POLYGRAPHY

Second Chances is neither a monograph nor an edited volume in the conventional sense. It is the work of eight people, four from Denmark and four from Uganda, coordinating closely to assemble one common body of material about a unique place and time in African history. Monographs are almost always solo books, written by a single author who disciplines the data to tell one story. In the nature of things, they cannot always fully reflect the contributions of colleagues, field assistants, interpreters, and informants. Edited volumes have multiple authors, each with a set of data and an analysis, often from different countries, intended to illuminate the same overall theme. Our book is a polygraph, written by a set of authors about a collection of people and families who share common circumstances. It is "multi-sighted" in that eight pairs of eyes (and ears) were at work, and it is multisited in that it describes a range of people, locations, treatment programs, and dimensions of concern. Taken together, the stories and chapters form one overarching narrative about the generation of people who knew acquired immunodeficiency syndrome (AIDS) as a fatal disease and experienced the advent of life-prolonging antiretroviral therapy. The polygraphic form suits the task we have set ourselves—to illuminate both the diversity and the historical uniqueness of a generation.

This polygraph does not pretend to be a lie detector, but like those machines, it records changes in the (social) body occurring simultaneously in response to questions—about how to live with the human immunodeficiency virus (HIV). Whereas lie detectors are supposed to assess the validity of people's evidence, our polygraph assembles evidence and gives the reader the opportunity to assess our interpretations of the first generation of AIDS survivors and its second chances.

Our corpus of material comes from long conversations with people about their lives before and after antiretroviral therapy (ART) and from repeated visits to their homes. By listening to their retrospective accounts and following them over time, we came to have a sense of the directions their lives were taking and the concerns to which they returned in conversation after conversation. We wanted to preserve the integrity and situatedness of persons, so we have built our book around eleven personal accounts. They are the main "cases"—biographical versions of our original inspiration from the extended case method of the Manchester School.[1] So often, excerpts from interviews or focus group discussions are used as anecdotes or snapshots to legitimate a point the analyst wants to make. In the process, lives and contexts are chopped up, leaving the reader with little possibility of an alternative interpretation. Even though we have chosen and edited these accounts in relation to certain themes, each provides a surplus of information and ideas relevant to other topics, as well. Our intention is to give readers the opportunity to think in cases, to compare them, and see how they complement one another.[2] Differentiation allows more interesting generalizations.

Each of these stories prefaces an analytical chapter about the primary concerns of members of the first generation. The chapter themes do not directly follow the categorical interests of many global health actors—such as adherence, stigma, disclosure, transmission, and counseling (although all of these are illuminated from our interlocutors' perspectives). They stay closer to the affairs and preoccupations of second-chance life worlds. Roughly, these are about the everyday dramas of treatment (chapters 1–3), family relations (chapters 4–6), and livelihood and daily life on medication (chapters 7–11).

The idea that we were studying a generation took shape gradually; it emerged partly through our interlocutors' accounts, but also through our own experience. We all knew the situation before AIDS treatment was available, and we were working together over the years when the antiretroviral medicines were rolled out. Thus, our own historical location was essential to the bigger story we were trying to grasp. Michael and I, the oldest members of the team, did our first fieldwork in Uganda from 1969 to 1971, not so long after independence, in the pre–Idi Amin period our younger acquaintances sometimes wistfully call the "original Uganda." Returning frequently after

1988 and keeping contact with families we had known, we witnessed the onset of the epidemic and mourned the loss of many friends from our early days as young doctoral students. The rest of our group came of age as researchers in the time of AIDS. Lotte Meinert and Hanne O. Mogensen were closely involved with people who were sick and dying during their fieldwork in eastern Uganda. Godfrey Etyang Siu, Jenipher Twebaze, Phoebe Kajubi, and David Kyaddondo, like all Ugandans, were affected by suffering and death in their own families and among friends and colleagues. Even more than we from Denmark, they could not get away from AIDS. Public talk of the epidemic was constant after 1986; private distress and helplessness over the lack of treatment was just as constant until 2004.

