HEALTH, CULTURE AND SOCIETY
STUDIES IN MEDICAL ANTHROPOLOGY AND SOCIOLOGY

The essays in this volume consider what medical anthropology means in the academy and outside of it. Written by a diverse group of anthropologists, some of whom also work as doctors, public health workers, and NGO staff members, the essays share personal insights on how they used anthropology to solve health problems and improve interventions.

Several of the contributors draw on their own illness experiences to reconsider the health challenges they have previously sought to understand, analyse, and document. Other essays come from authors who have struggled to incorporate anthropological methodologies and perspectives in multi-disciplinary research and medical relief work. Also included are essays from professional anthropologists who reflect on the value of their discipline's mission and methodology.

This collection demonstrates how anthropology is used in policy and health interventions and attempts to bridge the gaps between policymakers, clinicians, NGO workers, doctors, and academic researchers.

Rebekah Park *is a PhD candidate at the University of California, Los Angeles in the Department of Anthropology. She is currently writing her dissertation based on her work with the Association of Former Political Prisoners of Córdoba, Argentina.*
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HEALTH, CULTURE & SOCIETY

DOING AND LIVING MEDICAL ANTHROPOLOGY

REBEKAH PARK & SJAAK VAN DER GEEST

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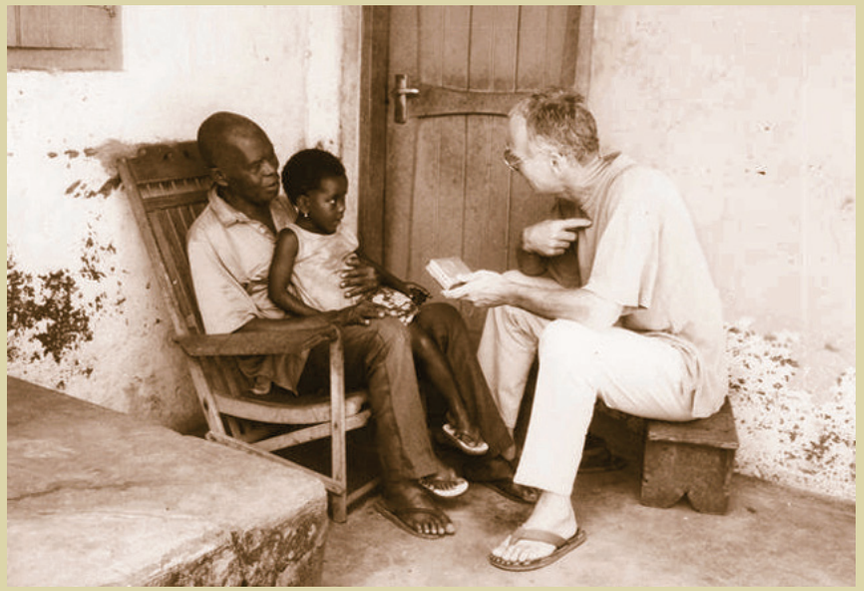

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(EDITORS)

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This book is dedicated to our teacher,
colleague and friend Els van Dongen († 2009).

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Illustration cover: Sjaak van der Geest conversing with Nana Kwaku Nyame, a Ghanaian elder, on the joys and pains of ageing. The cassette recorder is directed toward Nyame, and Van der Geest is pointing at himself: "doing and living medical anthropology". The photograph was taken by Patrick Atuobi, Van der Geest's co-researcher.
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Preface

In May 2007 the Amsterdam Master's of Medical Anthropology (AMMA) of the University of Amsterdam celebrated its tenth anniversary with a conference about "Teaching and Applying Medical Anthropology." This volume contains nine selected essays from this conference and two additional ones since the conference. AMMA graduates wrote seven of the chapters and faculty members penned the remaining four. The contributions feature autobiographical accounts on applying medical anthropology in diverse professional positions and in personal lives, contextualised within the broader history and theoretical development of the discipline. The authors engage in reflexive anthropology, delving into the role medical anthropology plays both in and outside of academia. Several essays recommend medical anthropological pedagogies and applications in settings of both theory and work.

The AMMA programme opened its doors in 1997 with eleven students. By 2010, 159 students had graduated from AMMA. From the start, the student body has always been, and remains, global. Each year, the classes are filled with extremely diverse individuals, of varying ages, professions, and cultural backgrounds. The vast majority of the students already possess an advanced graduate degree and work in various health-related fields. Students are often doctors, public health officials, social science researchers, and NGO workers who are looking to improve their existing professions with a medical anthropology perspective. They have encountered obstacles in their work, such as failing interventions due to lack of cultural knowledge, and desire knowledge on qualitative methodologies. They also look for a richer theoretical understanding of culture, particularly in terms of health, illness and medicine.

In many ways, the personal identities of the students create an ideal environment to learn anthropology because each class discussion is a practice for cultural brokering. Speaking about 'genital mutilation' with students who have undergone circumcision rituals, or classic early anthropological works conducted in 'primitive cultures' where many of the students are from, creates an entirely different experience than if taught to a homogenous student body. In AMMA, students are engaging with others who can draw from their personal and professional experiences, particularly since AMMA students are what

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the tradition has often defined as the 'other.' Thus, this programme not only trains a diverse generation of anthropologists, but it also teaches anthropology through its peers.

The student profile is also reflected in the main purpose of AMMA, which is to enable its graduates to help solve health problems with anthropological theories, concepts and methodologies. Faculty members take pride in showing how anthropology can be used to improve existing health efforts. While the length of time limits the breadth of knowledge that can be conveyed within a year, the programme still endows its students with core concepts that enable them to better champion an anthropological perspective in multi-disciplinary teams. In other cases, AMMA strives to equip the individual with the tools to consider cultural, political, and economic factors in the process of creating and implementing health interventions.

