result of several lengthy consultations with volunteers and other contacts at the clinics who had been involved in different research and other projects. Some advised me not to pay anything, because it might distort the information I got. Others warned me that people were used to "getting something", particularly people who had been in research projects, so I could not expect to get stories from anyone if I did not offer anything in return for their time. After long deliberations I decided on a compromise that was half the common rate for "transport reimbursement" in the medical research projects that I had heard about at the time, but still enough for *"relish"* (oil, tomatoes, onion and salt for sauce to go with *nshima*, the staple food). People's concern with this issue became a first (and quite one-dimensional) entry point to understanding what projects might be about. The negotiations about whether to pay interlocutors and how much is an example of the way an element in fieldwork can move back and forth between being a practical question, an ethical concern and becoming data.

Committee members were happy to distribute the slips and they returned about 20 completed slips, which led me to initial contact with many people. I stayed in touch with about half of them throughout my fieldwork. During the course of my fieldwork I was able to trace the relations between the people I met and the Committee members – an indication of how project possibilities are distributed in relations. I also met many of my interlocutors in the clinics, where they came to me. They were happy to put me in touch with others that they knew, but I did not keep snowballing through relations after that. Based on the hope that I would be able to follow changes in people's experience over the year that I stayed in Lusaka I prioritised getting to know relatively fewer people and then to get to know them and their relations to each other more in-depth.

I began all first interviews with a presentation of myself and my project. I gave interlocutors an information sheet in the language that they preferred and we went through the informed consent form that was a requirement from LSHTM and the ethical committee of TDRC. Informed consent forms that state aims and objectives of research have been discussed as working against the open and flexible approach to data production that is the hallmark of anthropology as a scientific discipline (Okely, 2012:47-48). I had stated the purpose of my research in quite broad terms, so I was not so much concerned with the contents of the form as with the procedure of obtaining consent as such. I had not worked with an informed consent form before and at first it felt like a foreign element in my usual anthropological attention to rapport, which I often tried to establish by keeping the atmosphere rather informal (by small talk and relaxed body postures), and by trying to make interviews feel more like conversations.

It turned out, however, that it was not as difficult to incorporate the informed consent form into my routine as I had expected. First of all, given my research topic, many of my interlocutors had filled in similar forms in their earlier contact with researchers and the procedure formed an opportunity to talk about their earlier experience with the same procedure. Second, I came to see my efforts at establishing an informal atmosphere as a particular, perhaps Scandinavian, norm that might confuse people who expected to be interviewed for a ‘serious’ project. Informality came later, together with rapport, with the people that I came to meet many times during my fieldwork. I met most of my interlocutors at least twice, because I made a photocopy of each signed informed consent form to give to them within a week or two from our first meeting. Since many people preferred that their first interview should take place in our house or at the clinic, my returning of their informed consent form gave me a chance to come to people’s homes, if they agreed to it.

I decided to pursue contact to lay people first and to delay contact with researchers. Mainly learning about research projects from lay people I only very gradually learned about past and present research projects in the catchment areas of the three district clinics that I had permission to work in.

I arrived six months after one of the larger trials had ended and I left some months before another large one started. Medical research activities were not so intense at the time I was there, so I mainly learnt of people's experience through their later *accounts* of it, rather than through my own observations or from 'fresh' stories. This has of course had implications for the kind of data and detail that I have about engagement and the kind of analysis that I have been able to make. I have not been able to observe interaction between lay people and project staff, but instead I have learnt from listening to what elements of their engagement that people have remembered and talked about themselves, and what elements I had to ask about in order to learn. What first appeared as a disadvantage to my research agenda became an opening for inquiries into aspects of lay engagement in medical research projects that seemed to become more apparent when research activities were *not* so intense (e.g. the time-limitation of projects, efforts to learn about possibilities and the importance of relations in this regard). Besides, I was able to follow how people engaged in other projects and how this engagement unfolded in relation to partners, relatives, friends and neighbours, and in relation to me.

Guides and interlocutors

I came with the intention to work with a semi-professional interpreter with previous experience, and during the first round of interviews in our own home I worked with a young woman from a compound north of the city centre, who had some previous experience in translation for foreign researchers. She was not a native speaker of ChiNyanja or ChiBemba, however, and she did not know the compounds south of "town", or the city centre, where I worked. As I learned how many people were in fact able to communicate quite well in English I asked her instead to transcribe interviews that I had tape-recorded. I began working with several different people whom I met at the clinics and who lived in the same areas where I did my interviews and observations. They agreed to introduce me to their friends and neighbours, and rather than assistants, I considered them guides, who helped me find my way in several senses.

My guides had often been involved in medical research themselves as outreach workers or community representatives and they continued their function as intermediaries in their work for me. Whenever I met people who preferred speaking in a local language, my guides would assist in translating. Working with non-professionals as interpreters has undoubtedly had consequences for the accuracy, nuance and depth of translations. It is impossible to assess to what extent this has had implications for my analysis, but I think about this choice as a matter of gaining the possibility to move in the mazes of the compounds and to gain insight into webs of relations. With time, and because I kept returning to the same people, I also got a sense of the way stories might be filtered through the evolving relations between my guides, my interlocutors and myself.

Apart from conversations with many different people, I formally interviewed 65 non-professionals (48 women, 17 men) engaged in one or more projects and programmes related to health or education. Of these, 32 (29 women, three men) were or had been engaged in one or more of five different transnational medical research projects. Of the 32, I followed 13 women and two men more closely. I did not have a schedule for meeting them, but because I moved so much around the clinics and the compound, and because we lived so centrally, I invariably met them weekly, fortnightly or once a month. They were engaged in transnational medical research as study participants, recruiters (outreach workers), peer educators and community representatives.

My youngest formally interviewed interlocutor was 18 years old and the oldest 75. Most were between 20 and 50 years of age. My interlocutors had very diverse education backgrounds, spanning grade 5 to grade 12 and further courses and degrees, often taken outside Lusaka. Many were born in Lusaka, and many had come later in life. Some had always lived in the compound, and others had come from other areas of Lusaka. In terms of language and religious denomination my interlocutors were diverse, reflecting the migration that has characterised urban populations in Zambia for about a century. My interlocutors spoke ChiBemba, ChiNyanja, ChiTumbuka, ChiLozi, ChiLala, ChiNsenga, ChiNamwanga, and ChiTonga. Most mastered more than one language and many were married to partners speaking another mother tongue than themselves. They belonged to the Protestant United Church of Zambia, the Roman Catholic Church, the Old and the New Apostolic Church, the Presbyterian Church, the Reformed Church of Zambia, Jehova's Witnesses, various Pentecostal congregations, Baptist congregations, the African Methodist Church and Muslim mosques. It was not unusual for my interlocutors to be married to partners of another denomination, and to have changed their own denomination for various reasons.

As mentioned in the introduction I mainly dealt with people who had been engaged in one or more of four different clinical trials[35], and a few who had been enrolled in a cohort for epidemiological research. I could have tried harder to find research subjects and volunteers in other kinds of health and medical research projects (e.g. intervention studies or observational studies), but the organisation and duration of clinical trials, with their fixed routines over a longer period of time and the products to test, reach further into people's daily lives (although I quickly realised that it might still not be very much) than most other kinds of medical research. People who engaged in the relatively more intense clinical trials, rather than in other kinds of medical research, simply had more stories to tell the curious anthropologist. Likewise, people who had been engaged in more than one study had more stories to tell. I have not pursued stories about how people might engage differently in different kinds of medical research, but I have made efforts to illuminate the trajectories of both the inexperienced and the experienced.

Sites

Over the course of my fieldwork I moved in and through several locations in Lusaka. Here I briefly present the clinic, our home, other people's homes, the compound, the city and Zambia as particular fieldwork sites. I also briefly describe research organisations as a fieldwork site that I did *not* move through, and what implications this might have had for my analysis.

---

[35] Clinical trials are often divided into at least three phases. Phase I tests safety and dose range, phase II tests safety and efficacy (if at all) on a relatively smaller number of subjects, phase III tests safety and efficacy on a larger number of subjects.

I began my fieldwork by visiting the three clinics that I had permission to work in. After formally introducing myself to the sister-in-charge and the chairs of the Neighbourhood Health Committees I began passing by the clinics regularly, usually weekly, to meet the volunteers that I gradually came to know. I chatted with the cleaners and the environmental health officers, hung out in the TB corner and in the waiting room of the VCT rooms, and in the hallways leading to the MCH section or the rooms where members of the Neigbourhood Health Committee met. Apart from five interviews with five TB patients at the beginning of my fieldwork (that served as a source of first impressions on how people got into health programmes), the clinics were spaces for informal conversations and rich observations rather than interviews. In this way I developed insight into everyday life in a clinic with a focus on the volunteers on the Neighbourhood Health Committee, and how they engaged in projects and programmes.

With the help of a Zambian housekeeper[36] for a Danish family in Lusaka that we came to know, my husband and I found a house in a local middle-class township of solid council houses built between 1959 and 1962, on a street that had once had tarmac. We were very well received in the neighbourhood and I came to know a handful of our neighbours, especially mothers and daughters. I am not drawing directly on what I learned from them in this thesis, but knowing them, in spite of their very diverse backgrounds and family situations, and even though they also struggled with rent and relatives, made me more aware of differences between living in a township and living in a compound (see Chapter 2).

Our home became the place for many initial interviews and for many informal visits. It turned out that people from the compounds often used our street when they had errands in town or when they were heading for the nearby clinic. This meant that we often had visitors passing by, which was extremely convenient and pleasant for me (but not always to the same degree for my husband). My husband came to know ‘the boys’ on the street and through him I learned of their various efforts to get by, which included buying large amounts of frozen fish that they tried to sell on before it thawed,

---

[36] We had hired her daughter to look after our 1- year-old daughter.

having our car serviced and washed by them, and loaning them money for various more or less successful business endeavours. Some months after our arrival in Lusaka my cousin came to stay with us for eight months. She became involved as a volunteer, fundraiser and board member in one of the many private orphanages in Lusaka, which gave me another window to learning about interventions in Lusaka.

As soon as I had copies of informed consent forms to return to my interlocutors I began asking to visit people in their homes. I kept returning to a handful of homes, where I also came to know relatives and neighbours – mostly women. Sitting around in my interlocutors' homes, sometimes taking notes, sometimes just making headnotes, I learned about interaction, relations, concerns, engagements and livelihoods among women in the compounds. I attended several special events in the domestic or home sphere, such as kitchen parties, funerals and a women's group's fundraising braai.

With time I became able to find my way in the maze of paths that crossed the compound to the homes that I visited most often. In the beginning it was with some caution, because Charles, whom I introduce in Chapter 8, had mentioned that it might be difficult for me to move in the community on my own because of the Satanism myths. In the first phase of my fieldwork I wondered about his use of the term "myth" (and also his term "the community") and to what extent this was a 'trial term' or his own – and also wanting to gauge what implications his observation might have for my movements. He explained how it was well known that white people were associated with blood-sucking and Satanism. Some white people were after the blood of people in Zambia and they somehow got rich from it. Later, people walking with me in the compound sometimes told me that others commented on their companion, asking them, for example: *"Why are you walking with Satan?"* Fortunately my guides didn't seem very concerned with these remarks. More on this in later.

Since researchers from the RLI began carrying out fieldwork in the Copperbelt mining towns in the 1950s, many ethnographers working in Africa have reflected on differences between conducting fieldwork in the (segregated) city and in a village. Epstein noted how classic participant observation had to be adjusted by "knocking on doors" and by making appointments because – contrary to village life – people would be working away from their homes and much social life would take place inside houses and not in the open (Epstein, 1981:8-9). Compared to my earlier fieldwork in a village in Northern Ghana (four months) and at the lakeside in Malawi (eight months) it was as easy to establish contact with people in Lusaka as in the villages. This was perhaps because I spent time in the clinics, where people were often sitting around and waiting; in the compound, where not so many people worked; and with volunteers, who often had a particular interest in me as a foreigner.

As mentioned earlier, my fieldwork could have taken place in many sites in Africa. It was coincidence and a connection that took me to Zambia and Lusaka, which turned out to be quite fortunate. The way medical research activities were organised in Lusaka – spread out and quite integrated into existing facilities at district level – made the analytical perspective that cast transnational medical research as an intervention among other interventions particularly suitable.

Before I left for Lusaka I had decided to wait and see with regard to contacting professionals working within the research organisations. Once in Lusaka, I prioritised finding my main interlocutors through members of the Neighbourhood Health Committees at the clinics and having a good basis of contacts there, before I contacted the professional staff. As I have already mentioned, research activities in the clinics were not so intense at the time of my fieldwork, so it was possible for me to move around the relatively large and often quite crowded clinic compounds without running into staff of research projects.

Still, some of the lower-level staff had heard of me. Quite early on, I was approached by a few staff members from research projects who were looking for additional job opportunities. Once they understood that I was not looking to employ an assistant I did not meet them again. By chance and on separate occasions, I also met two Zambian doctors, attached to two different transnational research organisations, who were also students at LSHTM, and very interested in my work. One of them told me about the procedures that I would have to go through to get permission to speak to study subjects in the organisation that she worked for, and the other asked me not to stay in touch because he would then feel obliged to report to his supervisors about our contact. An employee in one of the larger research organisations, who was also involved in a local NGO, was very eager to talk to me about my contact with a certain philanthropic donor, but politely declined to talk about his work. When I met a nurse in a dissemination seminar of the results of a trial she was very reserved and said “*normally we don’t allow our study participants to speak to other researchers”.* Based on these experiences I decided to wait until the end of my stay before interviewing researchers and staff of the research organisations in order to minimise the risk of uncomfortable situations for myself and my interlocutors that would not add data in relation to my main research interests. The few episodes mentioned above not only confirmed that it would be complicated to meet study participants through the research organisations, but also attuned me to the way some people not only saw research projects as a job opportunity, but also as a job with access to sensitive knowledge that could not readily be shared with other researchers.

Towards the end of my fieldwork I carried out about 10 structured interviewed with foreign and Zambian researchers and research assistants, usually in their offices. With one exception most interviews were quite brief and mainly concerned the history of medical research and research organisations in Lusaka. The interviews did not concern specific research projects and I do not have any study protocols. Thus, I am not able to say much more about the research organisations and their concrete studies than what I learned from my interlocutors and what I have been able to find out about the research organisations on the internet. With this approach inaccuracies and misunderstandings regarding particularities of the research projects will be inevitable, but they are most likely of an order that do not significantly alter my overall interpretations and arguments. After all, I was not out to measure people’s understanding of research compared to protocols and provided information, but to try to understand their *engagement* in research projects.

Phases, methods, and topics

After I had established initial contacts with volunteers at the clinics I began conducting structured interviews with them about health problems and programmes. My purpose was to open relations with my interlocutors in a relatively neutral way, to define myself as a researcher, and to get a feel for the kinds and levels of problems and activities associated with health. The initial interviews were followed by visits to the clinics where more informal conversations took place together with observation of life in the clinics from the volunteers' perspective. I also began visiting both volunteers and other interlocutors in their homes around this time. I tried asking about issues more specifically related to research projects, but relatively soon I stopped asking these questions because it seemed difficult for many people to respond, and I sensed that many people made efforts to respond 'correctly' to my questions. For example, one of the experienced volunteers in one of the clinics showed me her certificates that included a certificate for completing a course on research ethics for community representatives by Family Health International (FHI) in 2005. I asked her whether she remembered what she had learnt in the course and she replied, *"Eehh ,… remind me what ethics is about …"*

I did not yet know how to ask questions about research in a way so that it did not appear 'artificial' or out of context, so instead, I began studying engagement in projects more broadly by asking people about their past experiences, by listening for their remarks and concerns about present engagement and by accompanying them in their engagements. During this period I carried out fewer interviews. Instead, I observed interaction in the clinics and among volunteers, and I had more informal conversations with the people that I had come to know better in the clinics, in our home, in their homes, and moving around the compound. I focused on notions and practices of volunteering, which made me able to sometimes inquire more specifically about engagement in transnational medical research in a more relevant way. I ended my fieldwork with a month of more structured interviews, trying to tie up loose ends.

Precarious positions and relations

The sort and quality of data that an ethnographer can produce depends on the relations that she establishes. In this section I consider relations to my interlocutors, not as a prerequisite for producing data, but as data in itself that opened and deepened insights into engagement in transnational medical research projects. Ethical, epistemological and existential aspects of my positions and relations in the field-sites weaved into each other during my fieldwork, and their openings and closures formed my path through my field and my insights.

Anonymity and confidentiality

I have chosen to leave names of clinics, research organisations and research projects unchanged, since it would not be difficult to identify these, if one wanted to. I have changed the names of all my interlocutors, and often some demographic detail that does not influence the thrust of my analysis, but that veils their identity. For the same reason, I have avoided being very specific about places and clinics in my case studies. However, my interlocutors and others familiar with health and research interventions around 2009 in the three catchment areas of my study area might still recognise each other. I hope that the implied people will find the events described in a way that they can recognise, although they may not agree with my version of events as an implicated actor in various situations. Recognising that there is no neutral space in interaction, I have tried to make my own positions in the situations I describe, and in my interpretations of them, as explicit as possible.

Possibilities in precarious relations

I came to my field-site with particular hopes and expectations about what I would learn and I was met by people who had their own more or less explicit hopes and expectations of me, another foreigner at first, and later perhaps a promising connection, a well-wisher, a source of entertainment, even a friend, and sometimes all of the above. I began recording these inquiries to me as illuminations both of needs and hopes and of the kind of possibilities that people might associate with foreigners, researchers, employers, neighbours and resourceful friends (cf. Venkatesh, 2002).

When I first met people some asked whether I needed a nanny or someone to wash our clothes (I did not). Perhaps I could connect a founder of an NGO with the Danish Embassy (sorry, no), or share with a nurse how I obtained a scholarship for my PhD (of course). One of our neighbours asked if I could assist him and his friend in writing a proposal to an NGO (of course, but they never turned up). I have already mentioned how research assistants came to inquire about job opportunities, and many other casual conversations and first interviews often felt like job interviews, where people presented to me their schooling and skills. Carefully phrased declinations to various requests were often accepted with laughter, indicating that people had just tried their luck, but at other times my failure to meet people's more or less implicit hopes for possibilities cut off the contact.

When relations were more established I might get requests about whether I could contribute to a registration fee for a course (yes, sometimes) or a school uniform (yes), to rent (yes, partially), to bailing out someone's nephew from prison (yes), or to the establishment of an orphanage (sorry, no).

In the relations where I spent most time, possibilities and the way they developed was most enjoyable. Precious, who was one of my guides that I came to spend quite a lot of time with, enjoyed referring to me as her boss. She regularly reminded me that "*a good boss shares and gives away. A stingy boss is not good*". She invited me to join the Committee that prepared her sister's wedding (which included contributing to the purchase of the stove that the Committee planned to give the coming bride), and she invited me to visit her women's group that also included Rose, whom I will introduce in Chapter 5. Before leaving the group of about 10 members that day, Precious argued very convincingly that I should help the group do something. At that time, Rose had just joined a new cooperative. This cooperative was organised by a white woman, who wanted to buy crocheted bags made of used plastic bags. They sold at ZMK 20,000 (GBP 2.88) to a black woman from Avondale, who then decorated the bags and forwarded them to the white woman abroad. While we were talking, Rose crocheted and Precious also tried it out while asking me what I could do for them. I responded that I could only read and write and that I knew nothing of business. They all laughed in a mix of amusement and disbelief. They maintained that I was so educated and that I must know something. In fact, Precious said, there were people who needed to learn to read and to write. I asked them about adult literacy courses and I offered to put them in touch with my ChiNyanja teacher. Precious hesitated and said that they had planned something similar and that they already knew someone who could teach. They just needed to contact some NGOs now. (Later, I understood how Precious had improvised here. They did not want literacy training; they wanted a continuing relation to the foreigner.) Then they continued talking about how I could help them. I am not sure exactly who came up with the idea, but it was then decided to organise English conversation classes for 15 women at Precious' house Thursdays at 14.30 hours. We agreed that as part of the conversation I could ask them questions, so I could also learn at the same time. They immediately organised an executive committee for the classes. (Rose enjoyed that in particular – she slapped her thigh, leaned back and grinned: "God is great." Later she said something in ChiNyanja and English. I only understood "Bring those condoms" – I asked what she was saying and one of the others said that she was practising what she would say in the bedroom at home. She would begin her English conversation there.) Happy with the arrangement and still new to Lusaka and the way possibilities are shared, I asked whether the class should have minimum criteria for proficiency (which might exclude, I understood later), but Precious patiently suggested that some needed to learn, while others needed to practise.

Later, when I admired the bags that Rose crocheted and also bought some of them, some of the group members began producing bags that I took to Denmark to sell for them, when I did a presentation in Copenhagen. Stories about this success led to other business proposals, such as borrowing my oven for baking cakes for sale at the clinic, etc.[37]

Sometimes relations became quite complicated. Joyce and Joanna, for example, the protagonists of Chapter 6, eloquently made clear that they would not charge me for telling me their stories, but would be happy with whatever I could give them. They would continue by underlining that "*it doesn't matter that I am black and you are white. We are like what? Like family*". And "*I cannot charge you, my sister, like CIDRZ. You are a student and when people ask us, we say you are good and that you are not a Satanist. We should avoid talking bad about you when we are outside the gate.*" Apart from invoking sisterhood as a dimension of our relationship (Gluckman, 1965:173), one

---

[37] See Pritchett (2001:68-69) about the subtle and sophisticated, but relentless pressure on project personnel to share and become businesspeople in rural north-western Zambia.

of them asked for help with her rent and I sometimes agreed to lending her part of it, trying to live up to being a good neighbour and friend. They asked for shampoo and lotion, like friends might ask each other. I thought that I took up a kind of decent ”well-wisher” position when I gave one of them money to travel to the Copperbelt for a funeral of an aunt who had been in a traffic accident and who had not woken up after the doctors had operated on her (it was only much later and by coincidence that I learnt how the aunt, who had indeed been operated on after a traffic accident, had *not* passed away). Once, I asked Joyce about the informed consent form that they had promised to photocopy for me. I had given her the necessary cash to pay for the copying and Joyce explained that she had given all of it to a friend of hers to do the copying, but a thief had been there and had taken everything. These ladies were professionals in knowing “how to talk to people” as I will show, and they were also professionals in dealing with their gullible anthropologist.

I was not only challenged as a resourceful stranger and friend, but also in my capacity of being a researcher. Once, in Precious’ home, she showed me a book entitled *The Body Hunters* and she spoke very critically of foreign medical researchers working in Zambia. I took notes very quickly (see Chapter 8). Precious and I had worked together long enough for her to expect that I would take notes when she was talking, but Rose also noticed and asked me whether this was what I would write in my report. Given the perspective that Precious had just brought this up, this was quite a delicate moment. I explained again that I would collect these notes together with the transcriptions of all my interviews that were done by a young woman from another part of Lusaka who did not know anybody here. I would read what others had written about medical research in other places, compare it with what I had learned in Lusaka, write a report and eventually get a degree. Still agitated, Precious asked me whether I was the same? Whether I was also a body hunter? Perplexed, I said, that I didn’t know. Hesitating, I continued that I was never sure whether there was a good balance between what I collected and what I gave. I saw myself more as a *story hunter*, but I didn’t know if that would be the same as a body hunter. Now calmer, Precious said that it was different because I would not do anything to her body. Martha said, *"No, it is different … you are a catalyst"* referring to my involvement in their women's group.

Such enquiries and challenges have not only influenced my ethnographic insight into needs and aspirations, but also my analytical attention to the way relations are established and explored for possibilities, and how conflicts could unfold around possibilities in such relations. Precious, for example, told me once how a well-known volunteer at the clinic had said to the women's group: *"Do you think Birgitte comes with money to you? She is just a student."* Precious then reported how she had been proud of Rose who had answered: *"Birgitte comes with knowledge, and that is what we come for ..."* As will be clear in the coming chapters, this kind of attention to possibilities in relations often forms the impetus for analyses of further dimensions of lay engagement.

Another observation about my interlocutors' interaction with me was that some of my interlocutors were more familiar with the interview form and speaking with a foreigner than others. Assuming that I am a fair, and not a terribly bad interviewer, I came to see the 'failed' interviews with people, who did not really answer my questions and who did not 'explore' me, as interaction with people who were perhaps not so familiar with the kind of interaction with foreigners that for example unfold in research and other projects. Joyce and Joanna, and other more experienced lay people, were much easier to interview and to converse with than for example Tabita and her friends (in Chapter 4), and they were often the ones to initiate contact with me in the hope that I might be a possible source of future openings. Such differences conditioned my fieldwork and they were also data for me. To make this aspect of my data production explicit I have included a brief paragraph about the relation between the protagonists and me for each of the central cases in this thesis.

Limits to sharing and being?

Paying attention to precarious relations and people's expectations to me was not only a matter of learning something, but it could also very much be seen as a matter of ethics, because of the inequality in possibilities available to my interlocutors and to me (Nama and Swartz, 2002).

This inequality was sometimes dealt with by joking. Rose, for example, enjoyed scolding me for always serving biscuits: "*Why you never give us boiled sweet potatoes?*", a common snack in the compound, "*You should cook nshima for us!*" Much later, I understood her request as asking me to commit to our relationship.[38] On another occasion she was among the women in Precious' women's group whom I took to Arcades, one of the two big malls in Lusaka, in our car to explore the possibility for the women's group to open a stall in the weekend market for tourists. She so enjoyed having me as the driver, and instructed me to ask her "*Whereto, Madam*?" This kind of joking in our relationship could be seen as the least painful way of addressing and acknowledging our very different situations (cf. Geissler, 2013:25-26).

At other times jokes could not mediate differences between the possibilities and resources available to me and to my interlocutors. As I briefly describe above I had many and unusually explicit negotiations with Joyce and Joanna about what they would get from me for telling me their stories. It was only back in Copenhagen when I started writing out case studies that I realised how Joyce, in particular, was going through a time of intensifying difficulties during the time I was in Lusaka. In Chapter 6 I describe some of the elements in these difficulties and the uncertainties that they brought along, which should be the overall context for interpreting her negotiations and transactions with me. The chapter about Joyce and Joanna makes a point about uncertainty, but it also illuminates a situation of fading hopes and of disappointed expectations of me and of others that I eventually only witnessed, instead of trying to do more.

Expectations of me and the (lack of) exchanges could be framed as a matter of ethics and thus as based on an autonomous individual's psychologically and philosophically informed reflections and reasoning about difficult choices (Kleinman, 1999:72). From this perspective I have thought about whether I did the right thing in relation to Joyce, considering our different means and possibilities. More than framing the situation as ethical, however, such exchanges, relations and expectations – and disappointed expectations in particular – are perhaps better captured as existential in

---

[38] See Richards (1939:46-48) and also Geissler and Prince (2010:155ff) on the particular association between cooking and sharing food and the establishment and maintenance of relations.

the sense that Gluckman proposed in his *The Ideas in Barotse Jurisprudence* (1965). He wrote that “*The Law of Things and the Law of Obligations are both mostly contained in the Law of Persons, and each of these three is also the others examined from a different standpoint*” (ibid.:172). Gluckman’s point was that personhood and the materiality of morality constitute each other, and the implication is that the lack of (fulfilling an) obligation is the same as lack of relation, and lack of being. In this light, fieldwork relations – and any relation – are not so much about doing the right thing to the other (as an ethical problem, which implies and highlights a separation between the self and the Other), but more radically about *being together* (as an existential problem, which implies and highlights interdependence). In this light, my interlocutors’ requests to me and others were not just about opportunity, but more fundamental and existential probes into constituting relations and personhood (Englund, 2008). It is in this light that I now understand my deep sense of (failed) obligation in relation to my interlocutors.

Analysis and representation

I returned to Copenhagen with notebooks full of stories, recorded observations and transcribed interviews; plastic bags full of newspaper clippings and pictures; and my mind full of images and memories. In this section I will try to make explicit how this diverse material was sorted and organised into the chapters that form my analysis.

My data are characterised by a fairly high degree of homogeneity. I have many stories from people in similar situations, location and institutional set-up. A major challenge has been to identify the dimensions or differences in the stories that actually made a difference analytically – which presupposed that I had identified a set of suitable concepts for analysing my material. I attempted to code my interviews and my field-notes, but soon produced far too many codes for any of them to be useful, because I had not yet decided on an overall question to provide direction within an analytical frame. Instead, I decided to take as a starting point my best stories, meaning the case stories where I had the ‘thickest’ and most varied data and where I would have the best chance to offer a nuanced interpretation of my interlocutors’ engagement – suitably drawing from the Manchester School tradition of case analysis that was born in Zambia with the Rhodes Livingstone Institute (Kapferer, 2005; Mitchell, 1983; Werbner, 1984).

With a dozen stories as my platform, I returned to looking for various dimensions in my stories and the extent to which they could be illuminated by particular analytical concepts. This process was informed by reading and conversations with supervisors and colleagues. Along the way I explored the explanatory power of several conceptual frames, such as exchange theory and moral economy, and notions like value, experiment, technology, scenarios and imaginaries as leading analytical concepts. I explored ideas of altruism and self-interest and of citizenship. These concepts all had something to contribute, but in writing my stories 'through' these concepts most of the concepts became too tight to contain the complexity or the detail of my material, and I discarded them. Some of them have found their way back into the analysis in more proportionate versions. This process is still ongoing and the terms and concepts that give direction to the present analysis should be seen as a snapshot of a moment in a continuous process of attempts to capture and calibrate my field in different ways.

I will end this chapter with a few words on language and representation. In my portrayal of people I avoid applying terminology that draws from economy, such as 'invest' or 'maximise', and I do not refer to 'resources' or 'capital', nor 'strategy' or 'navigation'. It is not that there are no elements of calculation in people's acts and interaction, but as a counterweight to studies of individual motivation and rational decision-making in relation to participation in medical research, I hope to highlight not the rationality, but the *sociality* of trajectories of engagement, and not the utility, but the *circulation* of project possibilities.

As mentioned above, my interviews were either conducted in English or translated into English and then transcribed. When I cite excerpts from these interviews I have chosen to selectively edit the texts for two reasons. Spoken communication that is written down often appears more hesitant and disconnected than it is, reflecting back on the speaker in an unfavourable way. Besides, it can be difficult to read. Thus, in my excerpts I have tried to strike a balance between respect, readability and record. I will briefly illustrate how I have gone about this editing as follows:

Original transcription by Olivia of Malala interview:

> *Then they said, yes, we have tried this except that in other countries the only reports where were there they were just experiencing some silly noise in womb [….] But there is nothing harmful, so mainly why joined because sometimes we do fail maybe to buying medicine when you are sick, so again I was thinking may be now suppose the medicine does not work well in me, what will happen if I die because like the way I am explaining here for me to join any programme I have to sign meaning that I have accepted what someone wants, but I again I was thinking I said you what when you go to UTH when you sick there what they do is they will try different medicine to see which one will work.*

My edited version:

> *Then they said, "Yes, we have tried this, except that in other countries the only reports were that they just experienced some silly noise in the womb [...] But there is nothing harmful," so mainly I joined because sometimes we do fail, maybe, to buy medicine when we are sick, so again I was thinking: "Now suppose the medicine does not work well in me, what will happen if I die?" Because for me to join any programme I have to sign, meaning that I have accepted what someone wants. But again I was thinking that when you go to UTH when you are sick, what they do is that they will try different medicine to see which one will work.*

Two further notes on transcripts are due: three dots, i.e. …, signifies the speakers' pause, whereas three dots in square brackets, i.e. […], signifies that words have been taken out, because they were irrelevant to the point of bringing the excerpt. Double quotation marks are used for all quotes and expressions by my interlocutors or by other scholars, whereas single quotation marks are used for emphasising my own terms and expressions, such as 'something bigger' in chapter 4.

Vignette II: Tabita’s friend, Albetina

*Albetina, 23 years old, was married to a man who worked in one of the Chinese shops at the township market. They got married when she was 16 because she became pregnant. They and their three children lived in a rented room in the compound, divided into two by a curtain. When I visited her the first time she showed me the “ka-shop” (the ChiNyanja prefix “*ka-*“ is a diminutive, singular tense), outside their landlord’s house, where little piles of soap, biscuits, matchboxes, etc. were displayed for sale on a plank behind a wire net. Part of her husband’s salary went to buying goods for the shop that they rented for ZMK 50,000 per month (GBP 7.20) and that Albetina tended to. Next time I came by there were no goods in the shop. With an embarrassed laugh Albetina said that they had had to “eat” the goods, because there was no money.*

Albetina’s father worked at the City Council as a supervisor for those who go to check on street vendors. He had contacts at the local SPAR supermarket, where Albetina would like to work, but they wanted a full certificate, meaning a grade 12 exam, so Albetina, who had left school after grade 9, was looking for ways to continue her education. Her father had told her to wait for money.

Towards the end of my year in Lusaka, Albetina got a job at the City Council as an office orderly. Smiling broadly, she told me that the Council would pay for her schooling at some point and that she would then train to become someone to check on street vendors.

Chapter 4

Learning how to engage

Introduction

Medical research is usually thought of as a matter of gaining abstracted knowledge about a defined problem by experiment. The elaborate processes of producing such knowledge, however, also involves the production and proliferation of other kinds of knowing among the people who are variously involved. This chapter is about two different kinds of learning and knowing that follow from engaging as a lay person in transnational medical research projects in Lusaka. I will show how lay people learn *about* the purposes and procedures of medical research, but that this knowledge is supplemented by learning *how to* engage in medical research projects. The latter kind of more particular and implicit knowing, which must be learnt by all social actors in medical research, including project staff, is a precondition for the production of knowledge that is presented as abstracted and general.

To illuminate the processes in which lay people come to meet and appropriate these two orders of knowing in relation to transnational medical research in Lusaka, this chapter will follow Tabita and her friends' trajectory of engagement in a research project to test a vaginal gel to prevent HIV transmission.[39] Tabita and her friends were all in their late teens or early 20s, and they engaged in a research project for the first time with little or no prior experience of being in projects. As novices they are particularly suitable as protagonists in this chapter about learning and knowing.

The chapter opens with a brief discussion of the two main kinds of knowing that played out in the young women's process of learning to engage in the project, i.e. 'knowing about', which is imagined as a generalised or context-free kind of cognitive knowledge that can be transmitted as factual information; and 'knowing how to',

---

[39] This clinical trial phase II/IIb of vaginal gels, known as microbicides, was run by CIDRZ.

which is a more situational, practical and often implicit ‘common-sense’ and embodied order of knowledge that is less easily verbalised. The rest of the chapter falls into three parts that roughly follow the young women’s trajectory through the project over time. I begin by examining Tabita and her friends’ accounts of their first encounters with the project that they did not know much about. I show how their willingness to ‘learn about’ something that was both vague and highly ambiguous for the young women unfolded in caring relations. Second, I show how the young women’s accounts repeatedly emphasised how they enjoyed learning from the project that taught them about “how to keep themselves”. The satisfaction associated with this kind of ‘learning about’ could be seen in the context of the many disparate norms and kinds of information about womanhood, health, sexual relations and the risks that such relations entailed, but also as a wish to be part of a vague, but promising ‘something bigger’ in the form of a research project. The chapter closes with an examination of how the young women learnt to be part of this ‘something bigger’ by engaging in project routines and relations.

Learning ‘about’ and learning ‘how to’

Learning takes place in practical engagement with the world and its particulars and contingencies. This engagement, in all its varieties, produces knowledge of different kinds. Some kinds of knowledge acquire particular status as truths that exist in a realm of pure theory, unaffected by the conditions that they were produced under. The American pragmatist John Dewey referred to this image of knowledge as “the spectator theory of knowledge” (Dewey, 1929:23) that invokes (the search for) a speculative, detached, transcendent and enduring kind of knowledge. With this characterisation Dewey countered certain images and ideals of knowledge and truth within philosophy, and he argued that knowledge by a spectator is an illusion. Instead, he suggested, knowledge is produced by participators engaged in directed activity (Dewey, 1929:123), whether these participators are natural scientists or lay people.

Inspired by Dewey's distinction between the kind of knowledge that acquires status as generalised and independent of its context[40], and the kind of knowledge that is produced in continued engagement with particular problems, I will distinguish between 'knowing about' and 'knowing how to'. To briefly illuminate the difference between the two images of knowledge, 'knowing about' is the kind of knowledge that is typically taught in a classroom, whereas 'knowing how to' is the kind of knowledge that makes students able to come to the right class in time, find their seat and act as students. Both kinds of knowledge are involved in going to school, but 'knowing about' is often thought of and performed as cognitive knowledge. It is verbalised, it can be made secret, almost reified (as in 'a piece of information'), and even commoditised (Meinert, 2009a), whereas 'knowing how to' is often more implicit, fluid and embodied.

Since all knowledge, including scientific knowledge, is produced and invoked in interaction with particular and situated problems, as Dewey argued, the analytical distinction between abstract 'knowing about' and practical 'knowing how to' is not always very clear as they merge into each other in directed action or engagement. In fact, the distinction only becomes interesting and useful when it is combined with attention to such directed engagement and the purposes and possibilities that come with it. In the case of medical researchers the ultimate purpose and possibility is new and more scientific knowledge about problems (but also the possibility of a career, of gratification in contributing to improved health (cf. Tousignant, 2013) and of knowing people (Whyte, 2011)). In the case of study participants, purposes and possibilities can be very diverse, as I will show in this thesis, and so is the application and performance of knowledges.

This chapter explores how a group of young women came to engage both in 'knowing about' medical research and in 'knowing how to' be in a transnational medical research project. It shows how learning about medical research did not engage them very much. Instead they enjoyed learning about "how to keep

---

[40] Dewey's critique of the spectator theory of knowledge can be seen as preceding observations about the social production of science that are made in the large body of literature in science and technology studies inspired by Bruno Latour since the late 1970s.

themselves” and to be cared for in a large and resourceful setting, where learning how to engage in a project might be the most important lesson.

First ambiguous encounters

I was introduced to Tabita and her friends by Auntie Loveness, Tabita’ grandmother, whom I knew from the clinic. I first met the young women about four months after their involvement in the microbicide trial had been completed and about two years after they had first enrolled. They agreed to meet me regularly for interviews and chats. The first round of interviews with them in little groups of two or three took place in our house with the assistance of my interpreter, Olivia. The interviews were characterised by a friendly, but rather formal atmosphere. Later, I visited each one of them in their homes, but most often we met in Tabita’s home, where interviews and conversations took place in a much more informal atmosphere. Here, the young women had enough courage to speak English themselves, and they helped each other translate.[41] The following account is compiled from taped and transcribed interviews and from notes taken during and after conversations.

Tabita, whose relatives had managed to pay school fees for her until she completed grade 9 (junior secondary school), lived with her widowed mother, who brewed and sold *kachasu*,[42] and three sisters, two brothers, an uncle and a cousin in a three-roomed house in the compound. She was 19 years old, and had recently had a baby, when Tabita’s grandmother, Auntie Loveness, had encouraged her to go to the local clinic and join a certain project. Auntie Loveness was an outreach worker for the project, and in addition to her granddaughter, she also recruited her granddaughter’s friends. The following is an account of how Tabita and six of her friends first came to know about the project and what it might entail for them.

---

[41] Still, I always felt a certain reticence from the girls that I never overcame. They were polite, but they were not ”free” with me, as a local English expression goes, perhaps because of my age, status or being a foreigner. It could also be that they did not feel sure about the nature of my interest in them, but others whom I spent time with would address me with much less reservation. This texture of our interaction could be seen as another indication of the young women’s limited experience and lack of familiarity with projects and their (foreign) representatives.

[42] *Kachasu* is a spirit of varying strength (20–70% alcohol) made from maize.