We began working together under an Enhancement of Research Capacity project that ran from late 1994 to 2008. Supported by the Danish International Development Agency, it linked two Danish universities with the Child Health and Development Centre, a small, cross-disciplinary unit at Makerere University. The theme of our cooperation was the changing relation between communities and health systems. We called our project TORCH, for Tororo Community Health, Tororo being the district where our project was anchored and where, by the end, five of us had done long-term ethnographic research for doctoral dissertations. Although our project initially did not address AIDS (many other researchers were flocking to that topic), we did studies with health workers and families seeking treatment for all kinds of problems, which provided a necessary context for our work on second chances toward the end of the TORCH project.

We ourselves formed generations in an academic genealogical sense. Michael and I are the grandparents. Under TORCH, Michael was the supervisor of David, then a lecturer in Social Work and Social Administration at Makerere. I advised the two Danes, now my colleagues, Lotte and Hanne. The next generation of Ugandans, Jenipher, Phoebe, and Godfrey, all went on to earn doctorates in various aspects of AIDS in Uganda after TORCH ended. Hanne supervised Jenipher, who was awarded her degree in Copenhagen. David and I are co-supervising Phoebe, who is registered at Makerere University. After completing a master's at Copenhagen, which I co-supervised, Godfrey went on to earn a doctorate at the University of Glasgow, working with Janet Seeley, whom we met through our research. Academic generations are much shorter than kinship generations; still, by any standards, our engagement with one another has been enduring and fruitful.

When treatment for people with AIDS first became available in Uganda, it was far too expensive for most people. As the price fell, it came almost in reach of families with a modest income, while a few fortunate individuals were able to get the medicines for free. The inequities of this situation drew several of us to do a small pilot study of the diverse ways people were struggling to gain access to the life-saving treatment as a multitude of projects emerged after 2002. We retained an interest in diversity and the "projectification" of treatment when we launched the study that we have come to call Second Chances.

In late 2005, we approached six different sources of ART, three in Kampala and three in southeastern Uganda (Tororo, Mbale, and Butaleja districts), with a request to help us identify people willing to be interviewed about their lives and treatment. From earlier fieldwork, Hanne and Lotte knew people receiving treatment from a seventh source, whom we approached directly as friends and former neighbors. Using these methods, we found forty-eight individuals, whom we interviewed once between December 2005 and March 2006, in a very open format, taking extensive notes but without using a recorder. These were long life-story interviews about how they fell sick and got on treatment, but also very much about their families, partners, work, and daily lives. About half of the conversations were in people's homes, and most of the others took place in a quiet corner of the clinic, under a tree, or even, in one case, in the back of a car.

These forty-eight were by no means representative of people living with HIV or even of those on ART. People who were extremely ill at the time, as well as those whom the health workers considered difficult, and, most of all, those who did not have the economic, social, or cultural capital to get on treatment and stay on it for a while were not among our interlocutors. We tried to encompass variation by choosing both urban and rural sites and by identifying programs that provided only free treatment and others where some clients were paying a fee. We asked the treatment providers to help us find a balance of men and women, with different occupations, and to include people who were paying for treatment. We ended up with informants who were generally somewhat better educated than the average Ugandan in their age range of 30–50. But none were members of the powerful and prosperous elite; those people usually prefer discretion, and many get treatment from private doctors. The people whose lives we heard about, and those we later followed, almost all had financial problems, although there were differences in their livelihood situations. There were teachers, health workers, and soldiers who earned modest monthly salaries, artisans who maneuvered for contracts, and people struggling with small business ventures or farming. Most of these forty-eight people were well settled into their treatment regimes. Thirty had started ART more than a year before we spoke to them; only six had been on the drugs for less than six months. At that time, seventeen of the forty-eight were getting their antiretrovirals on a fee basis (although some were not paying out of their own pockets). The most common drug used was the generic Triomune from Cipla, an Indian pharmaceutical company. The forty-eight were evenly divided between men and women, and twenty-five were married.