On the occasion of its jubilee conference, the AMMA department invited all its alumni to submit a paper on their lives after AMMA. The invitation posed the following questions as possible themes for their contribution:

- What kind of work did you engage in after graduating from AMMA?
- How did you use the skills and knowledge gained from AMMA in your current work?
- Can you present and discuss concrete cases and/or projects in which medical anthropology made a difference?
- Can you present and discuss concrete cases and/or projects where the opposite happened?
- Are there case studies in which the integration of medical anthropology improved past failures in health-related initiatives?
- Could you, on the basis of your (and others') experiences draw wider theoretical, methodological, ethical or policy-related conclusions (or raise questions of more general importance)?

In total 33 abstracts were submitted for the conference, and 19 of those abstracts were chosen to be presented and discussed at the conference. As mentioned before, nine of the conference papers were eventually selected for this book, which were peer-reviewed and went through substantial revisions.

We encouraged the writers to personally reflect on the intertwinement of medical anthropology in work and life. Both the personal reflection and the emphasis on research outside academia follow the 'culture' of AMMA's teaching and organization. Applied medical anthropology is for many of the students a crucial objective, especially those who have previous training in medical and related professions to which they return to upon graduation.

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We hope that this collection of essays will not only serve as a – perhaps nostalgic – memory of a successful conference and ten years of AMMA life, but will also inspire present-day colleagues and future generations of the professional and existential potentials of medical anthropology.

And finally, we want to thank all who contributed to the success of the conference in 2007 and the production of this book, in particular Trudy Kanis, Peter Mesker, Janus Oomen and Chris Aldenhuijsen, the authors and their discussants during the conference, Susan R. Whyte, Michael L. Tan, Sera Young and Ria Reis who advised us in the selection of the conference papers, the anonymous peer reviewers, Anthony Holslag, and the other AMMA colleagues.

We dedicate this book to Els van Dongen, an original anthropologist and gifted teacher who taught eight generations of AMMA students. She passed away in 2009, at the age of 62. We are grateful that we have been able to include her last publication, a reflection on her final year, as patient *and* medical anthropologist.

Sjaak van der Geest
Rebekah Park

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Chapter 1

Doing and Living Medical Anthropology

An introduction

REBEKAH PARK & SJAAK VAN DER GEEST

This volume brings together essays written by people of extremely diverse backgrounds on how their study of medical anthropology has impacted their work and life – primarily outside of academia. It is our intention to shed light on how anthropology is practiced in non-academic settings through the eyes of those who are both within and outside of the university. Academics generally tend to regard applied anthropology as superficial, lacking theory and 'thin' in its efforts to gain attention from non-anthropologists working in public policy and clinical practice. Non-academics, in contrast, often regard the anthropology being practiced and taught in universities as slow, jargon-filled, and overly theoretical. These views underestimate the complexities of making research findings work beyond hypothetical scenarios, as well as the feasibilities of adopting an anthropological approach without working under the label of 'medical anthropologist.'

By and large, the authors have avoided the tired debate between theory and practice. The essays address three themes: methodology, personal experience, and anthropological thinking. This volume is less engaged with academic texts as it is with the actual work and life experiences of those trained in anthropology. For this reason, the majority of the chapters deal with methodological challenges within multi- or interdisciplinary projects. Other contributors ruminate on how their anthropological training has impacted their personal lives as they recover from or succumb to illnesses. Others describe ways that people have integrated an anthropological view into jobs, which are not anthropological, and how they are still able to utilize their training regardless of limitations. In our contributions to this volume, we reaffirm the strengths of anthropological methodology.

The idea that applied research is theoretically thin is a misunderstanding (Bailey & Van der Geest 2009). Adding practical consequences to ethnographic data rather requires complex theoretical reasoning on agency, situationality and

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political leverage (see Bailey 2009, Oosterhoff 2009). It also requires cultural translation, one of the main ambitions of anthropology.

It seems that anthropologists struggle more with bridging the cultural gap between policymakers and health practitioners than they do between themselves and their research participants – even when they do not speak the same language. Anthropologists are more eager to capture the 'villagers' point of view than to delve into the culture of policymakers. Their unwillingness to transition into the world of policy may have to do with academic ethnocentrism (Van der Geest 1985), lack of accountability (Glasser 1988), and romanticization of the exotic (Hemmings 2005), or its corollary, what Blok (2001) calls "the narcissism of minor differences." For Blok, narcissism hinges on the "idea that identity lies in difference, and difference is asserted, reinforced and defended against what is closest and represents the greatest threat" (Blok 2001: 123).

Thus, we present essays in which academic anthropologists reflect upon the utility and meaningfulness of their research findings to policymakers and clinicians, as well as writings by clinicians, public health workers, and policymakers who incorporate anthropological methods in their work despite financial, temporal, and ideological restraints.

The struggle to show that medical anthropology 'matters' is well described by veteran Dutch anthropologist Corlien Varkevisser who, in her retrospective essay, believes in the value of anthropology in the world of public health. She has continuously sought to share ownership of research projects with the people for whom the findings mattered, in hopes of ensuring that health interventions actually succeed in solving the problems at hand. Paul Bukuluki writes from Uganda about his work on a multidisciplinary team that initially rebuffed his efforts to incorporate anthropology into the research design. In the end, however, the team benefits from the nuanced insights gained from Bukuluki's anthropological approach, which reveals that the concerns of their young subjects about teenage pregnancy took precedence over their feelings about HIV/AIDS – a discovery that contradicts the assumptions about risk, fear, and stigma. Vanessa Van Schoor, raised in South Africa and Canada, reflects on her experience as newly trained medical anthropologist and emergency aid worker in Côte d'Ivoire. A long-time worker with Médecins Sans Frontières, Van Schoor credits her anthropological gaze as having helped her to take some distance from the hectic work in which she was involved, and thus identify her organization's misdiagnosis of the situation.