The HIV test and "lifestyle"

One of Tabita's friends, **Albetina**, who appeared in the vignette preceding this chapter, was 23 years old, married and had three children – the firstborn 7 years old. She remembered how Auntie Loveness told her about a project at the clinic particularly for young women. She had explained that "*there is a study at the clinic, they are interviewing women about your lifestyle and about diseases, if you have suffered from any sexual diseases and other related diseases*". Another friend, **Emelda**, 21 years old, recalled that Auntie Loveness had said that *"there is a project at the clinic – they are researching and if you want to join and if you feel comfortable with those things you can join".*

> *B: What were those things?*
> *Emelda: Okay, she said, there is a research. They are researching on lifestyle and if you want to know about yourself, you can join.*
> *B: Know yourself in terms of what?*
> *Emelda: In terms of life.*[43] *Knowing your status.*

Albetina and Emelda remembered how Auntie Loveness had focused on lifestyle and diseases in her descriptions of what the study was about. *"Lifestyle"*, *"diseases"*, *"sexual diseases and other related diseases"*, *"those things"*, *"to know about yourself in terms of life"*, and *"knowing your status"*. Within the space of a few sentences Albetina and Emelda applied several different more or less direct ways of referring to sexually transmitted infections, and particularly the HIV infection. Some of their circumlocutions have lost much of their softening effect, like Emelda's final attempt at explaining to me: *"knowing your status"*. This phrase has become so much a common expression for getting the results of an HIV test that it can hardly mean anything else in Lusaka.

The HIV test figured prominently in the young women's accounts of their first encounters with the project – almost as if this test was the primary purpose of the project. I asked **Estina**, 19 years old and staying in the compound with her mother,

---

[43] The ChiNyanja word *moyo* can be translated into both 'life' and 'health' in English. Likewise, the ChiBemba word *bumi* carries both meanings. Another ChiBemba term is *mutende*, which can be translated into both 'health' and 'peace'.

brother, sister and two children of a late sister, to tell me how she came to join the project. She replied to this quite open question by going straight to the issue of testing for HIV: *"When I first heard about CIDRZ, I went there and I was tested. They also tested some other things."* **Linda**, Tabita's cousin, had also been in the project. She was 22 years old, she had completed primary school (grade 7), and lived with her mother, five brothers, four sisters and her mother's sister in a relatively large and good house with lots of cupboards and kitchenware in the compound that they had moved to from a township in 1996 after Linda's father had passed away. Linda had a boyfriend and was the mother of a five-month old baby. I asked Linda what happened when she first went to the clinic and she said: *"I went there and got tested. I was scared but I waited for the results and they were negative."*

Tabita herself had not been prepared for the HIV test when she came to the clinic. Somehow, Auntie Loveness had not included this information when she told her granddaughter about the project. Tabita was indeed *"very scared and so afraid"* when she found out. She had observed how others coming to the clinic had left again, when they realised that they would have to be tested to be enrolled. Others had gone through with the test, but had run away instead of waiting for their result, because they were scared that maybe the result would be positive. Tabita had also wanted to run away, but in the end she went through with the test.

The HIV test was a process of getting to know about one's status, not only in terms of an infection, but also in terms of social and moral relations. Confronting the possibility to 'know about' one's status was deeply disturbing, because 'knowing how to' live with a positive status was limited for most people.[44] The result of an HIV test was closely associated with – indeed inseparable from – a broader context of "lifestyle". Only a few years earlier a positive HIV test had been closely associated with death[45] and it was still associated with having to confront a potentially negative moral judgement. For the young women this moral judgement invoked a rich, loose and

---

[44] Discourses about living positively were only beginning to be taught and learnt in support groups that were still few in Lusaka. In Kenya, such groups have been observed to be important loci of *learning how to* live and survive with HIV in a much wider and more practical sense than *knowing about* medicine, nutrition and moral outlook (Prince, 2012).

[45] ART became available for free in public clinics in Lusaka in late 2004.

sometimes self-contradictory complex of moral norms for womanhood, reproduction and sexuality that was compounded by many parts with diverse historical and contemporary roots (e.g. Geisler, 1995; Gough, 2008; Hansen, 1984; 2005; Ogden, 1996; Rasing, 2001; Richards, 1958). In the context of the microbicide project, however, this complex was not only made explicit in the particular way that the purpose of the project was presented to the young women by Auntie Loveness, but also condensed and even dichotomised into the positive or negative result of the HIV test that would almost inevitably be interpreted as a moral judgement and that figured so prominently in the young women's memory of their experience.

The intensity of the situation could be understood as a matter of the HIV test being a "vital conjuncture" defined as "*an experience of future-orientation, extreme uncertainty and the potential for radical transformation*" (Johnson-Hanks, 2006:22). The young women's fears illuminated how they saw the test as an open-ended turning point for life which had the potential to change everything. Indeed, the HIV test remains something that many people avoid or postpone (Bond, 2010; Simpson, 2009).[46] Part of the reason why the young women went through with the process of enrolling in spite of their fears was that they heard about the project from Auntie Loveness.

'Edited' information in caring relations

It was part of Auntie Loveness' job as an outreach worker to recruit participants for the trial. Her granddaughter fit perfectly into the criteria for inclusion in the project, but Auntie Loveness was also deeply concerned about Tabita and her friends' situation: "*The young girls are a problem here. They get married too young, before they know anything. When they realise, it is too late.*" She made sure that Tabita and her friends were among the first to hear about the study, and according to the young women's memories, she presented the project in a way so that it appeared to be an opportunity for them, relevant and not too frightening. Auntie Loveness 'edited' the information

---

[46] The HIV test was not particular for enrolling in the CIDRZ project. HIV status was relevant to most research projects that I learnt about in Lusaka, so most people who became study subjects would have to go through the moral confrontation that the HIV test generally posed – regardless of the result, and whether they were informed about it, as Malala in the introduction chose not to be.

that she gave the young women in this regard, particularly by avoiding any mention of the HIV test to Tabita.

Tabita edited information in the same way when her cousin Linda happened to call, just as Tabita was waiting for the result of her HIV test at the clinic. Tabita told Linda to join her at the clinic as there was a project, but she did not mention what it was about or that she would be tested for HIV. Tabita did not think Linda would have come if she had told her – and besides, Tabita reminded me, talk time is expensive. Apart from her cousin, Tabita had also told one of her friends to join, but this friend had refused, Tabita assumed, because she slept around with different men (invoking a particular aspect of the moral complex that I referred to above).

Both Auntie Loveness and Tabita wanted to share the project with people that they cared for and they edited the information that they shared. This editing of information about research projects may happen in many situations and relations, particularly by local "middle-figures", such as research assistants and recruiters. 'Editing' by community members employed as staff has primarily been examined in relation to the integrity of scientific data or in terms of research ethics (see Molyneux et al., 2010; Simon and Mosavel, 2010), but what is at stake for lay people who edit information about projects has been less addressed. In the particular relation between Auntie Loveness, the young women and their friends 'editing' could be understood as an expression of care by someone who believes in the possibilities that any project can offer, including perhaps the goodness of knowing about your status, but who also understands the fear that the test can instil.

The ambiguities of the initial HIV test were also reduced by the way the project staff interacted with the young women. Albetina explained: "*When we went there we told them that we were scared even if [though] we have come to be tested. They encouraged us and told us that 'whatever the outcome, we will be with you, and if the results will be positive we will call your partners and counsel you together'.*" Albetina describes how the young women were encouraged and reassured by the staff. I asked Albetina, Brenda and Emelda what was the difference between getting this information at the clinic and from the study. Emelda answered: "*When I got pregnant I* *was tested at the clinic and I was scared, but when I went for CIDRZ I was encouraged and welcomed. I felt open to discuss anything and at the clinic they just test and give you the results."* Albetina added: *"At CIDRZ they will counsel you nicely and welcome you and they will even tell you that you still be our friend even if you are HIV positive. But at the clinic they will just test you and forget about it. They won't even make follow-up."* The young women saw a contrast between the way they were treated in the study and the way they would have been treated in the clinic.[47] They felt that they would not be left to deal with the myriad of consequences on their own, if the test turned out to be positive. This was important in the context of the socially isolating stigma that might come along if a positive HIV test became known (Bond, 2006).

Summing up the main observation in this section, I have shown how ambivalent it was for the young women to join the project. Coming to know about their HIV status, an otherwise dreaded kind of knowing which had potentially life-changing consequences for the young women, took place in caring relations that carried the young women onwards into the project. They trusted Auntie Loveness, and project staff had the time and means to do their counselling work in a way that nurtured trust and promised continued care.

I have spent quite some time describing how the young women came to know about their HIV status in caring relations. I have done this in order to show the contrast to the way they came to know about the purpose and procedures of the research project that I will describe next.

Learning about project procedures: informed consent

During the first visits to the clinic and the procedure to obtain informed consent the young women learnt that the project entailed testing a vaginal gel to prevent the transmission of HIV. They would be asked to pick an envelope containing a note that told them which 'arm' of the study they were assigned to, i.e. whether they were to use either a gel with condoms or condoms only. They learnt that they were to come to the clinic every month where blood would be drawn from their arm and they would

---

[47] The portrayal of this difference resonates with the way people might talk about the difference between public and private clinics. Private clinics, that were out of economic reach for most people in the compound, were often associated with better care and better medicines than public clinics.

undergo a pelvic examination. They would receive gel and/or condoms to apply before sex with their partner for the following month and they would be tested for HIV every three months. They would be expected to stay in the study over a period of 18 months and not get pregnant for the next 30 months. They would be given a choice of different and free family planning methods for this purpose. They would also receive a pre-paid "health scheme card" which secured them and their partner free treatment at the public clinic and UTH for the duration of the study.[48] They would receive transport reimbursement of ZMK 20,000 (GBP 2.88), a meal and a soda with each visit.

This information was given to the young women as they went through a staged procedure over several weeks to give their informed consent, a procedure that Estina explained as follows: "*They gave me papers and someone read them to me. If I agreed, I had to sign, if you don't agree, you don't sign, you refuse. But for me, I signed all the consent papers and I joined the study."* Olivia, my interpreter, asked what was written on the papers and Estina explained:

> *The papers were on the study, and what was involved at CIDRZ, and what they were teaching about, and your permission to join the study. But you have the right to refuse to accept. When you are sick, they give you medicine and everything that you need. Or you go to the clinic and they give you a prescription. You can take it there, and they will give you the medicine or buy it for you.*

Estina presented the agreement as a matter of rights to refuse and access to free medicines if you agree. She understood the conditions of the arrangement and she demonstrated that she knew the vocabulary of informed consent.

Medical researchers and bioethicists generally ascribe very much importance to the informed consent procedure. Prospective study subjects' understanding of informed consent in transnational medical research may be explored, measured and discussed as a matter of knowledge, rationality and ways of weighing benefits against risks. Such studies may be designed on the assumption of the 'information deficit

---

[48] With a health card consultations would be pre-paid, because of a fee to enrol in the scheme and a lower fee each month to stay in the scheme.

model'[49] that has more information and education about science and research as an inbuilt remedy (e.g. Llewellyn-Thomas et al., 1991). Others have examined the procedure by highlighting social rather than cognitive aspects of consent, which often revolve around trust in the research organisation as such (Leach and Fairhead, 2011; Molyneux et al., 2004; Molyneux et al., 2005b).

The informed consent procedure was not very significant in the young women's recalling of their first encounters with the project. Generally, only very few of my interlocutors talked about the informed consent procedure without me bringing up the topic. When talking about the procedure they described how the project staff had read the papers with them, but they did not on their own initiative talk about the papers and their contents or the overall purpose of the project, most likely because it was not important for them (cf. Last, 1992).

A sense of possibility in 'something bigger'

The young women knew that the project was about research to test a new means for HIV protection, but they did not dwell on the product that was tested, and although they all knew what "arm" they had been in, they did not appear particularly interested in whether they had been in one or the other.[50] Besides, in the excerpts from my interview with Albetina and Emelda at the beginning of this chapter, they refer to *"project"*, *"study"* and *"research"* interchangeably. It appears that they did not consider it important to distinguish between these terms in English.[51] It could, indeed, be quite difficult to distinguish between research projects and other interventions in a wider landscape of projects with many overlaps between people, locations and procedures, and in the organisation of projects and their material manifestations that I

---

[49] Put very simply, the 'information deficit model' points to an idea that if 'the public' (however defined) is sufficiently informed about science and technology it will 'understand' and any reservations or resistance against science and technology will disappear (See Wynne, 1996:215).

[50] Their lack of interest in the overall purpose of the project, and the particular product on trial, might differ from that of the wives in the nearby army and police compound. I heard of a very active recruiter who had managed to recruit many of her friends into the study with reference to the fact that their spouses travelled a lot, implying that they would be more exposed to risk of sexually transmitted infections. I did not manage to meet any of these study subjects, but it is possible that they had a different interest in the purpose of the study and in which study arm they had been placed.

[51] People applied these English terms, even when speaking ChiBemba and ChiNyanja, as there were no good terms to cover their meaning in the local languages.

described in Chapter 2. Still, the young women's mixing of terms should not be seen as a lack of knowing about research, as I have shown, but instead as a reflection of the young women ascribing more consequence to knowing about projects than knowing about their particular purposes.

Following this thought, the young women may instead have understood the information given during the informed consent procedure as describing the terms and contours of a promising and continued relation to the project as 'something bigger'. 'Something bigger' was not a term that my interlocutors applied, but one I have coined to capture how people correctly assumed that there was more to a given staff, activity or facility than what met their eyes, but that the exact scope of this 'something bigger' remained unclear. It was the mandatory HIV test that was the moment to decide whether to become part of this 'something bigger' or not. Speculations about the possible results of an HIV test had the crystalising effect on their expectations and concerns that the procedures for obtaining informed consent did not have.

If the act of signing the informed consent documents did not reflect the kind of decision that it was intended to stimulate, it may have had another kind of significance for the young women. More than a statement of agreeing to the specificities of the papers' content they might see it as a required gesture, another step on a yet unknown path that had the potential to open new possibilities for them (cf. Whyte, 2011). A sense of possibility associated with something bigger in combination with Auntie Loveness' encouragement helped the young women sit out the counselling and testing in the clinic and proceed to the formality of signing the informed consent form that was presented to them by a member of staff.[52] The knowledge offered in the consent procedure, and the decision that it invited, was a kind of 'knowing about' the study that the young women immediately understood. This knowledge, however, did not lead to making a decision about participation. Instead, it led to 'knowing how to' go through a bureaucratic procedure in anticipation of what might come out of engagement later.

---

[52] Signing at the entry point of a health-related intervention is maybe a new procedure for many people in Lusaka, but it is not reserved only for medical research projects. People in 'Positive Living' courses also sign a confidentiality agreement that they will not share other participants' personal stories about being HIV positive that they hear during the course sessions.

’Knowing about’ and ‘knowing how to’ both played out in the initial phase of engaging in the research project. Knowing one’s HIV status was a kind of ‘knowing about’ that the young women associated with potentially grave consequences for their future. Acquiring this ambiguous knowledge, however, was cushioned in caring relations, which provided the young women with enough assurance to risk learning about their status. Contrary to learning about their HIV status, the young women did not associate any particular consequences with knowing about the purposes and procedures of the medical research project. They knew about the differences between research and other projects, but what mattered for them was a sense of possibilities in being attached to ‘something bigger’, i.e. a large and resourceful project staffed by people who recognised them and cared for them. To explore such possibilities, the informed consent procedure was less a matter of ‘learning about’ than a matter of ‘learning how to’ go through particular bureaucratic stages. One of the possibilities that the young women emphasised most when talking about their engagement was how they had *enjoyed* learning.

Learning about “how to keep oneself”

In my very first interview with Tabita and her cousin Linda, my first question to Tabita was how she had heard about the project. Tabita responded: *“We first heard about CIDRZ study in the community and we went to join and when we joined we learned about a lot of things.”* Tabita does not answer my question in very much detail, but jumps to tell me how she and her friends learnt a lot of things from being in the project. Olivia, my interpreter, asked what they learned at CIDRZ and Tabita replied: *“We learned on how to keep ourselves and how to protect ourselves from diseases such as HIV/AIDS and other sexually transmitted diseases and a lot more.” “How to keep ourselves”* refers to norms and practices for morally proper relations with boyfriends and partners that could be seen as part of the wider moral complex of womanhood that I referred to above. In a different interview with Estina and **Lukonde**, I asked Estina what she had expected from being in the project. She hesitated, but Lukonde, who was 25 years old and who had left school after grade 5 (two years short of completing primary school), jumped in: "*It's because we wanted to learn a lot of things about STIs, STDs and other related diseases and sometimes you don't know your status and could like to be tested. They were learning about a lot of things."* Similarly, **Brenda**, Emelda's sister-in-law, who had not heard about the project in time to join, also had expectations about learning something:

> *Brenda: The first day I knew about it was from Tabita. She told me that there is a group of people under CIDRZ, they* ***teach*** *about diseases and HIV/AIDS. But the time she was telling me it was the last day of their study, and they were going to celebrate. And second I heard about it from Auntie Loveness. She told me that there is a study and so I asked her if I can follow and she said yes. (My emphasis)*
> *B: Why would you like to join?*
> *Brenda: I would like to join because I want to know about a lot of things and about diseases.*

The young women spoke about the study as *"teaching"* them and they emphasised how they learnt something. The young women shared this knowledge with their friends. It turned out that Lukonde, who jumped in to tell me about all the things they had learnt from the project, when Estina hesitated to answer my question about her expectations, had, in fact, not been enrolled in the project herself. I asked her how she could possibly know all the things that she told me about. She laughed: *"I know,"* and continued:

> *I know, because when you want to join you first get all the necessary information from your friends about the study. Also that Auntie Loveness told me about this before she [Estina] even knew, because we were close neighbours with her. So she came to me and told me that there is a project and the clinic under CIDRZ and if you would like to join you can come. But at that time I was living with my husband and he couldn't allow me because he thought that it was for Satanists. Later, Auntie Loveness told me about another new project [workshop] for 10 days, but still my husband refused me to go and so I got most of the information from Auntie Loveness and friends.*

Lukonde had obviously appreciated how Auntie Loveness included her among the people that she informed about project possibilities, and she had enjoyed learning from the project through her friends (I will address her husband's remark about Satanism in Chapter 8).

"Lifestyle", *"how to keep oneself"* and diseases can be very pertinent issues for many girls and young women in urban Lusaka where the moral complex of womanhood mentioned above is played out in so many situations and relations, and where sex can be seen as an asset to manage (Kambou et al., 1998). Apart from what the young women implicitly learn about this moral complex as they grow up, these topics are otherwise only explicitly addressed at particular occasions in quite specific idioms, such as when the girls go through their initiation rite, when the *alangizi*[53] teach coming brides how to treat their future husband, or if a coming bride has a kitchen party (Hansen, 1997; Rasing, 1999; 2001). Other sources of information about these topics include the government and various NGOs, who present their messages in various forms in clinics, on the radio, on big posters along the road, etc. Yet another kind of information comes from the Churches, or from books and leaflets circulating in the compounds that speculate about the real origins of HIV and whether it comes from American laboratories (see Chapter 8). Also in the public sphere, a former government minister, who was among the relatively few who had talked publicly about the death of his son due to AIDS (similar to the first President of Zambia, Kenneth Kaunda), regularly appeared in the newspapers and on the radio either advertising for a herbal remedy that he claimed could cure HIV[54] or rallying for the new party that he had recently established.[55] Specifically with regard to cases of HIV and AIDS at home or in the neighbourhood, silence could be the most telling source of information (cf. Bond, 2010; Twebaze, 2013).

---

[53] Women who are specialised in initiating, or educating, girls and young women into woman- and wifehood.

[54] http://www.lusakatimes.com/2013/06/07/government-urged-to-quicken-sondashi-formula-trials/.

[55] http://www.zambianwatchdog.com/sondashi-says-his-party-will-win-in-solwezi/.

The value of learning

There were very many sources of disparate information on *"how to keep oneself"* and claims to authority were very different. The young women clearly appreciated the information that was "taught" in the project about these issues. I found it difficult to assess to what extent they, as young dependant women, actually applied the substance of the knowledge thay had gained in their daily lives and in their relations with boyfriends and husbands.[56] Assuming that it was quite limited, why did they talk so much about what they had learnt?

Their appreciation might partly draw from the absolute positive value ascribed to education in general, which has roots in Zambia's missionary, colonial and post-colonial history. Even if the project was not the same as school, the young women referred to the project as teaching them and they clearly enjoyed learning. On the other hand, they knew very well that what they learnt was not the kind of knowledge that would lead to a certificate and they did not seem to think of this learning as a stepping stone on a path to social mobility.[57]

Another frame for understanding their appreciation could be drawn from Tabita's response to Olivia and me:

> *Olivia: What was so good that made you to join?*
> *Tabita: I wanted to learn more of what my friends told me and also that I just wanted to join.*
> *Olivia: You say you wanted to learn more like what?*
> *Tabita: Like, if I have a friend that misbehaves I can be able to encourage her to stop or advise her to stick to one partner.*
> *Birgitte: Do you remember other reasons that attracted you to join?*
> *Tabita: I just wanted to join because at that time I was not doing anything. I was just staying at home.*

---

[56] Older and more experienced women often had a more independent position in relation to partners. One of my key interlocutors, who was also a volunteer at the 'clinic, told me how she had taken her husband to the clinic for treatment of 'pus' (chlamydia), and how she regularly brought home a rapid HIV test from the clinic to sit in the living room and test herself, without words, in front of her husband.

[57] I asked the young women whether they had considered becoming peer educators in the project, but Estina responded that nobody had invited them. She seemed to associate advancement with relations rather than with knowledge.

Tabita explains how she might apply the knowledge that she gained in the project in relation to her friends and in the context of the moral complex of womanhood referred to above. Besides, she says that she wanted to join because she had nothing else to do. Like so many other young people, and particularly young women in the compound, they were *"being kept"*, meaning that others provided food, clothes and housing for them (see also Hansen, 2008:102-103). They were just staying at home, as Tabita said. In Lusaka, the expression *"staying at home"* or *"sitting at home"* is a discursive metaphor (Hansen, 2005:10) for not getting anywhere in relation to the spatial, temporal and social terms that weave into each other (Gough, 2008).[58] Being in a project, a 'something bigger', that taught them things, might give the young women a sense of getting somewhere.

The point here is that if the young women applied what they learnt, it was by sharing it with friends who were not in the study, like Lukonde and others. Thus, the value of what they learnt might not so much lie in its application, but in the relations and attachment to the institutional frame ('something bigger') that it was taught and shared in. From this perspective it also becomes possible to understand Albetina's emphasis on the way the project made follow-up not as a matter of appreciating a free service, but as a matter of valuing one more point of contact in an extended relation.[59]

Here I suggest that the young women not only enjoyed learning about "how to keep themselves", but also simply being engaged, just like Kambou and colleagues observed about a group of older girls from a neighbouring compound. The girls were interviewed in a participatory research project about adolescent sexuality and during the next days they kept returning to the gates of the clinic where their group interview had taken place. The researchers asked them why they came back and they replied *"because we want to learn"* (Kambou et al., 1998:119). The girls talked about the

---

[58] Young people's sense of being stuck in both a spatial and temporal sense has become a common observation all over both rural and urban Africa. Studies explore how young people try to transcend this sense in various ways. See Barrett (2004) from rural western Zambia, Prince (2006) from urban western Kenya, Weiss from urban Tanzania (2009), Lucht from coastal West Africa and Italy (2012) and Newell from urban Côte d'Ivoire (2006).

[59] The appreciation of follow-up was mirrored by staff. A couples' VCT nurse that I interviewed mentioned how gratifying it was for her to be able to follow-up on a couple if they became 'members' of a programme (i.e. joined a research project) at the main office of her employer.

research procedures as learning, and they were eager to continue their engagement. It is perhaps also in this light that women's talk about feeling empowered by the HIV test in a microbicide trial in South Africa should be interpreted (Stadler et al., 2008). Perhaps their talk about feeling empowered grew from their attachment to a resourceful 'something bigger', rather than from knowing their status.

I will briefly support my point about the value of learning as a matter of attachment to 'something bigger' by summarising events in a community meeting in the compound organised and facilitated by the CIDRZ Community Advisory Board, usually referred to in short as the CAB[60], to educate the community about medical research. The meeting was held in one of the many church halls in the compound. Benches had been put in front of the elevated platform at one end of the hall. About 25 women of all ages were seated on the benches and seven men sat on the bench furthest at the back. Three members of the CAB were present. Two younger men sat on chairs facing the audience and a young woman, smartly dressed in blouse and skirt, wearing glasses and nail polish, stood next to a flip chart in front of the audience. The meeting opened with a prayer and the young woman began speaking in ChiNyanja. She turned to the flip chart and its text, which was written in English. The first headline was "What is a clinical trial? A planned study involving people to prevent a health problem." It continued: "At the end of the presentation people will be able to know what clinical trials are: to find better ways to prevent or treat a disease in people." On chart two the phases of clinical trials were listed and their particular objectives were described. The facilitator explained the phases and how many people they typically involved in ChiNyanja interspersed with English (and the ChiNyanja generic plural prefix *ma-* often put in front of English words). I caught *"ma-clinical trial"*, *"ma-scientist"*, *"STI"*, *"sexual transmitted diseases"*, *"study"*, *"ma-risks"*, *"ma-side effects"*, *"ma-benefits"*, *"study animals"*, *"voluntary"*, *"ethical committee"*. The third chart listed the benefits of joining a clinical trial as follows: "free screening and treatment; more knowledge about the study; helping researchers discover new medicines". Risks were listed as possible unknown side-effects and that studies might take too long. After

---

[60] The CAB was a body of representatives from the community that functioned as "a bridge" between the community and the researchers of a particular project or organisation.

going through these lists, the facilitator asked the audience, intonating like a teacher at school, about how many people are involved in each phase of a clinical trial. The chart closed with a summary: "Clinical trials are the best ways to test the safety and effectiveness of new treatment for HIV." The facilitator added that the HIV test was free. Following this presentation the other facilitators explained their role as CAB and toward the end of the meeting they asked if the audience had any questions. One young man got up from the bench at the back and asked in English if it would be possible to form a youth group under CIDRZ. The facilitator suggested that he write a proposal and then they would consider it.

My understanding of what was said in the meeting is of course severely limited by my lack of skills in ChiNyanja, but it is still possible to make observations about how knowledge about medical research is conveyed, i.e. the use of charts and their English text, the presentation of phases, and the 'examination' of the audience. The gender distribution of both audience and CAB members, and the difference in dress between the facilitators and the audience, is also noteworthy. The point I want to make here, however, is that the young man's question could be seen as an expression of hope to establish a relation with CIDRZ as a large and resourceful organisation.

Learning how to engage in the project

A few of the young women had been engaged in a project before. Auntie Loveness had facilitated their enrolment in hair-dressing and tailoring courses by CCF, an NGO, but the teacher in the tailoring course had not been "serious" and the course fell apart. Judging from their interaction with me (a foreign researcher), the young women were not yet very proficient in knowing how to be in projects. Still, they did manage to stay in the research project until it closed.

As novices, Tabita and her friends came to the research project with rather vague images of what the project might entail. As they engaged in the project they came to learn not only about their HIV status and about how to *"keep themselves"*, but also more implicit aspects of being in a project. This entailed learning where to go, when to go and how to act in relation to the different kinds of staff in the project. It entailed learning what to say and perhaps what not to say. Estina, for example, laughed out loud when I, putting together a few pieces of her story, realised that she had lied to get included in the study, claiming she was two years older to pass the minimum age limit. Specifically, a medical research project entails learning how to go about the informed consent procedure, and learning how to go through the sequence of procedures, i.e. registration, waiting, health talks, blood-taking, interview, examination, lunch. It is about learning how and where to sit, how to roll up your sleeve before blood-taking, and how to lie down during examinations. These procedures were repeated at each visit and with repetition came routine and learning.

We did not speak much about the process of learning this kind of embodied knowledge that can be relative easy to register for the attuned observer, but quite difficult to verbalise for the people involved – particularly after a while, when such situations of learning are no longer fresh in people's experience. There was one element in this learning, however, that the young women did mention and that was quite particular for research projects that need a high retention rate to sustain the statistical power of the data that is produced with each study subject. If study subjects did not appear for their monthly appointments at the clinic a project car would come to their home to collect a blood sample and encourage study subjects to come to the clinic for their next check-up. Such a visit would attract a lot of attention and raise suspicions about Satanism, so the young women spoke about how they always kept their appointments.

The young women appreciated learning how to keep themselves in the project, but what also stood out in their accounts was the way they had felt cared for. The way their initial fear of the HIV test was handled by the project staff transformed the intense discomfort associated with the test into a feeling of being cared for by the project and the project staff – although they did not meet the same staff every time they came to the clinic. This experience of being cared for deepened with time. Tabita's cousin Linda, for example, became pregnant during the study. She was in the condom arm, and had chosen injection as contraception, but she bled for a month afterwards, so she stopped the injections. She was still called for monthly check-ups and not expelled or frowned at in the project, as young women might have been at school, at the clinic, in some churches and at home.

At the end of the project they received a project *chitenge.*[61] Tabita missed the way CIDRZ took care of her, if she fell ill: *"CIDRZ will provide you with all the treatment and take care of you until you get better but at the clinic you find that they have no drugs and if you are very ill and you need injections, they will just send you to buy [at the pharmacy]. But at CIDRZ you get all the drugs and injections for free."* Contrasting the quality of services at the district clinic with the research organisation and its provision of free medicines, she describes how the project would take care of her, not only in terms of providing medicines, but also in terms of staying with her until she got better. The young women appreciated their access to free medicines and health care, but also the care and attentiveness that they received.

Knowing and caring

There can be many meanings of care in medical research (cf. Easter et al., 2006), and I suggest that the young women's experience of feeling cared for should not be interpreted as a matter of the much debated "therapeutic misconception" where people are seen to mistake research procedures for individualised health care (Appelbaum et al., 1987; Henderson et al., 2007). Tabita and her friends came to understand very well that they had become part of a research project to test a new product. The care that they enjoyed was instead predicated upon staff's attentiveness towards them, staff's recognition of them and their inclusion into a resourceful 'something bigger'.

As a sum of these processes and relations over time, the young women developed a kind of loyalty to the project that defined their relation to the project much more than knowing that they had "the right to refuse", as stated in the informed consent form. I asked Estina whether she had considered dropping out at a time when people talked of the Satanism rumours, but she responded: *"No, I just told them that*

---

[61] A cloth wrap of varying quality that many women wear at home or for various festive events, but not at work, if they have formal employment. A *chitenge* is a common element in projects and campaigns where they can carry particular messages, including images, logos and acronyms (just like cars and T-shirts).

since I have already joined, so I can't stop." Her response indicates how she and her friends felt committed to the project in such a way that they would not just leave. Another young woman that I interviewed said: *"If I drop out it means that I will disappoint them."* Her statement points to a relation to the researchers that is more than contractual. This sense of loyalty and obligation to the project also characterised the young women's relation to Auntie Loveness, who initially encouraged them to join. What seems to begin with a signature in an agreement, a bureaucratic gesture, was in fact be embedded in pre-existing and emerging relations of care and recognition. Thus, there is a discrepancy between the intention with the informed consent form from a research ethical point of view and the loyalty experienced by many study subjects as they engaged in multiple exchanges and relations with the project staff over time that weaved into and overlapped with relations outside the project.

This experience of feeling cared for in research projects has also been observed in Kenya, where many HIV-positive mothers appreciated the way they were cared for in a research project on prevention of mother-to-child transmission of HIV (Geissler, 2012) and in Dakar, where many registered sex workers felt cared for in a particular mix of regulation and scientific procedures (Poleykett, Forthcoming; see also Reynolds et al., 2013). Inspired by these studies, it is possible to make the point that 'knowing about' and caring, or attentiveness, need not be seen as opposites in the process of producing scientific knowledge, but that 'knowing about' and caring emerge together – and perhaps even merge – in practical engagement with situated concerns.

Summary: 'knowing about', 'knowing how to', and care

Medical research is about learning by practical engagement, often in the form of experiments. The purpose of this engagement is producing a particular kind of abstracted 'knowing about' that may acquire status as a kind of objectified knowledge that can be taught to others. This kind of abstracted knowledge can be contrasted to a different kind of fluid 'knowing how to' that also emerges in practical engagement with problems. This kind of knowledge emerges in the process of engaging together with others, but it is often practised, rather than objectified or talked about.

Here it is relevant to note that ‘knowing about’ is not exclusively associated with research activities and ‘knowing how’ with the lives of participants. The researchers’ production of knowledge about particular problems involves ‘knowing how’ to engage with study subjects. Study participants come to know about many things during their engagement, which may be of consequence for them. Project staff and study participants alike engage in both kinds of knowledge, but with different purposes, needs and hopes.

This chapter has shown how engaging in medical research projects is learnt and that knowledge about how to be in a research project was different from the knowledge about the research project that was conveyed in the informed consent form. At first, Tabita and her friends had rather vague and quite ambiguous images of what to expect from the project. They were concerned with the HIV test, and with rumours about Satanism. Later, they learned about medical research, and about how to keep themselves, but as they engaged in project routines and interaction with staff they also learned how to stay enrolled in a research project, and in a project in general – a resourceful ‘something bigger’, that entailed caring relations and that they positively wanted to be part of in spite of the ambiguities that it implied.

The young women’s experience of learning something was not specific to the microbicide trial. Even though not all studies in Lusaka included “teaching” many were indeed talked about in this way. Although people knew that the projects were research projects, they might describe studies as, for example, *“teaching couples how to live positively”*, or *“teaching mothers how to prevent transmission of HIV to their infants”*. Such phrases erased differences in purpose between research projects and the kind of education that is often associated with NGO projects and programmes at the clinics.

Differences in purpose between research and other kinds of projects were indeed less relevant for many of my interlocutors, who had learnt how to be in projects and who applied this knowledge in several different project contexts. None of the young women in this chapter, however, applied their knowledge of how projects work in other contexts (and none had taken an HIV test since the end of the project). One reason might be that they did not have to. After the project ended they trusted that Auntie Loveness would call them when the next project was about to begin – including Lukonde, whose husband had recently left her. Others among my interlocutors were more actively attentive to possibilities in this landscape of research and other projects. They are the protagonists of the next chapter.

Vignette III: Rose

*In early July on a Thursday afternoon, the weekly day of English conversation class in the women's group that Precious, my guide, had organised with me as the teacher, we were about 10 women sitting in the sunken sofas or on the floor in Vainess' small front room. Some were cutting up plastic bags, others rolled up the long strips into balls and yet others were crocheting handbags from the plastic strip balls. Today's topic in the English conversations class was marriage customs, "kitchen parties", and weddings in church "if you have money". There was talk of the money paid for "damage", i.e. the man's payment for making a girl pregnant outside any form of marital union, and about the "*alangizi*", professional women who were paid to prepare girls for the coming union with their husband. There was talk of some particular technicalities in this regard and a lot of laughter. In the midst of all this I mentioned to Rose that I had seen her walking for CHD (Community for Human Development) with the rest of the group on Women's Day. Women's Day was a big and formal event where thousands of women marched for hours through Lusaka under the sun and the banners of their church, union, NGO, political party or medical research organisation (CIDRZ, the largest research organisation in Lusaka, also participated with a group of Zambian and American staff and a few volunteers wearing the purple CIDRZ* chitenge*, or cloth wrap, with the logo for the new awareness campaign-cum-research project on cervical cancer that had just been launched). The march culminated in Showgrounds, a large exhibition area in the northern part of Lusaka, where the women passed the waving president's podium, each group trying to surpass the others in vigour and stamina. I hadn't expected Rose to join this kind of exhausting display, so as just another topic of light conversation I said to her that she kept surprising me, being involved in so many things. She looked at me, not laughing any more, and said: "I am researching for my life," and continued, looking down: "but I am a failure ..." Before I had a chance to respond we were interrupted by the others who wanted my opinion about the motto that would be printed on the back of the white polo-shirts that the group planned to have made for the coming* braai *(lit. grilled meat, meaning party) that they were organising to promote their catering service. About two years later I heard from Precious that Rose had passed away. Rose had refused to take ARVs and towards the end she had stopped eating.*

Chapter 5

Realising project possibilities

Introduction

Prospective study subjects receive information about the benefits of enrolling in medical research projects in informed consent forms. Benefits may include access to free medical care and treatment for the duration of the project and referral to other health facilities if necessary. This access may be extended to the research subject's partner and children depending on the condition and the treatment that the study examines. In a consent form that I saw in Lusaka, the section on benefits also included acquiring the information that was given in the study, and the personal satisfaction of being in a research study that contributed to more knowledge about a particular condition. It is noteworthy how these pre-defined benefits were not only material,[62] but also referred to the immaterial and moral value of contributing to knowledge and of learning something.

Tabita and her friends indeed enjoyed learning about how to keep themselves, but in addition to this they also came to learn something more implicit along the way about how to be in projects. The latter 'excess' learning was not included among the pre-defined benefits in the informed consent form, but it was a possibility that emerged as a significant 'extracurricular' outcome of the young women's trajectory of engagement in the research project. Likewise, Auntie Loveness, dutifully did her job when she recruited her granddaughter, but in the same act she also realised an 'extracurricular' possibility of taking care of her granddaughter and her friends. Thus, possibilities emerging around the implementation of research projects may not be limited to the stated benefits of the project and they are not restricted to research subjects only.

---

[62] The cash that people in Lusaka received when they came to their appointments at the clinic was not formally classified as a benefit, but as transport reimbursement. This distinction could be the cause of some confusion and it is a good entry point for exploring the practical negotiation of standard ethical guidelines (e.g. Geissler, 2012).

This chapter is about possibilities in medical research projects. It explores who sees what possibilities in such projects, and how possibilities may change over the course of engagement. With a particular focus on gender identity, the chapter shows how the relevance and realisation of project possibilities emerges in relations together with more or less subtle reorientations in relations and images of oneself.

I will begin the chapter by proposing an analytical distinction between benefits and project possibilities. The rest of the chapter is divided into five parts. By telling the stories of Rose and her husband of almost 20 years, the first two parts begin to explore who sees what possibilities in research and other projects, and how these possibilities may change. Rose and Mr Lungu, as she respectfully referred to her husband, engaged in the activities and procedures of the same research organisation in very different ways. Whereas Rose first emphasised one kind of possibility in the project and later learnt how to realise another, Mr Lungu refused to engage in the research and any other project activities with reference to being too busy, which was a common and legitimate reason for men not to engage in projects. The third part of the chapter discusses to what extent their different engagement could be explained with reference to gender identities and I introduce Chibuye, a young man with particular professional ambitions, to further illuminate this observation. In the fourth part, I show how some men might still see and seize particular possibilities in projects. This happened for Richard, a successful founder of an NGO, whose trajectory of engagement I describe towards the end of the chapter. I close the chapter by pointing to the way that possibilities in projects changed for both Rose and Richard during their engagement, and I discuss how such changes might resonate with shifts and transformations in their relations to others and in images of themselves.

Benefits and possibilities

A fundamental principle in standard codes for medical research involving humans is that prospective study participants should make an informed decision about their enrolment. An important part of the information that study subjects should receive relates to the risks and benefits of enrolment. Benefits may be both material and immaterial, but since the procedure of obtaining informed consent builds on a particular image of rational decision-making based on information, benefits should be identified and defined before the study begins (cf. Johansen et al., 2008).[63] Thereby they are also independent of who enrols in the research project.

As I showed in the previous chapter about Tabita and her friends, study subjects do not necessarily consider the specified risks and benefits during the informed consent procedure. Instead, a vague sense of possibility that was encouraged in caring relations carried the young women past their initial fears of the HIV test – which became the occasion to decide about enrolment – and into the project. As they engaged in the project their sense of possibility condensed into accounts of how they appreciated what they learnt about how to keep themselves. Because of the interaction with project staff, they also came to feel cared for in the project, which is different and more than having access to free medicines and treatment. To capture the emerging and open-ended character of such outcomes of engagement, I will refer to possibilities, or *project possibilities*.