Of these forty-eight, we chose twenty-four whom we contacted again to ask whether we might continue to visit them. We selected people from each of the seven treatment sites, men and women, including some who were paying for treatment. We tried to preserve the variety of livelihoods, and, of course, we approached people who had already indicated that they would be open to talking more with us. The ensuing seven visits took place between April 2006 and June 2007. From the first interview to the last visit, we thus cover a period of about eighteen months in the lives of these people. Two seemed uninterested in further visits, and we stopped bothering them, but one, whom we had decided to exclude because she lived so far away, kept looking in whenever she came to Kampala—she included herself in our study. Thus, we ended by following twenty-three people on treatment; in fact, there were more, for many households included several HIV-positive people, and some of these others were also on ART.

By “we,” I mean primarily the Ugandan members of the team, who alone did most of the original forty-eight interviews and made the follow-up visits, each having five to seven people to follow. The Danish team members occasionally went along when they were in the country and followed the visits through the written notes. Especially when the Danish researchers had known the family before, it was evident how the quality of the relationship depended on the particular people engaging one another. Sometimes Hanne and Lotte were surprised at the picture that emerged when a Ugandan researcher started a relationship afresh with someone they thought they knew.

In the follow-up visits, we found people in their homes or at their place of work. Talking to people in those places, rather than at treatment sites or nongovernmental organization (NGO) projects, as is often done in health research projects, decentered AIDS. Sometimes people did not even mention their illness and treatment during the several hours that a visit lasted. Family matters and everyday affairs engaged attention and conversation rather than the material needs and donor resources that preoccupy NGO project meetings. This produced evidence that was less influenced by clinic and NGO discourse and practice. It provided insight into how illness and treatment fit into other concerns. Even though the visits were relatively short and intermittent, they gave a social context for the patients who were treated as individuals at the clinics. Our method had something of the rhythm of ordinary social interaction, which involves meeting again, the next day or years later, and updating one another on what has happened in the interim.[3]

Calling our informants "interlocutors" is accurate. There was no real question guide, and the visits took the form of conversations. David, Phoebe, Jenipher, and Godfrey were from three regions of Uganda and spoke different languages, so that some of the conversations could happen in the mother tongues of researcher and interlocutor. Otherwise, they found a common language; in no case was an interpreter necessary. As visitors from the national university, the Ugandan researchers were treated with respect. They always brought a small gift in kind for the household and were often served refreshments. But the particular relationships and the kinds of engagements developed differently. Some people asked for advice; some wanted to borrow money; some phoned or sent SMS messages between visits. Several of the men asked to be given money instead of comestible gifts for the household. Some interlocutors became friends who wanted to share confidences. Others maintained a certain reserve throughout or seemed unforthcoming at some visits and much friendlier at others.

The characteristics of both parties shaped the relationships. Gender played a part in some, as when Jenipher realized that Dominic's wife assumed she was a potential co-wife, and his father called for a piece of charcoal to write her phone number on the wall of the house. David saw that it would be unwise to call on Jackie at home, given the jealous suspicion of her partner. Phoebe visited a soldier who was separated from the mother of his children. When they hung on Phoebe and wanted to go with her, their father explained that they were missing their mother. Friendship and enjoyment of each other's company developed in many cases as the researchers returned again and again. One of Godfrey's interlocutors, from his home area, always expressed admiration for his education and accomplishments and asked his advice on financial matters. David had a background as a trained AIDS counselor and social worker, besides being a full-time university teacher. It was difficult for all four Ugandans to convince interlocutors that they were not health workers or counselors associated with the treatment programs. But it was hardest of all for David, especially because three of "his" people sometimes visited him at his office in the health sciences faculty at Mulago, the national referral hospital.