Emily Bhargava, an American public health worker, discusses the role that anthropology played in a public health programme aimed at the elimination

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of health inequality in the Boston area of the United States. Anthropology, she asserts, provides a language and a framework for thinking about culture and difference in a neutral way that can help make conversations about disparities and cross-cultural partnerships more productive. Carla Donoso Orellana reports on the benefits and limitations of an anthropological approach to researching condom use among homosexual men in her home country, Chile. While her research uncovers important themes of love, pleasure and sexual experience in regards to condom use in homosexual relationships, she also finds herself limited by the epistemological gap that exists between her and her medical colleagues.

The uneasy relationship between theoretical and applied medical anthropology is the main issue in the essay by Dutch anthropologist Sjaak van der Geest. He argues for a rapprochement between both, and for a productive combination of qualitative and quantitative approaches in medical anthropology methodology. Reflecting upon his own past research, however, he admits rarely succeeding in 'selling' his results to policymakers or health practitioners (Shahaduz Zaman draws a similar conclusion in his essay.) Van der Geest's main audience is overwhelmingly anthropology students and colleagues.

Laura Ciaffi, a physician from Italy, writes about her decision to study medical anthropology to better prepare for emergency relief work in various cultural contexts. Now, several years later, she is ambivalent about her decision. On the one hand, she experiences a kind of 'revelation', now viewing her clinical work from a broader perspective and seriously considering what is at stake for the people she works with in the field. On the other hand, she realises (like Orellana) that the gulf between the medical and the anthropological gaze remains wide. As a doctor in the field, Ciaffi uses anthropological insights when working in different cultural settings. She goes beyond what is spoken and considers her patients within their context. What is more difficult, however, is actually making use of an anthropological approach – even applied medical anthropology – in her clinical work.

Rebekah Park, who is in the early stages of her academic career in the United States, rediscovers an appreciation for participant observation, one of anthropology's strongest methodologies in understanding the contradictions between what subjects say and do. Conducting research over a long period of time enhances an anthropologist's relationships in the field, and also the quality of her data. Park suggests that anthropological methodology is not only limited to the way we conduct research, but also includes the writing process. Choosing how and what to write entails balancing the priorities of the local communities in which we conduct our research with those of the academic community that shapes our theoretical approaches.

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In several of the contributions, personal life experiences intertwine with the professional sphere and anthropological research. Reflection on how medical anthropology affects personal lives is one of the major themes in this volume. The emphasis on the personal may be related to the pedagogy of University of Amsterdam's Applied Master's in Medical Anthropology program – where all of the authors have either graduated from or taught. Students from very different professional, national and cultural backgrounds are assembled together within an intensive course that forces them to be in each other's company continuously for a full year. This diversity is, in fact, an important element of the course; cultural differences among the students are openly discussed and demonstrate the ever present but elusive concept of culture. Cultural sensitivity, therefore, is practically required and enhanced by frequent reflection on personal biography and experience among people of varying backgrounds.

We chose the overlap of research and work with personal life because we believe it to be a crucial but under-exposed space where medical anthropology is done. In their collection of essays, Athena McLean and Annette Leibing (2007) speak of the 'shadow side' of fieldwork, or how the unacknowledged – hence shadowy – combination of autobiography and personal experiences directs research and analysis. McLean and Leibing draw their inspiration from Michel Foucault who observes the following about his own analytic process:

> Every time I have tried to do a piece of theoretical work it has been on the elements of my own experience: always in connection with processes I saw unfolding around me. It was always because I thought I identified cracks, silent tremors, and dysfunctions in things I saw, institutions I was dealing with, of my relations with others, that I set out to do a piece of work, and each time was partly a fragment of autobiography (cited in McLean & Leibing 2007: 6).

In this volume, we compare Foucault's observation with our own experiences on the intersection of autobiography and fieldwork. Personal reflections on the mundane become a part of the analytic framework, yet how and to what extent they do often goes undefined. In this volume, we seek to capture this interaction.

In his book on the production of ethnographic knowledge in Papua New Guinea, Crook (2007) argues that the personal life experiences of anthropologists like Margaret Mead, Reo Fortune, Gregory Bateson, Fredrik Barth and Annette Weiner influenced their theoretical and methodological approaches in their ethnographic work. For example, the "temperamental *ménage à trois*" of Mead, Fortune and Bateson in the field informed their ethnographic choices

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and analytical perspectives. Mead was then drifting towards Bateson, away from her husband Fortune. In her autobiography *Blackberry Winter* Mead wrote:

> Reo [Fortune] was both repelled and fascinated by the Mundugumor. They struck some note in him that was thoroughly alien to me, and working with them emphasized aspects of his personality with which I could not empathize (quoted in Crook 2007: 138).

This is a prime example of 'Sex and Temperament' *in statu nascendi.* Somewhat hyperbolically one could perhaps say that the three were channelling their emotional states into anthropology.

Anja Krumeich's ethnography *Blessings of Motherhood: Health, Pregnancy and Child Care in Dominica* is another illustration of how personal life and research converged in the field. Krumeich conducted research on mothers' ideas and practices during pregnancy and their care for young children in the Caribbean island of Dominica. At first, the mothers were friendly and helpful but reserved. They viewed Krumeich's questioning as a cross-examination and did their best to give the 'right' answers. However, when one of them discovered that Krumeich got pregnant with a Dominican man, everything changed. From that moment onwards the all-knowing anthropologist turned into a helpless young woman who, far from home, had become pregnant by 'one of those men' and needed the mothers' help and advise.

> All of a sudden people understood my presence and my silly questionnaires. They forgot I had asked them as a researcher, and interpreted them as a testimony of my helplessness. I instantly had a number of 'mothers' who felt responsible for teaching me the meaning of being a woman and preparing me for motherhood (Krumeich 1994: 138).

Unprompted the mothers started to tell Krumeich what she should do to protect her pregnancy and have a safe delivery. When her son was born – in a local hospital – they instructed her on how to raise a newborn child healthily and properly. The information she had tried to acquire as an anthropologist – with limited success – was suddenly given to her in abundance (Krumeich 1994).