Like the explicitly stated benefits of joining research projects, project possibilities may be both material and immaterial. They may overlap with pre-defined and 'closed' benefits (like free medicines), but they are often broader (like feeling cared for) and may 'roll on' and turn into new possibilities (like coming to know new people). They may be vague or well-defined as they emerge and become relevant for people who engage in projects with situated hopes and concerns. Relevance is a matter of who sees the possibilities. In other words, project possibilities are not just there to pick up, and they are not equally attractive and achievable for everyone. Seeing and seizing project possibilities may be linked to previous experience in projects (having learnt how to be in projects, like Malala), but certain aspects in the performance of gender identity may also influence the orientation towards possibilities and their realisation in projects. Seeing and seizing project possibilities may happen in relations with project staff, but also in relations outside the project organisation with partners, friends and neighbours.

---

[63] See the Introduction for references to literature that discusses this image of rational decision-making in informed consent.

Two more remarks about the way I explore project possibilities are needed before I continue. First, project possibilities are *positive* – I deal with dangers associated with projects in Chapter 8. Second, many possibilities associated with research projects are not specific to research projects. This chapter will make a point about the way people see and seize possibilities in projects, including research projects, more than it will address possibilities in research projects in particular.

Rose's trajectory through the wider landscape of projects

Rose became involved as a recruiter in a medical research project by coincidence. At first the research project was just another possibility for temporary piecework in a wider landscape of scattered projects. Later, she realised another possibility in the project. To illuminate this process I begin by briefly introducing Rose and our relationship before I sketch out her trajectory of engagement in various projects.

Rose was a thin and sinewy woman in her mid-thirties with a big smile and a quick mouth. Born in Northern Province she had been to school in the Copperbelt Province and had completed grade 9 (junior secondary school) in Kabwe, Central Province. In the early 1990s she came to Lusaka to stay with an aunt in a township and five years later she and her husband had moved to a rented house in the compound. Her husband, Mr Lungu, was in his early 40s and had passed grade 12 (upper secondary school) in the Copperbelt Province. They had six children between the ages of 19 and 3 years. Their firstborn taught at the same local community school that the three next children attended.

Rose was a member of Precious' women's group that I mentioned in the vignette that preceded this chapter, so I met her at least once a week. She invited me to visit her at home and she also came by our house sometimes. After I had known Rose for a while, I invited her for an interview at our house. Sitting in our sofa having a canned soda and some biscuits, I started by asking her how many different programmes she had been involved in since she came to Lusaka. She told me that the same year that she and her husband moved to the compound she became involved as a committee member in the community School that was run by CHD[64] and later supported by Care International. It all began one day when she had been coming from the town Shoprite and found a man and five children standing under a tree where the new wholesale Shoprite is today. At that time the place was just bush. They had greeted each other and he had explained that he was starting a community school for children on the street. He had asked her to come back the following week to assist him in teaching the children. She had hesitated and told him that she was not educated, but he had given her a book about the meaning of community schools. When she came back the following Tuesday there were many more children and she decided to assist him twice a week.

After only a month the man had wanted to move the school to a better place and had the UCZ[65] in the compound in mind. The owner of the church wanted to see the committee, so the man asked Rose to go and find five women and five men to form the school committee with herself, the coordinator and the director. Rose asked some of her friends and neighbours to join, the owner of the church in the compound found it a good project, and the school moved to the church hall. After some time they began receiving visitors and one day Care International also visited. The man who started the community school was a cousin of the coordinator at Care International: *"That's why they were fast,"* Rose remarked.

The same week, the school received toys, books and even clothes for the children. Care International then invited them all for a workshop and that was Rose's first. This was in 1997. The workshop was about the responsibilities of a committee and about the differences between children of different ages and how to care for them. After they came back from this workshop it was now CHD inviting them to form a women's group. Each of the 10 women in the school committee was told to bring 10 women and they were then given loans after attending a one-month workshop in 1998 on business management for micro entrepreneurs. Rose received a certificate of attendance for this engagement. In 2002 she joined a one-week workshop about

---

[64] This was the NGO that Rose marched for on Women's Day that I mentioned in the vignette preceding the chapter.

[65] United Church of Zambia. Many churches in the compounds can be rented for community meetings and other purposes.

behaviour change in the Catholic mission compound, St Lawrence, where they learnt how to carry out home-based care and where she also received a certificate.

Certified piecework

Care International again invited them for training in "psychosocial"[66] for children, and they went for home-based care organised by RAPIDS, learning about HIV and how to handle patients in the community. Rose mentioned how she had received a bicycle as a gift from RAPIDS, a conglomerate of international NGOs, that was now parked outside the entrance of her house, and a care kit to use when providing home-based care in the community. There had been five people on the course who received a bicycle and the care kit, but only two were active now (she showed me her kit that appeared untouched). From there, again, RAPIDS invited the women to become counsellors. They were trained in the theory, but they had to do the practicals at a district clinic with KARA, a national NGO. KARA charged for the practicals and expected RAPIDS to pay. They were told to wait for the payment, and up to now they were still waiting – more than two years after the training. Rose spoke about the training as if it might still happen, keeping the possibility open.

During my time in Lusaka I learnt that Rose, apart from her involvement in projects, also sometimes washed clothes in the neighbouring township where her aunt lived (a day's work would earn her about ZMK 30,000 (GBP 4.30)). Apart from being in Precious' women's group, where she was the head of the newly established catering group, she was also a member of a temporary cooperative that crocheted bags from plastic bags (these bags inspired Precious' group to make bags too – see Chapter 3). Rose also sometimes made clothes and curtains to sell, using a sewing machine that had been made available through an NGO that Precious had been involved with. I also sometimes found her at the local clinic where she took up various tasks. Once, through Precious' mediation, she had been called to the clinic to be an enumerator in a census of the compound: "*See,*" she said wryly when I met her at the clinic, "*I brought my big purse today, but I only got 20,000*" (GBP 2.88) for 10 days of counting people and

---

[66] 'Psychosocial' is the local jargon for psychosocial counselling.

indicating their age, water sources and sanitation conditions in the compound. She had expected ZMK 50,000, and was clearly dissatisfied.

Rose referred to washing clothes for others and the occasional tasks at the clinic as piecework. Piecework is a particular way of selling or exchanging labour. More than 70 years ago Audrey Richards (1939) observed how piecework labour assisted women in securing food in colonial Zambia (then Northern Rhodesia). Moore and Vaughan (1994) showed how piecework provided women in northern Zambia with an opportunity to exchange labour and food well into the late 1980s. During the height of neoliberal economic reforms in the 1990s piecework was a substantial survival strategy used by households in rural Zambia (Geisler 1992).[67]

Piecework is not restricted to rural areas or to the past. Instead, it is a very prominent and contemporary feature of urban life, which can be linked to the informalisation of the economy in Zambia and Lusaka (Hansen, 2008). Different from the small-scale and informal business people in the compounds of Lusaka who might have a small stall for repairing shoes or selling garden produce, pieceworkers moved from gate to gate in the townships or through markets to look for the odd job. For women this could include washing clothes or cleaning houses, and men could repair pipes, dig pits or transport goods on wheelbarrows that they rented for the purpose. Similar to the business people that often established special relations to particular customers, who then kept returning to them, pieceworkers also sometimes developed more stable relations to particular employers, whom they returned to regularly to sell their labour.

As Rose's trajectory illustrates, projects and project organisations could also be seen as included in the landscape of piecework opportunities in the city. Instead of cultivating the soil, people in the city could be seen as cultivating projects and the relations that might open potential project possibilities for them. On the way she accumulated not only an uncertain income, but also certificates. Rose's collection of certificates included a certificate for being trained a care-giver by RAPIDS, a certificate of achievement in completing a two-day training course in business management skills

---

[67] See also Cole and Hoon (2013).

in 2003, a special recognition certificate from CARE for being a volunteer in her community in 2006, a certificate in recognition of her status as an ambassador for peace by the Interreligious and International Federation for Peace (undated), and a certificate of attendance in a five-day workshop on gender and entrepreneurship in 2009. As much as proof of new knowledge and skills, these certificates can be seen as traces of a trajectory through projects that might open new possibilities (see also Prince, 2013b).[68]

Rose's trajectory of engagement unfolded in a landscape that embraced local organisations, such as the Community School committee, and UCZ, the Church, national NGOs, like CHD and KARA, and international organisations, like Care International and RAPIDS. She was also involved in two groups, the bags cooperative with international connections, and Precious' group that was connected to a national NGO. Besides this, she sometimes made clothes on the sewing machine that was supplied by the NGO, that she did not know, but that Precious had contacts with. Like pieceworkers moving on the streets and in the markets, possibilities in projects could be embedded in relations with people who were embedded in other relations. As a source of piecework it appeared irrelevant to distinguish between possibilities in research and other projects.

A new project possibility emerged for a while

At some point one more project possibility came up by coincidence: in 2007, when The Zambia-Emory HIV Research Project (ZERPH[69]) was in Chawama, the head of the Neighbourhood Health Committee at the local clinic had invited some women to join a workshop, but one of them could not come on the appointed day, so he called Rose to take the vacant place. She passed the interview and went on a three-day workshop and came out as an INA (Influential Network Agent) to recruit couples for HIV testing.

After the workshop Rose was assigned a particular geographical area that she was supposed to recruit couples from. She recruited friends and relatives (who would

---

[68] I was also asked to make certificates for the women who had been in the English conversation class that Precious organised for her women's group (see Chapter 3).

[69] At the time of my fieldwork ZEHRP carried out couples' VCT and recruited discordant couples for observational studies and for a cohort which would be ready for trials of HIV vaccines.

receive ZMK 20,000 (GPB 2.88) in “transport reimbursement” for being tested at that time. This reimbursement was later removed) wherever she went and she instructed them all to say that they were from her area, so that she would be registered as the recruiter. She earned ZMK 20,000 per couple recruited: *“So we made sure that at least at the end of the week you have three or four couples … we were enjoying with ZERPH money!”* Rose remembered this unexpected and temporary income[70] with a big smile and she showed me her certificate of participation in the training from June 2008 and another one recognising her subsequent work as an INA from October 2008.

I had heard that to become an INA, candidates would have to undergo couple counselling and testing themselves. When I asked Rose about this, she said that her husband had refused: *“No, why showing me where to go, it is my body, why there, Satanists, why ... doing what there, what, what?”* Rose said, mimicking her husband’s response. At that time, Rose’s husband was very ill and had been treated for relapsing TB several times. He used to have a part-time formal job in mechanical engineering, but some years earlier he had been fired because of long periods of absence from work due to his illness. He had taken many kinds of African medicine with the treatment for TB, but had been bedridden for several years on and off. At some point he even went to stay in his home village for eight months while he was very ill.

Rose had explained to the ZERPH staff that her husband was very difficult and that he accused her of bringing Satanism into the house. ZERPH had accepted her explanation and let her be tested on her own and she was found negative. She had begun recruiting couples, including her neighbour Vainess and her husband. They had come back from the couple testing and told her that they had both tested positive and that she had done a good thing, because they now knew their status. “*No, no, it’s confidential,*” Rose had said to them, but they had insisted on telling her. Rose had encouraged them and told them to continue going to the clinic to see the doctors. Then ZERPH closed down in Chawama and moved their clinic to Emmasdale, a

---

[70] In this project phase, people could only work as INAs for three months.

township north of the city centre.[71] "*Me,*" she continued, *"I go there with Vainess' husband, we went there."* Rose had become aware of a new possibility in the project, and since she could not go with her husband she asked Vainess' husband: *"Can you assist me, I want to see what is in Emmasdale, so he said 'no problem, let's go'*." Rose went to Emmasdale twice with Vainess' husband for lessons on HIV, and on:

> *how we should stay positive … yes, and the difference about positive people and negative people. When you are positive you should believe in it, and you should be just as you are, and don't take it 'oooh, aah, now I am finished'. You are still* ***a person****, you can even live years and years. In Emmasdale they encourage you more than in Chawama. They know that the Chawama people have already counselled you to be tested, so there they encourage you* (My emphasis).

It is possible that Rose and Vainess' husband received transport reimbursements to go to Emmasdale, but as the excerpt by Rose clearly shows, this was not the only reason for Rose to go there. Like Tabita and her friends, Rose appreciated what she learnt and not least that staff at Emmasdale dealt with a concern of Rose's in a way so that she felt encouraged and addressed as *a person*. Rose enjoyed learning very much, and she appreciated the encouragement and the recognition as a person that she received. Rose and Vainess' husband went to Emmasdale *"for more lessons, we learn more and more. They gave us an appointment, now he was not my husband, how can I continue there?"* Rose would have continued going to Emmasdale, but when they were given an appointment – perhaps to consent to enrolment in the cohort that the research organisation maintained – they had to stop their engagement. Continuing would have revealed them as a "false couple" which had become a problem for the research organisation.[72]

---

[71] According to Joyce and Joanna, whom I will introduce in Chapter 6, the Chawama clinic was closed because people stopped going there. There were many bars in the area and drunken people would shout at the visitors to the clinic and accuse them of being HIV positive.

[72] Joyce and Joanna (see Chapter 6) told detailed stories of the particular interview technique that would detect 'false couples' who might just be out for money. Many people knew that there might be cash involved when participating in project activities, whether it be sitting allowances in a seminar or transport reimbursement in a research project. Like Rose in the beginning, they might not consider differences between such projects.

Rose worked very hard in many different relations to patch together a livelihood and for opening new opportunities, for example, for the schooling of her children in the community school that she was involved in. When she came across another possibility for short-term employment and was trained and hired as an INA in a research project, she first enjoyed the income that it generated. Gradually, however, her attention was reoriented towards the possibility of learning something about *"how to stay positive"*. This possibility seemed to gain relevance as the combined outcome of her training to become an INA, the way her neighbours had come back to her grateful, and the fact that her husband had been so ill for so many years. She tried to unlock this possibility together with her husband, but he refused, so she mobilised her neighbour's husband, so that she, together with him, could learn more about something that was of deep concern for her. Her account of this time emphasised how she felt recognised and treated respectfully as a *person.*

Mr Lungu seizes an opportunity

Sitting in our living room, Rose said about the ZEHRP programme: "*It was good, we were enjoying, the community and me, I appreciated [that] I know more about HIV through ZEHRP and they gave us pamphlets so at least my husband [could] go through [them]. That's when we arranged for VCT."* Bringing home a pamphlet about HIV testing, and leaving it on the table for husbands to find, was a common way for married women to bring up the topic of HIV testing without confronting husbands directly. Rose's husband found the ZEHRP pamphlet and for some reason he was no longer so reluctant. Without telling Rose, he went to a clinic in another compound, Kanyama, to be tested. Rose explained how he tested positive, but kept quiet.

Some time later, when Rose asked him to come and get tested together with her as a prerequisite for her to join another workshop, he finally agreed. Agreeing to be tested together with her was a staged opportunity to disclose – another common tactic in married couples (cf. Twebaze, 2013). He had tested positive and she had tested negative. He had his CD4 count checked at the district clinic and it was very low, so he began taking medicine in 2008. Only after five months of taking this medicine, and getting a lot better, did he tell her that he had actually gone to be tested on his own before they went together.

Mr Lungu rejects any further engagement

Rose's husband agreed to an interview with me and on the appointed day Rose picked me up outside a noisy bar on the gravel road that ran through the compound. Later, sitting with Rose in their home he first told me about his former job in mechanical engineering and his present business of selling bananas in the market. We talked about the time that he had been ill and the time when he was tested.

After being tested together at ZEHRP, they had been invited to come back to Emmasdale, but Mr Lungu had excused himself with reference to his business in the market. He had also been invited to go and encourage other couples to be tested, like Rose who had been an INA, but he had refused this possibility, too. Referring to the way people could tease others because of being HIV positive, as we had talked about minutes earlier in the interview, I asked him (a rather leading question) about whether he had refused because he was worried that others would think that he might be positive? His response was prompt: "*No, people were going to know maybe I was just looking for money, that's what they believe here in Zambia when you go out inviting people. 'Getting money out of us' that's what they say and most of them don't accept. You can go to maybe 16 homes, only [in] one they will accept and there it will maybe only be the wife. The husband refuses.*"

Mr Lungu did not appear to worry about suspicions regarding his HIV status, although such suspicions could be a serious burden, particularly for people who had been ill for a long time. Instead, he expected people to suspect that he was just after money. Later in my interview with Mr Lungu I asked him whether he had considered joining a support group, but he replied:

> *Mr L: Have no time, cause I am busy at the market, so I can't manage spending time. Support groups are very difficult, even if I had joined a support group the people who had … who are already there they are too selfish.*
> *B: Really?*

> *Mr L: Yes.*
> *B: In what way?*
> *Mr L: They don't want others to join, they think when they are given something maybe by government or donors they will receive a small quantity when the number is big. That's what they do, especially at the clinic, very selfish, even leaders themselves […] the intended purpose of support groups was good, but because of this, I don't know, I can say, it is the animal in man.*

When Rose's husband speaks about *"the animal in man"* [73] he marks a clear distance from a group of people that he assumes are just looking out for themselves, similar to the people who recruit couples for testing. Although he was offered various entry points, he had only seen one possibility in the project, i.e. to tell his wife about his HIV status, and apart from that he saw no further possibilities for himself in the project, in the research organisation or at the clinic. He said that he had no time because of his business and he did not want to be seen as greedy and selfish. I will address his ideas about greed in Chapter 7 about sharing, but here I will discuss his remark about not having time.

Projects and gender

Mr Lungu disengaged with reference to having no time for projects because of his business. This remark should be interpreted in the context of a common observation among volunteers and staff at the clinic that people with jobs do not have time to volunteer for projects.

Furthermore, men more often have – or are expected to have – jobs than women. The environmental health officer at one of the clinics in my study, who also coordinated the work of the volunteers, mentioned how there were few men among the volunteers in the Neighbourhood Health Committee, because they were busy looking for money (piecework and informal business) or because they were working. It may be that Mr Lungu would have lost business, had he begun spending time away

---

[73] "The animal in man" was a recurring phrase by the first President Kenneth Kaunda when speaking of his philosophy of humanism. 'The animal in man' was invoked as working against Christian Protestant core values in his philosophy of compassion and restraint.

from the market to recruit couples for HIV counselling. Still, men without jobs or businesses might not see possibilities in recruiting couples for couple testing, as the following story of Chibuye will show.

Chibuye working hard as a man?

Just like Mr Lungu, Precious' younger brother, Chibuye, did not see himself as engaging in projects. Chibuye had completed grade 12 and had recently come to Lusaka to find work. He always wore very clean, often white and nicely ironed shirts and not the second-hand T-shirts that many young men in the compounds wore. This was quite a feat when ironing is a matter of easing hot and flaking charcoal into a hollow flat iron, and this effort could be understood as an expression of desire for a different status, like local volunteers in development workshops in Malawi, who set themselves apart from the "grassroots" that they were trained to educate by their smart dress (Englund, 2006:90). Chibuye certainly had ambitions. He was usually very shy, almost timid, in my company. In spite of this, he managed to enquire whether I might be able to assist him by sponsoring a particular course in clearing and forwarding, or part of it, so that he could go and work at the eastern border, where he knew someone who had told him that he could get work only if he got a diploma. I hesitated and while I pondered over a response, he asked me to talk to his parents in the Northern Province on the phone as an element in trying to persuade them to sponsor him too (which I agreed to, as compensation for my hesitation).

Later, when I asked Precious about his situation, she told me about her previous attempts at assisting him. She already supported two of her sisters in their education as teachers and she had also tried to help her younger brother. First she had encouraged him to join ZEHRP and become a recruiter. Chibuye himself had already told me about this. He had taken the recruiter course and had become an INA, but he found it very difficult to carry out the job. The men were very difficult to convince about testing, so in the end he stopped trying. The previous year Precious had fought hard to get him on a malaria spraying course at the clinic, which would enable him to earn money afterwards from spraying people's houses. She had told him to open an account and save some of the money. When the course finished and he had sprayed some houses she asked him how much he had in the account. It turned out that he had nothing and Precious had been very disappointed with him. She had told him that if he had managed to save up, he could have paid for the clearing and forwarding course himself. She told me that she actually had enough money to help him, but he had not worked hard *”and he is even a man”.* She advised me to tell him to work hard as a man. He should go and do piecework. He had even seen how she had been earlier on. She had sold charcoal, and so on, some years back.

About a month later Precious came by our house with Rose. Just as they got seated on our sofa, Rose’s phone rang. It was Vainess (the neighbour, whose husband Rose had borrowed to go to ZEHRP), who had called Rose to speak to Precious, since Precious had no battery on her phone. Vainess reported that Precious’ brother was not on the malaria spraying course that she was also attending. Precious borrowed the battery from Rose’s phone and immediately called her brother who claimed that he was indeed on the course. Precious seemed upset, but hung up. She explained to me that if people miss one day they are out of the course. She had paid ZMK 100,000 (GBP 14.42) to get him on the course again that year, so she was indeed upset. She had told him that she did not have money to put him on the clearing and forwarding course, so he would have to bank the money that she expected him to make after the spraying course.

Chibuye was given several possibilities to engage in projects by someone he trusted, but he did not pick up these openings. Instead, he hoped and worked for a different kind of opportunity that would open a future for him that better suited his aspirations as an educated young man. He was ready to work hard as a man, like his older sister expected of him, but not on projects. Like Mr Lungu, who had also passed grade 12 and who began our interview by talking about his former job, Chibuye was also oriented towards a formal job.

Projects as women’s domain

Rose and Mr Lungu saw very different possibilities in projects. This mirrored a general observation in Lusaka that many more women appeared to engage in projects than men. Without going into a more theoretical discussion of the constitution of gender in urban Zambia, I will discuss this empirical observation in terms of different elements in men and women's performances of gender identity.

Mr Lungu refused engagement in projects with reference to his business and Chibuye only reluctantly engaged in projects for a while until he could get on the course that would qualify him for the job he hoped to get. Both reflect the expectation that men work, but they do not volunteer. The association between men and wage labour that became a fundamental element in male personhood during the twentieth century in southern Africa is still strong, although illusory for many – with implications for male personhood (Ferguson, 2013).

Women, instead, appear very willing to engage in projects. Particularly with regard to medical research, there is of course the fact that many studies only enrol study subjects that fulfil particular inclusion criteria, for example gender. It did seem that most studies in Lusaka, and definitely those that enrolled the largest number of study subjects, were aimed at HIV-negative women or HIV-positive mothers, perhaps indicating a short-circuit in science between HIV and women (Booth, 2004). Still, this trend cannot in itself explain why so many more women engaged in (research) projects than men.

Part of the reason could be that women have fewer legitimate possibilities to generate an income than men, which is as true today as it was in the past (Hansen, 1984; Richards, 1939). This means that piecework in projects may be among the few possibilities for women to *"have something by the end of the day"*.

Another aspect in explaining the difference between men and women's engagement in projects is that many projects, whether they are run by local, national or international organisations, have their organisational centre at the clinics or in the churches. In particular clinics, but also to some extent churches, are often more frequented by women than men, so the sites and organisational structure of projects may be familiar to more women than men. Likewise, many health projects tend to have homes and neighbourhoods as 'the field', rather than offices, markets and streets, where more men spend their time (might this express a parallel short-circuit between health, development and women?).

Besides, it seems that the majority of projects, both within health and social development, relate to HIV and AIDS. HIV and AIDS generally appear to be more difficult for men to address than it is for many women, who by now are familiar with the practically mandatory HIV test of antenatal care visits to clinics. Specifically with regard to medical research projects that usually involve HIV testing, husbands are repeatedly referred to as a problem, in line with Simpson's observations about how HIV/AIDS has brought particular challenges to the hegemonic construction of masculinity in Zambia (Simpson, 2009). Joyce and Joanna, whom I introduce in the next chapter, and who worked as recruiters for ZEHRP said that women agreed, but the men tended to be difficult. Joyce and Joanna explained: *"'Why do you want to go? Are you a prostitute?' they will say ... so first we target the man. We go even to offices to recruit and they accept us." "If you convince the man you know you have won the couple,"* they said.

The association between men and work, the inclusion criteria of research projects, women's limited opportunities to make an income, women's larger familiarity with the sites of projects, and many projects' focus on HIV could probably explain why many more women were, and are, engaged in research and other projects than men. Still, some men came to see possibilities in projects, as happened for Richard.

Richard's lucky day

Seeing a possibility for piecework in a project that later turned into something else, as it did for Rose, also happened for Richard. Different from Rose, however, Richard's engagement put him into contact with people at a different level of project organisations, who were positioned in a way that they could keep opening new project possibilities for him.

Richard was in his 30s and lived in the compound with his wife and their six children. He grew up and graduated from grade 12 in another province before he got a job in a bank in Lusaka. In 1996 the bank employees were retrenched. With the package he was given at the time he built a house and some flats that he rented out. He also established a "ka-shop" that is still running. He explains how he became involved in projects as follows: *"I have lived in this compound since 1991, since 1991 I have been here and I know quite a lot of people here. So one of my friends tipped me about a workshop."* Richard went to the workshop that turned out to be about HIV. The workshop was led by a certain woman and *"After listening to what they were teaching about ... I got interested and she said that 'We are going to conduct a workshop, so that we train the peer-educators, and of course there will be some allowances.' So that attracted a lot of people from the community and so that's how I started."* The participants in the workshop received ZMK 15,000 (GBP 2.16) per meeting, for 19 Wednesdays in total, and by attending all, participants would qualify for a project that would begin after the end of the workshop series.

At first Richard did not feel free to speak about the topics that the peer-educators were taught to talk about, "*But as time went on I got used. In fact, everyone felt shy and so we said 'let's end this. This is reality and were are here to learn'."* Probing why he stayed on in something that was awkward for him he explained:

> *One of the incentives is that at the end of the day you will get something, so as there was that incentive, they tried to continue because there is money. And me, I didn't really [...] that my aim was at least to [...] at first to have something, but I have realised that money is nothing, but knowledge is, because knowledge has made me who I am today.*

Richard's response shows the same change in what he initially saw as a possibility, namely an income, to a focus on knowledge that Rose also experienced.

Richard referred to knowledge of how to communicate about HIV stigma and discrimination and other skills that he has learnt in workshops and training, but referring back to the point in the previous chapter about different kinds of learning I suspect that he has also very quickly learnt how to *be* in projects, to speak 'project language' (including the language of telling a success story about himself), and to form the contacts and the network that kept supplying him with more project possibilities.

I asked him what he had imagined that he would be doing with the training that he received and he replied: *"I was uncertain. In fact I didn't even think I would reach this far. It was just my lucky day, because when I was attending the workshop in the* *compound conducted by KARA counselling, and Family Life Movement of Zambia – there was this lady, we were there together […] She said 'after this workshop I will invite you to our workshop in home-based care'."* Richard trained in home-based care, as the lady at the workshop had suggested, but he never began working. Instead he met someone from KARA who was about to start a project in the compound. He was trained in communication by KARA, and after conducting a test workshop, he won the possibility to run a project on HIV stigma and discrimination for two years funded by America (as unspecified as that). Around the same time he met a friend in KARA and they decided to establish their own NGO to assist orphans and vulnerable children back in his home area. They have been successful in raising funds from CHAZ that is again funded by Global Fund. In 2006 he heard about ZEHRP's project from a friend and he worked for three months as an INA, like Rose. The same year he attended workshops about TB and about the Well Woman project (that Tabita and her friends were in) that was about research to find medicine for the prevention of HIV. Both workshops offered an allowance of ZMK 20,000 (GBP 2.88) and lunch. Furthermore, Richard had been a member of the Neighbourhood Health Committee. Richard said, *"At the bank I was just a simple grade 12 clerk [...], but now I have a diploma in counselling and a certificate in project management."* I asked him whether salary was included in the project that he and his friend managed, but they only had 5% of the funding at their disposal, so what he was doing was just voluntary work: *"We don't get much. It is God that is keeping us."* He made a living from rent and the "ka-shop" that he ran with his family. I asked him what he would like to do in the future. He hesitated and then talked about how he wanted to go to university, where he had in fact been accepted after he graduated from grade 12, but his father could not afford his education at the time. If one day it would be possible he would start part-time in the evenings and study social work.

Through friends, Richard heard about the possibility of attending a workshop where he would be able to make a bit of cash, and this became the starting point for seeing new possibilities that he summarised as a matter of knowledge, that had taken him to where he was today. His education and previous work experience probably worked to his advantage in seizing these new possibilities. Many of the possibilities that he pursued seemed to open, new possibilities, so that he did not, for example, have to work as a home-based caretaker in the compound. Instead he could move on to another course, which qualified him to work at management level. Richard's trajectory appears similar to observations made in Kanyama, a township in Lusaka, where it was often the less poor and relatively more educated men, rather than women, who were able to access the limited salaries, sitting allowances and training that was available for HIV and AIDS activities funded by international NGOs and bilateral donors. The few posts available tended to be used as stepping stones towards even better posts and possibilities (Baylies et al., 2000:111).

Richard was one of the few who made a career out of his engagement in projects and I have highlighted how his trajectory of engagement fits with expectations about men and wage-labour – not so much in terms of making a stable income, but more in terms of performing a male gender identity as providing for others (cf. Ferguson, 2013).

From pieceworker to person and from clerk to manager

In this chapter, I have shown how Rose appreciated how she was recognised as a person in the research project that she was about to become part of for a short while, and how Richard was proud to have made the move from clerk to manager. I have also shown how Mr Lungu and Chibuye did not engage, and I have suggested that their disengagement was related to performance of gender identity. The observation here is that engagement in projects is also about gendered selves, whether people see and seize new project possibilities or not.

Capturing aspects of selves, whether they change in engagement or not, can be attempted in various ways by applying terms such as subjectivity, self-image, identity or personhood – each with a rich heritage of definitions and building on different sets of observations. Rather than discussing people's talk about themselves in the light of one of these concepts, I will briefly consider what they said about themselves in relation to the projects and in what particular contexts. I will point to ways that such expressions about selves might overlap with or enhance other aspects of selves, and how these (new) images might be activated and mirrored in relations beyond the particular project context.

First, it is necessary to note that some people did not see themselves engaging at all. Not everybody saw possibilities in projects in a way that it became relevant for them to engage. In Lusaka, this could be a matter of performing gender identity, as for Mr Lungu and Chibuye.

In the particular context of concern about HIV, Rose mentioned how she felt recognised as a person in interaction with project staff, implicitly compared to the way she might be treated in a clinic and outside. It seems that the project enhanced a certain positive self-image in her for a while. This self-image was not lasting, however. In fact, it seems from the vignette preceding this chapter that she sometimes saw herself as a failure – perhaps because she could not stay in the project, or perhaps because the project and all the other projects that she engaged in did not really help her.

Richard both learnt a new language and established connections in the project world. Soon he found himself rising in a new hierarchy of projects and relations – going from being a clerk to becoming a project manager. Richard’s engagement led to more radical and lasting change in terms of new skills that led to a new position in an new organisation and in terms of his relations to others. His skills and position were recognised by others and became part of his (gendered) identity as a successful man, who could provide for others.

Acknowledging the diversity in the way engagement in projects might influence or enhance aspects of selves and how they are expressed and unfold in relations within and outside the project context, I will continue to pay attention to this aspect in trajectories of engagement in the coming chapters by observing (shifts in) positions and relations. As I have shown in this chapter, positions can shift. A position may be subtle and temporary, as it was for Rose, or it may sediment and resonate with other aspects of personhood to become part of a wider identity, as it did for Richard. Positions may be more or less reflected in relations to partners, relatives, friends and neighbours, and also relations to researchers (including me) and research projects. I will return to aspects of selves how they are animated in relation to engagement in research and other projects in the concluding observations of this thesis.

Summary: seeing and seizing possibilities

This chapter has made a distinction between pre-defined benefits and emerging possibilities for people who engage in projects. People may speak of such possibilities, or outcomes, as end-points, i.e. learning something, a temporary income, or employment, but I have shown that outcomes may change during engagement. I have also shown how possibilities are mediated in relations that may 'roll on' to new openings and opportunities. To capture this emerging and open-ended quality, I have chosen to speak of possibilities instead of outcomes.

A major observation is that the possibilities people see and seize, i.e. making an income, learning something, etc., are not specific to research projects. Acknowledging this observation, I have explored who sees what kinds of possibilities in both research and other kinds of projects. To the extent that it makes sense to characterise engagement in projects as instrumental (since people have more or less explicit hopes and expectations), it is relevant to note that some people do not know what exactly to hope for, and others may become engaged in quite a different way than they expected.

I have shown how possibilities may change during engagement and how such possibilities are often mediated in relations; how gender performance makes a difference to the kind of possibilities that people may see and realise in research and other projects; and how the realisation of possibilities may prompt or reflect a change, shift or transformation in images of oneself, and in relation to others – for a short while or for longer.

Rose, who had previous experience with various projects, first got involved as a recruiter in a research organisation as a kind of piecework, but gradually became attentive to the possibility of learning something about a matter of concern for her by coming to the research clinic. For Rose, the research project transformed from being a matter of piecework to a possibility for learning and for being recognised as a person, which might subtly have influenced her image of herself for a while.

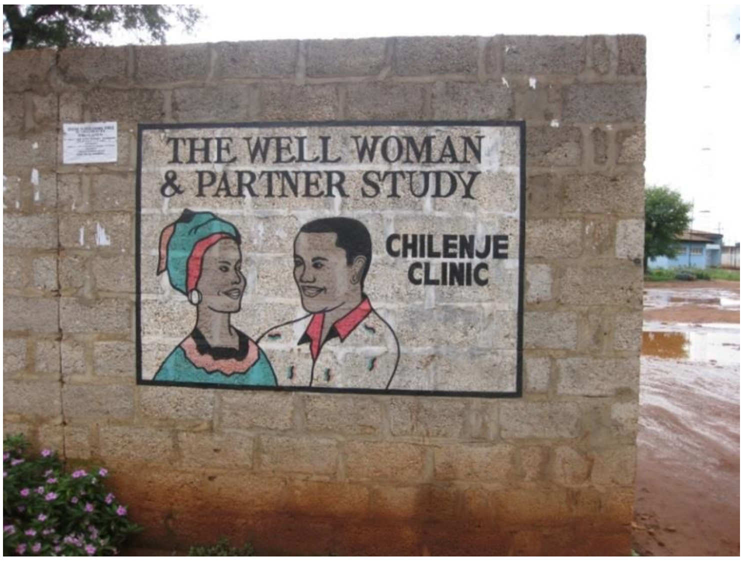
Creatively, perhaps even controversially, Rose pursued the new possibility of learning something by borrowing her neighbours' husband, since her own husband had refused to engage so far. It turned out, however, that he was not so disinterested after all. For her husband, the project offered an opportunity to disclose his positive HIV status to his wife, but nothing else. Like many other men, including Chibuye, who were oriented towards wage labour, he did not see any relevant possibilities (or relations) in projects.

Richard's story is also about how the possibility of making a bit of money by joining a workshop transformed into appreciation of learning something. It was in the workshop that he met the people who could open new project possibilities for him, which came to form the basis for a career in the project world and pride in having become a project manager. Different from Mr Lungu and Chibuye, Richard saw possibilities in projects and he quickly advanced in the hierarchy of project management as appropriate for an educated man.

Rose and Richard had learnt to move in the landscape of projects that Tabita and her friends had just become acquainted with. They had learnt how to be attentive to the possibilities that this landscape might offer and for Richard it had become a career. He had the education and the connections that Rose did not have to make a more stable attachment to an organisation. Joyce and Joanna, who are the protagonists of the next chapter, had also managed to make a career, particularly in transnational medical research projects. This was quite an achievement when projects were not only relatively scarce, but also time-limited.

Vignette IV: Joyce and Joanna

Joyce's brother's health had deteriorated and she had taken him both to the clinic, to UTH and to a herbalist. Her sister's husband was also not well, so while her sister had gone to the Copperbelt to buy maize, Joyce took care of her two nieces. Joyce's mother had been ill with dysentery and had been treated with both medicine and herbs. A few weeks later Joyce herself became ill and her mother was still not well. Her husband had been away for three months and he had only managed to send her money once – about 400,000 which was not enough. Apparently, he was waiting to farm, but the tools had not come yet. His daughter from another wife was still there with Joyce. She struggled to pay rent: "I can fight for food. Tomatoes are one pin. But rent …" The landlord had sent her son to go and talk to Joyce about her due rent. He needed the money to go back to the Copperbelt, where he worked.



Chapter 6

Making an uncertain career

Introduction

Engagement in transnational medical research projects is temporary. Projects come to an end, as Tabita and her friends experienced, or engagement is interrupted because obstacles appear, as it happened for Rose. Like both Tabita and Rose, however, many people see possibilities in these projects so that they are ready to try engaging again. A few people manage to engage in several research projects, thereby gaining a kind of cumulative experience over time that can be thought of as specialisation that becomes the basis of a career.

This chapter explores elements in making a career in temporary transnational medical research projects. To illuminate these elements the chapter will have Joyce and Joanna as protagonists. They were both experienced study subjects, recruiters and peer-educators in several different medical research projects. This chapter explores their trajectory of engagement and how they came to make a career – albeit uncertain – in medical research projects as both study subjects and employees.

For the purpose of the argument in this chapter I begin by establishing a difference between trajectories and careers as analytical concepts. To illuminate their dimensions I briefly apply both concepts to the cases of Tabita, Rose and Richard. Next follows an account of Joyce and Joanna’s trajectories and how their engagement turned into a career. Drawing from the discussion on different kinds of knowledge from Chapter 4, the third part of the chapter explores the elements that went into their specialisation as both study participants and employees, and I close the chapter by reflecting on how the common organisation of research interventions into time-limited projects influenced their attentiveness to possibilities in research projects.

Trajectories and careers

In this thesis I follow trajectories of engagement as a basic empirical and analytical entry point into understanding engagement in research projects. In this particular chapter I explore careers as a more specific entry point. Trajectories and careers are both paths or courses. Both can be described by points in space with a focus on topography and distance, and in time with a focus on duration and tempo. A career, however, often implies progression and accumulation in a way that a trajectory does not. Coupling this distinction between trajectories and careers with attention to who engages in medical research projects, it becomes possible to discern a kind of specialisation by the few lay people who manage to engage in these projects again and again. In this chapter I will focus particularly on the temporal aspects of the paths that lead to repeated engagement with medical research projects and what elements are involved in specialising and making a career in such projects. I will explore what it is that accumulates when lay people manage to make a career in medical research projects and how such accumulations are applied when projects end.

To clarify how I apply the concepts of trajectories and careers I will briefly return to Tabita, Rose and Richard. Tabita's path through one research project for the first time was a trajectory of learning something about many things, including how to be involved in projects. Her trajectory was short, however. When I left Lusaka she had not yet had the chance to apply her accumulated knowledge about how to engage again, although she had the intention to do so. Through her relation with Auntie Loveness, however, it is very possible that she was able to enrol again and to make a next step in a budding career in research projects.

Rose's trajectory through various kinds of projects was multi-pronged and intermittent. At one point her engagement also embraced a research project where she engaged first in the capacity of being a recruiter on a time-limited contract, and next in the capacity of being a prospective member of a cohort. During this engagement she learnt both about possibilities for employment and for enrolment and she was ready to continue along both paths. The certificates that she had obtained previously, however, did not accumulate to form the basis for further employment.

Her accumulation of knowledge about how to be involved in research projects was interrupted by her husband's unwillingness to join in. She went as far as she could in exploring the possibility and she stayed attentive to new possibilities, including my research project, just as she kept the possibility to continue her practicals as a counsellor open – even after two years.

Richard was one of the few people who had managed to make a career out of his engagement in projects. Once he had heard from friends about the chance to enrol in an NGO workshop about HIV it appeared that he quickly made new contacts, who opened new training possibilities for him within the same field, which eventually led him to establishing his own NGO to support orphans in his home province. Although these possibilities did not appear in medical research projects, I include the story of his career here to show how careers within projects can have different durations and tempi. Now, I turn to Joyce and Joanna, whose trajectory of engagement specifically in transnational medical research projects also turned into a career.

Getting to know Joyce and Joanna

I was introduced to Joyce and Joanna in one of my first visits to one of the three clinics that I had permission to work in. I had no appointments with anyone, but soon after I had entered the gates of the clinic compound a young, smiling man came towards me, greeted me and struck up conversation. The young man quickly made sure to ask what I had come to Lusaka for, and he immediately arranged for me to meet Joyce and Joanna, who happened to also be in the clinic compound that day. He told me that Joyce and Joanna were very experienced and had been involved in many projects. They presented themselves to me as volunteers at CIDRZ and I asked them whether they would be interested in telling me about their experience. We agreed on a day and a time when they could come to our house.