The challenge for Jenipher, David, Godfrey, and Phoebe was not so much establishing rapport; they are all experienced fieldworkers and friendly, interested people. The difficult part in this type of research is writing up notes immediately and fully to capture the conversation and convey the situation. The Ugandan scholars managed this brilliantly. Theirs was the task of polygraphy in the old sense of copious writing. Their notes filled hundreds of pages and were full of particulars that made people and circumstances come alive for us in Denmark. As individuals, the four visitors were sensitive to different nuances, but all wrote notes that were rich and thoughtful. Their notes were the direct source of the eleven case accounts in this book. To remind readers that this kind of global health "evidence" is produced through intersubjective relationships, we retain in the accounts some details of personal interaction as the researchers recorded them.

After a failed attempt at a computerized thematic analysis, we sat down together at the broad hardwood conference table in our research center in Kampala to brainstorm. On the basis of the interviewers' field notes and headnotes, experiences and reflections, we agreed on the main topical concerns that became the chapters of this book. At further meetings in Kampala and one in Copenhagen, we discussed possible ways to deal with the themes and chose the protagonists whose stories would be presented at greater length. Jenipher organized the notes, and I went through them all and made a kind of index according to our themes. We agreed that the material is ours in common and that any one of us can use it in teaching and writing.

In an attempt to keep everyone involved, we divided the cases and the chapters. Each of the Ugandans wrote about the people they visited, with editorial input from the Danes who followed each "case." Danes and Ugandans drafted the analytical chapters, each working on topics in which they were especially interested. My task differed from the usual responsibilities of editors. The common material was enormous, and I had to decide what would be used where, since the chapters drew on all forty-eight original interviews and twenty-three extended cases. As the overall conceptual themes of generation, sociality, and second chances emerged, I tried to develop them from chapter to chapter to create in our polygraph something of the coherence of a monograph.

Confidentiality was an issue right from the start. Sometimes the visitors were warned not to speak about the reason for their visit when certain others were present. Godfrey became adept at changing the subject whenever one of Matayo's colleagues came into the room where they were talking. Jenipher was quick to hide her notebook when a customer called at Alice's shop. Phoebe visited one family where no one but the mother and one daughter knew why she kept coming. In the notes and in conversations with one another, we used a pseudonym for each interlocutor—so systematically that we hardly remember their real names any longer. In writing, we have sometimes changed details that might make people recognizable.

After the visits ended, Jenipher continued to follow some of the people she had worked with in our study as part of her doctoral project, and a few of the others kept in touch sporadically. Mostly, though, the engagements with our interlocutors ended after the eighth visit. It had to be so. Social life is as much about cutting relationships as about creating and maintaining them. Still, for a few who became friends, the classic fieldworker worries about having exploited friendship remains. Godfrey wrote about John, who admired him so much:

> I worked with John through his grief and joys, and this is perhaps what ensured that we had such a productive connection during the study. However, I feel a great sense of shame and guilt for failing to reach out to John and find out what has happened after fieldwork. My failure to keep his phone number after fieldwork at times haunts me, and I feel I betrayed John. I prioritised my work, my other research, and abandoned the relationship I had built with another human being, a person who had lots of expectations for long-lasting ties. My research colleagues and I know that this is the right thing to do since the research had come to an end; yet looking back, it is obvious to me that this wasn't the best decision.

We from Denmark felt that our engagement with the challenge of AIDS endured through our Ugandan colleagues, who remained at Makerere as a strong resource base for future projects on AIDS. But they ended their relations with the interlocutors whose lives and experiences are the substance of our book. As Godfrey wrote, that sometimes feels wrong. Yet in a broader sense, the Ugandan researchers continue to follow closely the fate of the first generation struggling with second chances. It is their generation, too.

SUSAN REYNOLDS WHYTE

Notes

1. Kapferer, "Situations, Crisis, and the Anthropology of the Concrete."
2. Biehl and Petryna, "Critical Global Health."
3. M. Whyte, "Episodic Fieldwork, Updating, and Sociability."