Moreover, it was not only 'information' that was offered to Krumeich. Getting pregnant, having a baby, looking after her son, and arguing with the child's father enabled Krumeich to experience the range of emotions that are seen to be integral parts of the motherhood experience in Dominica. At one point, when the child's father had beaten Krumeich, the mothers (who by now

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had become her friends), offered their comfort. Participant observation was no longer just a methodological tool; it had become her personal reality as well.

Gerhard Nijhof, a sociologist, who after being diagnosed with colon cancer and undergoing extensive treatment, wrote about how his cancer changed not only his life but also his sociology. Nijhof spent an anxious period in the hospital and had to learn how to live with his disease. He later published *Ziekenwerk* (Sick work), where he attempted to forge a new kind of medical sociology from an insider's perspective (Nijhof 2001). For most medical sociologists, however, serious illness is not a personal experience. They conduct surveys or hold interviews and return to their universities to analyse and write their findings. The concepts they use reveal their provenance: the minds of healthy sociologists. Nijhof became acutely aware of this when he became sick, encountering completely different perspectives. One of these was the *unspoken* word. For years, analysing texts had been his main occupation, but he suddenly realised that people may remain silent about certain experiences. "Yet, we continue to pay attention only to their speaking… The things about which they don't speak escape us." That is the reason that "interrogating sociologists miss so much of what sickness means to sick people." Serious illnesses like cancer are often surrounded by silence.

Sociologist Ian Craib's own experience with cancer, which he ultimately died of, led him to reconsider what his colleagues called a 'good death.' Using this concept, he wrote that sociologists produce, "a sanitized version of dying, hiding the powerful feelings, contradictions and horrors" (Craib 2003: 292).

Other examples of researchers who were affected by serious sicknesses and used their experiences to write more analytically about illness are Robert Murphy and Arthur Frank. Murphy (1998) began writing about his illness from the moment the first symptoms of his spinal cord tumour presented themselves, and continued to write to the point at which he became restricted to his wheelchair and dependent on others, eighteen years later. This ethnography of one person demonstrated how illness could shape social identity. Frank (1995, 2001) has written extensively about his own illness experiences, using them as 'data' to provide in-depth insights on sickness and suffering. Arthur Kleinman (2006) reflected on his life as a psychiatrist and anthropologist and realised that he did not really understand the pain of those who approached him for help. Experiences of pain and misfortune in his own life have since opened the world of others to him (see also Van der Geest 2007).

Three authors in this volume use their personal experiences as starting points for reflections on medical anthropology. They focus less on experience as a way to do better anthropology and more on how they used their anthropological 'worldview' to interpret their own lives.

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Shahaduz Zaman, a physician from Bangladesh, considers his own journey with medical anthropology. He began his career as a 'reluctant doctor', who was instead interested in becoming a writer, and eventually escaped clinical life by devoting himself to public health. Then, by a twist of fate, he was given a chance to study medical anthropology in Amsterdam. Anthropology provided him with the ability to blend together his interests in medicine, culture, and literature. Medical anthropology enriched him both as a doctor and as a writer. These three 'souls' constituted a type of internal 'triangulation'. Medical anthropology, Zaman concludes, has helped him to discover himself.

In his essay, Michael Golinko, a physician from the United States, discovers the value of medical anthropology through the experience of becoming a cancer patient. While he did gain new insights into the practice of medicine by using an anthropological perspective, he did not apply those lessons to his clinical practice until he experienced cancer. Golinko realizes that doctors – actually his colleagues – treated him differently from other patients because of his medical degree, even though he harboured as many doubts as other patients did. Golinko embarked on a personal journey that taught him empathy – a quality he had not fully realized in his previous attempts to assuage his patients' fears before having had cancer himself.

Els van Dongen, a long-term faculty member at University of Amsterdam who passed away in 2009, writes about her experience living with cancer both as a patient and as a medical anthropologist. For the better part of her career, Van Dongen devoted her writings to narratives on social suffering. She finds herself battling the tension between her intellectual acknowledgment of maintaining moral practices while being sick, and the desire to reject the social obligations of putting on a strong face to lessen the burden of her death for others. Her conviviality and willingness to present a stronger self-image enables others to offer their comfort and to be comforted themselves. She wants to care for her husband and children as much as they care for her. Likening her experience to Job's trials and the tests of his faith, Van Dongen finds herself continually facing gruelling and frightening treatments, and yet remaining optimistic. In the end, she discovers that "being ill is trying to remain a social being."

This volume strives to show what medical anthropology means to scholars not only in their work and scholarship, but also in their personal lives. Several of the contributors draw from their own experiences with illness, which offer the most direct knowledge of the kinds of challenges they seek to understand, analyse, and document. For others, struggling to apply the new insights of medical anthropological theory and methodology in their non-anthropological jobs becomes almost a personal cause. As a whole, the volume brings together the views of anthropologists who are both in and outside of the university as

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a way to bridge the gap between policymakers, clinicians, NGO workers, and academics.

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Chapter 2

Staking a middle ground between public health and medical anthropology to reduce health disparities

EMILY BHARGAVA*

As a community health specialist trained in medical anthropology, I have struggled with the fact that the public health system – the system that pays my salary – does not have the same point of departure or the same priorities as the medical anthropological approach in which I was trained. Despite this discomfort, I believe that although the two fields look at the world through different lenses, their goals are not in opposition and they can even complement one another. The public health system is responsible for monitoring health status, ensuring solutions to health challenges, and educating and mobilizing the population around health issues (Corso et al. 2000: 2). In turn, medical anthropology in its purest form is intended to increase knowledge about multiple health beliefs, health practices, and health systems. As an academic pursuit, medical anthropology does not require researchers to take responsibility for the health of the people around them in the same way public health obliges its practitioners to do. But when utilized in the interest of public health, I have found that applied medical anthropology becomes a set of tools and techniques as well as a perspective that can complement and strengthen the work already being done to improve population health.