Seated on our sofa, Joyce and Joanna proudly introduced themselves by their low ID numbers in the recently completed 035 study, as they referred to it, indicating that they had been among the first to join.[74] We continued chatting for a while, but soon Joyce asked me why I did not turn on my tape recorder. Joyce and Joanna were, indeed, very experienced and they meant business in many and more and literal ways than I expected. Going through my field-notes about being with Joyce and Joanna throughout my year in Lusaka I see that a large part of them are recordings of prolonged and unusually explicit negotiations about our relationship in terms of how often we should meet and what they would get from telling me about their experience (see Chapter 3).

Joyce was 24 years old, married, and had a son of 4 years. She had wanted to become a nurse, but did not have enough money for the training. Instead, she graduated as a preschool teacher in 2004 but saved up and took a course in "psychosocial" (counselling) at KARA in 2005 – *"Thank God, it happened,"* she said. The same year she took a course on home-based care and worked as a KARA counsellor at a public clinic earning ZMK 900,000 (GBP 128) per month for six months, until she became pregnant and had to stop working. Her husband, who was a minibus driver, was fired shortly after I met them, and he left for the Copperbelt to look for work with his brother who was a minibus driver there. His 12-year-old daughter of another marriage often stayed with Joyce and she also looked after her brother who was often ill, and her sister's husband who had begun slimming (losing weight can be understood as a sign of illness, particularly AIDS).

Joanna rented one of several small rooms facing a shared yard and latrine owned by a landlord, who lived behind the rented rooms. A lace curtain parted the 'bedroom' from the 'sitting room/kitchen' that was crammed with a sofa, a chair, a small table and an electric stove. Buckets, baskets and mats were squeezed under a low metal

---

[74] This was the same phase II/IIb microbicide trial that Tabita and her friends in Chapter 4 had been enrolled in to test the safety and efficacy of a vaginal gel to protect against the transmission of HIV. Tabita and her friends sometimes referred to the trial as the "Well Woman project", which was short for the name that the project had on signboards and murals in the clinics in Lusaka, i.e. "CIDRZ Well Woman and Partner Project". The number that Joyce and Joanna referred to is the project's number within the HIV Prevention Trial Network (HPTN), a large network of American-funded clinical trials taking place in partnership with research centres in parts of the world where transmission is high. I only heard staff and community representatives referring to the project by number. This number distinguished the project from other studies, but referring to the study by number also served as a marker of knowing the language of the trade.

rack with cooking oil, sugar, salt, tomatoes and onions. Two TV sets were stuffed into a low plastic stand with their surround-sound speakers hanging on the drying rack among the cups and plates. There was also a DVD player, and a large printer under one of the TV sets. The whitewashed walls were dotted with calendar posters by various NGOs displaying messages about HIV, a framed picture of two pink roses captioned ”Love is the giving and sharing of two hearts together”, a clock, several brightly coloured images of a blond Jesus and faded photos of herself and her relatives. The room and many of its most visible items told a mixed story about both lack of means and middle-class consumption (cf. Cahn, 2008). It was located on the edge of the township facing towards the compound across the railway. Her rent was ZMK 350,000 (GBP 50) per month, which was quite steep, but she wrinkled her nose in scorn when one day we talked of the possibility of her moving to the compound, where Joanna lived, and where the rent was much lower.

Joanna was 28 years old, married and had two children. I never met the husband that she mentioned, and I am not sure he was much around. She and her relatives lived in a cluster of low huts and houses full of sofas and low tables, cupboards with many pots in different sizes, and shelves with plates. There was no electricity so a *mbaula* (a charcoal brazier) was used for heating water and cooking food. During the time that I stayed in Lusaka, Joanna tended to two terminally ill relatives; one who would start drinking as soon as she got better, and another who had a newborn infant that Joanna took care of as the mother gradually got worse.

During my year in Lusaka we met at least every two or three weeks, either in our house or increasingly often where Joyce lived. Joyce’s son and her husband’s daughter sometimes came to play in our house. Joyce and Joanna took me along to a church service and to a party in their congregation that was held in the compound; Joyce invited me to join her at a market in another township where she used to live, to visit her cousin in her hair-dressing salon, and to consult a lady who healed with the help of God, herbs and some sticks, about treatment for her brother. One memorable afternoon in the compound they bought me a bottle of sparkling wine, “Autumn Harvest”, while they had a carton of *chibuku* each. Sitting under a blooming pink bougainvillea, we were in the company of an older man that they addressed as ”Grandfather”. Luckily, he maintained that I should not die alone and offered to help me with the bottle.

The following is a description of Joyce and Joanna’s trajectory of engagement through several research projects and other activities that I have compiled on the basis of two taped interviews with them, several interviews where I took extensive notes, and field-notes from visiting and moving around with them.

From KARA to “ZUP” to ZEHRP to CIDRZ

In the mid-1990s Joanna, like Joyce, trained to become a counsellor at KARA and upon completion she worked in a public clinic for a year until she became pregnant with her first-born. Around that time KARA began having certain money problems and counsellors were no longer given a salary.[75] Then some people came to the clinic from “ZUP” [76] to invite 30 women between 18 and 20 years to join a study to test a medicine to insert in the vagina to prevent HIV infection. After giving birth Joanna joined the study, but it was stopped after two years and two months because the professor at UTH had said that maybe the medicine could have unwanted effects on unborn babies. In the next study, Joanna learnt they would instead recruit older women. Joanna waited to be called again, but meanwhile she heard about the CIDRZ project to test a vaginal gel. She brought her certificate from KARA to CIDRZ and also began working as a peer educator there. At some point “ZUP” that had now turned into ZEHRP started enrolling again and Joanna joined as a recruiter. She explained that:

> *I didn’t go back [as a study participant], but they called us, because we were interested, as you have seen us coming here, and we were good*

---

[75] In the early 2000s KARA’s funding priorities changed, so that counsellors were no longer paid. In early 2012 The Lusaka Times reported that the organisation faced closure due to misappropriation of over ZMK 9 billion (almost GBP 1.3 million).

[76] According to Joanna, this was the medical research project that later became ZEHRP (Zambia-Emory HIV Research Project). Joanna did not know how to spell “ZUP”, but it could have been ZUAB, because at the time the American professor running the research organisation worked at the University of Alabama, Baltimore (UAB). In 2004 the professor moved to University of Emory and the research organisation became ZEHRP. Much earlier, in 1986, the professor had started a Project San Francisco, a couples’ VCT project in Kigali, but after 1994 she moved to Lusaka where she established a sister project under the same name (http://www.ncbi.nlm.nih.gov/pubmed/9376093).

> *participants there. They called me to go out and enrol some women from the community that are married of 30–40 years. They needed both a man and woman that are living together. So that's how I started. They were calling us INAs*.

Joanna's account summarises how they had been interested and how they had quickly learnt how to be good participants. The research organisation then called on her to work as a recruiter for "ZEHRP couples", as she referred to the project, for 18 months. It was possible to combine working for CIDRZ and ZEHRP, because recruitment for ZEHRP could be done any time. Besides, ZEHPR only had meetings once a month during weekends and not on weekdays, like CIDRZ.

Joanna's friend, Joyce, who had also worked for KARA, first heard of the CIDRZ Well Woman and Partner Project, as she also referred to it, when she took her first-born for BCG vaccination at the clinic. The nurses from a research organisation brought brochures and had said that women who were breastfeeding could join the study after six months. Joyce explained:

> *I read that one and I went back home. I decided to join that one. I was given an informed consent form and I read it, I volunteered and that's when I joined. I was chosen by the boss to help recruiting. He saw the information I was giving. I liked talking about HIV/AIDS while we were waiting in the room – before I was chosen, I recruited 10 women to the study. I wanted other friends to be part of the study and to see if we could prevent HIV. Before they chose us we were trained in peer education. They asked us whether we were trained and whether we know how to recruit and talk to people. And then we got a one-week refresher course in recruitment. We were 13 women who were already enrolled. I went in the field together with Joanna.*

Joyce and Joanna maintained that they recruited a quarter – if not half – of the several hundred women that were in the study. As study participants they would follow the same routines as described for Tabita in Chapter 4, and as peer educators they worked for three days per week at the clinic giving health talks to the other study participants in the reception room and assisting with translation when necessary.

Joyce and Joanna had not only worked for ZEHRP and CIDRZ, but like Rose in the previous chapter, they had been attentive to other possibilities. For example, a Polish student had come to the clinic a year before my arrival in Lusaka to test a new type of condom. He needed people to recruit study subjects for him, so the sister-in-charge in one of the clinics had called all the volunteers in the Neighbourhood Health Committee that included Joyce and Joanna. Joyce and Joanna had been hired for six months, together with 28 other volunteers. They were promised ZMK 80,000 (GBP 11.53) per day for transport and lunch. He had said that he would be back a month later, but he never returned.

During my fieldwork they were both about to enrol in a new study of a similar product as the one they had been testing for CIDRZ. Joyce and Joanna had heard about the study from one of Joanna's very good friends who had been hired as one of the four recruiters in the new study to go "flat out" to recruit 600 participants. Joanna told them that she was curious about the study because she had been doing this work before. The recruiters had been very encouraging and interested in her, she said. Soon after, Joyce and Joanna went to the marketing research bureau, where the study was run from. They appeared like prospective study subjects who were very experienced with the kind of product that was to be tested, but only, of course, to be able to report to their "boss" at CIDRZ, and to me, what the study was about: "*We just went there for our own information. Because us, we like going there even in different studies, so we want to learn, all we want is to have the information and learn, not just staying in projects because of money."* Rumours had it that they would make ZMK 150,000 (GBP 22, which was over seven times more than what they got at CIDRZ) per visit to the clinic as study subjects in the new study, but they emphasised their wish to learn that both Tabita and Rose also referred to in the previous chapters.[77] In their visit to the

---

[77] Rumours of this new trial also reached the managers of the CIDRZ trial. In a much later interview with a staff member from CIDRZ I was told that CIDRZ staff had wondered how any ethical committee could approve the sum that women would get per visit to the clinic. The sum indicated that the study might not have been through any ethical committee at all. When one of the senior American research coordinators went to the marketing research bureau to propose collaboration and knowledge-sharing, and also to avoid recruiting the same women for both studies, the project manager at the marketing bureau had quickly become difficult to contact. Soon after she had left for her holidays. It had not been possible for the bureau to share any information about who was behind the trial.

marketing office they also learned that the new study did not offer family planning and that they would not be given condoms to use with the gel. They understood the nurse's argument that condoms would make it harder to assess the effect of the gel, but they still found it dangerous, and did not approve of it.[78] Eventually, the study closed before it had really started, and it remains an open question how Joyce and Joanna would have handled the possibility to engage in the project, had it started.

Towards the end of my fieldwork, Joyce and Joanna went to information meetings run by a European doctor attached to the UTH, who had carried out research projects in the compound for many years, and who was about to start a new research project. They both knew the doctor already, and they had heard from friends that the project would need discordant couples (i.e. couples where one is HIV positive and the other HIV negative), so they joined the meetings to explore possibilities of becoming recruiters.

Other engagements

Apart from specialising in medical research projects, Joyce and Joanna were also volunteers on the Neighbourhood Health Committee as mentioned above, where they sometimes participated in various campaigns. Joanna was active in a prominent women's committee in the Catholic church that they both belonged to. She performed the *buomba* dance at special masses, which was seen as a mark of distinction by many.[79] Drawing from her authority in church, Joanna could also be hired as *alangizi* to teach young women who had had their first period, or more commonly, who were about to get married *"how to treat their future husbands"* (see also Rasing, 2004). Besides, Joyce and Joanna both had some business experience, not entirely successful. Joyce explained how they had taken all their money last year after the CIDRZ study had ended, and gone to Botswana to buy blankets. After that they went to sell them in the

---

[78] Joyce and Joanna's concern reflects a central debate in HIV prevention research and their awareness of this issue tells of their position as a kind of semi-professional lay people.

[79] The *buomba* groups were seen as "traditional Bemba" referring to people who used to perform in chiefs' palaces, but since the early 1990s, groups of women and a few male drummers had started performing in church (in some church circles it is debated to what extent the traditional should be 'imported' into Christian practices and to what extent it is fitting that women form such groups among themselves). Some of the group members also performed initiation rites, seeing themselves as teachers of the traditional (Rasing, 2001:191-192).

Copperbelt. They gave them away and said that they would come and collect the money toward the end of the month. But people failed to pay, and it was expensive to go travelling so far to get payments. So they lost a lot of money.

Before going to buy blankets, however, Joanna had opened a bank account in Barclays, where she had put money for her first-born's schooling. He had passed grade 7 and she was able to pay for his continued schooling. Joanna beamed when she told me that he was now in grade 9. Her daughter also passed and she was also in school, grade 8, by virtue of that same bank account. Joanna had taken chances in business, but only after she had secured her children's education. Joanna underlined how she was a responsible mother by adding how her own mother had reacted when she heard about this bank account: *"I thought you were just drinking."* Joyce and Joanna indeed enjoyed drinking when there was something to celebrate, and they were not always very discrete when they poured *tujilijili* into their 1 litre 3–5% *Chibuku* maize beer cartons.[80]

Joyce was planning to open an orphanage. Some years back she had been involved in another orphanage that had been established by a South African pastor. It fell apart, however, when Joyce and her colleagues found out that the pastor apparently used the orphanage to fundraise for his own needs. Together with her former colleagues from this orphanage she had registered an NGO and opened a bank account. Joyce was now looking for offices where they could start working on applications for funding.

Like Rose in the previous chapter, Joyce and Joanna were attentive to several different possibilities in the landscape of projects, which formed a considerable, but not all-encompassing, part of their daily lives and social position. They were sufficiently experienced and educated to pursue such openings, and they had managed to repeatedly engage in medical research projects, sometimes several at the same time, in different capacities. In the next section I will explore their career as a matter of specialisation, which grew from different kinds of knowledge, including knowledge of how to relate to project staff and colleagues, but also an attentiveness to project

---

[80] *Tujilijili* were 60cl plastic sachets of strong alcohol (40%) selling at 1 pin each (ZMK 1000 or GBP 0.14). They were made illegal to manufacture, sell and consume in April 2012.

possibilities that were intensified by the uncertain availability and time limitation of projects.

Elements in specialisation

A lay person is by definition not trained or specialised in relation to a given subject. Nonetheless, Joyce and Joanna ’s story shows how it is possible for lay persons to form a career within a complex and highly specialised project organisation such as transnational medical research. Here, I will illuminate some of the elements that went into their specialisation.

Education and knowledge

Joyce and Joanna were trained as counsellors and their certificate from KARA had paved the way for them to become peer educators and recruiters for several different research organisations. In a situation where it was very difficult to obtain a formal job, HIV counselling courses were very attractive for people who had managed to reach beyond a basic level of education. Such courses were often seen as an entry point into more or less temporary positions in NGO projects, as was the case for Joyce and Joanna, and for many other people that I met, including the well-dressed woman that I met as I passed through one of the clinics in my study.

I had seen her earlier that day as she approached a senior HIV counsellor very politely and made a curtsy as she addressed him. She came over to me and asked me whether I was involved in the programmes at the clinic. I told her that I was a researcher and not involved in any particular programme. She continued that she was a trainee in psychosocial counselling at KARA and that she had just come from her practicals that she did two mornings a week. She had a full-time job in a large international bank, but she also did this for her community. I asked her why she bothered with counselling when she already had a full-time job *“if you don’t mind me asking*?”[81] She said that pension age in Zambia was 55. She was 53 and she wanted to have something to keep her busy in two years’ time. That was why she began preparing slowly now. She planned to do the advanced level next year, “*and maybe I*

---

[81] By this time I had learnt that people who work are assumed not to have time for volunteering.

can get work in one of the NGOs in the future". By contacting me, a foreigner in the clinic compound, she perhaps hoped to make initial contact with such an NGO.

Having the right kind of certificate was good, but recalling the distinction from Chapter 4 between 'knowing about' and 'knowing how to', their central qualification was knowing 'how to talk to people', rather than having 'factual' knowledge about HIV testing. Knowing how to talk to people was a recurring phrase when Joyce and Joanna described their work (see both the quote from Joyce above, and from Joanna below). They had performed this skill in the waiting room at the trial clinic, which had attracted the attention of their future boss, who had then invited them to train as peer-educators. Richard referred to the same skill in a more professionalised style, i.e. 'communication', as the basis for his certificate and his career in the landscape of projects.

Apart from knowing how to talk to people, they had also learnt how to talk to researchers. When I met Joyce and Joanna, they had worked for CIDRZ for four years. As mentioned above, they referred to different projects by the number of the research projects that researchers and staff used and they told me how they taught newcomers to the organisation who did not know anything. They had learnt a particular language, which could be applied to denote a difference in status to people who would otherwise be their peers (cf. Englund, 2006:87ff), but they also applied this language in relation to their employers to demonstrate their skills.

Joyce and Joanna both applied the jargon that comes with development projects (i.e. "stigma and discrimination", "sensitise", "volunteer", "the community", "the field"), but also the more specialised language that comes with medical research specifically (i.e. "follow-up", "screening", "mapping", "retention", "informed consent form"). Talking about their most recent engagement in ZEHRP, that had started rolling out couple counselling services in the public clinics[82] they applied the common acronym language that comes with experience in various interventions: *"The ZEHRP training officer called all NHC members and CHPs who can talk to people in the*

---

[82] ZEHRP's research was funded by NIH and IAVI, but in 2009 ZEHRP received money from CDC to carry out couple counselling as a general health service and not with recruitment for research as primary purpose. This move from research to also providing services as an NGO is interesting and also happened for CIDRZ that became a large ARV distributor.

community and then 30 DCPs were chosen."[83] Joyce and Joanna had been among the 30. They were not exactly sure what DCP stood for, but they thought it might be district child promoter or perhaps district clinic promoters. They were very sure of what their task was, however, which was to recruit couples for the counselling service.

They were also very sure about what their task was in CIDRZ. Joyce and Joanna explained how CIDRZ had 10 peer educators and 15 outreach workers. The peer educators had the same "programme" (i.e. job) as the outreach workers, but outreach workers would not be participants in the study and they did not all have certificates (in counselling), like the peer educators had. I asked them whether they would be interested in other assignments within the organisation, but Joyce responded that *"We would have joined CAB*[84] *long time ago, if we wanted, but we get much more allowances than them."* I asked them what they got and they specified that for 1½ hours meeting with a 20 minute tea break they would get ZMK 20,000 (GBP 2.88). If the meeting lasted up to noon they get would get ZMK 40,000 and if it lasted to 2 o'clock they would get ZMK 80,000. On workshop days they would get ZMK 200,000 (GBP 29) and lunch. As peer educators they got ZMK 120,000 (GBP 17.30) per day. Their emphasis on allowances should of course be taken at face value – it made a vast difference to their daily lives that they had a good and stable income for years. In addition they were happy and proud to have a real job with a large international organisation and to be good at it. They enjoyed speaking project jargon in an offhand way and their position as well-connected and educated women who could help others.

When looking for possibilities in research projects both Joyce and Joanna applied their formal training as counsellors. Their certificates opened possibilities for them that were closed to many others, like Rose, who might also be very good at knowing how to talk to people, but who did not have the right papers. Formal education was important for making a career in projects, even if this education was not relevant for the particular area of work involved. This was true for Richard, and also for Richard's friend

---

[83] It is interesting to note that Joanna refers to the Neighbourhood Health Committee by its acronym. Most others applied the full name of the committee when they referred to it (and so do I in this text).

[84] The board could influence many aspects of the relation between the research organisation and local interests. Members were not given a salary, but allowances and the opportunity to go for trainings and travels.

who had worked for many years as a volunteer in the TB corner in one of the clinics. He used to be a successful engineer, but prolonged illness and a positive HIV test had completely turned his life around. He now applied his academic skills in other ways, for example by writing project proposals for his friends (cf. Swidler and Watkins, 2009:1187 about semi-professional proposal writers who know the particular language that is expected of such documents). Just before I left Lusaka, he got a job as paid peer-educator in a large research organisation.

Joyce and Joanna's formal training and their previous experience as study subjects, peer educators and recruiters in such projects, and their knowledge of how to talk to people and researchers, of project procedures, and of the organisation of projects, was not alone in making their specialisation. It also grew out of their interaction with project staff and peers.

Relations and interaction

Joanna often described researchers as depending very much on Joyce and herself. In the first quote in this chapter, Joanna mentions how they had been good study participants with ZEHRP, and how ZEHRP had called them to enrol in the next study. In CIDRZ, Joyce and Joanna had the chance to develop more intense relations with project staff than study subjects could. As peer educators they interacted with project staff in meetings and in campaigns, and not just as study participants in the clinic. Joanna told me how their bosses at CIDRZ loved them[85] because Joyce and Joanna brought attention to any problems that had arisen. If Joanna was quiet in a meeting, they would ask her why she did not say anything. They would do anything Joanna advised, she said. Joyce and Joanna were even better than the old women working for the project, they told me, because they were young and knew how to speak to young women.

Joyce and Joanna were convinced that they would get hired again when the next project was to begin, and meanwhile they attended to their relations with project

---

[85] In both ChiNyanja and ChiBemba there are few terms for different kinds of positive affection such as love, like, adore, sympathise with, etc. The verb roots *temwa* (ChiBemba) and *konda* (ChiNyanja) are often translated into the English 'love' and the texture of the particular affection is determined by the context.

staff, as this example illuminates: one day Joyce mentioned to me how their boss, Mrs Mudenda, had asked her and Joanna about me and whether they had talked to me. Someone had told Mrs Mudenda that I went around to get information and that Joyce and Joanna knew me. Mrs Mudenda herself had in fact seen Joanna and Joyce talk to me at the clinic. They had told her that I was their friend and that I did not talk to them about being in the trial. She had said that they were lying, but they had insisted and had said, "*No, she is a student, she is our friend here."*

I told Joyce and Joanna that I had met Mrs Mudenda in another clinic already and that I had introduced myself and my project. We talked about how to handle Mrs Mudenda's concern with my research in the light of our relation. I asked them if they were sure that they would still talk to me because I did not want to create any problems for them, and I told them that I would never tell her who I was talking to. They both confirmed and approved this point. Joanna mentioned the confidentiality I had promised them and that if anyone saw us together they could not know what we were talking about. They told me that they would help me and that they had found papers for me – consent forms and quizzes that they had filled in, that they would show me. They would help me in any way they could, they said. We talked about what kind of trouble they would get into if others found out that they had shared this material with me. It was not only Mrs Mudenda they had to be careful with, but also other members in the group of peer-educators, outreach workers and CAB members. Recently, there had been a meeting with all the big bosses where Mrs Mudenda had emphasised Joyce and Joanna as being very helpful: *"These two are my eyes, they made the study,"* she had said. She had not mentioned others from the community, and so they were now looking for information about Joyce and Joanna that could be harmful to them, so they would be fired. "*But they don't find it,"* Joanna said.[86]

Later in the afternoon, when Joyce and Joanna escorted me a bit of my way home as good hosts do, we talked about their relation to their boss again. I told them

---

[86] During the afternoon, that I mention above, when we sat drinking under the bougainvillea, a colleague of Joyce and Joanna cycled by very near us. They were slightly worried that he might have seen us together and that he would tell their boss about it. Days later, they told me that their boss had not mentioned anything, so they assumed that the colleague had not seen us when he passed by. Perhaps because he had been drunk, they guessed.

that I was worried that they might get into problems and I said that I seriously thought that I was doing nothing wrong, but that Mrs Mudenda might be afraid of losing Joyce and Joanna. They cheered and said I was right: *“Yes, she is afraid that we will go with you,”* and Joyce laughed: *“We go wherever there is money,”* looking good with her lilac eye-shadow and matching satin stretch pants.

I end this story where Joyce refers to money, which I will address in the next chapter, but the story is mainly about the way Joyce and Joanna, in spite of their apparent nonchalance, paid attention to their relations with a key employer and with their peers. Maintaining trust in relations to the “boss” and being attentive to envy in relations with peers was important for their possibilities to stay in the projects and for their chances of learning about new project possibilities (which included me and my project). They surveyed the landscape of projects and shared new project possibilities in relations with friends, and their own friendship was strengthened in the same way. Staying abreast of new possibilities through relations was an important skill in Joyce and Joanna’s specialisation.

Attentiveness in the landscape of time-limited projects

In the introduction to this chapter I mentioned how careers can be described in both spatial terms with a focus on topography and distance and in temporal terms with a focus on duration and tempo. With regard to distances, Joyce and Joanna’s careers did not take them out of Lusaka, but they had very good insight into the topography of careers and projects in Lusaka.

Their remark about not wanting to be part of the CAB tells about their insight into different positions in the organisation of research projects that Tabita and her friends, for example, did not yet have. While Tabita and her friends took their first steps into ‘something bigger’, and Rose moved between piecework opportunities across homes, clinics and projects, Joyce and Joanna were among the relatively few lay people who distinguished clearly between projects and organisations. They knew that there were several different research organisations in Lusaka and several departments within each organisation, each running different research projects. They knew not only which clinics the research organisations operated in, but also where the head offices of the research organisations were located. They knew how several projects and organisations were linked to each other and often what projects and organisations had preceded them. They knew that they were engaged in a wider organisational structure that was linked to similar projects in South Africa and elsewhere. They did not know about all research projects in other compounds and at the UTH, but what they knew about research projects south-west of the city centre enabled them to develop a sense of where to go with various concerns, and to be attentive to new possibilities in the wider landscape of projects in a more directed way than Rose in the previous chapter.

Many of my interlocutors were not in a position to choose between or even compare research projects (unlike people in different ARV programmes in Uganda (Meinert, 2009b)). They might not know of enough different projects, or know the right people who could connect them, and besides the projects were time-limited in a way, so that they could rarely be in more than one project at a time, even if they had wanted to be. Joyce and Joanna, however, were more experienced and specialised, so they were in a position to compare research projects and their specific differences in terms of what they had learnt about safety (as in the case of the study by the marketing research bureau) and in terms of what position they wanted to occupy (peer-educators rather than community representatives). Still, it would be misleading to think of their mode of engaging as 'opportunity shopping' (cf. Abadie, 2010). There were relatively few projects for them to engage in and I never heard that they had refused engagement in any project.[87] In general, when people declined to engage in research or other projects, it was not based on comparison or weighing of different project possibilities, but because other kinds of possibilities appeared within reach, as for Chibuye, or because their fear of the HIV test was too great.

With regard to the temporal aspects of careers in the project landscape, a prominent characteristic of projects is that they are time-limited even if the organisational framework around projects may last and initiate new time-limited projects. This 'start-stop' dynamic is not only a characteristic of research projects, but

---

[87] They did tell me of a good friend who was involved in a test of crocodile fat as a cure for HIV that was run by a herbalist in a nearby township. They were not involved in this study (they were not HIV positive), but they knew about it.

has also become increasingly common in the delivery of general public health services with the changes in funding mechanisms of health services in many countries in sub-Saharan Africa towards largely external funders. With reference to programmes such as PEPFAR, some scholars speak of a “projectification” of health care services (Meinert, 2009b; Prince, 2013a).

The ‘start-stop’ way of operating was not so intensely felt by people who had less experience with projects, like Tabita and her friends, who trusted Auntie Loveness to tell them about the next project. It might be more actualised for Rose in Chapter 5, who kept the opportunity for getting onto the practicals in connection with her counselling training open for years. Very experienced people, like Joyce and Joanna, knew how research projects are not only explicitly time-limited but that they may also stop even before they begin, like the research project by the Polish student, or the study run from the marketing bureau. Knowing how fickle possibilities were in projects made them even more attentive to such possibilities. The fact that Joyce and Joanna managed to specialise and to create a kind of continuity in the cut-up landscape of time-limited projects bears witness to their proficiency in applying their knowledge of projects in relation to both staff, colleagues and friends, so that they could stay informed about project possibilities. Their specialisation was one of the landscape of projects and its relations, rather than of a particular topic or condition, a project or an organisation, or of attachment to a particular person.

The contingency of project possibilities forges a particular kind of active attentiveness among lay people, who see possibilities in the projects. As Swidler and Watkins have observed in Malawi, people may “hunt and gather” in a terrain of not so many projects (2009:1183) or they may be “tarmacking” as Prince observed in Kenya (Prince, 2013a). This attentiveness to possibilities and the ‘start-stop’ kind of engagement that follows from it is also a skill that is learnt on the basis of accumulated experience with time-limited projects. Joyce and Joanna actively explored the organisations and worked to extend their attachment beyond the duration of individual projects. They did not just wait to be called, like Tabita and her friends in

Chapter 4, and they had established stronger relations with the right kind of staff than Rose in Chapter 5.

People may know the landscape of projects, and the people in it, and they may try to stay ahead of developments with a view to future opportunities, but – like Joyce – they cannot control what happens.

Cumulative experience and “time for suffering”

Recapitulating the previous sections on the elements that went into Joyce and Joanna’s specialisation and how they accumulate these in making a career I have mentioned their certified knowledge about HIV testing, but also their knowledge about how to talk to people and to researchers, shifting between appropriate languages, and their knowledge about how to move in the differentiated set-up of projects and organisations. This kind of knowledge provided a wider vista of the landscape of projects and how its possibilities might develop over time than Tabita or Rose had glimpsed.

Besides, Joyce and Joanna were conscious about their relations with both project staff and peers. They enjoyed the recognition that they received in their interaction with staff – not only as study participants and persons, like Tabita and Rose, but also as peer educators and employees. It was through tending to their good relations with staff, but also with colleagues and friends that they could stay engaged and informed about new possibilities, like the next trial by CIDRZ, or the study by the marketing research bureau. All this combined to form a kind of specialisation – not about medical research, but about how to stay engaged. This specialisation is not unlike the “hidden curriculum” about how projects work, that Swidler and Watkins refer to in their analysis of interstitial elites in Malawi, who are trained by NGOs to carry out development work in their communities (Swidler and Watkins, 2009). Specialisation, however, was no guarantee that Joyce and Joanna could continue their career.

After the CIDRZ project had ended (a few months before my arrival in Lusaka), Joyce and Joanna waited for the next project to begin, just like so many others among my interlocutors. Joyce took a course in hair-dressing while she waited, but she did not appear to work a lot. One day when I passed by her house she mentioned that she did not have anything to eat for dinner. Her husband had not sent money for a while. I asked whether she had tried to get a counseling job at New Start, where she had done her practicals. She said that she had tried, but *'you know here in Zambia if you don't have relatives there that pushes for you ...'.* She continued that at KARA there was no money, and that at CIDRZ you would have to be trained as a counsellor all over again, because they had their own programme.

About a month later Joyce talked about moving to Kuku, another compound further south, as soon as she had enough money. A week later she had found a cheaper place to stay in Chawama, where she used to live. She had gone to CIDRZ to borrow money to make the move, but they had said that they did not have the money for community workers yet, so she could not borrow. They had said, however, that from next month they would start training people again. Joyce and Joanna took this as a sign that the new project would soon be approved (it had still not started, however, when I left Lusaka). Joyce had also been to CHAZ to look for work as a trainer in peer education or counselling, but they would only start their programmes in August. She had been to JK, a compound after Chawama, to visit a friend from a time when she was in a rotating funds club with her relatives in Chawama. This friend was also a good person who shared, just like Joyce herself, who grew up in a household where there had always been many people around who were not even relatives. She had asked her friend for money, but she had just given money to someone else. For Joyce the previous month and this month had been very difficult. *"This is the time ..."* she said. *"The time?"* I asked. *"Yes, the time,",* she repeated. *"The time for what?" "The time for suffering."*

Joyce told me how this house had once had a freezer and a computer that she had sold after her husband lost his job as a driver. Now she wanted to find a buyer for the printer that she had. She also had the two TV sets with surround sound speakers, but that would be a lot of value to lose, even if she moved to a house without electricity. I asked her (far too bluntly) whether her husband might perhaps be leaving her and she looked me straight in the eyes and then away: *"No, he is not."* But she added that it is easier living single. Later in the afternoon she said that when her husband had lost his job that's when she thought it easier to live alone.

Towards the very end of my stay Joyce was diagnosed with TB. She was irritable and she talked about being worried about her mother and her young son, because they depended on her. The possibility that she was also HIV positive hung heavy in the air, but no one addressed it. She said that she would be better off without her husband because he did not send any money. Besides he was probably moving around with women there, in the Copperbelt.

Just before I left I distributed invitations for the community meeting that I would host in the compound on the coming Saturday as a dissemination, thank you and goodbye event. I found Joyce in her yard with the children after their bath. Her brother's young daughter was also there. Joyce did not look very energetic. She said that she was not well. I gave her the invitation, she briefly looked at it – and asked if there were any reimbursements. I said no. She asked for pictures and the soap that she had asked for the other day. Her requests were shadows of the spirited negotiations that we used to have. I don't know what happened to her and her family after I left Lusaka.

This part of Joyce's story is not so much about engagement in medical research, but it is very much a story about a life where even specialisation cannot insure against uncertainty and contingency.

Summary: start-stop engagement and stretching project possibilities

A career in medical research is rare for lay people. Recalling the distinction between knowing about and knowing how to from Chapter 4, making a career in research projects is not only a matter of knowing about research, but also about knowing how to move in the landscape of time-limited projects that was outlined in Chapter 5. The latter entails attentiveness to project possibilities and to relations, both 'above' and 'next to' oneself. Through accumulating knowledge about research, knowledge of how to move in the landscape of projects, and attentiveness to relations it may become possible to ‘stretch’ project possibilities beyond the short duration of the individual projects, thereby creating a career.

Joyce and Joanna had a lot of experience with medical research projects and here I characterise their engagement as that of specialists – not in the purposes and procedures of research, but in the landscape of projects and medical research projects in particular. What began with a course in counselling for Joanna and a routine visit to the clinic with her infant for Joyce led them into relations where they heard about various possibilities for engagement, including medical research projects. In these projects, their certified ability to speak to others about HIV turned into a qualification that led to project employment, which led to learning a particular language and a way of being in research projects, which led to more employment opportunities, while they were also engaged in other activities in church, at the clinic, in the NGO sphere and in business.

Drawing from previous experience and being attentive to new openings in projects and webs of relations, Joyce and Joanna actively looked for and engaged with many projects in shifting positions as volunteers and employees for as long as it could last. Knowing the temporality of interventions and being good at judging organisational set-ups (many people guessed and often misjudged) was a useful skill based on previous experience in organisational work. Even if they might not be in a position to choose between possibilities in projects, they were able to compare projects and prepare for or worry about future developments. Establishing relations to project staff, and being attentive to relations to peers, was central for them when they tried to extend their engagement beyond the duration of single projects. From a focus on individual careers in this chapter, the next chapter moves to exploring engagement in research projects in terms of such relations.

Vignette V: Auntie Loveness

One morning Auntie Loveness came to our house, but her voice was gone. She had screamed and screamed two nights ago because four boys had climbed the wall fence, jumped down on the sweeping pile and broken into her house at three in the morning. Whispering and croaking, she told me that the boys had taken her TV, her DVD, her money and her phone as well as some clothes. They had a car ready outside. She had screamed and her five orphaned grandchildren that lived with her had screamed. Neighbours only came to help after they heard the car had gone. She had reported to the Titanic police station near the compound (so named "because the place is going down") and they had called her that morning to tell her that they had recovered her things. It was not her things, however, but from another robbery that took place last night. She would go to ZAIN [mobile telecommunications company] later in the afternoon to get her phone traced. Poverty made the boys do these things, she said. They have nothing to do, so they drink. They get the money for drink from stealing. There is no future for them. And they picked her because she is known in the community. People that she doesn't know say "Hi, Auntie Loveness!" "Perhaps because they see me moving with white people, they think I have something!"

Weaving our way through the diverse high-density area of the compound towards the more uniform and solid council houses of the township, Auntie Loveness and I attracted quite a few glances and remarks from people that we passed. Auntie Loveness sometimes responded to people's reactions and smiling, she told me that she had moved with many white people in the compound. Tourists, students, researchers. Once a Canadian woman walking with her had seen a tiny little baby whose mouth was too small to breastfeed. The lady had sent milk powder for the baby once a month for a long time. Auntie Loveness hopes that the lady will come back to see the baby who is now a big girl. That was the time when Auntie Loveness became very popular in the neighbourhood. Another foreign couple asked Auntie Loveness to gather 12 girls to go to the maids' school for three months, which they paid for. The girls are now working abroad or in lush and spacious Kabulonga, the part of Lusaka where the local elite and the expats live. The foreign couple also asked whether they could take Auntie Loveness' daughter with them home to give her an education. The couple sent money for a visa application, but Immigration did not want to give her two years there. "You have only met them, have you heard of human trafficking?" they had said, so the money was lost. Then they tried again after three months, and she went. She was 21 years old and now she has been with the couple for three years. She will finish her studies in business administration in December this year. She will not settle in Zambia, because of the situation here, but she thinks of the UK, because people speak English there.

Chapter 7

Sharing project possibilities

Introduction

My notebooks are full of stories of the way people shared project possibilities with others. Apart from recruiting one's grandchild, like Auntie Loveness, sharing project possibilities could include telling friends about what one learnt in a project, like Tabita told Lukonde, whose husband would not allow her to join the project; tipping friends and neighbours about an income possibility, like when Rose, Joyce and Joanna recruited couples for HIV testing; and sharing information about workshop possibilities with peers, like Precious and Richard did.

In the previous chapter I focused on how such sharing of possibilities was involved in individual trajectories and careers. In this chapter I shift the focus to the relations and positions in which project possibilities are shared and to how the virtue of sharing is enacted in these relations. With a particular focus on lay people who are employed in research organisations, I explore in more detail who shares project possibilities with whom. I explore what relationships and positions are created and maintained in the act of sharing – or keeping – project possibilities, and how medical research projects and organisations figure in these relations and positions.

The main purpose of this chapter is to show how working for a research organisation overlaps both with volunteering for the community as a distinct practice, and with the virtue of sharing in relation to relatives and in patron-client relations. The chapter also shows how these overlapping relations and positions may conflict, and it closes by showing how lay employees may incorporate research organisations into the precarious relations and positions of sharing.

The focus of this chapter is the relations that Auntie Loveness engaged in and the positions that she took up in these relations, including her relation to the research organisation that she worked for as an outreach worker. Auntie Loveness had many years of experience with health and development interventions at the clinic and in various NGOs, including several research projects. She had been among the first members of the Neighbourhood Health Committee when it was established in the mid-1990s and ever since she had been the elected representative in the committee of people in her “zone” of the compound. She was active in the Parent Teacher Association of her grandchildren’s school, where she was involved in decisions about who could get government grants and free uniforms and shoes. Furthermore, she was an elected member of the Ward Development Committee, the lowest tier of local government structures (Chikulo, 2009), and she was sporadically active in a local religious charity group. In other words, she had many different relations to local institutions and people. To make observations about Auntie Loveness’ relations and positions more clear, the chapter will also introduce Elisabeth, another employee in a research organisation, and will point to relations between people introduced in the previous chapters.

Following this introduction the chapter will briefly present sharing as a particular practice that is discussed within anthropological exchange theory and as it is applied as a local term in Lusaka. The first of the three subsequent sections in the chapter describes how project possibilities are shared – or not – in various relations between my interlocutors. The section explores how both egalitarian and hierarchical patron-client relations and positions are created and maintained in these acts of sharing and keeping, where moral obligations and entitlements, but also mistrust and competition, play out. The next section illuminates how talk about and practices of the virtue of sharing may invoke both “the community” and the possibility of being a volunteer. The position as a volunteer is associated with with particular notions of doing good and obligations to share that may, however, conflict with other obligations. The chapter ends with a section that shows how working for a research organisation overlaps with notions of doing good for the community, and how research organisations are incorporated into relations where obligations and entitlements are at stake.