Soon after graduating from university I worked at a small social service organization in a poor neighborhood of Boston. Most residents of the neigh-

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borhood were Latino, African-American and Cape Verdean. As a staff member of the agency's public health department, I was responsible for designing and implementing health programs on topics ranging from teen pregnancy and HIV prevention to nutrition and lead poisoning prevention. Again and again in my efforts to design programs to address these issues, I struggled with funders who wanted me to run programs that had been tested and proven effective. Unfortunately, the programs that had been proven to be effective had only been tested with Caucasian populations, a different demographic than the ones with whom I worked. What works for one kind of community does not necessarily work with another, and yet, if I adapted the programs, I would be using untested interventions. It would take years to see if these adapted programs would prove effective, and I had no basis for arguing that our projects would be successful at achieving their outcomes.

While my colleagues and even some funders understood the importance of culturally appropriate programming, they were unable to resist the dominant paradigm in public health that funding should be directed to programs that have been tested, evaluated and proven effective, and that these programs should be run exactly as they were developed. In our small struggling agency and in our neighborhood, there was no money to adapt and test programs to make them suitable for our diverse populations. As a result, we adapted models as much as we could within the constraints of the program design and our reporting requirements. We developed innovative and culturally appropriate programs on a shoestring budget, and I seethed about how difficult it was to convince funders that we needed a new paradigm and a new set of funding guidelines.

This process was what brought me to the Amsterdam Masters in Medical Anthropology (AMMA) – the recognition that I needed not only a language to argue more strongly for culturally relevant programming, but also the tools and techniques that would let me test the efficacy of those programs and create new culturally-appropriate prevention programs.

The public health context and the emergence of health disparities as a key concern

At local and state levels in the United States, the public health system has a limited set of human and financial resources to assume the gargantuan task of maintaining the health of the whole population. As a result, public health tends to take a highly epidemiological, biomedical approach and focus strongly on the cost-effectiveness of interventions (Roberts & Reich 2002, Rafael &

Bryant 2003). This in turn limits the amount of time that those of us working in the field can spend on the planning, assessment, research, and refinement of programs for sub-populations. Recognizing the uniqueness of health cultures, as medical anthropology does, implies that culture-specific interventions are necessary. The careful ethnography required to create a nuanced understanding of every sub-population's beliefs about every health concern, however, takes time and money – resources that the health system lacks. And yet health is inextricably linked to culture, illustrated most starkly in the United States by the striking health disparities that exist between cultural groups.

Over the last decade, there has been increasing attention paid to health disparities by scholars and journalists. A prime example is the publication of *Unequal Treatment: What Healthcare Providers Need to Know About Racial and Ethnic Disparities in Healthcare* (Smedley et al. 2002) that explores the issue in detail. As a result of the public discussion of health disparities, it has become hard for health institutions and health systems to continue to function without a good deal of self-reflection. The idea that we not only want to increase healthy choices and decrease the incidence of disease, but also reduce the disparities in health between racial and ethnic groups, requires a deep understanding of cultural identity. It also requires a framework within which to define, design and implement interventions that target the groups with the worst health outcomes in a way that is culturally appropriate and respectful.

When I returned to the workforce armed with the perspective and the skills of medical anthropology, the context around me had changed. There was more talk than before about cultural competency. National standards for culturally and linguistically appropriate services (Stinson 2000) were now being required of all healthcare providers, and health disparities were on the tip of everyone's tongue. I entered the job market with some of the skills that public health practitioners (and funders) were suddenly seeking. I was hired for a technical assistance role, where I was in a position to support groups in furthering their own health promotion and prevention goals, and I contributed my medical anthropology-informed perspective at every stage.

Although the intentions of the field of public health with respect to cultural competency had changed and the importance of tailoring health efforts to specific cultural needs was being recognized at many levels (Brach & Fraser 2000, Cooper et al. 2002, Betancourt 2005), practice, for the most part, had not changed. It has been a struggle to maneuver the interplay between those good intentions and the established habits of public health. These habits include bowing to budget constraints and focusing on quantitative evidence to drive expenditures. Stretching resources can result in generalizations and simplifications that fly in the face of anthropology. Focusing too heavily on quantitative

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evidence devalues lived experience and the qualitative techniques that can be key in targeting and addressing pockets of need.

Public health surveillance systems lend themselves to an etic description of health concerns and health behaviour, describing, defining and comparing health and illness carefully. I have used an anthropological perspective to complement this view with more etic descriptions, contextualizing the information we have about health practices and health beliefs, and learning directly from the populations that have experienced differing health status. This contextualized understanding of health concerns that our communities are trying to prevent, including substance abuse, obesity, violence and suicide, has led to stronger health programs that address the unique needs of particularly affected groups.

In order to work within the realm of public health I have had to compromise medical anthropology in certain ways. One is that as a concession to the pressures of time and funding, I have decreased the intensity, if not the integrity, of ethnography and participant-observation as they are practiced in academic settings. Despite this compromise, I have tried to bring medical anthropology's respect for and acknowledgement of the differences between cultures, its broad definitions of health and culture, and its techniques for listening to, capturing, and validating personal stories to the work that I do as Director of the Regional Center for Healthy Communities (Metrowest) in Massachusetts.

Experiential learning to inspire changes in institutional practice

Our understanding of health disparities in the United States is built on careful and consistent use of epidemiology to identify the difference in disease incidence, rates, and outcomes in different populations. This has helped us to identify specific and striking differences in numbers between African Americans and Caucasian, Latino, or Asian populations. One of the many factors that influences health outcomes is access to care. Recognizing this, a Boston-based healthcare advocacy organization called Community Catalyst created a healthcare access simulation called Walk in My Shoes®. The simulation allows each participant to take on the identity of a patient trying to access medical care for him or herself and for his or her family. While participating in the simulation myself, I was particularly taken with the fact that the experience mirrored my fieldwork experiences, placing me in an unknown context in order to understand the realities and the factors that shape a person's lived experience and decisions. The simulation was a powerful tool for experiential learning, which had the potential to complement the more quantitative understanding we had of local health disparities. For the coalition that I worked with,

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the simulation could also help us explore more deeply the reasons why these disparities existed, to understand through first-hand experience some of the social determinants of health, and to use this understanding to make our own services more culturally competent.

Many anthropologists (and others) have argued that narrowly defined health interventions are limited in their ability to address health disparities because multiple factors influence health access and health outcomes (Farmer 1996, Marmot 2005), but a purely academic argument about the influences of multiple factors on health is hard to grasp and even harder to use to change practice. This simulation allowed people to deeply understand the connections between not having a car and missing doctors' appointments; having trouble reading English and not being able to fill out the form for government insurance; or having three children and a father who all need medication and choosing whose medicine – theirs or your own – to purchase with the few dollars that you have for healthcare. It explains the complex connections between language, poverty, and health status in a concrete way that makes an eloquent, non-academic argument for improving access.

I encouraged the coalition to consider hosting its own Walk in My Shoes® simulation and we decided to sponsor the event. We worked hard to bring legislators, physicians, service recipients, insurance providers, the state department of public health as well as nurses and front-line staff from local hospitals to participate. Over a hundred people participated in the simulation as either 'patients' or 'providers'.

On the day of the simulation, each participant received an identity, indicating his or her gender, ethnicity, English proficiency, insurance status, employment status, and health needs. During the hour-long simulation participants tried to access healthcare for themselves and their families at the stations set up around the room representing an emergency room, a community health center, government offices (where they filled out real government forms to register for subsidized insurance), and a pharmacy. To make the simulation more realistic, there were 'interpreters' in the room to help those with limited English speak to any of the providers.

Following the simulation the whole group had a chance to discuss the experience. They talked about how hard it was to balance employment and obtaining healthcare, how frustrating it was to be in a long line of people waiting to fill out insurance application forms, and how disheartening it was to know that they had to choose between their own healthcare and that of their children or their elderly parents. Those with insurance and those without compared their experiences. Those who had to wait for interpreters compared their experiences to the stories of English speakers. The providers who sat behind the tables at

each station mentioned how difficult it was to take time to hear each person's story when they had a long line of patients waiting. The experience allowed people to feel and to hear about some of the barriers to accessing care, and also initiated important conversations about how service providers can make their services more welcoming. Participants identified the relationship between health outcomes and systems, and the personal pain of those denied access to what should be a basic human right.

Just as fieldwork immerses a medical anthropologist in the context she wishes to understand and brings new insight into the behaviors, beliefs and needs of the culture she is studying, the simulation places providers and patients in each other's positions, to understand more fully the pressures and needs that underlie the behaviors and expectations that they see in clinical settings. The simulation and the conversations that followed generated some wonderful energy around improving healthcare access. For the first time in my experience, providers were included in the conversations about how to make changes to the system to reduce disparities in access to care. Following the simulation, the coalition concluded that improving access also meant improving the quality of provider-patient interactions, and offered funding to local organizations to help them work on the issue. As a group they reached a medical anthropological conclusion: that healthcare is more than treating physical illness. The professionals who participated are now able to bring their new perspective on quality interactions to policy decisions, intakes, clinical visits and advocacy. Many of the projects that the group has funded since the simulation have helped local care providers become more accessible and more welcoming to people of all backgrounds. Through their experience as the 'other,' providers have thought carefully about how their services feel to outsiders and may now be more compassionate and understanding of the broader context from which clients and patients enter their doors.

Since running the simulation with the community coalition, I have been working with the simulation's developer, Community Catalyst, to make the tool more accessible and affordable to communities. It has proven its utility in broadening and deepening a group's understanding of health disparities, and I hope that it will do the same for many more groups.

Illuminating survey data with qualitative techniques to craft appropriate group-specific interventions

Many of the cities with which I work conduct a Youth Risk Behavior Study (YRBS) each year. The survey includes questions about violence, sexuality, men-

tal health, substance use, nutrition and other health behaviors. A few years ago I listened as one community reviewed data that showed that the city-wide rates of physical activity were low, and the rates of watching two or more hours of television each day were high. A report had been drawn up that recommended "a school wide campaign to educate youth with regard to excessive 'screen-time' specifically television viewing, computer use and video games" (Collins 2007: 8). During the conversation, a local resident who organizes a group of immigrant youth pointed out that he had heard from newly-arrived families that the city seems very dangerous, and they do not want their kids to go out alone. Many parents work multiple jobs, and the children have to stay home alone, often watching television for hours. He wondered whether simply educating kids about not watching television would have any impact if the reasons for watching were so complex.

The YRBS data alone indicated that a problem existed, but it did not provide the contextual information that was needed to inform the development of a successful intervention. In this case, the personal stories shared by the resident complemented the quantitative data from the survey. This strengthened and targeted the report's recommendations by suggesting interventions for particular groups whose contexts they understood, such as safe supervised space for physical activity outside of the home. In many cases, the public health agenda and the design of prevention and intervention programs are driven by quantitative data with very little contextual or qualitative information to explain the numbers that are gathered. Public health journals tend to publish highly quantitative research; epidemiologists conduct the assessment and evaluation, and numbers and percentages are the health status information reported in public health briefs. In contrast, systematic qualitative data collection and analysis is often disregarded as unrepresentative or unscientific. Medical anthropology's tradition of ethnography and participant-observation depends heavily on qualitative data. While ethnographic accounts may not tell the whole story on their own, they do fill in information that quantitative data cannot.