"Sharing" as a local term and transaction

Chatting with people I often heard the phrase *"sharing the little we have"* which was a common English phrase and appeal in relations where people passed on food and lent small amounts of cash to others. But many other kinds of resources could be – and were indeed expected to be – "shared" including project possibilities. Auntie Loveness, for example, first shared information about the Well Woman Project with her granddaughter and her friends. Later, she also arranged for the young women to meet me, as one more new project possibility. Rose shared the possibility to be committee members in the community school with her neighbours and friends, just like Joyce and Joanna shared information about employment opportunities with their friends. They also shared their access to the project doctors.

One day, for example, I passed by Joyce's home just as she had finished cooking. In a common gesture of sharing food with relatives, friends and neighbours, she sent a child with a plate of relish (vegetable sauce) to the landlord, who lived in a room behind the rented room that Joyce stayed in. Whispering, Joyce told me that some years back her landlord had periods that did not end. Joyce had taken her to CIDRZ at the clinic and there they had told them not to waste time and go straight to UTH. *"There they have machines, I tell you, Birgitte, they have machines. They put her in a machine that touched her four places around the waist and it kind of massaged her with light. She almost died, but she is much better now. But she is not grateful. If we are late with the rent, she does not greet us."* Joyce had applied her connection to the CIDRZ project as a means for care and cure (of cancer) that she felt should at least have made her landlord grateful.

In anthropological exchange theory sharing is seen as a fundamental element in social relations. Sahlins saw sharing as an expression of generalised reciprocity, where transactions are "putatively altruistic" as in Malinowski's "pure gift". Such a gift is given without expectations of return, as in sharing a meal among kinsmen (Sahlins, 1974:193-94).[88] Sharing is typically characterised by intimate and face-to-face interaction over time. It is not about keeping balances or calculation. In this way

---

[88] See also Richards (1939:196-197) on how Bemba children learnt to share food as an act that does not require a 'thank you'.

sharing should be seen as distinct from reciprocity (Price, 1975; Woodburn, 1998) and both gift and commodity exchange (Belk, 2009). Sharing does not involve reciprocal obligation and debt as in gift exchange (cf. Mauss, 2002 (1950):50-55), but it still reproduces relations between people (cf. Geissler and Prince, 2010:155)[89] contrary to commodity exchange that reproduces rights to objects.

Writing about different forms of reciprocity Sahlins also pointed to moral norms for exchanges that are relative to the proximity between the people who reciprocate. Thus, sharing, as a particular kind of reciprocity, can be expected to be more common and to be considered more appropriate among kinsmen than among strangers. Between strangers, instead, barter or even theft may be more common, and theft would not necessarily be considered as bad as it would have been if it had taken place between kinsmen. In addition, Sahlins emphasises the well-known observation that having moral norms for exchange does not mean that everybody acquiesces in them (Sahlins, 1974:198ff).

Attention to acts of sharing means attention to the formation and maintenance of relations and to the way moral norms for sharing and for 'doing the right thing' are animated. Among my interlocutors sharing is a virtue, if not a basic moral imperative in many areas of life. As a local (English) term, it can be applied to denote acts that could be classified as acts of either sharing, reciprocity or a kind of commodity exchange, and it is precisely this polyvalence of the term that is put into play when people speak of and practise sharing in Lusaka. In this chapter I will be less concerned with the exact taxonomic differences between sharing and other kinds of reciprocity. Instead, I am interested in the way relations and positions are constituted in exchanges that weave in and out of principles that we can variously associate with sharing, gift or commodity exchange, that may unfold between kinsmen or strangers alike (Shipton, 2007:27-28) and – inspired by Sahlins – that are charged with moral values whether they are

---

[89] Woodburn, in fact, argues that sharing does not create relations, or rather, that sharing creates only egalitarian relations. Individual Hadza, hunter-gatherers in Tanzania, may wish to accumulate, but the demand to share or gamble away what could be accumulated is too strong. Thus, individual Hadza cannot create relationships and alliances with others on the basis of reciprocity. The obligation and demand to share can be seen as a measure against accumulation and inequality, or, indeed, as a political ideology (Woodburn, 1998).

upheld or not. I will explore how the sharing of project possibilities plays out in a web of ongoing exchanges that involve moral obligations and entitlements and where relations and positions are at stake.

The virtue of sharing project possibilities with others

Project possibilities might be shared in a way so that relations and positions are confirmed, whether these relations and positions are egalitarian, as among friends and neighbours like Tabita and Lukonde, or more hierarchical, like Auntie Loveness' relations to her neighbours, which could be understood as patron-client relations.

Patron-client relations, i.e. unequal relations not based on kinship where there is mutual advantage, although not equally distributed (Mair, 1961:315), are often discussed in relation to state and governance (Chabal and Daloz, 1999), but also in relation to donor-funded development projects including HIV and AIDS projects (Swidler, 2009a). Depending on the context, patrons can offer protection or enable access to scarce material resources in return for labour, votes, loyalty or support, even where differences in wealth or access to resources are small. The relation is often personalised and has been described as a "lop-sided friendship" (Pitt-Rovers in Wolf, 1966:16)

Many of Auntie Loveness's relations could be understood in the light of patron-client relations. The predicate "auntie" that many younger people applied when referring to her, and that she liked to use when referring to herself, is borrowed from a vocabulary of kinship and it spoke both of respect for someone senior and of closeness. She saw a possibility to protect and educate her granddaughter and her granddaughter's friends by encouraging them to join the reseach projects which confirmed her care for them. She not only provided for her relatives, but was also a trusted and well-known person around the clinic, in her neighbourhood and in her village outside Lusaka, where people consulted her about many concerns.

Once, I had an appointment with her, but she was very late, and when she arrived she explained that she had had to help some people with a very sick person. Auntie Loveness' phone rang once (a common way to ask to be called) and she asked to borrow my phone. When returning my phone she explained that some people had just been refused at the hospice. She could not understand why, because she had made sure that they got a nicely written referral letter from the medical officer at the clinic. While I prepared some toast for Auntie Loveness her phone rang again and she was told that the person – someone from her home village – had just passed away. She was not even very old. Relatives had called the day before and Auntie Loveness had told them to come to Lusaka. Auntie Loveness looked very tired on our sofa before she got up to return to the clinic so that she could help put the body in the cold room.

Auntie Loveness shared the possibilities that came out of her connections and her engagement in projects in a way that suited her age and position as an older woman, whom others relied on (cf. Baylies, 2002). Different from Tabita and her friends, or Rose, she had a patron position in many relations to younger or less well-connected people. Possibilities stemming from research and other projects were incorporated into acts of sharing and whether this sharing was a gesture of care by a grandmother or a favour in a patron-client relation, it confirmed these relations and positions.

Refusing or keeping project possibilities

Sharing project possibilities might, however, not always be received in the intended manner or they might even be kept. When sharing is not received in the intended manner, or refused, it puts a strain on the relation. Joyce's landlord, for example, whom Joyce had taken to UTH for cancer treatment, had rejected the offer to turn their landlord-tenant relation into something else that might include elements of friendship. She even failed to maintain a minimum level of politeness when she refused to greet Joyce. Joyce disapproved of this, but she still sent a child with a plate of food to her landlord.

Likewise, Precious had been very disappointed with her younger brother, who had not received her help to get into the malaria spraying course that I described in Chapter 5, but she was outright angry (perhaps denoting more distance in the relation) with Mr Chishimba, another volunteer at the clinic. One day as we walked towards her home, Precious told me how she had argued with Mr Chishimba a few days earlier. He had gone to a meeting with the World Food Programme as a representative of the Neighbourhood Health Committee, but was sent back to bring Precious along. He had been told that if she did not join he should not come back. He had not informed her about the meeting in advance, so when he came back from the meeting to get her, she had told him that she was busy. She did not want to go with him because he had not shared the meeting with her. "*He keeps information to himself,*" she said, *"he is only interested in money."* She had quite clearly punished Mr Chishimba for not sharing a project possibility with her, and she accused him of being greedy. Her evaluation of Mr Chishimba's acts resonates with Rose's husband, Mr Lungu's description of people who recruit for HIV testing and who engage in support groups as *"too selfish"*.

Issues of sharing or keeping project possibilities were particularly pertinent in relations between peers who volunteered at the clinic and who were interested in the same project possibilities. One day as I was taking Precious in our car and was about to drop her off near the compound her phone rang. I understood that it was Mercy, another volunteer at the clinic who was calling and Precious confirmed that something had been very tasty. The conversation soon ended (talk time *is* costly). I must have looked puzzled, because Precious began laughing and then explained how Mercy was very happy that she had been selected to work in the coming Child Health Promotion week. It was in fact the current chairman of the Neighbourhood Health Committee who had selected Mercy, but she had assumed that it was Precious, because she had also been present when the selection had been done at the clinic. Mercy had been so happy for the assignment and she had sent Precious a sausage as a thank you.

A month earlier, Precious then told me, Mercy had complained to the leader of the malnutrition programme at the clinic about not being selected for job of monitoring children in the community, but the leader had told her that she did not do her job well and that Precious was much more thorough. He had called Precious and asked her whether she had carried out an assignment of writing lists, which she had. In front of Mercy he then assigned Precious the job of monitoring children in the malnourishment programme and also told her what he had just said to Mercy. She had been quiet, Precious recalled. Precious continued to tell me how she learnt that there was ZMK 40,000 (GBP 5.76) per day for doing this job, but that she went without knowing that there was money. Mercy, however, was just after money. Precious did not like to work with Mercy because she did not work hard and she did not know how to write (Mercy indeed knew how to write, but Precious had completed grade 12 and felt more educated). On another occasion Precious said about Mercy: *"We are together and we share, but I don't trust her."*[90] Sharing project possibilities does not automatically lead to solidarity (cf. Bähre, 2007). Still, Precious had accepted the sausage from Mercy as a gesture of friendship.

In this section, I have traced how relations and positions may be confirmed or recalibrated in the act of sharing project possibilities – or not. Refusing to share or receive a project possibility may create or maintain distance or suspicion in a relation, whether it is a relation to one's brother, one's landlord, or perhaps particularly a relation to one's peers and fellow volunteers at the clinic. In the next section I will show how the virtue of sharing is also articulated in relations between volunteers and "the community".

Having "a heart for the community"

Auntie Loveness often explained her engagement in the clinic and at the school by saying that she had *"a heart for the community"*, which was a common expression among people who were regular volunteers at the clinic. This expression invoked a particular social entity, "the community', as a kind of recipient,[91] and it opened a possibility for assisting the community as a volunteer and at the same time sharing projects from a patron-like position. Elisabeth's trajectory of engagement will

---

[90] This remark fell in connection with a conflict between Precious and Mercy about some sewing machines that members of Precious' women's group had received from an NGO following a sewing course, under the condition that they would be paid off in stages. After two years the women had not managed to repay and Mr Chishimba had called the NGO which told him to take the machines back and sell them to others who could pay. Two years had passed again and now the group had enough money (which Mr Chishimba and Mercy assumed to be from me) to pay for the machines, but Mr Chishimba and Mercy demanded a price as if the machines were new, although they needed servicing.

[91] Remember how Rose in Chapter 5 also invoked 'the community' when she talked about her time as a recruiter for ZEHRP: *"It was good, we were enjoying, the community and me, I appreciated [that] I know more about HIV through ZERPH and they gave us pamphlets so at least my husband [could] go through [them]."*

illuminate how the volunteer position could be enacted and the community could be forged.

Working with passion and invoking the community

Elisabeth was slightly younger than Auntie Loveness and I met her by chance in one of the clinics that I had permission to work in. She was involved in CIDRZ studies as a CAB member. We met regularly during the rest of my stay – either in our house or in her middle-class home, where she lived with her husband and those of her children who had not yet settled with a spouse. She also brought me along several times to the clinic where she volunteered as a VCT counsellor in antenatal care and to the clinic laboratory where the she and the other counsellors processed the rapid HIV and syphilis tests.

Elisabeth used to work as a clerk in one of the para-statals, but when it was closed during the mid-1990s she was just at home. Three years before she lost her job she had had her first child and she used to go to the regular under-5 clinic at one of the district clinics in my study area. One of the nurses that used to attend to her told her about a breastfeeding mothers group that taught women about breastfeeding and how to care for their infants. She asked whether Elizabeth wanted to join as a teacher and Elizabeth agreed: *"You know, when you are used to work it's like you want to go out of the home eight hours and you come back when its evening."* She went for a one-week workshop and then joined the group that taught other women about the goodness of breastfeeding. She was also trained as a child health promoter by Care International:

> *The sister-in-charge had already seen that I had an interest and they were also choosing people from the Neighbourhood Health Committee, from our committees, so already the chairperson of the Neighbourhood Health Committee knew that I was doing the breastfeeding so I was chosen from my unit to attend that course […] we were the first group that trained and so we had a lot of knowledge, they gave us more information, we learned about child health […] so we were like a link between the clinic and* ***the community****, so it was quite interesting and I used to come maybe twice or three times a week just to help out, because most of the people they feel*

> *tired, the nurses, sometimes they are so busy and have other work […] it was quite interesting doing all those things and to help, so later on CIDRZ wanted some people from the community, who knew about voluntary work and who can […] they wanted to involve us in a research study* (My emphasis).

CIDRZ came to the clinic in the early 2000s and they were looking for potential CAB members. Elisabeth was picked for the CAB to meet once a week and to function as a link between the research project and the community. This involved regular meetings with project staff to discuss implementation of projects, organising community meetings to educate the community about research, and contact with a wide network of other community representatives in other project countries.

Apart from her volunteering in the CAB, Elisabeth was a VCT counsellor at the clinic. She had recently resigned from the Neighbourhood Health Committee, but the new Neighbourhood Health Committee members kept calling her for advice. Elisabeth was also a Sunday school teacher and she was attached to a particular project started by the son of American missionaries, who was born here. God had asked him to do something for Zambia, so he had started a project. She had heard about it from a friend and came for the interview without really knowing what the project was about, but now she volunteered to teach children in community schools about the word of God for one week every year. Each volunteer would teach for eight weeks moving from school to school.

Laughing, she told me how her husband had asked her why she was so busy. She had told him that she had only one life and that she had to do all the things she would like to do within that same life. She explained how she worked with passion to help in the community and that there was something spiritual in it for her. She had stopped looking for profit, because that would not take her anywhere. As a CAB member she would get transport reimbursement when she went for meetings, but not a salary. She mentioned how her neighbours did not believe that she did not get anything for her work. They saw her dress well every day and go out, so they assumed that she earned money. She had given up explaining and she just said that she was going to work.

Elisabeth engaged as a volunteer in research and other projects with a sense of contributing her skills, and her (Christian) compassion to help the community. She invoked the community in relation to the clinic and the CAB that she was a member of, and in relation to CIDRZ that needed volunteers.

Unlike patron-client relations that unfolded in homes and neighbourhoods, relations between the volunteers and "the community" were often enacted in particular places and at particular times. In the clinic, various members of the Neighbourhood Health Committee gathered for both regular and special events in the name of health and development. Apart from members of the Neighbourhood Health Committees, volunteers from church groups came to clean the clinics on particular weekdays. Volunteers also gathered in the neighbourhood on campaign days, for example to march for TB or to clean up the environment before the rainy season. Volunteers from the clinic went from door to door and entered homes in the compound when they were out to look for people who were eligible for inclusion into the target group for various projects – typically malnourished children or HIV-positive mothers. In all these cases and places the volunteers related to "the community" in ways that could overlap with patron-client relations and relations to relatives. I will return to this observation, but first I will briefly explain the volunteer position as a composite of several elements.

The volunteer position

The community invoked in the expression *"to have a heart for the community"* and the volunteer position that is often associated with this expression draws from a moral discourse on doing something good for the community and volunteering that has grown out of several particular historical layers in Africa. Preceded by Christian missionaries, including, of course, David Livingstone, one historical layer emphasising enlightenment, charity and humanitarianism emerged in the later years of colonial rule, when the broader welfare and education of the colonised populations became a matter of concern for administrators in the colonial territories who needed healthy workers (Packard, 1997; Schumaker, 2008). In many cases, however, this was more rhetoric than practice (Vaughan, 1991). With urbanisation and budding ideas of independence another layer of volunteering emerged, emphasising unity across differences, that included the formation of (apolitical, conservative and elite) women's groups (Geisler, 1987) and other voluntary associations (Wheeldon, 1969) that have since faded or metamorphosed into other forms, such as labour unions, or subsections of UNIP, the dominant and only legal political party for many years under Kenneth Kaunda. In the mid-1990s the village and neighbourhood health committees were established in Zambia. The establishment of these committees can be linked to the Alma Ata Conference on primary health care in 1978 where community participation was promoted. Borrowing a rhetoric that emphasised solidarity they have also been seen as expressions of the neoliberal development ideology that came with the Structural Adjustment Programmes of the 1980s and 1990s, where volunteering by locals was in fact a cost-saving measure (Janes, 2004; Maes, 2012). During the same decades many international NGOs established themselves in Zambia, forming groups and training people to become volunteers to work for their community. Such training might "convert" participants, especially the educated – but not sufficiently educated – interstitial and precarious elites, who hoped for income and jobs, to really believe in and practise the cause of the training and projects (Nguyen, 2009b; Swidler and Watkins, 2009).

It is in the light of these historical layers of volunteering that both Auntie Loveness' heart for the community and Elisabeth's passion should be interpreted. When Auntie Loveness and her peers at the clinic said that they had a heart for the community, and when the bank employee in the previous chapter said that she trained to become an HIV counsellor to work for her community, they all drew from a discourse of volunteering and doing something good for the community where enlightenment, charity, unity and solidarity were implied to various degrees.

Conflicting obligations

Sharing project possibilities with the community as a volunteer was, however, not always simple. For example Auntie Loveness told me about a man who had once asked her and her friend to pose in a picture with him. He then enclosed the photo in an application for two sewing machines from either Canada or Denmark, she could not remember, but he got four! Auntie Loveness and her friend worked for him for some months, but then he disappeared with the machines – apparently to his farm, where he had built a house. They realised that he had used them to get the sewing machines. Before this happened they had got almost 50 women together who all had paid ZMK 5,000 (GBP 0,72) in commitment fee. Auntie Loveness and her friend had returned the money to all the women and Auntie Loveness pointed out that this was part of the reason why she and her friend were trusted in the community today. Since then they had been looking for sewing machines elsewhere, to continue the work with the women – keeping the project possibility open.

The man with the sewing machines had obviously cheated the women, and Auntie Loveness and her friend had felt responsible in a way so they paid back the commitment fee to the participating women, thereby maintaining their relations with their neighbours and friends and their position as both patrons and as people doing good for the community.

Sometimes, however, it was more complicated. One day as I passed by one of the clinics I found Auntie Loveness and Mrs Mwale at the table in the open malnutrition pavilion, where Mr Kaboi, the head of the Neighbourhood Health Committee sat. Precious and a few other members of the Neighbourhood Health Committee were also there. We exchanged the usual greetings and then there was silence. Usually our greetings would be followed by joking and mutual enquiries about home, but not on that day. Auntie Loveness started addressing me in ChiNyanja, almost aggressively, and the situation turned even more awkward. Gradually, I learnt that three volunteers, two women and a man, had just been caught red-handed stealing Plumpy'nut[92] supplies meant for the malnourished children in the catchment area. Everybody was much taken aback, *"How can you steal from children?" "That means that they have been stealing all along,"* and *"They should not steal, but if they ask they will be given."* I had stumbled into an intense situation where my interlocutors were shocked, but also sad and understanding as the last remark indicates.

---

[92] Plumpy'nut is the registered trademark of a peanut-based paste in a plastic wrapper for treatment of severe acute malnutrition as a ready-to-use therapeutic food (see Redfield, 2012 for a point about how such products promote a certain valuation of life as biological).

This was supported a few days later when I came across Mr Nalwamba. I asked him what had happened since. Looking away, he said that the three volunteers would not be put on the rota list for nutrition again and that they would be given cleaning jobs at the clinic from now on. He added that they were volunteers and that they worked the whole day, and then went home with nothing, so they wanted to bring something for their children. Mr Nalwamba applied a register of compassion and understanding in his version of events. Although the stealing volunteers had done something grossly wrong according to norms for volunteering, they were not very harshly condemned by their fellow volunteers,[93] nor by the clinic. There was an understanding of the volunteers' situation and the conflicting obligations that they were faced with.

In this section I have shown how the virtue of sharing is also actualised in the relation between community and volunteers, but also how both community and the volunteer position might be at stake when obligations conflict. Through trust and suspicion, obligations and entitlements as well as inclusion and exclusion are at stake. In the last sections of this chapter I will explore how the virtues of sharing and doing good for the community are articulated by people who engage as research subjects and as employees in transnational medical research organisations, and how these virtues may also be invoked in workers' relation to research organisations.

Working for a research organisation

Medical research is also about doing something good. This was reflected in the informed consent form that I referred to in Chapter 5, which listed personal satisfaction from being part of a research study that contributed to more knowledge about a particular condition. It was also mirrored in the text on a certificate of participation given to outreach workers upon completion of a trial: "*Your contributions help pave the way for women in your community and all over the world to one day have a safe and effective way of preventing HIV transmission.*"

---

[93] People who are assumed to be thieves can get very serious mob-treatment.

Interestingly, and different from implicit norms in ethical guidelines for medical research and statements by study subjects in Europe (e.g. Hoeyer, 2003), the aspect of doing something good did not appear very important for people who enrolled as study participants, like Tabita and her friends. They did not associate any moral value with their engagement in the project as a research project. I only met one study subject who brought up the scientific purpose of the study that he and his wife had been involved in at the UTH (to test various barrier methods against the sexual transmission of HIV) when we talked about how he had come to enrol in it. He explained his engagement with reference to the way it might benefit others in the future. Besides, he added, being in the study had also helped him remember the importance of taking his ARVs on time every day. He was no longer involved, because since then he had become too busy as the president of an organisation for HIV-positive people, established within one of the large research organisations.

Recruiters, outreach workers and community representatives, on the other hand more often cast their engagement as doing something good for the community, like Elisabeth. They drew from the language of development projects in their work. For example, when I talked with Joyce and Joanna about their volunteering at the clinic, Joanna replied that they *"had the heart of caring for others"* and *"At the clinic we get information. We teach our friends. I have to take any message I have for my friends."* Joanna referred to her friends, and not the community, but – in line with the point about overlaps in this chapter – the word "friends" had a double meaning: it could both refer to the few people that one chose to share more intimate thoughts with, but it could also mean peers in egalitarian development lingo.

Auntie Loveness also saw her work for the research organisation as doing something good for the community, and her case shows how her assignment as an outreach worker in the research project converged with her responsibility as a grandmother at home and her position as a patron in her neighbourhood, when she saw the project as a possibility to guide and protect someone she cared for.

Before I end this section I will briefly add one more observation about the paradox in the way study subjects did not associate any moral value with their engagement in medical research projects, whereas lay staff did. Some staff even scolded study participants for not understanding or respecting the purpose of medical research projects. Mr Kaboi, a long-term volunteer at the clinic, and outreach worker for CIDRZ told me that only 1 in 10 study participants had used the gel: "*I know them, I stay in the community,*" he said. He explained that the women were not asked to come back with the gel applicators at the beginning of the study, but they were just asked whether they had used them or not. Sometimes he had found the applicators lying all over the ground after coming from the clinic. He said to me: *"These women you are teaching, they are not using the gel. They just go there as if it was a salary now."* He not only implied that many women were not committed to the purpose of the research (cf. Saethre and Stadler, 2013), but he also invoked the same image of people joining projects only to gain something that Mr Lungu had expressed and that seemed to be a common suspicion. Such suspicions about greed, selfishness and keeping information could be seen as inverted expressions of the same virtue of sharing in precarious relations.

Closing this chapter on the virtue of sharing in different relations and positions I will return to Auntie Loveness to show how expectations of sharing, obligation and entitlement were also at stake in her relation to – and position in – the research organisation that she had worked for.

"They should show us appreciation"

Auntie Loveness' rented house had two small rooms behind a padlocked door, a covered kitchen area and a small yard. In her front room she had a book case displaying a TV and DVD player (given to her by a friend, after her own had been stolen), teddy bears, flowers, a small souvenir from Denmark, that I had given her earlier, and some greeting cards that she gave me to read: one from her daughter in Europe, and one from an American employee in CIDRZ who regretted that she could not come for Auntie Loveness' kitchen mending party (but she had sent her contribution anyway).[94] Auntie Loveness knew project staff as more than providers of care and as employers.

Once, when Auntie Loveness passed by our house, she had brought an envelope with pictures of herself and others in the company of a Canadian researcher who had worked on environmental health in the area over many years. She and three of her colleagues in the Neighbourhood Health Committee had been invited to attend a 10-day workshop together with professors at UNZA. The Canadian researcher had told the professors to listen to them, because they knew what was really going on. Auntie Loveness had enjoyed it *"sooo much"* and on the final evening the Canadian had thrown a ball and they had *danced*, she said with emphasis. Winking and laughing, Auntie Loveness recalled how she had danced with a certain Frenchman all night. She had enjoyed being recognised as a local authority and as a woman among the very educated in a situation that was not only about work or volunteering.

Back in the present, after the CIDRZ project had ended, Auntie Loveness was waiting for the next study to begin, like so many others. She was in regular contact with staff at CIDRZ and she also worked for them for a few days, as a kind of piecework, to find study subjects who had not come for their results after the end of the study. She complained that she did not receive much for this work and that CIDRZ had said that because of the global credit crunch (this was in early 2009) they could not be paid as well any more. CIDRZ had said that they needed Auntie Loveness and the other outreach workers, but that the outreach workers also needed CIDRZ. Auntie Loveness scoffed at this, but she carried out her assignment anyway. One day, as we were sitting in her relatives' sunken plush chairs waiting for Tabita and her friends, she told me that:

---

[94] Rasing reports from the Copperbelt that mission clergy needing new kitchen utensils organised kitchen mending parties, not to be confused with kitchen parties, in the early 1990s (Rasing, 1999). In Lusaka in the late 2000s, kitchen mending parties appear to be a variant of *chilimba* or rotating saving clubs, where a group of women take turns in hosting a party, and where the invited guests come with a previously agreed amount of cash. They could involve much larger sums – more than a million ZMK – than, for example, the much smaller *chilimba* that Tabita was in with her friends, her mother and her aunt. It is possible that such money is actually spent on mending kitchens among the more affluent, but among the women in the compound, who have taken up this practice, such money were instead spent on school fees and business investments.

> *there is this lady who came […] from Canada. She has offered a scholarship for a two-week advocacy training in Canada. We have been asked to write why we want to go there. Everybody wrote, Mrs Mwale and me, we went to write. They will pick two outreach workers and two CAB members […] Me and Mrs Mwale were supposed to go to Brazil in 2006 to represent the outreach workers but the boss called us and said "Sorry, we are taking this lady here, who is HIV positive." She is also an outreach worker, but it was our turn. Mr Musole already went to Tanzania, then it was supposed to be me and Mrs Mwale, but the boss picked the person she wanted. This time – instead of picking us, she asks us to write something first. She comes and asks everyone to write – she can't pick. Although she knows that they have been successful in their studies because of us, not because of those with degrees! CIDRZ has just opened a very big cancer clinic at UTH, they will need people to work there, they could at least squeeze people in there, in the kitchen or in the offices, but they can't. But some of the Zambians are very greedy, they will put their relatives. I complained to the DHMT [District Health Management Team, a government body] that at least they should give us a job, because we are the old people, Mrs Mwale, Mr Musole and me, we opened the study with them and they should show us appreciation.*

Auntie Loveness' comments give a glimpse of the many more possibilities that projects can offer, such as travel or wage-labour that is not limited by the timeframe of projects, for lay employees in the research projects. Such possibilities do not figure for study participants like Tabita and her friends.

Auntie Loveness understood these possibilities as deeply entangled in different forms of merit and recognition, entitlements and obligations, competition and envy. She was very conscious about her position in the organisation, her position in relation to other volunteers, what she had given, and what she felt that she should be entitled to. She had seniority, experience and connections to offer, which used to be sufficient to get involved in projects, but she worried that this would not be sufficient in relation to the workings of the research organisation.[95] Usually occupying a patron position, she took more of a client position in relation to the research organisation.

---

[95] I helped her organise her CV to submit with the writing for the advocacy course in Canada, and it mainly consisted of a long list of courses, seminars and workshops over the years, but no employment since the late 1980s when she worked as a typist.

At the time of our conversation there were rumours that the next study would pay outreach workers based on performance (number and retention of recruited study subjects) instead of a monthly salary (she had received 60 pin per day (GBP 8.65), three days a week). She was not pleased with this prospect and she was uncertain about her future relation to the organisation. Towards the end of my fieldwork she told me that there had been a meeting at CIDRZ where they had been told that they would still get a monthly salary when the new trial started. Training would begin in October and then they expected the trial to begin the following year. Auntie Loveness was very pleased and mentioned that Mrs Mwale and herself had speculated whether I might have gone to talk to CIDRZ to make them keep the old system of giving a salary. In her efforts to stay abreast of developments she tried to understand the workings of the research organisation through the moral logic of patronage, connections and entitlements, which also included me.

Summary: overlapping relations and positions

So far in this thesis I have shown how lay engagement in transnational medical research projects involves learning how to be in such projects; how variously positioned people may see and seize possibilities that go beyond the particular purpose and duration of the projects; and how one such possibility is to make a career, although uncertain, which involves a particular kind of specialisation.

In this chapter I have explored how engagement in medical research projects is also about the virtue of sharing project possibilities in various relations and positions. The main observation in the chapter is that working for a research organisation overlaps with volunteering for the community and with patron-client relations and that these relations and positions may conflict.

In the course of showing these overlaps and their conflicts I have also shown how both ”the community” and ”the volunteer” may be invoked and enacted in acts of sharing, and how ”the community” might be at stake when sharing goes wrong. I have pointed to the interesting paradox that study participants do not associate their engagement with doing good, while recruiters and outreach workers do. Finally, I have shown how research projects are incorporated into these relations and positions, where obligations and entitlements are not always clear-cut.

In this chapter I have shown how the sharing of project possibilities, as defined in Chapter 5, unfolds in precarious relations and positions. In the next chapter I will explore how doubts about transnational medical research, as opposed to possibilities, play out in such relations and positions.

Vignette VI: Precious

At the district clinic Precious was involved in three different donor-funded programmes at the Mother and Child Health Department (MCH) that had to do with infants and nutrition. One programme was by the World Food Programme, supplying mealie meal, cooking oil, soap and 2kg of beans each month for families with malnourished children. Precious would get ZMK 40,000 (GBP 5.76) per day in the field for this programme. Another was a Lusaka District programme distributing Plumpy'nut to severely malnourished children identified by measuring their upper arm circumference. For each mother to an infant that she brought to the clinic, Precious got ZMK 5,000 (GBP 0.72). And finally, the International Baby Food Action Network (IBFAN) that encouraged breastfeeding. For this job she did not get anything.

In addition, she traced HIV-positive mothers of newborn infants who had not showed up for CIDRZ's prevention of mother to child transmission programme and she entered data on this into the computer at the clinic. She did not earn anything for this job. "I am just a volunteer. I am just helping them since I know, and I have been trained," she said. The people at the clinic had said that maybe in the future they would pay her for this job. Usually, Precious did all four programmes at the same time when she went "in the field".

Precious was active in her church choir, she had contacts in NGOCC and CHD, and she was active in the Neighbourhood Health Committee. She was often asked to carry out various tasks by the staff at the clinic. In return, she was often selected by the sister-in-charge at the clinic to participate in workshops and seminars, because she was good at sharing the knowledge she gained from them. "The sister-in-charge loves me very much because she knows I am a hard worker," she said. She often talked about the value of education and how important it was to have knowledge – especially as women, who could not be sure that their husbands could or would provide for them. She emphasised the necessity and moral virtue of hard work, which she tried to teach the members of the women's group that she had established and also her relatives, including her younger brother, Chibuye.

Chapter 8

Doubting transnational medical research

Introduction

In the previous chapters I have shown how lay people engaged in transnational medical research projects with a variety of hopes, expectations and reservations that were also articulated in relation to many other kinds of projects and interventions. People were often aware of the purpose of medical research projects in general terms, but for most of my interlocutors this purpose was often just another variation among projects in a wider landscape of rare project possibilities, where matters of knowing someone who could connect you, or possibilities of making new connections might be of more relevance than a project's specific purpose and procedures. In other words, many of my interlocutors had learnt to be attentive to possibilities in projects in general – however vague or even ambiguous – and they tried to engage in these projects in order to see what might happen.

In some situations, however, and for some people, elements of medical research projects appeared unsettling and even dangerous. Like possibilities in the projects, concerns or dangers might not be specifically associated with the purpose and procedures of the medical research projects as such. Concerns could include the HIV test, the time limitation of projects, and relations to staff and peers. Other concerns related more specifically to the projects as transnational medical research projects.

In this chapter I will examine situations in trajectories of engagement where transnational medical research projects were somehow set apart from other projects and interventions by the risk or the danger that was associated with them as medical research projects. I explore who had what kinds of doubts and how they were articulated and dealt with. I show that when medical research projects were set apart from other projects as risky or even malevolent they focused on matters of blood and the body and on the transnational aspect of their organisation in various ways. Finally, I will show how such reservations and concerns were variously incorporated into people's pragmatic engagement with the projects as sources of possibility.

Concerns with the combination of blood, body, health (including HIV) and medical research by resourceful foreign organisations were expressed in different idioms, each invoking particular, but also overlapping, images of what medical research is about and how it may render bodies, health and relations vulnerable. Here, I have grouped these idioms of concern into three clusters that organise this chapter: Satanism, foreign medical researchers and risks to health.

Satanism appeared as a concern for Tabita and her friends at some point and Rose's husband, Mr Lungu, also referred to Satanism in relation to his wife's engagement in a project. With these two examples, I explore how Satanism, an idiom of concern with a rich heritage of anthropological studies of witchcraft and rumour, appeared, and how it was variously handled as an obstacle and applied as a legitimate deflection. A second idiom of concern revolved around an image of resourceful foreign medical researchers exploiting poor Zambians to their own advantage. This idiom draws from contemporary political discourse and was articulated by Charles and Precious in particular situations that I will examine. A third idiom of concern was risk to body and health by the medical procedures and products on trial. This concern, drawing from biomedical discourse, was often pragmatically dealt with by conditional engagement, which I will illuminate with reference to Elisabeth's and Precious' trajectories of engagement.

I will briefly explore the meanings and historical contexts of the three idioms of concern and their overlaps as I have listed them above, but more than their meanings and roots I will pay attention to the particular situations and relations in which they were articulated and dealt with in order to highlight their pragmatic incorporation into lay engagement.

Satanism

Once, interviewing in Tabita's home, I asked if Emelda and Albetina had ever considered dropping out of the project that they had been in. Emelda explained:

> *Okay, when you start with CIDRZ and you want to stop they didn't allow to stop – more especially if it was after they stopped enrolling, because when you stop there will be a gap. When you get pregnant while in the study you don't stop, but you just stop using gel if you were on gel, and stop using condom if you were on condom. Many people wanted to stop, and I also wanted to stop, because when drawing blood I used to feel dizzy and bad.*[96]

Emelda referred to a time when rumours of Satanism intensified at some point after the CIDRZ microbicide trial had begun. Lukonde explained:

> *The reason why people said that they were Satanists, is because when you go to the clinic at CIDRZ they will interview you and draw blood for testing and after that you will be given money for transport and for your time that you have spent there. When you go home you tell your friends that they drew blood and gave money. People think that the money is in exchange with the blood.*

Albetina added: "*Some people were saying that they were Satanists because they were drawing three bottles of blood and so when drawing it felt like sucking and the rumour was sent out in the neighbourhood that they were selling the blood. Many people got scared."*

Money for blood is a core element in stories about Satanists. Another element is big, often black, cars. Estina heard about the CIDRZ project from her neighbour, Auntie Loveness, and she knew that her friend, Tabita, had enrolled already. She hesitated, though: *"It was my first time hearing about 'project, project' – I didn't know much about it. But some people were saying that they are Satanists. They were saying that 'what do they do with the big ambulance for donating blood?' But I finally joined."* I

---

[96] Besides, she mentioned that she had lost a lot of blood when giving birth five months earlier, and she speculated that this might have contributed to the dizziness that she felt when blood was drawn from her. She operated with parallel idioms for understanding the link between having lost blood and her feeling of dizziness.

asked Estina whether it had been difficult to make the decision to join, but she laughed and said *"No, no, it wasn't difficult […] the only problem was that I didn't want to be followed at home with the vehicle if I missed the appointment and I will get so many questions from neighbours."* Tabita added:

> *Yes, there was a rumour about that because people that were in the study were chased with a vehicle to their homes if they didn't keep their appointment, and the other thing was that when testing you, they draw about three bottles of blood, and people say that they suck blood, and when you tell your friends that are not in the study that they draw three bottles of blood … they think that they suck your blood.*

This particular research project did not employ ambulances for blood donation,[97] but if study subjects did not appear for their monthly check-up at the clinic, they would be visited at home by project staff in a project car. A big, new car was one of the most visible and most desired signs of wealth in Lusaka and when such cars on rare occasions inched into the compounds, tilting and wobbling, they usually attracted attention.

Satanism is associated with blood, cars and money. Joyce and Joanna mentioned how people had talked about the project logo on the T-shirts that came from the project: *"Eee, they have come from the Satanists, see their T-shirt, a man and a woman wearing red things,*[98] *that symbol is showing that … Satanism"[whispering].* Joyce had then asked people: *"A Satanist living in one room? Not having mealie meal?"* implying that Satanists could not be as poor as her. Satanism was also associated with HIV.[99] Joyce and Joanna recruited many women for the 035 study, because "*We used to go in the same community where we are already well known,*" but they had problems in the beginning. "*People would say that we have HIV – 'otherwise, why do they like to speak*

---

[97] Estina probably referred to the fleet of white estate cars with logos for the Zambia National Blood Transfusion Service, Ministry of Health, donated by the Global Fund and PEPFAR that was parked at the UTH and that was used for 'outreach' activities to encourage and collect blood donations.

[98] The logo of the CIDRZ Well Woman and Partner Study consisted of the semi-profiles of a woman and a man smiling at each other. The man's white shirt had a red collar and the woman's green headscarf and dress had red edges. Another research project, The Zambia/South Africa TB and AIDS Reduction Project (ZAMSTAR), had a five-pointed star as its logo, which some people associated with a pentagram and Satanism (personal communication with researcher).

[99] See Bawa Yamba for observations about the association between HIV and witchcraft in rural Zambia (1997).

about it so much?' But they came to see that we and our families were still well, so they could see that we were not victims of Satanism."

Satanists, witches and *Banyama*

Talk of Satanism is a fairly recent phenomenon in Zambia, first recorded in the 1990s.[100] Stories vary, but like witches, Satanists are generally known to be able to fly, walk through walls, and cause harm and death at a distance. Satanists are particular, however, in their cosmopolitan attire. They are rich, they own many desirable consumer goods and they drive black cars that are fabricated in the underworld (Udelhoven and The Fingers of Thomas, 2009). Among the differences between witchcraft and Satanism is that Satanism is seen as an international phenomenon and not as an "African science". Satanist spirits are regarded as much more powerful and far-reaching than older spirits (or 'demons' in more recent Christian terminology) that may possess people to harm their close relatives or neighbours. Satanists do not necessarily do their work on people that they know. Satanism is seen to be a particularly urban phenomenon (ibid.).

Apart from certain shared features with ideas of witchcraft, Satanism is closely linked in attributions to older images of *Banyama* (White, 1993a) or stories of "vampire men" (White, 1995:236) that spread from Tanganyika to Northern and Southern Rhodesia and into parts of Belgian Congo from the 1930s until the mid-1950s. The *Banyama* abducted innocent people and sold their blood to Europeans, who needed African blood for medication and modern medicines (Musambachime, 1988). They would move in red vehicles[101] and lure people into them by magic (Udelhoven, 2008). Strangers, chiefs, European doctors, fat administrators,

---

[100] The figure of Satan is, of course, not new (Gordon, 2012), but Satanism as a named denomination is new. A popular (Pentecostal) explanation for the strength of Satanism in Zambia is that the devil is very angry with the country, because the first act of the newly elected (born again) President Chiluba in 1991 was to declare Zambia a Christian nation (Gifford, 1998).