In projects as varied as reducing opiate overdoses and in helping communities prioritize the results of local health assessments, I encourage groups to use conversation logs, conversations with key informants, and focus groups to complement the numbers that they can gather from secondary sources. I have found that among public health professionals, statistical analysis is more comfortable than qualitative analysis, and it has taken some time for communities and their evaluators to become proficient in incorporating new tools into their work. As we design surveys, our partners try to turn every question into a numerical scale or a quantifiable 'yes' or 'no' answer. I help them experiment with leaving some narrative responses to see how rich the data can be, and then

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assist them in processing the responses efficiently. Time and time again, this qualitative data begins to make sense to our community members. The data reflects their own experiences and helps make sense of the numbers. Working on teams with epidemiologists and struggling with the balance between quantitative and qualitative data, I often think back to the AMMA course and the lessons I learned about how to bridge the two approaches. Medical anthropology has shaped the way that I approach data collection, but the tools that I use, and the analysis techniques I employ, are necessarily adapted, and perhaps even compromised, to be practiced in public health projects.

I am also in a position to help community coalitions design evaluation plans, choose data collection instruments and think often for the first time, about heath assessment. While the message from funders and evaluators is often to put the most faith and energy into quantitative data, my strong foundation in qualitative collection and analysis techniques has allowed me to teach the communities to balance their surveys with stories and focus groups. These devices allow them to look deeper into the explanations behind their data, thereby designing well-informed and well-tailored interventions acceptable to the communities we are working to support.

In terms of ultimately reducing health disparities, some of the most valuable applications of anthropology to evaluation design and data analysis have been in providing a framework for thinking about how community is understood locally. In some places residents divide themselves by neighborhood, in others by ethnicity or age, and further still, sometimes by membership in a faith community. These local understandings are relevant to the design of any health intervention, and they often help explain why the disparities exist. When data collection tools incorporate these local distinctions the resulting data is more relevant and more easily translated to program design.

Cross-cultural exchanges in the most unlikely of places

The center where I work is involved with numerous community coalitions that have come together to prevent substance abuse. Through a combination of rigorously tested programs and locally-developed interventions, the coalitions try to both educate young people about drugs and change the community environment to make it less conducive to drug use. One coalition in particular has been working hard to incorporate young people in decision-making, planning, and implementation of projects. They have formed a peer leadership group, invited youth to their quarterly meetings, and considered creating positions for young people on their steering committee.

Although they had not thought about it ahead of time, engaging with youth culture by inviting young people to join the coalition required a cross-cultural conversation. Anthropology gave me the language to articulate group norms and practices, and in this case, I used anthropology to help them distinguish between the practices and assumptions of adult culture and youth culture, school culture and meeting culture. This meant that the assumptions could be acknowledged and intentionally shared; and when someone acted 'inappropriately,' there was a shared explanation and no offense committed. The discussions helped prepare the youth for meetings with adults by explaining how they should indicate that they wished to speak, what clothes were appropriate to wear, and how to address adults in the room. Knowing this in advance helped them to be taken seriously and allowed them to participate more actively. Importantly, anthropology also gave me the language to talk about power dynamics, and I was able to discuss the dynamics between the dominant adult culture and the less powerful youth culture with coalition leadership and with the youth who were being asked to join.

For the coalition, having youth involved has not been easy. They have had to hire a staff person to oversee the peer leaders; they have had to change elements of the meeting culture at their quarterly meetings to make them more welcoming to young people; and they have had to give up some of their own decision-making power to allow youth a voice. On the other hand, youth have given the adults a first-hand explanation of why young people are or are not using particular drugs, what their motivations are for using drugs, and how young people might respond to coalition efforts. The coalition has invested time and energy in involving youth, and bridging the gap between youth and adult culture. The coalition hopes to learn from the young people how to make their future programs more successful and effective. These steps have already facilitated better programming for parents and strengthened youth-to-youth education about drugs.

While the adults' understanding of the lives of young people in the coalition is still fairly distant, it is much closer than it was before the youth became involved. By becoming part of a group and building strong relationships, the youth offer knowledge on the context in which health decisions are made and prompt coalition members to ask more probing questions about the nature of a health concern. Coalition members have learned that treating young people as equal members of a coalition can provide more helpful insight than simply looking at survey results. As Phillipe Bourgois recognizes with respect to using participant-observation techniques on the streets of New York, "Only by establishing long-term relationships based on trust can one begin to ask provocative personal questions, and expect thoughtful, serious answers" (1996: 13). These

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serious answers can inform the development of successful initiatives targeting specific sub-populations. Bringing multiple voices to the table early and building trusting relationships during the initial stages of a project saves time and energy later in the process.

Opening the space for complex conversations using the language of anthropology

As the United States Attorney General Eric Holder stated, the American people are "essentially a nation of cowards" when it comes to talking about race (Cooper 2009). For reasons of historical hegemony, oppression, segregation, and dispute, we're not comfortable with the conversation. Discussions of ethnicity, particularly when it comes to health disparities, are only a small step more comfortable. Because our health data is collected and reported in terms of black, white, Asian and Hispanic, discussions of disparities often derail into discussions of race and racism, or are avoided altogether because of discomfort.

Many groups that I work with have stated their intention to work on health disparities, and yet the conversations are mired in this discomfort. These discussions have begun haltingly within diversity committees of hospitals, community coalitions thinking about how to be more representative, and even the Massachusetts Department of Public Health (DPH). The DPH recently began a five-year process to align their internal practices with the national standards for culturally and linguistically appropriate services (CLAS) (Stinson 2000) in order to better meet the needs of a more diverse population. The CLAS standards were developed to help hospitals provide culturally competent care, but the DPH recognized that the intent of the standards applies to their own work as well. They have taken the ambitious step of trying to find ways to use the standards to strengthen the cultural competence of internal DPH policies and practices in order to ultimately eliminate ethnic and racial health disparities. By working to change policy at such a high level, the CLAS initiative has the potential to positively impact all of the DPH offices as well as the thousands of vendors who receive state funding. I have had the honor of being involved in the process as a participant and as a consultant.