[101] It is interesting to note the shift in colour from red to black cars. The colours red, black and white have been analysed in terms of their possible symbolic meanings in southern and central Africa (e.g. Jacobson-Widding, 1979; Turner, 1966), and it would be interesting to explore contemporary associations and applications of these colours (the Ministry of Health's cars for collecting blood for blood transfusion were white – the colour of many 'project' cars). Still, like the logos of research projects, the colour of cars probably only gets ascribed significance at all in particularly precarious situations and relations.

prospectors, surveyors and tourists were highly suspected of being *Banyama*, but Roman Catholic priests and African broadcasters were also suspected (Musambachime, 1988). Contemporary rumours of Satanism also involve blood and money as central elements, and they may involve priests, doctors, and medical researchers, whether foreign or Zambian. Such rumours are powerful enough to mobilise both people and the government.

The power of rumour

On several occasions rumours of Satanism have mobilised people in Lusaka to smash windows and burn down property of churches accused of practising Satanism, which in turn has compelled the government to ban at least one church from operating in Zambia. For example, the Universal Church of the Kingdom of God, an otherwise very successful Brazilian Pentecostal Church in southern Africa, was barred from operating in Zambia by the government in 1998 because of alleged "unchristian practices", a decision that was ruled against by the Zambian High Court (Freston, 2005).

In 2003 the same Church built the giant cathedral at the Southern Roundabout, that several of my interlocutors pointed out to me. They had all heard variations of stories about buckets full of human blood kept behind the altar that were used in rites to enrich the devil worshippers.[102] Reacting to public accusations of Satanism, and a series of attacks on the building, the government banned the Church again in 2005 (Reuters, 2005). The same Church, with its promise of instant riches, was associated with Satanism in northern South Africa (Comaroff and Comaroff, 1999:291), where it figured in the report of a provincial Government Committee of Inquiry into Witchcraft Violence and Ritual Murders.[103]

Satanism is not only associated with particular Churches. Schools, especially boarding schools, are seen as recruitment places for Satanism (Udelhoven and The Fingers of Thomas, 2009) and clinics as sites of blood-sucking. 'Delivered' Satanists

---

[102] Compare with Maxwell's studies (1998; 2005) of the way people engage in the Pentecostalist prosperity/security gospel in Zimbabwe and van Wyk's description of how the Universal Church of the Kingdom of God is an anomaly among already very diverse Pentecostal Churches (2011).

[103] For an analysis of issues that increasingly compel the post-colonial state to intervene in witchcraft accusations in Cameroon, see Chapter 6 in Geschiere (1997).

state in their widely published and retold testimonies that ‘most clinics are run by Satanists to gain supplies of blood’ (Udelhoven and The Fingers of Thomas, 2009). A director of district health in Lusaka once observed that any new research or health programme would be suspected of being Satanic (Bond and Shanaube, 2005). The link between the increase in cases of HIV and the huge amounts of money available to address the epidemic also attracts suspicion (ibid.)

Rumours that involve blood and bodies in relation to (foreign or outside) interventions in Africa have attracted considerable academic interest and interpretation. In Luise White’s extensive writing about the *Banyama* and their association with firemen in particular, she suggests that the *Banyama* stories’ focus on blood was a way of speaking of money and its circulation, since the stories could be seen as idioms for debating a new phenomenon coming with the Europeans, i.e. labour, and particularly its (unfair) remuneration in specific relationships.[104] This debate took the form of accusations of those who were not seen as participating in the circulation of money as they should, and of rumour (White, 1993b). White understands rumours as debates that mirrored local concerns with modernity in its broadest materialisations: foreigners, the religious practice of Catholic mass, labour, remuneration; each retelling of the stories foregrounding what might be different and dangerous in each setting (ibid.:171).

Rumours can be seen as expressions of concern or unease that other forms of expression or discourse do not have a vocabulary for (cf. Englund, 2006:192) and they often relate to health-related interventions. Schumaker interprets stories about a magic river snake causing death in the Copperbelt as a comment on colonial intervention to control malaria (Schumaker, 2008). Saethre and Stadler interpret rumours about the selling of blood in connection with a microbicide trial in South Africa as more than critical commentaries on exploitation, but as expressions of *“deep personal, economic and social anxieties that suffuse the postcolonial world”* (Saethre

---

[104] Money is indeed ambivalent (e.g. Comaroff and Comaroff, 1999). Once, when Rose had received money from me for a bag she had crocheted she brought the cash to her pastor in UCZ to make him pray over the money to find out whether I was a Satanist. Rose told me that everybody prays over their money to break any connection to the devil “*because you cannot know where they come from*” (cf. Meyer, 2003).

and Stadler, 2013:108). Feldman-Savelsberg and colleagues interpret rumours of sterilisation in connection with child immunisation in Cameroon as a local response to global and national projects (Feldman-Savelsberg et al., 2000).

Specifically with regard to rumours of blood-stealing, Fairhead and colleagues argue that such rumours in connection with medical research in The Gambia are not an indigenous idiom of resistance, nor a meta-commentary on colonial oppression, millennial capitalism or exploitative techno-science (e.g. Comaroff and Comaroff, 2000). They argue that overarching notions such as “rumour” or “the occult” obscure the specificity of blood-stealing which has particular local meanings that are better explored as a matter of economy in a more concrete sense than the Comaroffs use the term. Fairhead and colleagues offer a reading of blood-stealing rumours where the relation between economy and body is not so much metaphoric as it is substantive. Blood-stealing is an interpretation of a field of (unjust) transactions, rather than an idiom for understanding societal change. Thus, stories of blood-stealing cannot be countered by improving communication or demystifying research procedures (e.g. by visiting laboratories), but is a matter of real economic disparities and reasonable exchanges that research ethics and communication efforts risk overlooking (Fairhead et al., 2006b).

It is possible to interpret rumours about Satanism in Lusaka as specific debates about the circulation and accumulation of money and commodities in a globalizing world, or as a phenomenon that makes more connections, and builds on many more layers of interpretation, than that (e.g. White, 2000). Such assertions would, however, need much more careful analysis than I am able to offer here. Instead, inspired by Geissler (2005) who shows how the shifting intensity of rumours of blood-stealing *kachinja* in Kenya is linked to shifts in the texture of relations between particular people in particular situations, I will turn attention to the way the idiom of Satanism was applied in particular relations and situations in Lusaka.

Satanism as obstacle and excuse?

As mentioned in the introduction there had been many rumours about Satanism at some point during Tabita and her friend’s engagement in the Well Woman Study.

Albetina's parents had told her to stop at the time when the rumours intensified, but she did not. Estina had laughed at my question about whether it had been difficult to join because of the Satanism rumours, and said that it had not been difficult. Emelda had not dropped out of the project even though she felt dizzy and suspected Satanism. She explained the importance of staying in the project with language that she had learned in the project ("*there will be a gap*"). The association between the project and Satanism could have been very unsettling, but why did it not really seem to have become an issue for the young women?

Their lack of concern could perhaps be interpreted with reference to the interrelation between timing, different knowledges, and relations. The rumour intensified some time after the young women had enrolled, by which time they had already learnt about the project through their own engagement. Had the rumour been intense at the time of their enrolment, they might have hesitated more. With regard to knowledges, I suggest that their knowledge about the project and how to be in it was more relevant for them than the knowledge about the project that Satanism stories conferred. Here, these two kinds of knowledge should, of course, not be understood as a matter of the difference between fact and imagination, but as two equally valid versions of what medical research projects are really about. Finally, the kind of knowledge that rumours of Satanism carried forth did not involve relations for the young women that were more relevant for them in terms of possibilities than their relations to project staff – unless they were in a situation where they had to choose between relations, like Lukonde, whose husband did not allow her to join with reference to Satanism.

Rumours of Satanism, and the relations they were articulated in, appeared more as an obstacle to the young women than as a relevant image of what medical research was about. The young women handled this obstacle and its appearance in relation to partners, parents and neighbours, who might disapprove of their engagement, by not always telling others about their engagement at first (later, most partners and parents came to know) and by keeping appointments at the clinic to avoid visits by project cars.

At the time of my fieldwork rumours of Satanism were not very intense, but Satanism was still actualised in particular situations. Mr Lungu, for example, apparently together with many other men, referred to Satanism when they refused to get tested for HIV and to join projects at the clinic. Without subtracting from the very real and powerful concerns that images of Satanism reflect, their invocations of Satanism in these particular situations and relations could be seen as legitimate 'excuses' or deflections of unwanted confrontations. Women might of course also refuse to be tested for HIV, like Malala, who opened this thesis, but it seemed that women did not so often refer to Satanism in this connection.

Foreign medical researchers

I met Charles, a young man in his mid-thirties, in one of the clinics where he was working on the agenda for a meeting in the CAB of the CIDRZ microbicide trial. I invited him to come by our house and a few days later he turned up. Referring to himself as a bridge between the researchers and the community he was sometimes unsure about how to balance this bridging and for this reason he found it interesting to discuss my observations. Charles became a regular visitor with us, and I also visited him in his home where he showed me a book that he had borrowed from another volunteer at the clinic entitled *What if everything you thought you knew about AIDS was wrong?* by prominent American denialist Christine Maggiore (1996). As one of the organisers, Charles brought me along to the community meeting about medical research that I briefly described in Chapter 4. Charles' trajectory of engagement in medical research had begun when he got fired from his job in sales and marketing in the 1990s. He became a volunteer and since then he had been involved in various NGOs and also trained as a psychosocial worker. His trajectory of engagement in projects, and in research projects in particular, was similar to Richard's career in many ways. He told me how he knew many people and that many people had seen his potential. He added that there were also always some who did not share information, as I discussed in the previous chapter, and how that blocked him. "*Information is power,*" he said, and he sought it broadly and in many relations.

Charles knew a certain man that he thought I should meet, given my topic of research. One afternoon, he took me to one of the narrow and busy streets in the grid of the central business district. A Zambian-Indian[105] shop owner had transformed the front part of his large hardware shop into a display room and library of newspaper cuttings and printed websites, photocopied with a note on source and date, and piled neatly in separate boxes on shelf after shelf, so he could hand them out for free. He had several messages, but one of the more prominent ones was to share evidence that HIV had been manufactured in the USA to harm Africa and Africans. The front of the store was made into an exhibition of posters, and enlarged and laminated newspaper articles and compilations of news. Important lines of the text were underlined, with titles such as "Origin of AIDS scares cowards" (*Weekly Angel*,[106] 31 May–6 June 2007) and "AIDS 'made to kill blacks'" which apparently was a typed compilation of text from the Kenyan newspaper, *The Standard*; the Zambian newspaper *The Post*; and *Herald Sun*, an Australian tabloid, quoting the Kenyan Nobel Prize winner, Wangari Maathai, for saying that AIDS is a tool created by scientists for biological warfare. On the front of his shop he had put a large banner with his own text and emphases:

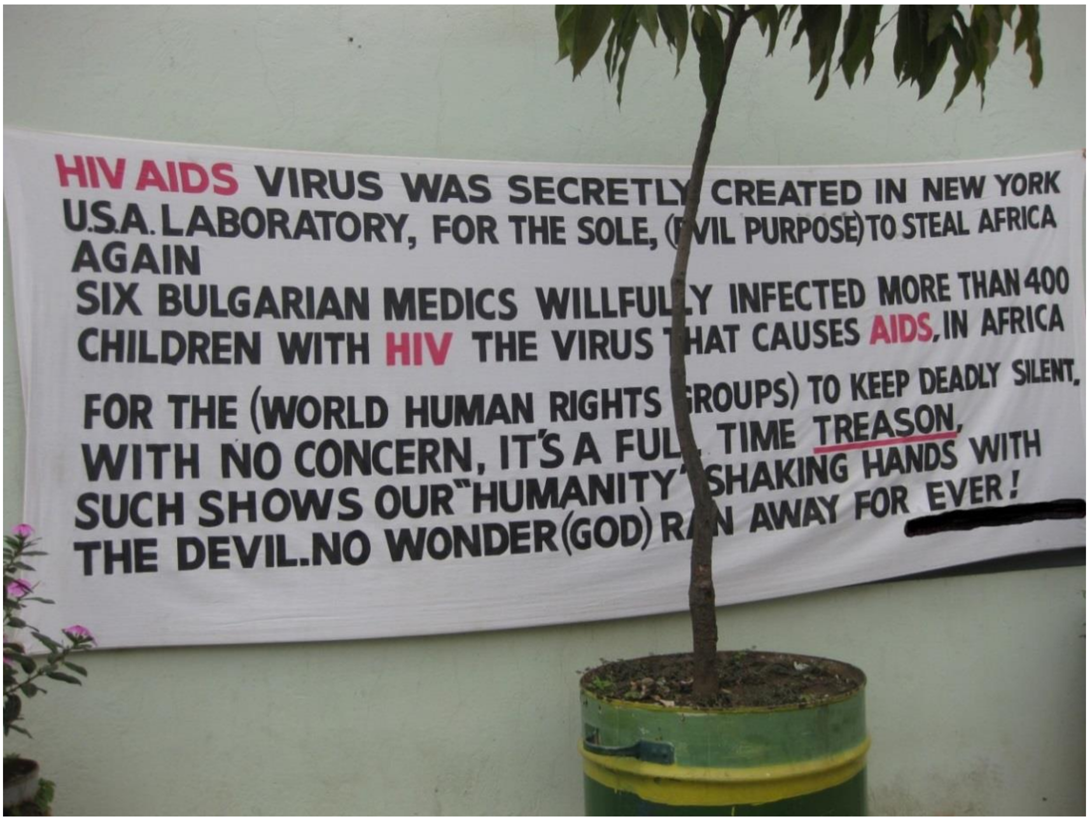
> *HIV AIDS virus was secretly created in New York U.S.A laboratory, for the sole, (evil purpose) to steal Africa again. Six Bulgarian medics wilfully infected more than 400 children with HIV, the virus that causes AIDS, in Africa.*[107] *For the (World Human Rights Groups) to keep deadly silent, with no concern, it's a full time treason, such shows our 'humanity' shaking hands with the Devil. No wonder (God) ran away forever.* (Original emphasis and colours)

---

[105] The shop owner's middle name suggested Indian descent. In ChiNyanja slang, Indians, often associated with owning businesses, are called *amwenye* (pl.) which literally means 'aliens' or 'strangers'. The shop owner occupied an ambivalent position in a long history of inequalities.

[106] Small local newspaper.

[107] The banner refers to a widely published scandal in Libya in 1998, where a Palestinian medical intern and five Bulgarian nurses were sentenced to death for infecting well over 400 children with HIV. In 2007, a year before my fieldwork, they were extradited to Bulgaria and freed. The French President Sarkozy and the EU acted as intermediaries and rumours of cash and arms transactions accompanied the deal.



The owner of the shop was a gentle and forthcoming man, who had many observations to share with me about the HIV virus and about the medical research that had produced it. He supported his observations with newspaper articles and other written statements by doctors, including a flow chart that describes the “United States Special Virus Cancer Program” by the Pentagon and the National Institute of Health to develop HIV.[108] The shop owner was also keen to tell me about the importance of vegan nutrition, the need to cultivate more local plants and vegetables, and children’s need to grow up with both their mother and their father. Before we left his shop the owner walked up and down his aisles to carefully select a pile of photocopies to give me, so I could write about the ideas he wanted to share. He also suggested that I gather a group of women, for a start, to discuss the documentation that he had just given me. He would be pleased to supply more, when I was ready.

The manufacturing of the HIV virus in the USA and transnational medical research projects in Lusaka might not appear to be related, but perhaps it was for

---

[108] Boyd Graves, the American lawyer, who claimed to have found the flow chart in US research archives, filed a lawsuit in 1998 against the American President on the basis of the flow chart.

Charles who took me to meet the shop owner. References to laboratories, HIV and the involvement of African bodies might be among the links that connected the two phenomena for Charles. Afterwards, Charles asked me what I thought of meeting the shop owner. I thanked him for taking me, but I did not reflect on the shop owner's messages as Charles had perhaps hoped for. Earlier, Charles had told me how he spent quite a lot of time in the CAB office with the project computers (that was among the perks of being a CAB member) searching on the internet for information about HIV and AIDS. It seemed that Charles was open to several versions, not only of what HIV was about, but also how it had come to Africa and how it might be linked to wider relations in the world. He was curious and he pursued his interest in several different relations, including ours. So did Precious.

Body hunters

Precious came to Lusaka from the Copperbelt in the mid-1990s. She was one among 10 children of a headmaster and a vice-headmaster at a public school and she had completed grade 12 the year before coming to Lusaka. She was married to an unlicensed taxi driver and they had a son. She did not have a formal job, but was very active as a choir leader in her church; as a trainer, and trainer of trainers in catering, tailoring and tie & dye[109] for various religious NGOs; and as a very busy volunteer at the local district clinic.

One afternoon in Precious' small living room I was with Precious, Rose and Martha "foot-foot" (because she always walked so fast), who were members of the women's group that Precious led. We talked about where the group could sell more of the crocheted bags that some of the members had started producing, largely because I had placed an order for bags to take to Denmark to sell for them after a presentation that I had been invited to give there.

Without any further occasion, Precious pulled out some papers from her bulky bag, and came over to show them to me. They were a photocopy of a chapter in a book entitled *The Body Hunters* by Sonia Shah, an investigative journalist, with a foreword by John le Carré, and published in New York in 2006. The book critically

---

[109] A technique for dyeing cloth.

examines examples of “Big Pharma”’s medical research for the benefit of the industry and rich consumers in the global North at the expense of poor people in the global South. Profoundly surprised, I told her that I already knew of this book. She looked at me expectantly and I told her that I had read the book in Copenhagen before coming to Zambia. I asked her where she got it from, but she smiled and looked away. She said she got it from the computer, but I observed that it looked more like a photocopy and not a printout. She smiled again and then showed me that the chapter mentioned the same doctor that had once enrolled her in the endoscopy study. I asked her whether I could get a copy and she hesitated. She asked *“What if someone asks you where you got it from and you say Precious?”* She mentioned something about a friend abroad: *“I have connections ...”* The same friend gave her a pamphlet with a very good explanation of medical research. They had shown the pamphlet to another well-known volunteer at the clinic, who worked closely with CIDRZ and they had asked for an explanation. “*Tomorrow,*” he had said, but when they returned he had said that the pamphlet had been misplaced. Now Precious got agitated:

> *In the future I will join the CAB, because they don’t stand up for us. They should provoke researchers much more. How can they just come here and use us just because we are poor? The Zimbabweans said no to this, but here it was accepted.*[110] *And then they start insulting us! They should not get an advantage of our poverty. They are even contributing to our poverty by giving us 20,000 because that does not make us do anything new. They will say* ‘Zambians are weak, just give them 20,000 and you’ll get what you want.’ *I don’t know how Zambians permit them to come and do this work? And soon the doctor will become a Professor just because of us. They should teach us skills so we can work. They should say,* ‘Let’s try to help them where they are weak.’ *But most people will join the researchers ... here is a researcher offering everything. A family who has lost a child will say* ‘Let’s join the researchers.’ *I don’t want anybody touching my body any more. I am never going to join research again.*

---

[110] Precious probably refers to a passage in the chapter from Shah’s book that describes how an American doctor had tried to set up medical research on HIV in Zimbabwe, but that it had not been possible in the early 1990s to discuss sero-prevalence and vaccines there. Zambian officials, however, had been more forthcoming to his inquiries in their search for international assistance with the HIV pandemic. Shah quotes the doctor as saying: ”Anything is fair game. This is a special thing about Zambians – and the fact that they can only say yes” (Shah, 2006:28).

There is very much to say about this situation, but what I want to highlight here is how Precious expressed her concern about foreign researchers in an idiom that draws from political and development discourse. She blamed Zambians with influence for letting foreigners exploit poor Zambians without influence – a scenario framed in terms of both national and international politics and power relations.

Precious did not question the purpose of transnational medical research, but that it took place in Zambia. She cast researchers as people coming from outside, who 'use' poor Zambians for their own personal benefit (becoming professors) and she cast herself as a citizen of Zambia and a representative of the poor making claims on what foreign and resourceful researchers should be doing for poor study subjects. Invoking a scenario of global inequalities, she chided the researchers for the little money they gave people. She did not call for access to medicines and other 'classic' benefits from ethical codes of conduct for medical research and neither did she speak of abstract 'rights'. Instead, she wanted the researchers to teach people skills so they could work.

This expectation repeated what Precious said to me the first time I met her at one of the clinics. We had been sent to get drinks for a meeting and I briefly introduced myself and told her about my project. I asked her whether there had been many researchers at the clinic, but she only responded with a smile. Walking on, she said that *"The researchers come and take our information and then leave, and leave us where we are, without empowering us."* I asked what she meant by empowering and she explained that someone who was a volunteer for them would not have a job afterwards, when they had left. That someone would even have difficulties getting things to do in the clinic as a volunteer, because they would be told that they work for the researchers.

At that time she talked about the way researchers "took information" and she added that another problem was the envy and competition between volunteers at the clinic that I referred to in the chapters about Joyce and Joanna and about Auntie Loveness. That afternoon, however, in the company of her fellow volunteers, she emphasised how foreign researchers took something from poor Zambians that was of value to the researchers without giving anything useful back.

Precious framed her critique of transnational medical research as an unequal relationship between foreigners and poor Zambians, a relationship that has deep historical precedents in colonial times, and one in which elite Zambians have been complicit. Her sense of being exploited resonates with developments in the early 1990s when President Chiluba took over from President Kaunda. He privatised many state assets, enabling rampant corruption among the elites and deepening poverty among 'ordinary' Zambians, which was exacerbated by the Structural Adjustment Programme that Zambia underwent at the same time. Precious' outburst should not just be seen as fear of exploitation in terms of not getting the right price, but as reverberating with insecurities and frustrations about many-layered and enduring unequal relations between more or less privileged Zambians and between Zambia and richer countries.

Political discourse as idiom of educated critique?

The concern with transnational medical research conducted in countries like Zambia has attracted much academic and popular critique, as I describe in the introduction to this thesis. This critique often draws from a political discourse of global inequalities. Precious, Charles and the shop owner also drew from such a political discourse that resonated with many other local and historically rooted images of the marginalised position of Africa and Africans in the world (see Ferguson, 2006), sometimes taking the shape of conspiracy theory (see Niehaus and Jonsson, 2005). Charles introducing me to the shop owner and Precious bringing out *The Body Hunters* book to show it to me could be seen as part of their extended debate and search for answers to questions about what transnational medical research (and HIV) is really about, just like rumours of Satanism could be seen as expressions of such a debate.

The mediums for questioning were, however, quite different. Charles' book by the AIDS denialist, and his searches on the internet, the shop owner's newspaper clippings and photocopies, and Precious' printout from a book bore witness to a certain level of education and access to written and electronic media. It was not that mastering the medium's political discourse excluded other idioms of concern, such as

Satanism,[111] but it seemed that the educated had more idioms available to them to express their concerns with transnational medical research in Zambia.

Among most of my interlocutors, concerns with transnational medical research relations were rarely expressed in an the idiom that drew from political discourse.[112] In fact, Precious, and to a certain extent Charles, were the only ones who articulated concerns in this idiom. I never heard them refer to having discussions about medical research in this idiom with others – which is certainly not to say that they did not – but here I will have to limit my interpretation of their articulation of this idiom as it was expressed in relation to me, another foreign researcher.

Charles introducing the shop owner to me and Precious' outburst about foreign researchers were perhaps a test of me and my intentions and of my connections to other researchers in Lusaka. In Precious' living room, in the company of Rose and Martha foot-foot, the situation that I described above developed into an enquiry about my research project, and my purposes of being a researcher (see Chapter 3). Perhaps Precious wanted to show her neighbours that she knew a lot about medical research and that she could challenge researchers, including me. Her outburst was general, embracing all transnational medical research that enrolled poor Zambians, but her critique was perhaps no less a way of assessing whether she could trust me in particular.

Risk to health

The last idiom of concern that I will discuss is the idiom of risk to health. I will explore when and in what relations risks to health figured as a relevant concern and how was it

---

[111] Charles told me many stories of what went on in the church at the Southern Roundabout, and how people in Zambia who wanted to get rich had started moving to Tanzania to obtain human hearts in order to prosper.

[112] But see comments by anonymous, often ex-pat Zambians to a series of Zambian online newspaper reports about the unsuccessful results of a large multi-country phase III clinical trial of a microbicide in southern Zambia, e.g. http://www.lusakatimes.com/?p=22619, http://www.lusakatimes.com/?p=22619, http://www.lusakatimes.com/?p=22399. The comments evoked a range of adverse images of the Zambian government, medical researchers, the pharmaceutical industry and the West in general. The particular and aggressive language of these comments should, of course, be interpreted in the light of the medium that they appeared in: a website where contributors could remain anonymous, except for their user names.

dealt with. I will begin by returning to Elisabeth, the volunteer who worked with passion for the community, whom I introduced in the previous chapter. Like so many others among my interlocutors, she did not appear to ascribe much importance to the difference between engaging in research and other projects, except when it came to her own body.

Elisabeth's concern with the product

When she was first appointed a CAB member, Elisabeth also decided to enrol as a participant in the one-year preparation study for the subsequent 'real' trial (the preparation study did not test any medicines, but produced various baseline data). She joined to get all the health check-ups – including the HIV test. The CIDRZ staff had emphasised that people working with HIV issues should know their own status, so Elisabeth first went to get tested at New Start, an HIV testing organisation funded by USAID, before she went through with the test at CIDRZ. The check-ups and test in the preparation study helped her to know her own health, because they included tests that were not available in government clinics and which she would otherwise have had to pay for in town or somewhere else. Later, I learnt that Elisabeth suffered from diabetes and that she saved on the strips to measure her blood sugar, because they were so expensive (so she tested her blood sugar less often than she was advised to). She considered the regular check-ups during the project a way of monitoring her health :

> *So my mind used to tell me I am OK health-wise and it helped me to be strong in my mind to share easily with other people about the goodness of joining the study. But when 035 [the real study] started I was a bit nervous because of the new products that came in because you know it is a research and in research studies you don't know about those products, whether they are safe, whether they are infected or not. So applying those products were like, I felt 'no'…. joining the study I didn't feel safe, so many things went through my mind, 'suppose it doesn't work, suppose they have side-effects on me' – already having seen that my body is OK.*

Elisabeth distinguished very clearly between the preparation study and the subsequent *real* study and she declined to join the latter, where she would have had to apply the products on trial. She found it too risky to her health, so she continued her involvement as a community representative, but not as a research subject. Unfortunately, I was not quick enough to catch her remark *"whether they are infected or not",* and to probe whether she considered the possibility that the gels were made to harm study subjects. This fear that medical products might be infected or otherwise harmful was a recurrent and widespread concern, not only in Zambia.[113] Whether she had such doubts or not, the point here is that Elisabeth referred to concerns about risks to her health and her body, and not to Satanism or foreign medical researchers, as the reason for not joining as a research subject when the real trial began. So did Precious, but in a slightly different way.

Precious studying the researchers

Precious had been involved in three different medical research projects over the years as a study participant and recruiter. She had begun her involvement in medical research as a recruiter for ZEHRP, when ZEHRP was still in Chawama.[114] She heard about ZEHRP from her teacher in the women's group where she had been picked to work as a trainer in tie & dye (the trainer was a member of the Top 10 at the Neighbourhood Health Committee). She recruited couples for VCT, but it was not an easy job, because people asked so many questions and challenged her. Some even threw stones at her and accused her of being a Satanist. She kept on trying to educate people, *"but they kept on saying so many things and I was not sure about the research".*

A few years later some people came to the house where she stayed with her husband and some other relatives in the compound: *"They were saying that 'We are picking a group of people that would be helping them.' They did not say that it was a study [...] they were moving around the compound, yes, they were educating us on the*

---

[113] Around the beginning of my fieldwork a rumour circulated that the injectable contraceptive Depo Provera was contaminated by HIV. See http://www.irinnews.org/printreport.aspx?reportid=76565.

[114] This account is put together from several different interviews and conversations. The same events were not always relayed in the same way and chronology was often opaque and sometimes even contradictory. The account may not be true to actual events but it is true to Precious' exploratory and ambiguous relation to the projects she was involved in and the critical stance she wanted to convey to me.

doctor's programme. After they had explained to me, I said I would join." On a different occasion she said: *"I joined the study because I wanted to know what they were doing and what they were after. I just joined the study to study them" (laughing).* The study was run by a foreign doctor, who had worked in the area for some years. Precious was not sure what the study was about, but it involved taking pills every day.[115]

Participants were also asked to collect stools and urine. Precious asked the workers many questions about why they should take the medicine and why they should collect the stools and urine. The workers explained that it was for the project and that they would get money for it (about ZMK 40,000 (GBP 5.77) per monthly visit to get tablets). They kept encouraging Precious, but she could not manage. When the doctor himself came to the area Precious asked him many questions. That was how she learnt that it was a study to find out whether the pills could control severe diarrhoea: *"I was not taking the medicine, I was not [laughing] … me I was scared of taking tablets when I asked him about that rod".*

The study also entailed being anesthetised and having an endoscopy down the throat in a theatre at UTH every six months. Precious had asked the researchers whether they would use the same endoscope for all the people in the project. They had told her that they did not change it, but that they cleaned it well in between patients. She had not been convinced that it was safe, so she had dropped out of the project after six months when she was called to go to UTH for the endoscopy. The call to go for the endoscopy, and not the informed consent procedure, was the decisive point in time for Precious, just like the HIV test became the occasion to decide whether to join or not for the young women in Chapter 4. Precious talked about how she refused to join as long as she did not know what was going on. Some people had TB, others died, some were HIV positive, and she did not know whether they were sick before they joined the study or whether this happened because of the study.

She and her family had moved out of the project's catchment area around the same time, from a one-roomed house to something bigger in the compound, but the research assistants, who were Zambians but not from the compound, had followed

---

[115] This doctor and his team at the UTH have conducted several different health research projects over the years, working from UTH, from a district clinic in Lusaka and from a mission clinic.

her. They had told her that she should go, and about the advantages of going, but she did not go. On an earlier occasion, Precious had told me how her sister had also enrolled in the study and how she was suddenly found HIV positive. Precious took her sister and brother-in-law to the other research organisation that Precious knew, ZEHRP, for couple counselling and testing, and there her sister had tested positive, but her in-law had tested negative. Precious suspected that it was the endoscope that had given her sister HIV, because it had not been properly sterilised.

At the time she was recruited for this study Precious had first and foremost been looking for information about HIV/AIDS, she explained. When she met the doctor, she had asked him a lot of questions about HIV, but he had told her that he was not a specialist in that field and she had then looked for other programmes about HIV/AIDS. That was when she heard about CIDRZ, and she joined the organisation as a recruiter. She was asked to enrol in the study herself, but she refused. She did not want to risk that a male doctor would examine her inside and because she was scared that the researchers might be Satanists, who would sell her blood.

However, after they had been invited to visit CIDRZ's central laboratory in Kalingalinga compound and seen what happened to the blood samples, she had been convinced that there was no Satanism.[116] Still, she was worried about the blood testing, because she was anaemic, and felt that she did not have enough blood to give the researchers. Nevertheless, as a recruiter she encouraged other people to join until CIDRZ told her that she had to join herself, if she wanted to continue being a recruiter. She was worried about the medicine that she might have to take, if she joined, which might not be good for her, and besides she was concerned with the purpose of running the study in Zambia:

---

[116] This visit was organised by the research organisation. Laboratories also addressed the public in other ways, for example over a week in April 2009 when the Biomedical Society of Zambia celebrated the annual Laboratory Awareness Day under the theme "Accurate diagnosis for proper health care". According to the programme published in the *Daily Mail* on 18 April 2009 the aim was to "*sensitize the public on the importance of biomedical science in the delivery of quality health care and correct patient management. As professionals, we believe that the role of the medical laboratory is not well understood, hence it is not fully appreciated in the manner that it should".* The programme included several radio and TV broadcasts, an interdenominational prayer service, a march by laboratory professionals, a football tournament and a dinner dance, as well as an awards presentation in a conference centre.

> *I had a lot in my mind, I was thinking a lot … I don't like these researchers because I would think, 'Why are they testing us? Why are they doing their test on us instead of doing it in their own country?' But they decided to come to us. Is it because we are poor, or what? I was thinking a lot. Instead, I decided not to get any money from there and then quit. It is better I suffer than getting money from them.*

Later she mentioned that even though many of the staff at CIDRZ were Zambian, the "owners", i.e. the people whom she saw as leaders of the organisation, were not. This contributed to her unease with the work of the organisation. Precious decided not to sign the informed consent form at CIDRZ.

Risk to health as a legitimate reservation?

Precious and Elisabeth were both experienced volunteers in the district clinics and involved over several years in different transnational medical research projects. Both had reservations about being study subjects in medical research projects, however, and both justified their reservations by referring to concerns about risk to their health. They attributed this risk, however, to different aspects of research interventions, i.e. products, procedures and the transnational character of research projects. Elisabeth spoke of concern with the particular product on trial, thereby placing risk or uncertainty in the same aspect of medical research projects as researchers do, and as it is made explicit in informed consent forms.[117] Precious also had reservations about submitting her body to medical research, but she variously situated her doubts about risk to her health in several different aspects of research, i.e. the product on trial (the pills), the procedures (the endoscopy, and the blood taking), and the organisation of the studies (the fact that foreigners were involved).

The difference in the way Elisabeth and Precious situated risk could be understood in the context of their relations to the research organisation and its staff. Elisabeth had been involved in the same organisation for a long time and she knew the people that ran he project in Lusaka very well, both at the clinics and in the head office. Besides, in her capacity as a CAB member, Elisabeth had travelled extensively to

---

[117] This concern might have been enhanced by her being diabetic.

the other African countries involved in the previous study and also to the USA. She participated in regular conference calls with CAB members and other staff from the other countries in the study. She personally knew people working in the same research organisation in other countries in Africa and in the States. She knew the project staff and the organisation in a very different way than most others.

Precious, on the other hand, had no particular or enduring relation to any research organisation. Apart from her own intermittent contact with research projects and their staff, she learnt about medical research from books and other indirect sources. She was not part of a research organisation in the same way as Elisabeth. Here, I suggest that when people apply the idiom of concern that refers to risks to their body and their health it may depend on their relation to the research organisation and its staff whether they situate – and limit – this risk in the product on trial, or place it more widely in the procedures applied and the organisation as such.

Joyce and Joanna's concerns about risk to their health can illuminate the point about risk and relations to research organisations further. In Chapter 6 I showed how they found it wrong that study subjects in the trial conducted by the marketing bureau were not offered condoms to use with the microbicide. They were not concerned with the safety of the product on trial, but they found it wrong that they would not get condoms as in the CIDRZ study that they had been part of. In the CIDRZ study they had not been concerned about the product on trial either. On the contrary, it seems that they had felt safer health wise in the trial than if they had not been in the trial. After the ZEHRP study to test a vaginal gel had ended Joanna talked about how she joined the CIDRZ study: *"I was interested because I knew already my body was good and I knew a lot about the study."* She joined CIDRZ as a study subject "*and every month when I go for my monthly check-up I was tested for urine to see if I was pregnant. I was also tested to see that my cervix is ok, due to the medicine that they were using. They didn't want any risk on my body."* It seemed that Joanna felt safer in the study because of the regular check-ups and in spite of the unknown product on trial. A similar observation was made in a study from a clinical trial of microbicides in South Africa (Saethre and Stadler, 2013:113). When study subjects feel taken care of by staff and organisations that they know and trust, like Joanna, the sense of risk to health and body is lessened,[118] (and so are rumours about blood stealing, like it happened for Tabita and her friends in Chapter 4). Consenting to medical research may have more to do with trust in research organisations, as already observed by Molyneux and colleagues (2005a), but doubts may remain concerning the particular product on trial, like it happened for Elisabeth.

Whether people doubt the product on trial or wider aspects of the medical research project, risk to health is an apolitical and legitimate idiom of concern in the context and language of medical research, and in relations to research staff. It allows people to engage in the projects in a conditional way, like Elisabeth did and like Precious also did. In spite of her many doubts and reservations, Precious kept recruiting for the research projects. This observation is the impetus of the last section in this chapter.

Pragmatic engagements

In the excerpt from Precious' outburst above she declared her intention of joining the CAB, so she could challenge the researchers much more (not only the researchers in the project that had organized a CAB, it seemed). Instead of challenging researchers by applying the idiom of Satanism, she talked about applying a means of action that belonged to a political sphere and that would cast her as a critical citizen, or even an activist and representative of the community - but she never did. Instead, she kept encouraging others to join the research projects.

Likewise, Charles seemed to be open for different interpretations about what medical research by foreign researchers was really about, but as a CAB member he educated the community about the phases of clinical trials and their purpose of developing new medicines at the same time. Elisabeth was not sure about the product on trial, but she limited her doubt to the match between the product and her own health, and not the health of others.

---

[118] Trusting the research organisation and its staff does not mean that study participants necessarily apply the products on trial. Instead of associating such lack of compliance with notions of risk, it might also be understood as a matter of inconvenience with the products.

Precious, Charles and Elisabeth dealt with their doubts in a pragmatic way. This was not only a matter of keeping possibilities open for themselves in the research organisations, but also a matter of fulfilling obligations in relations to others. I asked Precious how she could continue encouraging others to join in spite of her own doubts and she explained that people in projects learned many important things. She referred to what appears to be the most legitimate reason for engaging in research projects in Lusaka. Besides, having a patron-like position and being a volunteer at the clinic she could not *not* share access to research projects without compromising her relations to friends and neighbours, as I showed in the previous chapter.

Summary: Doubts and possibilities

In this chapter I have explored three different idioms of concern that express doubts specifically about the research component of medical research projects. I have briefly reflected on the contents of the idioms and then focused on the situations and relations that they were expressed in to understand how such expressions of doubt figured in various trajectories of engagement.

Satanism as an idiom of concern was well-known and latent in the compound. It can be interpreted as a particular way of debating the fair circulation of money in a globalizing world in a language that could make many more connections between elements of concern than political discourse. A few of my interlocutors were forbidden to enrol with reference to Satanism, like Lukonde, or blocked from new possibilities, like Rose, when her husband refused to join her for couple counselling. Mostly, however, the idiom of Satanism and the relations that it was expressed in seemed to be of little consequence for my interlocutors, as it would close a project possibility that they wanted to keep open.

The idiom of concern that pointed to the transnational nature of medical research projects and foreigners' use of poor Zambians was much less articulated among my interlocutors. A few of my interlocutors told me how they had asked researchers about the products on trial and why it was conducted in Zambia, like Malala in the introduction to the thesis, who had asked the doctor in charge of the study whether they had tried the vaccine on people in other countries. Framing her question with reference to other countries drew from a critical discourse that invoked Zambia as a country among other countries and it indicated her (educated) attention to inequalities between countries. It seems that this idiom that drew from a critical political discourse was more available and relevant for people of a different level of education and social position than was common in the compound. With various degrees of suspicion, Charles and Precious also expressed doubts in this idiom – but not in the company of medical researchers. Instead, they seemed to explore my insights and opinions – being another foreign researcher - about the transnational nature of medical research in Zambia.

The idiom of concern that referred to risk to health could embrace concerns with many aspects of research, not just the product on trial. Contrary to the idiom of concern that expressed doubts about foreign researchers, concern with risk to health was an apolitical and legitimate idiom of concern in the context of medical research projects that enabled people to engage in such projects in a conditional way.

The same people could apply several different idioms of concern depending on the situation and relations that they were part of, like Precious, who variously referred to her earlier concerns with Satanism (she was no longer concerned with Satanism, but with others associating her with it), her present concern with the fact that research was carried out by foreign researchers among poor Zambians and with possible risks to her health. Doubts, reservations and concerns were, however, often incorporated into people's continued pragmatic engagement with the projects in order to keep possibilities stemming from the research organisations open and in order to fulfil obligations to others as patrons, relatives and providers.

Vignette VII: Continuing trajectories

Several years after I left Lusaka my phone rang. It was Precious saying, "Hello boss, how are you?" Apart from a few letters that I had sent to her through friends going to Lusaka, we hadn't been in touch since I left. I had heard that she had given birth to another baby, just like me, but that was all I knew. It was such a nice surprise to hear her voice again, and we began talking simultaneously, both trying to outsmart the delay on the phone. Precious had to repeat several times that she had found my number to inform me that Mr Walubi, her husband, had divorced her that March and that their last-born had passed away the previous October. She was now back at school somewhere outside Lusaka studying human resources.

The latest news from Zambia is that Precious has married again and that she and her new husband have moved to another city in the country. Her husband works at the district clinic as a counsellor and she is also there. They have bought a plot of land and plan to build on it next year and then open an orphanage. Her brother, Chibuye, works at a filling station in Lusaka and he is now "keeping" his two sisters, who are "pushing papers" to get teaching positions. Auntie Loveness is still very active as a volunteer at the clinic.

Chapter 9

Concluding observations

In this thesis I have explored dimensions in lay engagement in publicly-funded transnational medical research projects in Lusaka around 2008–09 in the context of uncertain daily lives and as part of a wider history of interventions and landscape of health and social development projects.

With an empirical and analytical starting point in trajectories of engagement in transnational medical research, and other projects by people with situated concerns and aspirations, I argue that lay engagement is about learning a pragmatic attentiveness to possibilities and dangers in such projects that may stretch beyond both the purpose and the timeframe of the individual medical research project. Both the process of learning how to be in such projects, and the realisation of possibilities and dangers associated with them, are deeply embedded in – sometimes precarious – relations, not only with project staff, but also with partners, relatives, friends, neighbours and peers, animated by the virtue and obligation of sharing.

This argument has emerged from exploring how lay people engage in transnational medical research projects. In the following I will summarise my observations about the dimensions of lay engagement and how I have tried to capture them analytically. Next, I will more explicitly address the two other overall questions that have guided my enquiry and that have run as undercurrents through the previous chapters so far: what does lay people's engagement make transnational medical research, and who do lay people become themselves, as they engage?

Building on my argument that lay engagement is about learning how to pay attention to possibilities and dangers in transnational medical research projects, I will continue by specifying how such possibilities and dangers can be seen as associated with three analytically distinct aspects of such projects: as providing health care; as development projects; and as medical research, respectively. I suggest that many of my interlocutors handled these sometimes contradictory aspects pragmatically in an effort to keep possibilities open and to meet their various obligations. Next, picking up from Chapter 5 on the realisation of project possibilities, I will consider how my interlocutors' ways of engaging in and across the three aspects of transnational medical research projects were reflected in (changes in) the ways that they talked about themselves in relation to the projects and in relation to others. Finally, I will close the thesis by briefly considering how my observations could have implications for the conduct of transnational medical research.

Dimensions in lay engagement

The first dimension in lay engagement that I have examined is knowledge. I have distinguished between 'knowing about' medical research and 'knowing how to' engage in medical research. Study subjects, who may have rather vague and even ambiguous conceptions of what transnational medical research projects entail at first, soon learn about the purpose and procedures of such research. More importantly, they also learn how to engage in such projects through project routines and interaction with staff. Learning is embedded in caring relations that also help to overcome ambiguities associated with the project.

The second dimension that I have explored is the differentiated attentiveness to the variety of possibilities that emerge from the projects. I have defined possibilities broadly as positive, open-ended, and both material and immaterial. They embrace new knowledge in both senses defined in the previous chapter, cash, piecework, employment, care, recognition, medicine and connections. Thus, transnational medical research projects – together with other kinds of projects – make possibilities available that are not necessarily related to the stated purposes and benefits of the projects, but in terms of their organisation, implementation and the relations they entail. Certain project possibilities may appear more relevant to some people than to others, and I discuss how many seem more relevant for women than for many men in Lusaka.

One of the possibilities that my interlocutors pursued was the possibility of making a career in medical research projects, which is quite a feat, given their relative scarcity and time limitation. I have devoted a whole chapter to this possibility to highlight a third dimension in lay engagement, which is accumulation of experience into a specialisation that traverses knowing about medical research, knowing how to engage in it, knowing the wider landscape of projects and being attentive to relations with both project staff and peers.

A fourth dimension of lay engagement is articulations of the virtue of sharing. Project possibilities were shared – or kept – in relations with partners, relatives, friends, neighbours and peers in overlapping positions that could be framed as part of patron-client relations, volunteer-community relations and project staff-community relations. Flows, tensions and conflicts between these precarious relations and positions also embraced transnational medical research organisations.

A final dimension is articulations of doubt in different idioms of concern about transnational medical research projects that were often invoked in relation to the specific products and procedures of the research projects. I have shown how my interlocutors tended to embrace these aspects of the projects not as a matter of rational weighing of possibilities against doubts, but as co-existing aspects of the projects that were handled pragmatically in order to keep possibilities open and to meet obligations in daily lives, characterised by insecurity, uncertainty and contingency.

Aspects of transnational medical research projects

In this thesis I have decentred the scientific purpose of transnational medical research projects to focus on lay people’s engagement in them. It has been a starting point – indeed a point – that people engage in transnational medical research projects as part of a wider landscape of health and social development projects. It was only in the last chapter about doubts that I followed my interlocutors in setting transnational medical research projects apart from other kinds of projects. I also showed how they dealt pragmatically with their doubts. In this section I will briefly describe in a slightly different way how transnational medical research projects figure in the wider landscape of projects by making an analytical distinction between three overlapping aspects of medical research projects. By separating these three aspects I can also show more clearly how people engage pragmatically in them.

A first aspect of transnational medical research projects is their resemblance to health and development projects that offer various services. People learning how to engage in medical research projects soon come to appreciate possibilities, such as access to free medicines, cash and perhaps food, the regular health checks, and the attention and reassurance of continued inclusion into 'something bigger' that comes with enrolment, which may even embrace their partner and children. In this way, transnational medical research projects appear similar to other health and development projects, often funded by foreign donors. Framed as a health project, the transnational character and the apparent resources of the projects is not considered a danger. Access to this aspect of transnational medical research projects is often embedded in caring relations to relatives, patrons or project employees – sometimes all in the same person.

A second aspect of transnational medical research projects is their infrastructure in terms of their organisation, implementation, specialised language, etc. that they share with most other health and development projects, that are also often funded by outside donors. People who have learnt to relate to this aspect of projects see possibilities for piecework, employment, new knowledge, certificates and new contacts in medical research projects and other projects, and a few manage to specialise particularly in transnational medical research projects. Framed as development projects the transnational character of the projects is not considered a danger, but the way that the resources of the projects are applied may be considered problematic. Involvement in this aspect of transnational medical research is often embedded in – sometimes precarious - relations to patrons, peers and project staff.

A third aspect of transnational medical research projects is the research element itself, with its particular purpose of creating new knowledge, and its products and procedures, that may appear similar to health services in many ways (i.e. blood-taking, health checks), but that differs because of the unknown effects of the products, the number of blood tests and the quantity drawn, and the discipline involved in enrolment. The research aspect was unlike any other kind of health and development project and in this context the transnational set-up and obvious resources of the research organisations could appear disquieting, when the experimental element was mediated and articulated in relations outside the projects to relatives and neighbours, when it was informed by books, newspapers, web-sites and other 'educated' sources, and when it was communicated by the research organisations themselves.

It has been observed many times before that medical research projects are often understood as health care (Molyneux et al., 2005b; Reynolds et al., 2013). It has also been shown that people engage in medical research projects in terms of job opportunities (Geissler, Forthcoming; Prince, 2013b). Likewise, it has been shown that medical research projects give rise to rumours and other expressions of concern (Geissler, 2005; Stadler and Saethre, 2010). What this thesis shows is that the same people may operate with all three, sometimes contradictory, aspects of the research projects, if they have learnt how to, and that they variously invoke or set them aside depending on the relations and sense of possibility that people associate with the projects. This pragmatic engagement with medical research projects is not only a matter of knowledge, education or accumulated experience, but also a matter of being ready for possibilities, and of efforts to meet various obligations in daily lives that are profoundly uncertain.

Projects, selves and others

In the problem statement of this thesis I pointed to the way many studies of transnational medical research have explored the formation of subjectivities within the context the political economy and procedures of globalizing health science. I referred to studies that suggest how research subjects become experimental subjects in industry-funded genomics research, and to studies that point to lay people becoming a part of new collectives emerging around transnational medical research projects for public health purposes, thus producing new subjectivities and identities in relation to transnational research organisations, rather than to the state. When transnational medical research is considered part of wider trends of experimentality in governance, both HIV-positive people and medical research subjects may be cast as 'victims' (Nguyen, 2009a; Rottenburg, 2009).

In this section I will specify how my study may contribute to these observations. How does engagement in transnational medical research influence people's images of themselves? Who do they become in relation to the projects, and how might this reverberate in other relations? Ways of thinking about oneself and performing oneself can be variously captured with concepts such as subjectivity, identity, self-image or personhood that each come with a rich heritage of definitions and theoretical implications. Rather than discussing the applicability of these concepts to my empirical observations, I will remain close to my ethnographic data, like the RLI scholars who studied wider social changes. Taking as a starting point ethnographic attention to how people talked about their own engagement, I will focus on positions in relations to others in my brief examination of how engagement in transnational medical research projects might have implications for the way lay people think about and 'perform' themselves.

First, it is necessary to emphasize that interventions and projects initiated outside Zambia that variously involve lay people and their bodies have unfolded in Zambia for over a century. In this light transnational medical research projects are not a new phenomenon in Zambia, and they should be seen as part of a long history of social change in contemporary Africa that influences the way people see themselves.

It is also necessary to begin by saying that many did not see relevant possibilities or relations in the projects, and that they did not engage. Men might in fact confirm aspects of their masculine identity by not engaging. Second, people who engaged in the projects might do so fleetingly, like Rose, who first had her identity as a pieceworker confirmed in her engagement and later felt recognised in the project for a moment that ended before she had wanted it to. Her engagement seemed to have left a memory only. Third, there is great diversity in the way people who engage for a longer period talk about their engagement. This diversity partly has to do with the different aspects of the projects that I described in the previous section.

People who engage for a longer time than Rose did may not talk about themselves in a new way or think about themselves as anyone in particular in relation to the project, like Tabita and her friends, who mainly engaged with the care aspect of the project. They did not talk about themselves as study subjects or volunteers, but observations of the young women's loyalty towards the project and the way they felt cared for by the project staff suggest that their engagement could be understood in terms of learning to engage as clients (cf. Meinert, 2009b; Whyte et al., 2013) or beneficiaries. This position might somehow echo their position at home as dependent and "kept", while at the same time it challenged this position, because they regularly had a purpose for leaving home to be part of 'something bigger'. Still, the project did not take up much of their daily lives, and they did not turn their engagement in the project into a more lasting identity, reflected in relations with others.

The few who managed to engage in medical research projects for a longer period, and particularly in development aspect of projects such as infrastructure, might refer to themselves as volunteers, invoking an identity as someone doing something good for the community, or as employed peer educators, or as community representatives, like Joyce and Joanna, Elisabeth and Auntie Loveness. Such positions often reverberated with similar positions in other projects, and it might become a more explicit part of people's identity and status that was reflected in their relations with others as patrons and 'pillars of society'.

Finally, a very few of my interlocutors engaged in the projects selectively or conditionally. This was the case for people who related more explicitly to the aspect of the projects that had to do with research procedures – perhaps it is more accurate to say that they engaged *in spite* of the research aspect of the projects. They seemed to move between engaging in different aspects of the projects depending on their concerns about the projects and the relations that they were part of. Good examples are Elisabeth, and particularly Precious. They both shared project possibilities with others like volunteers and employees, but they did not engage as study subjects themselves. On the contrary, Precious could take up a position as a critical citizen or activist, questioning the organisation of transnational medical research and how it benefited poor Zambians, but I did not hear about her pursuing this position outside conversations with me.

Medical research projects can be seen as consisting of several different aspects and people engage with them pragmatically – thus articulating or enhancing latent aspects of themselves in different ways. The relation between research projects, selves and others was diverse and processual.

Implications for the implementation of transnational medical research

I end this thesis by briefly reflecting on what my argument might mean for the implementation of transnational medical research in sub-Saharan Africa and other low-income settings.

It is, of course, vital to understand transnational medical research as embedded in larger political and economic structures that condition the unequal distribution of possibilities, like Crane has observed (2013). Continued attention to such conditioning is essential, as well as continued attention to developments in the formulations of codes of research ethics.

At the level of implementation of transnational medical research, however, where inequalities and ethical codes are negotiated in practical engagement with variously positioned others every day, it might be relevant to understand how unequal relations may not necessarily be considered a problem by lay people, but rather a precondition for relations, as many of my interlocutors did. Instead of inequality, the important aspect of the relation is, instead, the obligation to share in acknowledgement of the relation, the persons and the wider community involved in the sharing.

Would it be possible to bring this insight about inequality and obligation to organisational levels beyond the implementing level? Obligation in acknowledgement of others is a different starting point for approaching issues of inequality than assumptions, ideals and rhetoric of partnership that implies partnership. Sharing in unequal relations is a complicated process, however, which demands continuous and careful attention to possibilities and relations, as well as recognition of one's positions and obligations in a web of relations. For research organisations and their staff this entails a radical readiness to recognise oneself and one's projects in all the aspects that I described above as part of a particular history and landscape of interventions in a particular locality, including the obligations that come with such a position. This is what many foreign and Zambian researchers and research assistants already do in their daily efforts and interactions with study subjects, peer educators, outreach workers, community representatives, research assistants and colleagues, but it is perhaps less acknowledged - and supported - as an integral part of the particular kind of knowledge production that we know as scientific.

References

ABADIE, R. 2010. *The Professional Guinea Pig: Big Pharma and the Risky World of Human Subjects,* Durham: Duke University Press.

AGAMBEN, G. 1998. *Homo Sacer: Sovereign Power and Bare Life,* Stanford: Stanford University Press.

ANDERSON, W. 2009. From subjugated knowledge to conjugated subjects: science and globalisation, or postcolonial studies of science? *Postcolonial Studies,* 12**,** 389-400.

ANGELL, M. 1997. The Ethics of Clinical Research in the Third World. *New England Journal of Medicine,* 337**,** 847-849.

APPELBAUM, P. S., ROTH, L. H., LIDZ, C. W., BENSON, P. & WINSLADE, W. 1987. False Hopes and Best Data: Consent to Research and the Therapeutic Misconception. *The Hastings Center Report,* 17**,** 20-24.

ARNOLD, D. (ed.) 1996. *Warm Climates and Western Medicine: The Emergence of Tropical Medicine 1500-1900,* Amsterdam: Rodopi.

BARRETT, M. 2004. *Paths to Adulthood. Freedom, Belonging and Temporalities in Mbunda Biographies from Western Zambia.* PhD, Uppsala University.

BAYLIES, C. 2002. HIV/AIDS and older women in Zambia: concern for self, worry over daughters, towers of strength. *Third World Quarterly,* 23**,** 351-375.

BAYLIES, C., CHABALA, T. & MKANDAWIRE, F. 2000. AIDS in Kanyama: contested sexual practice and the gendered dynamics of community interventions. *In:* BAYLIES, C. & BUJRA, J. (eds.) *AIDS, Sexuality and Gender in Africa. Collective Strategies and struggles in Tanzania and Zambia.* 95-112. New York: Routledge.

BEECHER, H. K. 1966. Ethics and Clinical Research. *New England Journal of Medicine,* 274**,** 1354-1360.

BELK, R. 2009. Sharing. *Journal of Consumer Research,* 36**,** 715-734.

BIEHL, J. 2001. Vita. *Social Text,* 19**,** 131.

BINKA, F. 2005. Editorial: North-South research collaborations: a move towards a true partnership? *Tropical Medicine & International Health,* 10**,** 207-209.

BOND, V. 2006. Stigma When There Is No Other Option: Understanding How Poverty Fuels Discrimination toward People Living with HIV in Zambia. *In:* GILLESPIE, S. (ed.) *AIDS, Poverty, and Hunger: Challenges and Responses. Highlights of the International Conference on HIV/AIDS and Food and Nutrition Security, Durban, South Africa, April 14–16, 2005.* 181-197. Washington, D.C.: International Food Policy Research Institute.

BOND, V. & SHANAUBE, K. 2005. Making Sense of Satanist Accusations in Zambia: A Modern Witchhunt against Exploitation and Disorder? Paper presented at the conference 'Locating the Field: The Ethnography of Medical Research in Africa', December 4-9, Kilifi, Kenya.

BOND, V. A. 2010. 'It is not an easy decision on HIV, especially in Zambia': opting for silence, limited disclosure and implicit understanding to retain a wider identity. *AIDS Care,* 22**,** 6-13.

BONNEUIL, C. 2000. Development as Experiment: Science and State Building in Late Colonial and Postcolonial Africa, 1930-1970. *Osiris,* 15**,** 258-281.

BOOTH, K. M. 2004. *Local Women, Global Science. Fighting AIDS in Kenya,* Bloomington: Indiana University Press.

BRIVES, C. 2013. Identifying ontologies in a clinical trial. *Social Studies of Science,* 43**,** 397-416.

BURDETTE, M. M. 1988. *Zambia: between two worlds,* Boulder: Westview Press.

BÄHRE, E. 2007. Reluctant solidarity. Death, urban poverty and neighbourly assistance in South Africa. *Ethnography,* 8**,** 33-59.

CAHN, P. S. 2008. CONSUMING CLASS: Multilevel Marketers in Neoliberal Mexico. *Cultural Anthropology,* 23**,** 429-452.

CANDEA, M. 2007. Arbitrary locations: in defence of the bounded field-site. *Journal of the Royal Anthropological Institute,* 13**,** 167-184.

CENTRAL STATISTICAL OFFICE 2007. Demographic and Health Survey. Central Statistical Office. Lusaka.

CENTRAL STATISTICAL OFFICE 2008. Labour Force Survey. Central Statistical Office. Lusaka.

CHABAL, P. & DALOZ, J. P. 1999. *Africa works, disorder as political instrument,* Oxford: International African Institute in association with James Currey.

CHIKULO, B. 2009. Local Governance Reforms in Zambia: A Review. *Commonwealth Journal of Local Governance***,** 98-106.

CIOMS 2002. International Ethical Guidelines for Biomedical Research Involving Human Subjects. Council of International Organizations of Medical Sciences. Geneva. http://www.cioms.ch/publications/layout_guide2002.pdf

COLE, S. M. & HOON, P. N. 2013. Piecework (Ganyu) as an Indicator of Household Vulnerability in Rural Zambia. *Ecology of Food and Nutrition,* 52**,** 407-426.

COLEMAN, S. & COLLINS, P. 2006. 'Being...Where?' Performing Fields on Shifting Grounds. *In:* COLEMAN, S. & COLLINS, P. (eds.) *Locating the Field. Space, Place and Context in Anthropology.* 1-21. Oxford: Berg.

COLSON, E. 2010. The Social History of an Epidemic: HIV/AIDS in Gwembe Valley, Zambia, 1982-2004. *In:* DILGER, H. & LUIG, U. (eds.) *Morality, Hope and Grief.* 127-147. New York: Berghahn Books.

COMAROFF, J. 1993. The Diseased Heart of Africa. Medicine, Colonialism and the Black Body. *In:* LINDENBAUM, S. & LOCK, M. (eds.) *Knowledge, Power and Practice. The Anthropology of Medicine and Everyday Life.* 305-329. Berkeley and Los Angeles: University of California Press.

COMAROFF, J. 2007. Beyond Bare Life: AIDS, (Bio)Politics, and the Neoliberal Order. *Public Culture,* 19**,** 197-219.

COMAROFF, J. & COMAROFF, J. 2000. Millenial Capitalism: First Thougths on a Second Coming. *Public Culture,* 12**,** 291-343.

COMAROFF, J. & COMAROFF, J. L. 1999. Occult economies and the violence of abstraction: notes from the South African postcolony. *American Ethnologist,* 26**,** 279-303.

COOPER, M. 2008. Experimental Labour—Offshoring Clinical Trials to China. *East Asian Science, Technology and Society: an International Journal,* 2**,** 73-92.

CRADDOCK, S. 2004. AIDS and Ethics: Clinical Trials, Pharmaceuticals and Global Scientific Practice. *In:* E. KALIPENI, S. CRADDOCK, OPPONG, J. R. & GHOSH., J. (eds.) *HIV & AIDS in Africa. Beyond Epidemiology.* 240-251. Oxford: Blackwell Publishing Ltd.

CRANE, J. 2011. Scrambling for Africa? Universities and global health. *Lancet,* 377**,** 1388-1390.

CRANE, J. T. 2013. *Scrambling for Africa: AIDS, Expertise, and the Rise of American Global Health Science,* Ithaca: Cornell University Press.

CURTIN, P. D. 1992. Medical Knowledge and Urban Planning in Colonial Tropical Africa. *In:* FEIERMAN, S. & JANZEN, J. M. (eds.) *The Social Basis of Health and Healing in Africa.* 235-255. Berkeley: University of California Press.

DE LA GORGENDIÈRE, L. 2005. Rights and Wrongs: HIV/AIDS Research in Africa. *Human Organization,* 64**,** 166-178.

DE WAAL, A. 2007. Humanitarianism reconfigured: philantropic globalisation and the new solidarity. *In:* FEHER, M. (ed.) *Nongovernmental Politics.* 183-195. New York: Zone Books.

DEWEY, J. 1929. *The Quest for Certainty: A Study of the Relation of Knowledge and Action,* New York: Minton, Balch & Company.

EASTER, M. M., HENDERSON, G. E., DAVIS, A. M., CHURCHILL, L. R. & KING, N. M. P. 2006. The many meanings of care in clinical research. *Sociology of Health & Illness,* 28**,** 695-712.

ENGLUND, H. 2006. *Prisoners of Freedom. Human Rights and the African Poor,* Berkeley: University of California Press.

ENGLUND, H. 2007. Pentecostalism beyond Belief: Trust and Democracy in a Malawian Township. *Africa: Journal of the International African Institute/Revue de l'Institut Africain International,* 77**,** 477-499.

ENGLUND, H. 2008. Extreme Poverty and Existential Obligations: Beyond Morality in the Anthropology of Africa? *Social Analysis,* 52**,** 33-50.

ENGLUND, H. 2013. ZAMBIA AT 50: THE REDISCOVERY OF LIBERALISM. *Africa,* 83**,** 670-689.

EPSTEIN, A. L. 1964 (written in 1957). Urban Communities in Africa. *In:* GLUCKMAN, M. (ed.) *Closed Systems and Open Minds: The Limits of Naïvety in Social Anthropology.* 83-102. Edinburgh: Oliver & Boyd.

EPSTEIN, A. L. 1981. *Urbanization and Kinship: The Domestic Domain in the Copperbelt of Zambia 1950-56,* London: Academic Press.

EPSTEIN, S. 2007. *Inclusion. The Politics of Difference in Medical Research,* Chicago: The University of Chicago Press.

EVENS, T. M. S. 2006. Some Ontological Implications of Situational Analysis. *In:* EVENS, T. M. S. & HANDELMAN, D. (eds.) *The Manchester School. Practice and Ethnographic Praxis in Anthropology.* 49-63. New York: Berghahn Books.

FAIRHEAD, J., LEACH, M. & SMALL, M. 2006a. Public Engagement with Science? Local Understandings of a Vaccine Trial in The Gambia. *Journal of Biosocial Science,* 38**,** 103-116.

FAIRHEAD, J., LEACH, M. & SMALL, M. 2006b. Where techno-science meets poverty: Medical research and the economy of blood in The Gambia, West Africa. *Social Science & Medicine,* 63**,** 1109-1120.

FASSIN, D. 2007a. Humanitarianism as a Politics of Life. *Public Culture,* 19**,** 499-520.

FASSIN, D. 2007b. Humanitarianism: A Nongovernmental Government. *In:* FEHER, M. (ed.) *Nongovernmetal Politics.* 149-159. New York: Zone Books.

FASSIN, D. 2009. Another Politics of Life is Possible. *Theory, Culture & Society***,** 44-60.

FELDMAN-SAVELSBERG, P., NDONKO, F. T. & SCHMIDT-EHRY, B. 2000. Sterilizing vaccines or the politics of the womb: retrospective study of rumour in Cameroon. *Medical Anthropology Quarterly,* 14**,** 159-179.

FERGUSON, J. 1999. *Expectations of Modernity. Myths and Meaning of Urban Life on the Zambian Copperbelt,* Berkeley, Los Angeles, London: University of California Press.

FERGUSON, J. 2006. *Global Shadows. Africa in the Neo-liberal World Order,* Durham: Duke University Press.

FERGUSON, J. 2013. Declarations of dependence: labour, personhood, and welfare in southern Africa. *Journal of the Royal Anthropological Institute,* 19**,** 223-242.

FISHER, J. A. 2013. Expanding the Frame of "Voluntariness" in Informed Consent: Structural Coercion and the Power of Social and Economic Context. *Kennedy Institute of Ethics Journal,* 23**,** 355-79.

FISHER, W. F. 1997. DOING GOOD? The Politics and Antipolitics of NGO Practices. *Annual Review of Anthropology,* 26**,** 439-464.

FRANKLIN, S. 2000. Global Nature and the Genetic Imaginary. *In:* FRANKLIN, S., LURY, C. & STACEY, J. (eds.) *Global Nature, Global Culture.* 188-227. London: Sage Publications.

FRESTON, P. 2005. The Universal Church of the Kingdom of God: A Brazilian Church Finds Success in Southern Africa. *Journal of Religion in Africa,* 35**,** 33-65.

FYLKESNES, K., MUSONDA, R. M., KASUMBA, K., NDHLOVU, Z., MLUANDA, F., KAETANO, L. & CHIPAILA, C. 1997. The HIV epidemic in Zambia: socio-demographic prevalence patterns and indications of trends among childbearing women. *AIDS,* 11**,** 339-345.

GEISLER, G. 1987. Sisters under the Skin: Women and the Women's League in Zambia. *The Journal of Modern African Studies,* 25**,** 43-66.

GEISLER, G. 1995. Troubled Sisterhood: Women and Politics in Southern Africa: Case Studies from Zambia, Zimbabwe and Botswana. *African Affairs,* 94**,** 545-578.

GEISSLER, P. W. 2005. 'Kachinja are coming!' Encounters around a medical research project in a Kenyan village. *Africa,* 75**,** 173-202.

GEISSLER, P. W. 2011a. Parasite Lost. Remembering Modern Times with Kenyan Government Medical Scientists. *In:* GEISSLER, P. W. & MOLYNEUX, C. S. (eds.) *Evidence, Ethos and Experiment: The Anthropology and History of Medical Research in Africa.* 297 - 333. Oxford: Berghahn Books.

GEISSLER, P. W. 2011b. Studying Trial Communities: Anthropological and Historical Inquiries in to Ethics, Politics and Economy of Medical Research in Africa. *In:* GEISSLER, P. W. & MOLYNEUX, C. S. (eds.) *Evidence, Ethos and Experiment: The Anthropology and History of Medical Research in Africa.* 1-28. New York: Berghahn Books.

GEISSLER, P. W. 2012. "We are not paid - they just give us": Liberalisation and the longing for biopolitical discipline around and African HIV prevention trial. *In:* GEISSLER, P. W., ROTTENBURG, R. & ZENKER, J. (eds.) *Rethinking Biomedicine and Governance in Africa.* 197-227. Bielefeld: transcript Verlag.

GEISSLER, P. W. 2013. Public secrets in public health: Knowing not to know while making scientific knowledge. *American Ethnologist,* 40**,** 13-34.

GEISSLER, P. W. Forthcoming. The Archipelago of Public Health. Comments on the Landscape of Medical Research in Twenty-First-Century Africa. *In:* PRINCE, R. J. & MARSLAND, R. (eds.) *Making Public Health in Africa. Ethnographic and Historical Perspectives.* 231-284. Ohio: Ohio University Press.

GEISSLER, P. W. (ed.) In press. *Para-states of science: ethnographic and historical perspectives on life-science, government and public in 21st century Africa,* Durham: Duke University Press.

GEISSLER, P. W., KELLY, A., IMOUKHUEDE, B. & POOL, R. 2008. `He is now like a brother, I can even give him some blood' - Relational ethics and material exchanges in a malaria vaccine `trial community' in The Gambia. *Social Science & Medicine,* 67**,** 696-707.

GEISSLER, P. W. & MOLYNEUX, C. S. (eds.) 2011. *Evidence, Ethos and Experiment. The Anthropology and History of Medical Research in Africa,* New York: Berghahn Books.

GEISSLER, P. W. & PRINCE, R. J. 2010. *The Land is Dying. Contingency, Creativity and Conflict in Western Kenya,* New York: Berghahn Books.

GESCHIERE, P. 1997. *The Modernity of Witchcraft. Politics and the Occult in Postcolonial Africa,* Charlottesville: University Press of Virginia.

GIFFORD, P. 1998. Chiluba's Christian Nation: Christianity as a Factor in Zambian Politics 1991-1996. *Journal of Contemporary Religion,* 13**,** 363.

GIKONYO, C., BEJON, P., MARSH, V. & MOLYNEUX, S. 2008. Taking social relationships seriously: Lessons learned from the informed consent practices of a vaccine trial on the Kenyan Coast. *Social Science & Medicine,* 67**,** 708-720.

GLICKMAN, S. W., MCHUTCHISON, J. G., PETERSON, E. D., CAIRNS, C. B., HARRINGTON, R. A., CALIFF, R. M. & SCHULMAN, K. A. 2009. Ethical and Scientific Implications of the Globalization of Clinical Research. *N Engl J Med,* 360**,** 816-823.

GLUCKMAN, M. (ed.) 1964. *Closed Systems and Open Minds. The Limits of Naïvety in Social Anthropology,* Edinburgh: Oliver & Boyd.

GLUCKMAN, M. 1965. *The Ideas in Barotse Jurisprudence,* New Haven: Yale University Press.

GORDON, D. M. 2012. *African Histories: Invisible Agents: Spirits in a Central African History,* Chicago: Ohio University Press.

GOUGH, K. V. 2008. 'MOVING AROUND': THE SOCIAL AND SPATIAL MOBILITY OF YOUTH IN LUSAKA. *Geografiska Annaler Series B: Human Geography,* 90**,** 243-255.

GREENHOUGH, B. 2012. Room with a rhinovirus? Blurring the boundaries between research and therapeutic space. *Transactions of the Institute of British Geographers,* 37**,** 402-417.

HANNERZ, U. 1980. *Exploring the City. Inquiries Toward an Urban Anthropology,* New York: Columbia University Press.

HANSEN, K. T. 1984. Negotiating Sex and Gender in Urban Zambia. *Journal of Southern African Studies,* 10**,** 219-238.

HANSEN, K. T. 1997. *Keeping House in Lusaka,* New York: Columbia University Press.

HANSEN, K. T. 2004. Who Rules the Streets? The Politics of Vending Space in Lusaka. *In:* HANSEN, K. T. & VAA, M. (eds.) *Reconsidering Informality. Perspectives from Urban Africa.* 62-80. Uppsala: Nordiska Afrikainstitutet.

HANSEN, K. T. 2005. Getting Stuck in the Compound: Some Odds against Social Adulthood in Lusaka, Zambia. *Africa Today,* 51**,** 2-16.

HANSEN, K. T. 2008. The informalization of Lusaka's economy: Regime change, ultra-modern markets, and street vending, 1972-2004. *In:* GEWALD, J.-B., HINFELAAR, M. & MACOLA, G. (eds.) *One Zambia, Many Histories.* 213-239. Leiden: Brill.

HASKI-LEVENTHAL, D. 2009. Altruism and Volunteerism: The perceptions of altruism in four disciplines and their impact on the study of volunteerism. *Journal for the Theory of Social Behaviour,* 39**,** 271-299.

HAYNES, N. 2012. Pentecostalism and the morality of money: prosperity, inequality, and religious sociality on the Zambian Copperbelt. *Journal of the Royal Anthropological Institute,* 18**,** 123-139.

HAYNES, N. 2013. Desirable dependence, or what we learn from Pentecostalism. *Journal of the Royal Anthropological Institute,* 19**,** 250-251.

HENDERSON, G. E., CHURCHILL, L. R., DAVIS, A. M., EASTER, M. M., GRADY, C., JOFFE, S., KASS, N., KING, N. M. P., LIDZ, C. W., MILLER, F. G., NELSON, D. K., PEPPERCORN, J., ROTHSCHILD, B. B., SANKAR, P., WILFOND, B. S. & ZIMMER, C. R. 2007. Clinical Trials and Medical Care: Defining the Therapeutic Misconception. *PLoS Medicine,* 4**,** e324-1738.

HOBSON, D. 1996. *Tales of Zambia,* London: The Zambia Society Trust.

HOEYER, K. 2003. 'Science is really needed - that's all I know': informed consent and the non-verbal practices of collecting blood for genetic research in northern Sweden. *New Genetics & Society,* 22**,** 229-244.

HOPPE, K. A. 2003. *Lords of the Fly: Sleeping Sickness Control in British East Africa, 1900-1960,* Westport, Connecticut: Praeger.

HUNT, N. R. 1999. *A Colonial Lexicon of Birth Ritual, Medicalization, and Mobility in the Congo,* Durham: Duke University Press.

IDÄNPÄÄN-HEIKKILÄ, J. & FLUSS, S. 2004. The CIOMS view on the use of placebo in clinical trials. *Science and Engineering Ethics,* 10**,** 23-28.

IRWIN, A. & WYNNE, B. 1996. Conclusions. *In:* IRWIN, A. & WYNNE, B. (eds.) *Misunderstanding Science? The Public Reconstruction of Science and Technology.* 213-221. Cambridge: Cambridge University Press.

JACKSON, M. 1998. *Minima Ethnographica. Intersubjectivity and the Anthropological Project,* Chicago: University of Chicago Press.

JACOBSON-WIDDING, A. 1979. *Red-White-Black as a mode of thought. A study of Triadic Classification by colours in the Ritual symbolism and Cognitive Thought of the Peoples of the Lower Congo,* Uppsala: Almqvist & Wiksell.

JANES, C. R. 2004. Going Global in Century XXI: Medical Anthropology and the New Primary Health Care. *Human Organization,* 63**,** 457-471.

JANZEN, J. M. 1978. *The Quest for Therapy in Lower Zaire,* Berkeley: University of California Press.

JOHANSEN, M. V., AAGAARD-HANSEN, J. & RIIS, P. 2008. Benefit - a neglected aspect of health research ethics. *Danish Medical Bulletin,* 55**,** 216-218.

JOHNSON-HANKS, J. 2006. *Uncertain honor, modern motherhood in an African crisis,* Chicago: University of Chigaco Press.

JONSEN, A. R. 1998. *The Birth of Bioethics,* New York: Oxford University Press.

KAMBOU, S. D., SHAH, M. K. & NKHAMA, G. 1998. For a Pencil: Sex and Adolescence in peri-urban Lusaka. *In:* GUIJT, I. & SHAH, M. K. (eds.) *The Myth of Community. Gender issues in participatory development.* 110-120. London: ITDG Publishing.

KAPFERER, B. 2005. SITUATIONS, CRISIS, AND THE ANTHROPOLOGY OF THE CONCRETE. *Social Analysis,* 49**,** 85-122.

KATZ, J. (cop. 1972). *Experimentation with human beings, The authority of the investigator, subject, professions, and state in the human experimentation process,* New York: Russell Sage Foundation.

KELLY, A. 2011. Remember Bambali: Evidence, Ethics and the Co-production of Truth. *In:* GEISSLER, P. W. & MOLYNEUX, C. S. (eds.) *Evidence, Ethos and Experiment: The Anthropology and History of Medical Research in Africa.* 229-244. New York: Berghahn Books.

KELLY, A. H., AMEH, D., MAJAMBERE, S., LINDSAY, S. & PINDER, M. 2010. `Like sugar and honey': The embedded ethics of a larval control project in The Gambia. *Social Science & Medicine,* 70**,** 1912-1919.

KESBY, M. 2005. Retheorizing Empowerment-through-Participation as a Performance in Space: Beyond Tyranny to Transformation. *Signs: Journal of Women in Culture and Society,* 30**,** 2037-2065.

KLEINMAN, A. 1999. Moral Experience and Ethical Reflection: Can Ethnography Reconcile Them? A Quandary for 'The New Bioethics'. *Daedalus,* 128**,** 69-97.

LACHENAL, G. 2013. Kin Porn. *Somatoshpere* [Online]. Available from: http://somatosphere.net/2013/01/kin-porn.html [Accessed 14 February 2014].

LAST, M. 1992. The Importance of Knowing about not Knowing: Observations from Hausaland. *In:* FEIERMAN, S. & JANZEN, J. M. (eds.) *The Social Basis of Health and Healing in Africa.* 393-406. Berkeley: University of California Press.

LATOUR, B. 1987. *Science in Action: How to Follow Scientists and Engineers through Society* Cambridge, Mass.: Harvard University Press.

LATOUR, B. & WOOLGAR, S. 1979. *Laboratory Life. The Construction of Scientific Facts* Beverly Hills: Sage Publications.

LEACH, M. & FAIRHEAD, J. R. 2011. Being 'with the Medical Research Council': Infant Care and the Social Meanings of Cohort Membership in Gambia's Plural Therapeutic Landscapes. *In:* GEISSLER, P. W. & MOLYNEUX, C. S. (eds.) *Evidence, Ethos and Experiment: The Anthropology and History of Medical Research in Africa.* 77-98. New York: Berghahn Books.

LEGER, M. C. 2008. Clinical globalization: A case study of privately-sponsored HIV research in Mexico. *Social Identities,* 14**,** 189-213.

LIVINGSTON, J. 2005. *Debility and the Moral Imagination in Botswana : Disability, Chronic Illness, and Aging,* Bloomington: Indiana University Press

LLEWELLYN-THOMAS, H. A., MCGREAL, M. J., THIEL, E. C., FINE, S. & ERLICHMAN, C. 1991. Patients' willingness to enter clinical trials: Measuring the association with perceived benefit and preference for decision participation. *Social Science & Medicine,* 32**,** 35-42.

LONG, N. 2001. *Development Sociology. Actor Perspectives,* London: Routledge.

LONG, N. & LONG, A. (eds.) 1992. *Battlefields of knowledge: The interlocking of theory and practice in social research and development,* London: Routledge.

LUCHT, H. 2012. *Darkness before Daybreak. African migrants living on the margins in southern Italy today,* Berkeley: University of California Press.

MACLEOD, R. 2000. Introduction. *Osiris,* 15**,** 1-13.

MACMILLAN, H. 1995. Return to the Malungwana Drift - Max Gluckman, the Zulu Nation and the Common Society. *African Affairs,* 94**,** 39-65.

MAES, K. 2012. Volunteerism or Labor Exploitation? Harnessing the Volunteer Spirit to Sustain AIDS Treatment Programs in Urban Ethiopia. *Human Organization,* 71**,** 54-64.

MAGGIORE, C. 1996. *What if everything you thought you knew about AIDS was wrong?,* Studio City: American Foundation For Aids Alternatives.

MAIR, L. P. 1961. Clientship in East Africa. *Cahiers d'Études Africaines,* 2**,** 315-325.

MARSH, V., KAMUYA, D., MLAMBA, A., WILLIAMS, T. & MOLYNEUX, S. 2010. Experiences with community engagement and informed consent in a genetic cohort study of severe childhood diseases in Kenya. *BMC Medical Ethics,* 11**,** 13.

MARSLAND, R. & PRINCE, R. 2012. What Is Life Worth? Exploring Biomedical Interventions, Survival, and the Politics of Life. *Medical Anthropology Quarterly,* 26**,** 453-469.

MASQUELIER, A. 2001. Behind the Dispensary's Prosperous Façade: Imagining the State in Rural Niger. *Public Culture,* 13**,** 267-291.

MAUSS, M. 2002 (1950). *The Gift. The form and reason for exchange in archaic societies.,* London: Routledge.

MAXWELL, D. 1998. 'Delivered from the Spirit of Poverty?': Pentecostalism, Prosperity and Modernity in Zimbabwe. *Journal of Religion in Africa,* 28**,** 350-373.

MAXWELL, D. 2005. The Durawall of Faith: Pentecostal Spirituality in Neo-Liberal Zimbabwe. *Journal of Religion in Africa,* 35**,** 4-32.

MCKAY, R. 2012. AFTERLIVES: Humanitarian Histories and Critical Subjects in Mozambique. *Cultural Anthropology,* 27**,** 286-309.

MEINERT, L. 2009a. *Hopes in Friction. Schooling, Health and Everyday Life in Uganda,* Charlotte: Information Age Publishing.

MEINERT, L. 2009b. Therapeutic Clientship and 'Projectification' of ART in Uganda. Paper presented at the conference 'Publics of Public Health', 7-11 December Kilifi, Kenya.

MEINERT, L., MOGENSEN, H. O. & TWEBAZE, J. 2009. Tests for life chances: CD4 miracles and obstacles in Uganda. *Anthropology & Medicine,* 16**,** 195 - 209.

MEYER, B. 2003. Commodities and the Power of Prayer: Pentecostalist Attitudes Towards Consumption in Contemporary Ghana. *In:* MEYER, B. & GESCHIERE, P. (eds.) *Globalization and Identity.* 151-176. Oxford: Blackwell.

MITCHELL, J. C. 1983. Case and situation analysis. *Sociological Review,* 31**,** 187-211.

MOLYNEUX, C. S., PESHU, N. & MARSH, K. 2004. Understanding of informed consent in a low-income setting: three case studies from the Kenyan coast. *Social Science & Medicine,* 59**,** 2547-2559.

MOLYNEUX, C. S., PESHU, N. & MARSH, K. 2005a. Trust and informed consent: insights from community members on the Kenyan coast. *Social Science & Medicine,* 61**,** 1463-1473.

MOLYNEUX, C. S., WASSENAAR, D. R., PESHU, N. & MARSH, K. 2005b. `Even if they ask you to stand by a tree all day, you will have to do it (laughter)...!': Community voices on the notion and practice of informed consent for biomedical research in developing countries. *Social Science & Medicine,* 61**,** 443-454.

MOLYNEUX, S., KAMUYA, D. & MARSH, V. 2010. Community Members Employed on Research Projects Face Crucial, Often Under-Recognized, Ethical Dilemmas. *American Journal of Bioethics,* 10**,** 24-26.

MORFIT, N. S. 2011. 'AIDS is Money': How Donor Preferences Reconfigure Local Realities. *World Development,* 39**,** 64-76.

MULDER, S. S., RANCE, S., SUAREZ, M. S. & CONDORI, M. C. 2000. Unethical ethics? Reflections on intercultural research practices. *Reproductive Health Matters,* 8**,** 104-112.

MULENGA, C. L. 2003. The case of Lusaka, Zambia. The Bartlett Development Planning Unit, UCL. London. http://www.ucl.ac.uk/dpu-projects/Global_Report/pdfs/Lusaka.pdf

MUSAMBACHIME, M. 1990. The Impact of Rapid Population Growth and Economic Decline on the Quality of Education: The Case of Zambia. *Review of African Political Economy***,** 81-92.

MUSAMBACHIME, M. C. 1988. The Impact of Rumor: The Case of the Banyama (Vampire Men) Scare in Northern Rhodesia, 1930-1964. *The International Journal of African Historical Studies,* 21**,** 201-215.

NAMA, N. & SWARTZ, L. 2002. Ethical and social dilemmas in community-based controlled trials in situations of poverty: a view from a South African project. *Journal of Community & Applied Social Psychology,* 12**,** 286-297.

NCOB 2002. The ethics of research related to healthcare in developing countries. Nuffield Council on Bioethics. London. http://www.nuffieldbioethics.org

NCOB 2005. The ethics of research related to healthcare in developing countries. A follow-up Discussion Paper. Nuffield Council on Bioethics. London. http://www.nuffieldbioethics.org

NEWELL, S. 2006. Estranged belongings: A moral economy of theft in Abidjan, Cote d'Ivoire. *Anthropological Theory,* 6**,** 179-203.

NGUYEN, V. K. 2009a. Government-by-exception: Enrolment and experimentality in mass HIV treatment programmes in Africa. *Soc Theory Health,* 7**,** 196-217.

NGUYEN, V. K. 2009b. Therapeutic Evangelism—Confessional Technologies, Antiretrovirals and Biospiritual Transformation in the Fight against AIDS in West Africa. *In:* BECKER, F. & GEISSLER, P. W. (eds.) *AIDS and Religious Practice in Africa.* 359-378. Boston: Brill Academic Publishers.

NIEHAUS, I. & JONSSON, G. 2005. Dr. Wouter Basson, Americans, and Wild Beasts: Men's Conspiracy Theories of HIV/AIDS in the South African Lowveld. *Medical Anthropology,* 24**,** 179-208.

OGDEN, J. A. 1996. 'Producing' respect: the 'proper woman' in postcolonial Kampala. *In:* WERBNER, R. P. & RANGER, T. (eds.) *Postcolonial Identities in Africa.* 165-192. London: Zed Books.

OKELY, J. 2012. *Anthropological Practice. Fieldwork and the Ethnographic Method,* London: Berg.

ONDRUSEK, N. K. 2010. *Making Participation Work: A Grounded Theory Describing Participation in Phase I Drug Trials from the Perspective of the Healthy Subject.* PhD dissertation, University of Toronto.

PACKARD, R. M. 1993. The Invention of the 'Tropical Worker': Medical Research and the Quest for Central African Labor on the South African Gold Mines, 1903-36. *The Journal of African History,* 34**,** 271-292.

PACKARD, R. M. 1997. Visions of Postwar Health and Development and Their Impact on Public Health Interventions in the Developing World. *In:* COOPER, F. & PACKARD, R. M. (eds.) *International Development and the Social Sciences.* 93-115. Berkeley: University of California Press.

PETRYNA, A. 2002. *Life Exposed. Biological Citizens after Chernobyl,* Princeton: Princeton University Press.

PETRYNA, A. 2005. Ethical Variability. Drug development and globalizing clinical trials. *American Ethnologist,* 32**,** 183-197.

PETRYNA, A. 2006. Globalizing Human Subjects Research. *In:* PETRYNA, A., LAKOFF, A. & KLEINMAN, A. (eds.) *Global Pharmaceuticals. Ethics, Markets, Practices.* 33-60. Durham: Duke University Press.

PETRYNA, A. 2009. *When Experiments Travel. Clinical Trials and the Global Search for Human Subjects.,* Princeton: Princeton University Press.

PETRYNA, A. 2011. The Competitive Logic of Global Clinical Trials. *Social Research,* 78**,** 949-974.

PFEIFFER, J. 2003. International NGOs and primary health care in Mozambique: the need for a new model of collaboration. *Social Science & Medicine,* 56**,** 725-738.

PHIRI, I. 1999. Why African Churches Preach Politics: The Case of Zambia. *Journal of Church & State,* 41**,** 323.

POLEYKETT, B. Forthcoming. Molecular and Municipal Politics: Research and Regulation in Dakar. *In:* GEISSLER, P. W. (ed.) *Para-states of science: ethnographic and historical perspectives on life-science, government and public in 21st century Africa.* Durham: Duke University Press.

PRICE, J. A. 1975. Sharing: The Integration of Intimate Economies. *Anthropologica,* 17**,** 3-27.

PRINCE, R. 2012. HIV and the Moral Economy of Survival in an East African City. *Medical Anthropology Quarterly,* 26**,** 534-556.

PRINCE, R. 2013a. “Tarmacking” in the Millennium City: Spatial and Temporal Trajectories of “Empowerment” in Kenya. *Africa,* 83**,** 582-605.

PRINCE, R. J. 2006. Popular Music and Luo Youth in Western Kenya: Ambiguities of modernity, morality and gender relations in the era of AIDS. *In:* CHRISTIANSEN, C., UTAS, M. & VIGH, H. E. (eds.) *Navigating Youth, Generating Adulthood. Social Becoming in an African Context.* 117-152. Uppsala Nordiska Afrikainstitutet.

PRINCE, R. J. 2013b. Precarious Projects: Conversions of (Biomedical) Knowledge in an East African City. *Medical Anthropology,* 33**,** 68-83.

PRITCHETT, J. A. 2001. *The Lunda-Ndembu. Style, Change and Social Transformation in South Central Africa,* Madison: The University of Wisconsin Press.

RABINOW, P. 1996. Artificiality and Enlightenment: From Sociobiology to Biosociality. *In:* RABINOW, P. (ed.) *Essays on the Anthropology of Reason.* Princeton: Princeton University Press.

RAJAN, K. S. 2005. Subjects of Speculation: Emergent Life Sciences and Market Logics in the United States and India. *American Anthropologist,* 107**,** 19-30.

RAJAN, K. S. 2006. *Biocapital. The Constitution of Postgenomic Life,* Durham: Duke University Press.

RAJAN, K. S. 2007. Experimental Values. Indian Clinical Trials and Surplus Health. *New Left Review,* 45**,** 67-88.

RAKNER, L. 2003. *Political and Economic Liberalization in Zambia 1991-2001,* Uppsala: Nordiska Afrikainstitutet.

RASING, T. 1999. Globalization and the making of consumers: Zambian kitchen parties. *In:* FARDON, R., VAN BINSBERGEN, W. & VAN DIJK, R. (eds.) *Modernity on a shoestring. Dimensions of globalisation, consumption and development in African and beyond.* 227-245. Leiden: EIDOS.

RASING, T. 2001. *The Bush Burnt, the Stones Remain: Female Initiation Rites in Urban Zambia,* Munster: Lit Verlag.

RASING, T. 2004. The Persistence of female Initiation rites: reflexivity and resilience of women in Zambia. *In:* VAN BINSBERGEN, W. & VAN DIJK, R. (eds.) *Situating Globality. African Agency in the Appropriation of Gobal Culture.* Leiden: Brill.

REDFIELD, P. 2005. Foucault in the Tropics: Displacing the Panopticon. *In:* INDA, J. X. (ed.) *Anthropologies of Modernity. Foucault, governmentality and life politics.* 50-79. Malden: Blackwell.

REDFIELD, P. 2006. A less modest witness. *American Ethnologist,* 33**,** 3-26.

REDFIELD, P. 2012. Bioexpectations: Life Technologies as Humanitarian Goods. *Public Culture,* 24**,** 157-184.

REICH, M. R. 2002. Reshaping the state from above, from within, from below: implications for public health. *Social Science & Medicine,* 54**,** 1669-1675.

REUTERS. 2005. *Zambia bans Brazilian church in Satanism row* [Online]. Available: http://wwrn.org/articles/19706/?&place=southern-africa [Accessed 13 Feb 2012].

REVERBY, S. M. 2009. *Examining Tuskegee: The Infamous Syphilis Study and Its Legacy,* Chapel Hill: University of North Carolina Press.

REYNOLDS, J., MANGESHO, P., LEMNGE, M. M., VESTERGAARD, L. S. & CHANDLER, C. I. R. 2013. '… in the project they really care for us': Meaning and experiences of participating in a clinical study of first-line treatment for malaria and HIV in Tanzanian adults. *Global Public Health,* 8**,** 670-684.

RICHARDS, A. I. 1939. *Land, labour and diet in Northern Rhodesia. An economic study of the Bemba tribe,* London: Oxford University Press.

RICHARDS, A. I. 1958. *Chisungu,* London: Faber and Faber Limited.

ROBINS, S. 2004. 'Long Live Zackie, Long Live': AIDS Activism, Science and Citizenship after Apartheid. *Journal of Southern African Studies,* 30**,** 651-672.

ROSE, N. 2007. *The Politics of Life Itself. Biomedicine, Power, and Subjectivity in the Twenty-First Century,* Princeton: Princeton University Press.

ROSSI, B. 2006. Why Donors and Recipients Should Not Be compartmentalized into Separate "Worlds of Knowledge". *In:* LEWIS, D. & MOSSE, D. (eds.) *Development Brokers and Translators. The Ethnography of Aid and Agencies.* 27-49. Bloomfield: Kumarian Press.

ROTTENBURG, R. 2009. Social and public experiments and new figurations of science and politics in postcolonial Africa. *Postcolonial Studies,* 12**,** 423 - 440.

SAETHRE, E. & STADLER, J. 2013. Malicious Whites, Greedy Women, and Virtuous Volunteers. *Medical Anthropology Quarterly,* 27**,** 103-120.

SAHLINS, M. 1974. *Stone Age Economics,* London: Routledge.

SANJEK, R. 1990. On Ethnographic Validity. *In:* SANJEK, R. (ed.) *Fieldnotes. The Makings of Anthropology.* 385-418. Ithaca: Cornell University Press.

SARIOLA, S. & SIMPSON, B. 2011. Theorising the 'human subject' in biomedical research: International clinical trials and bioethics discourses in contemporary Sri Lanka. *Social Science & Medicine,* 73**,** 515-521.

SCHLYTER, A. & SCHLYTER, T. 1979. *George - the development of a Squatter Settlement in Lusaka, Zambia,* Stockholm: Swedish Council for Building Research.

SCHUMAKER, L. 2001. *Africanizing Anthropology. Fieldwork, Networks and the Making of Cultural Knowledge in Central Africa,* Durham: Duke University Press.

SCHUMAKER, L. 2008. Slimes and Death-Dealing Dambos: Water, Industry and the Garden City on Zambia's Copperbelt. *Journal of Southern African Studies,* 34**,** 823-840.

SCHUMAKER, L. 2011. The Mosquito Taken at the Beerhall: Malaria Research and Control on Zambia's Copperbelt. *In:* GEISSLER, P. W. & MOLYNEUX, C. S. (eds.) *Evidence, Ethos and Experiment. The Anthropology and History of Medical Research in Africa.* 403-427. New York: Berghahn Books.

SCHUMAKER, L. Forthcoming. The Mosquito Taken at the Beerhall: Malaria Research and Control on Zambia's Copperbelt. *In:* GEISSLER, P. W. & MOLYNEUX, C. S. (eds.) *African Trial Communities: Ethnographies and Histories of Medical Research in Africa.* New York & Oxford: Berghahn Publishers.

SERPELL, R. 1993. *The significance of schooling: Life-journeys in an African society,* Cambridge: Cambridge University Press.

SETH, S. 2009. Putting knowledge in its place: science, colonialism, and the postcolonial. *Postcolonial Studies,* 12**,** 373 - 388.

SHAH, S. 2006. *The body hunters: testing new drugs on the world's poorest patients,* New York: The New Press.

SHIPTON, P. 2007. *The Nature of Entrustment. Intimacy, Exchange, and the Sacred in Africa,* New Haven: Yale University Press.

SIMON, C. & MOSAVEL, M. 2010. Community Members as Recruiters of Human Subjects: Ethical Considerations. *American Journal of Bioethics,* 10**,** 3-11.

SIMPSON, A. 2003. *'Half-London' in Zambia: Contested Identities in a Catholic Mission School,* Edinburgh: Edinburgh University Press.

SIMPSON, A. 2009. *Boys to Men in the Shadow of AIDS. Masculinities and HIV Risk in Zambia,* New York: Palgrave Macmillan.

STADLER, J. & SAETHRE, E. 2010. Rumours about blood and reimbursements in a microbicide gel trial. *African Journal of AIDS Research (AJAR),* 9**,** 345-353.

STADLER, J. J., DELANY, S. & MNTAMBO, M. 2008. Women's perceptions and experiences of HIV prevention trials in Soweto, South Africa. *Social Science & Medicine,* 66**,** 189-200.

STAMBACH, A. 2000. *Lessons from Mount Kilimanjaro : Schooling, Community and Gender in East Africa,* London: Routledge

STEWART, S. 1997. Happy Ever after in the Marketplace: Non-Government Organisations and Uncivil Society. *Review of African Political Economy,* 24**,** 11-34.

STONES, M. & MCMILLAN, J. 2010. Payment for participation in research: a pursuit for the poor? *Journal of Medical Ethics,* 36**,** 34-36.

SWIDLER, A. 2007. Syncretism and Subversion in AIDS Governance: How Locals Cope with Global Demands. *In:* POKU, N. K., WHITESIDE, A. & SANDKJAER, B. (eds.) *AIDS and Governance.* 145-163. Aldershot: Ashgate.

SWIDLER, A. 2009a. Dialectics of Patronage. Logics of Accountability at the African AIDS-NGO Interface. *In:* HAMMACK, D. C. & HEYDEMANN, S. (eds.) *Globalization, Philanthropy, and Civil Society. Projecting Institutional Logics Abroad.* 192-220. Bloomington and Indianapolis: Indiana University Press.

SWIDLER, A. 2009b. Responding to AIDS in Sub-Saharan Africa. Culture, Institutions, and Health. *In:* HALL, P. A. & LAMONT, M. (eds.) *Successful Societies. How Institutions and Culture Affect Health.* 128-150. Cambridge: Cambridge University Press.

SWIDLER, A. & WATKINS, S. C. 2009. "Teach a Man to Fish": The Sustainability Doctrine and Its Social Consequences. *World Development,* 37**,** 1182-1196.

TILLEY, H. 2011. *Africa as a Living Laboratory. Empire, Development, and the Problem of Scientific Knowledge, 1870-1950,* Chicago: The University of Chicago Press.

TOUSIGNANT, N. 2013. PHARMACY, MONEY AND PUBLIC HEALTH IN DAKAR. *Africa,* 83**,** 561-581.

TURNER, V. 1966. Colour Classification in Ndembu Ritual. A Problem in Primitive Classification. *In:* BANTON, M. (ed.) *Anthropological Approaches to the Study of Religion.* London: Tavistock Publications.

TWEBAZE, J. 2013. *Medicines for life. Confidentiality and information control in the lives of clients and providers in Ugandan ART programs.* PhD dissertation, University of Copenhagen.

UDELHOVEN, B. 2008. Satanism in Zambia: a new tree with old roots. The Faith & Encounter Centre Zambia (FENZA). www.fenza.org

UDELHOVEN, B. & THE FINGERS OF THOMAS 2009. Satanism in Zambia: a pastoral challenge. The Faith & Encounter Centre Zambia (FENZA). www.fenza.org

UNAIDS 2012. Zambia Country Report. Biennial report. http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/ce_ZM_Narrative_Report.pdf

UNDP 2013. Millenium Development Goals. Progess Report 2013. UNDP. Lusaka.

VAN VELSEN, J. 1967. The Extended-case Method and Situational Analysis. *In:* EPSTEIN, A. L. (ed.) *The Craft of Social Anthropology.* 129-149. London: Tavistock Publications.

VAN WYK, I. 2011. Believeing Practically and Trusting Socially in Africa. The Contrary Case of the Universal Church of the Kingdom of god in Durban, South Africa. *In:* ENGLUND, H. (ed.) *Christianity and Public Culture in Africa.* 189-203. Athens: Ohio University Press.

VAUGHAN, M. 1991. *Curing their Ills. Colonial Power and African Illness,* Cambridge: Polity Press.

VENKATESH, S. 2002. `Doin' the Hustle': Constructing the Ethnographer in the American Ghetto. *Ethnography,* 3**,** 91-111.

WALDBY, C. & COOPER, M. 2008. The Biopolitics of Reproduction: Post-Fordist Biotechnology and Women's Clinical Labour. *Australian Feminist Studies,* 23**,** 57-73.

WEISS, B. 2009. *Street Dreams & Hip Hop Barbershops. Global Fantasy in Urban Tanzania,* Bloomington: Indiana University Press.

WENDLAND, C. L. 2008. Research, Therapy, and Bioethical Hegemony: The Controversy over Perinatal AZT Trials in Africa. *African Studies Review,* 51**,** 1-23.

WERBNER, R. P. 1984. The Manchester School in South-Central Africa. *Annual Review of Anthropology,* 13**,** 157-185.

WHEELDON, P. D. 1969. The Operation of Voluntary Associations and Personal Networks in the Political Processes of an Inter-Ethnic Community. *In:* MITCHELL, J. C. (ed.) *Social Networks in Urban Situations. Analyses of Personal Relationships in Central African Towns.* 128-180. Manchester: Manchester University Press.

WHITE, L. 1993a. Cars Out of Place: Vampires, Technology, and Labor in East and Central Africa. *Representations***,** 27-50.

WHITE, L. 1993b. Vampire Priests of Central Africa: African Debates about Labor and Religion in Colonial Northern Zambia. *Comparative Studies in Society and History,* 35**,** 746-772.

WHITE, L. 1995. Tsetse Visions: Narratives of Blood and Bugs in Colonial Northern Rhodesia, 1931-9. *The Journal of African History,* 36**,** 219-245.

WHITE, L. 2000. *Speaking with Vampires: rumour and history in colonial Africa,* Berkeley: University of California Press.

WHYTE, S. R. 1997. *Questioning misfortune. The pragmatics of uncertainty in eastern Uganda,* Cambridge: Cambridge University Press.

WHYTE, S. R. 2002. Subjectivity and Subjunctivity. Hoping for Health in Eastern Uganda. *In:* WERBNER, R. P. (ed.) *Postcolonial Subjectivities in Africa.* 171-190. London: Zed Books.

WHYTE, S. R. 2009. Health Identities and Subjectivities. *Medical Anthropology Quarterly,* 23**,** 6-15.

WHYTE, S. R. 2011. Writing Knowledge and Acknowledgement: Possibilities in Medical Research. *In:* GEISSLER, P. W. & MOLYNEUX, C. S. (eds.) *Evidence, Ethos and Experiment. The Anthropology and History of Medial Research in Africa.* 29-56. New York: Berghahn Books.

WHYTE, S. R. 2013. Engaging with ART in Uganda. Paper presented at the SMA/EASA conference 'Encounters and Engagements: Creating New Agendas for Medical Anthropology', June 12-14, Tarragona.

WHYTE, S. R., WHYTE, M. A., MEINERT, L. & TWEBAZE, J. 2013. Therapeutic Clientship: Belonging in Uganda's Mosaic of AIDS Projects. *In:* BIEHL, J. & PETRYNA, A. (eds.) *When People Come First: Anthropology and Social Innovation in Global Health.* 140-165. Durham: Duke University Press.

WMA 2008. Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects. World Medical Association. http://www.wma.net/en/30publications/10policies/b3/17c.pdf

WOLF, E. 1966. Kinship, friendship and patron-client relations. *In:* BANTON, M. (ed.) *The Social Anthropology of Complex Societies.* 1-22. London: Tavistock.

WOODBURN, J. 1998. 'Sharing is not a form of exchange': an analysis of property-sharing in immediate-return hunter-gatherer societies. *In:* HANN, C. M. (ed.) *Property Relations. Renewing the anthropological tradition.* 48-63. Cambridge: Cambridge University Press.

WYNNE, B. 1996. Misunderstood misunderstandings. Introduction. *In:* IRWIN, A. & WYNNE, B. (eds.) *Misunderstanding Science? The Public Reconstruction of Science and Technology.* 19-47. Cambridge: Cambridge University Press.

YAMBA, C. B. 1997. Cosmologies in turmoil: witchfinding and AIDS in Chiawa, Zambia. *Africa,* 67**,** 200-223.

ZINK, S. 2001. Maybe We Should Pay Them More. *The American Journal of Bioethics,* 1**,** 88.

Appendix 1: Ethical approvals UK and Zambia

LONDON SCHOOL OF HYGIENE
& TROPICAL MEDICINE

ETHICS COMMITTEE

APPROVAL FORM
Application number: **5364**

Name of Principal Investigator	**Birgitte Bruun**
Department	**Public Health and Policy**
Head of Department	**Professor Anne Mills**

Title: **Local engagement in medical research in Lusaka, Zambia**

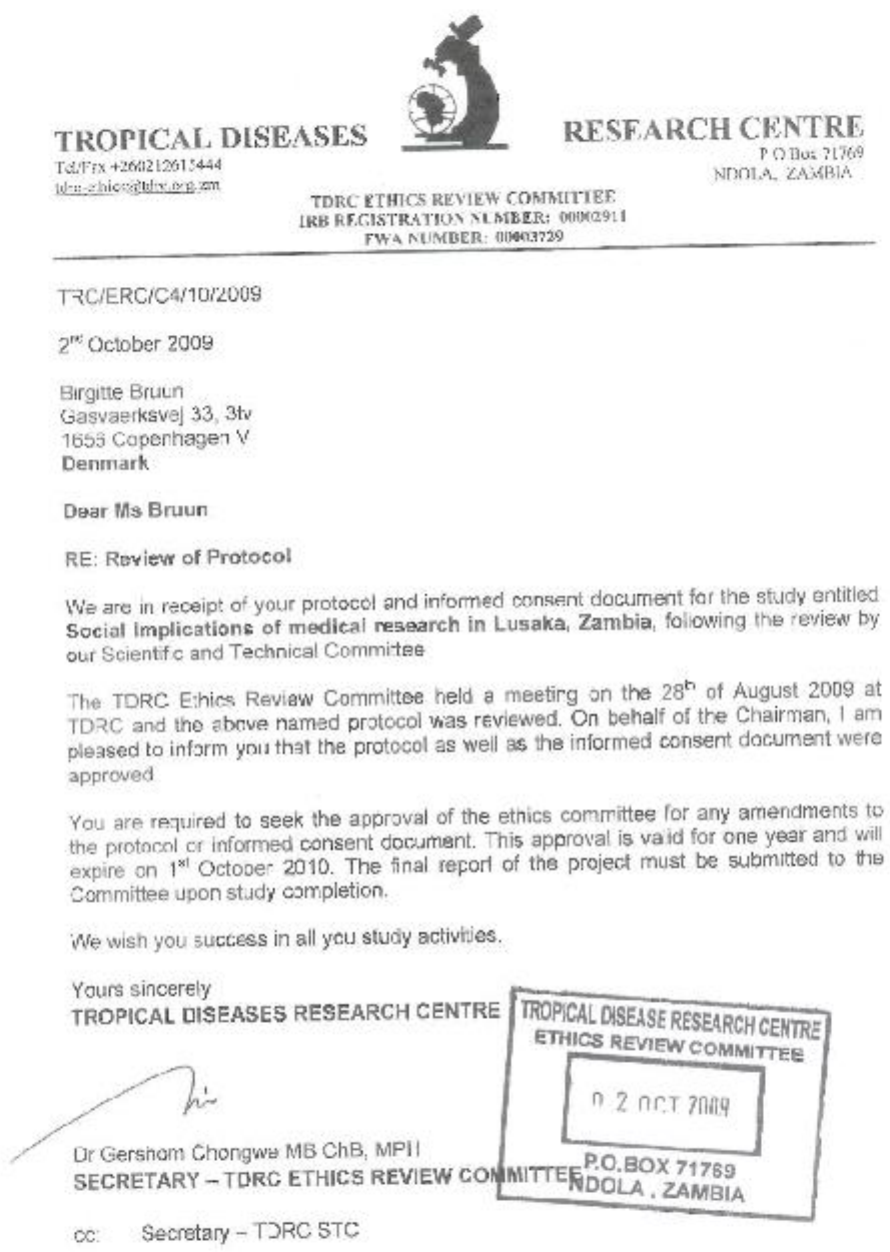
This application is approved by the Committee.

Chair of the Ethics Committee ...... T. W. Meade ....

Date ....28 August 2008..

Approval is dependent on local ethical approval having been received.

Any subsequent changes to the application must be submitted to the Committee via an E2 amendment form.



TROPICAL DISEASES RESEARCH CENTRE
Tel/Fax +260212615444
tdrc-ethics@tdrc.org.zm
P O Box 71769
NDOLA, ZAMBIA

TDRC ETHICS REVIEW COMMITTEE
IRB REGISTRATION NUMBER: 00002911
FWA NUMBER: 00003729

TRC/ERC/C4/10/2009

2nd October 2009

Birgitte Bruun
Gasvaerksvej 33, 3tv
1655 Copenhagen V
Denmark

Dear Ms Bruun

RE: **Review of Protocol**

We are in receipt of your protocol and informed consent document for the study entitled **Social Implications of medical research in Lusaka, Zambia**, following the review by our Scientific and Technical Committee

The TDRC Ethics Review Committee held a meeting on the 28th of August 2009 at TDRC and the above named protocol was reviewed. On behalf of the Chairman, I am pleased to inform you that the protocol as well as the informed consent document were approved.

You are required to seek the approval of the ethics committee for any amendments to the protocol or informed consent document. This approval is valid for one year and will expire on 1st October 2010. The final report of the project must be submitted to the Committee upon study completion.

We wish you success in all you study activities.

Yours sincerely
TROPICAL DISEASES RESEARCH CENTRE

Dr Gershom Chongwe MB ChB, MPH
SECRETARY – TDRC ETHICS REVIEW COMMITTEE

TROPICAL DISEASE RESEARCH CENTRE
ETHICS REVIEW COMMITTEE
02 OCT 2009
P.O.BOX 71769
NDOLA . ZAMBIA

cc: Secretary – TDRC STC

Appendix 2: Information and consent sheets

1. English
2. ChiNyanja
3. ChiBemba

London School of Hygiene & Tropical Medicine
(University of London)
Department of Public Health and Policy
Health Policy Unit
Keppel Street, London WC1E 7HT
Tel: +44 (0) 20 7636 8636 Fax: +44 (0) 20 7637 5391
Telex: 8953474 E-mail:
birgitte.bruun@lshtm.ac.uk

Department of Public Health & Policy

Health Policy Unit

September 2008

Local engagement in medical research in Lusaka, Zambia

Information Sheet

My name is Birgitte Bruun and I am part of a group of Zambian, Kenyan, British and Danish students from London School of Hygiene and Tropical Medicine in the UK. I am in Lusaka for one year to study the perspectives of people who have engaged in medical research projects and health programmes. The study will form the basis for my PhD thesis.

I would like to speak to you about your past experience with medical research and health programmes. I am also speaking with people who are involved in implementing research and health programmes and other social development projects.

I have permission to carry out my study from the Tropical Diseases Research Center (TDRC) in Ndola, from the Zambian Ministry of Health, from the Lusaka District Health Management Office and from the London School of Hygiene and Tropical Medicine in the United Kingdom.

My study entails interviews and follow-up visits, but no physical tests or examinations. I will work with an interpreter from Lusaka and I will take notes from interviews and conversations. I will sometimes ask for permission to record interviews. If statements are used in reports or presentations at a later stage I will make sure that these can not be traced to specific study participants. Participation in the study is voluntary and you may withdraw at any time without giving any reason. No quotes or other results arising from participation in this study will be included in any reports, even anonymously, without your agreement

Should you choose to participate in this study I thank you very much in advance.

I can be contacted at 0966 916 061 or through the mail address above.

Yours sincerely

London School of Hygiene & Tropical Medicine
(University of London)
Department of Public Health and Policy
Health Policy Unit
Keppel Street, London WC1E 7HT
Tel: +44 (0) 20 7636 8636 Fax: +44 (0) 20 7637 5391
Telex: 8953474 E-mail:
birgitte.bruun@lshtm.ac.uk

Department of Public Health & Policy

Health Policy Unit

Date

Interview code

Local engagement in medical research in Lusaka, Zambia

Consent form

1. I confirm that I have read the information sheet dated September 2008 for the above study and that that I have understood its contents.
2. I confirm that I have had the opportunity to ask questions.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
4. I consent to interviews with me may be tape recorded upon due notification from the researcher and that written notes may be taken during my conversations and interviews with the researcher.
5. I understand that all comments will be kept anonymous by the researcher.
6. I do / do not agree to quotes, photographs or other results arising from my participation in the study being included, even anonymously in any reports about the study.
7. I agree to take part in the above study.

Name (in print) ________________________________ Date __________

Signature ________________________________

Researcher (in print) ________________________________ Date __________

Signature ________________________________

London School of Hygiene & Tropical Medicine
(University of London)
Department of Public Health and Policy
Health Policy Unit
Keppel Street, London WC1E 7HT

Tel: +44 (0) 20 7636 8636 Fax: +44 (0) 20 7637 5391
Telex: 8953474 E-mail:
birgitte.bruun@lshtm.ac.uk

Department of Public Health & Policy

Health Policy Unit

September 2008

Local engagement in medical research in Lusaka Zambia

(Kuona kuti anthu agwapo bwanji pa nkhani za umoyo mu Lusaka, Zambia)

Information Sheet

(Kudziwa za nchito yanga)

Ine ndine Birgitte Bruun, ophunzila ochokela ku sukulu ya ku London ya maphunzilo ya ukhondo na mankwala (School of Hygiene and Tropical Medicine). Nili pamozi na gulu ya omphunzila ochokela ku Zambia, bena ku Kenya, Britain na ku Denmark. Nizankala mu Lusaka caka chimozi, kuti niziwe maganizo ya banthu bamene banachitako maphunzilo ya za umoyo na kufufuza pa za mankhwala. Ndika phunzila izi zizanithandiza kulemba PhD.

Nifuna tikabisaneko pali zimene munapitamo pamene munatengako mbali mu magululu imene ikufufuza pali za umoyo naza mankhwala (medical research) . Nikamba nso na baja bamene bayanganila za umoyo na zamankhwalidwe abwino ya banthu.

Bananivomeleza kuchita ivi ni ba Tropical Diseases Research Centre (TDRC) ku Ndola, ba Ministry of Health mu Zambia, Lusaka District Health Management team na ba London School of Hygiene and Tropical medicine ku United Kingdom (UK).

Maphunzilo yanga aya yafunikila kukambisana kamozi na nakukambisana futi nthawi ina. Sikuzankhala kupima pa thupi ngu mayeso yai. Nizasebenza na otanthauzila wa mu Lusaka, anso nizalembako vina vimene tizankala kukambilana. Penangu nizampempako ku jambula (record) makambidwe yatu. Kukambisana uku nikuzipeleka, anso mungaleke kuchitako izi nthawi iliyonse kosapsa chifukwa chilichonse. Pa zokambisana zatu kulibe zizalembedwa mu buku nikalibe kuvomelezewa na imwe.

Ngati mwavomomela kuchitako makambisano aya, zikomo kwambili.

Munganitumile pa numbala iyi: 0966 916 061 olo pa keyala (address) ili pamwamba.

Ndine wanu

London School of Hygiene & Tropical Medicine
(University of London)
Department of Public Health and Policy
Health Policy Unit
Keppel Street, London WC1E 7HT
Tel: +44 (0) 20 7636 8636 Fax: +44 (0) 20 7637 5391
Telex: 8953474 E-mail:
birgitte.bruun@lshtm.ac.uk

Department of Public Health & Policy

Health Policy Unit

Siku

Interview Code

Local engagement in medical research in Lusaka, Zambia

(kuona kuti anthu agwapo bwanji pankhani zaumoyo mu mzinda wa Lusaka, Zambia)

Pepala lachizindikilo

1. Ine nizindikila kuti na belenga mau yonse pa pepa iyi siku ya September, 2008 pa phunzilo iyi naku vesesa zonse.
2. Zoona nankhala na mwayi ofunsa mafunso.
3. Namvesesa kuti chigwirizano changa ni chaulele ndipo ningasiye chigwirizano nthawi iliyonse imene ningafune kosapasa chifukwa.
4. Navomera kufunsiwa mafunso na kujambula (tape recorder) ngati napemphewa, na kulemba mau yanga pokambisana na ofunafuna (researcher).
5. Namvesesa kuti zonse zimene nizakamba zizasungiwa mobisika na ofunsa (researcher).
6. Nili/sinili ovomela kusebenzesa vifanizo (pictures), vamene nakamba olo vilivonse vamene takambisana kuiikidwa muma lipoti (reports), olo osanilemba zina.
7. Navomela kutengako mbali kumapunzilo aya.

Dzina (malembo akulu) __________________________ Siku (date)________

Signature _____________________________________

Ofunafuna (researcher) _________________________ Siku (date)______

Signature _____________________________________

London School of Hygiene & Tropical Medicine
(University of London)
Department of Public Health and Policy
Health Policy Unit
Keppel Street, London WC1E 7HT

Tel: +44 (0) 20 7636 8636 Fax: +44 (0) 20 7637 5391
Telex: 8953474 E-mail:
birgitte.bruun@lshtm.ac.uk

Iciputulwa Cabumi na Mafunde

Ubumi nama Funde

September 2008

Local engagement in Medical Research in Lusaka, Zambia

(Ifya Medical Research mumusumba wa Lusaka, mu chalo cha Zambia)

Information Sheet (Ipepala Lyaku Ilondolola)

Ine nine Birgitte Bruun, ndi mwana wesukulu pe sukulu lya busaka no muti ku London (London School of Hygiene and Tropical Medicine) ndi pamonebumba ilya abana besukulu aba mu Zambia, Kenya, Britain elyo na Denmark. Pali ino nshita ndeikala mumusumba wa Lusaka umwaka umo, pakutila inkasambilile ifyo abantu bapendulula ifya miti no bumi mu chalo cha Zambia. Ukusambilila kwandi ekukaba umufula wamasambililo yandi aya PhD.

Ndefwaya tulanshanyeko pafyo mupitamo elyo musendako imbali mukupendulula (research) pafya miti no bumi, elyo kabili ndelashanya na bantu abo abaitumpa muku pendulula ifya bumi, nefya kutwala ichalo pantanshi.

Ninkwata ulusa ulwa kuchita ifi nalanda ukufuma kuchitente icipendulula ifya malwele ku Ndola, naku chiputulwa cimona pa bumi (Ministry of Health) elyo nokufuma ku Chilonganino cimona pa bumi mu Lusaka (Lusaka District Health Management Team). Elyo na kwisukulu limona pa busaka nemiti kubulaya (London School of Hygiene and Tropical Medicine in the United Kingdom (UK)

Nakula lanshanya na bantu munshita munshita ukwabula ukubapima nangula uku bapela amashindano. Nakula bomba nowa kunondolwela efyo tukalalanshanya na bantu. Nkala ipusha limo limo ngakuti mwampelako ulusa ulwa kukopa amashiwi pakalimba (record). Ukuibika muli uku kupendulula kwandi cili kuli abo abalefwaya abene elyo kuti bafumamo nga balefwaya inshta ili yonse eyo batemwa. Ifyo bakalanda tafya kabikwe mufyo nkalemba kano abene bampela ulusa.

Ndemutotela apakalamba nga cakuti mwasumina ukuba muli uku kupendulula.

Kuti mwantumina lamya pa nambala 0966 916 061, nagula mwabonfya akeyala pamulu.

Nine Birgitte Bruun

London School of Hygiene & Tropical Medicine
(University of London)
Department of Public Health and Policy
Health Policy Unit
Keppel Street, London WC1E 7HT

Tel: +44 (0) 20 7636 8636
Fax: +44 (0) 20 7637 5391
Telex: 8953474
E-mail: birgitte.bruun@lshtm.ac.uk

Iciputulwa Cabumi na Mafunde

Ubumi nama Funde

Date

Interview Code

CONSENT FORM (UKUSUMINA)

1. Nasumina ukuti nimbelenga ifilembelwe muli ili pepala ilya mu September 2008. Ningumfwa fyonse ifilembelwe.
2. Nasumina ukuti naliikwata ishuko lyakwi pusha amepusho.
3. Ningufwa ukuti ukuba muli uku kupendulula kufwaya kwandi, elyo ngandefwaya kutinafumamo ukwabula ukulondolola.
4. Nasumina ukuti ukulashanya naine kuti bankopa ishiwi lyandi pakalimba, elyo umwana wesukulu (researcher) kuti alemba fyonse efyo twalalanshanya nankwe.
5. Ningufwa ukuti fyonse efyo nkalanda tafya kebulululwe ku mwana wesukulu (researcher).
6. Nasumina/nshisumine ukti efyo nkalanda, ifikope nafimbi ifikafuma muli uku kulanshanya fikabe nagula fikaba mufyo umwana wesukulu alalemba.
7. Nasumina ukuba muli uku kwelulula (study).

Ishina (Mufilembo Ifikulu)…………………………... Date (Ubushiku)………………

Signature…………………………………………

Kafwaya (Researcher)…………………………….. Date (Ubushiku)……………

Signature………………………………………….