These conversations about health and culture – about the relationships between diversity and health disparities – are complex. While I was not invited to participate in the process specifically as a medical anthropologist, I have contributed broad definitions of health and culture employed by medical anthropology and bring to the process my experience discussing the connections between culture and health. Early in the process of leading the group

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through creating a logic model to shape the initiative, it became clear that members of the group had very different ideas about the meaning of the words 'diversity' and 'culture.' I was able to provide them with a working definition of culture that encompassed a breadth of groups to consider. The definition, borrowed from anthropology, was not value-laden or limited to racial and ethnic distinctions, and it freed the group to engage in a deeper conversation about the identities of all the groups that might need culturally competent services and what those services should look like.

With the state's CLAS process, and with coalitions and committees thinking about diversity, I have found anthropology's value-neutral, broad definition of culture to be extremely helpful in re-starting conversations. It can open the space for conversations about who really constitutes the population we serve and how health, illness, needs and assets are distributed among that population. This is a healthy starting point for addressing health disparities.

Conclusion

Public health is competent at defining and describing the extent of health disparities, but is less practiced at learning why the disparities exist and at designing culturally appropriate interventions to reduce them. As described above, medical anthropology makes an important contribution by providing techniques to elicit detailed information about the nature of the disparity and its root causes, including ideas about why it exists in a particular population in a particular place at a particular time. This information can be used to inform the development of locally tailored interventions as well as systems-change to reduce health disparities. Additionally, anthropology provides a language and a framework for thinking about culture and difference in a neutral way that can help conversations about disparities and cross-cultural partnerships become more productive. Anthropology also contributes a deep respect for lived experience and recognizes that by doing participant observation, we learn and understand. In order to bring together the strengths of medical anthropology with those of public health, practitioners of both fields must learn to address challenges together.

In my work as a community health specialist I have seen that while the medical anthropological perspective is not always considered at the highest levels of decision-making, it is continually validated by the solutions and conclusions that community groups reach. The lived reality experienced by the powerless, the underserved, and the populations suffering from the most extreme health disparities (those with the quietest voices) reinforces the notion that

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health is influenced by multiple factors; different groups have different health needs. In order to meet all of those needs, it is imperative to listen to the groups themselves as the authority on their own experience and to consider the social and cultural context within which health behaviors are chosen. As a public health provider working at a community level I try to listen to those quietest voices to inform local health promotion, which requires ethnographic skills and the anthropological valuing of stories.

Yet taking the time to hear these stories through qualitative research techniques, experiential learning and cross-cultural dialogue takes patience and energy. In a resource-strapped field, time is at a premium. To address health disparities successfully as a partnership, both public health and medical anthropology should be prepared to compromise. In order to work with medical anthropologists, public health practitioners should allow a slightly longer period of time to assess a problem and design the project. In order to work with public health officials, medical anthropologists must be prepared to compromise the intensity of ethnography and participant-observation and respect the constraints under which the public health system works. To make more of an impact on health disparities, public health should apply the lessons learned from integrating medical anthropology at a local level by scaling up to the work done at state and national levels. To learn these lessons and to impact the populations suffering most from acute health challenges, public health must allocate a significant proportion of its existing resources to community efforts, where these anthropology-informed techniques can be put into practice most appropriately. Local program designers can consult most directly with their target populations, hear stories, collect and analyze qualitative data to inform prevention programming.

Where these anthropological perspectives are already being applied in the realm of public health, we should watch for successes and applaud the advances of the field. Where they are not, there is room for us as medical anthropologists to contribute our suggestions. While public health has experience and power, medical anthropology has new perspectives and tools to share in the fight to eliminate health disparities.

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Chapter 3

A medical anthropology contribution

Participatory research with young people in Uganda

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Since I graduated in 1999, I have worked on various research projects within multidisciplinary teams. I was frequently hired as a medical anthropologist, but struggled to incorporate medical anthropology methods in the research process. In this paper I outline one case study from a research project on HIV/AIDS among youth in Uganda to illustrate this struggle. This experience demonstrates how the skills and knowledge I gained from the Amsterdam Master's in Medical Anthropology program at University of Amsterdam (AMMA) helped me uncover an important finding in this case study because of anthropology's ethnographic methods. I also demonstrate how the anthropological method of revising questions throughout the preliminary analysis improved the quality and relevance of this research. I conclude with the lessons learned from my experience in championing the merits of medical anthropology to non-anthropologists.

The project

In 2004, the Faculty of Social Sciences at Makerere University began a research project that investigated personal, sociocultural, environmental and economic

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determinants of behaviours that lead to HIV infection among young people in Uganda. The Swedish International Development Agency (SIDA) provided funding, while the Social Science and Medicine Africa Network (SOMA-NET) offered technical support. The study was conducted in Jinja, a district with a strong rural-urban mixed population in Eastern Uganda with a high HIV/AIDS rate. The specific research areas within Jinja were chosen for their rural-urban mix, cultural diversity, and variety of economic sectors. Research participants included the following: fishermen of the Masese landing site; plantation and migrant labourers in the Kabembe area; unemployed and impoverished youth of the urban slum area Bugembe; rural workers of Budondo; and residents living in Buwenge, a stable, non-slum and semi-urban area. The study population consisted of females and males between the ages of 9 and 25 years old who lived in urban and rural areas, and included both married and unmarried couples. A total of five dialogue meetings were held with youth groups between the ages of 15 and 25 years old.

Selecting methods

Initially the research team grappled with how we planned to conduct participatory research with the youth in our study. During my medical anthropology studies, I interpreted participatory research to mean that participants were something more than informants by being co-researcher, whereby they set the agenda, formulate research questions, and develop the research themes. My definition of participatory research was shaped by the work of Cornwall and Jewkes (1995: 1667) who observe that, "Participatory research focuses on a process of sequential reflection and action, earned out with and by local people rather than on them. Local knowledge and perspectives are not only acknowledged but form the basis for research and planning." Cornwall and Jewkes further argue that the key element of participatory research lies not in methods but in the attitudes of researchers, which in turn determine how, by and for whom research is conceptualised and conducted: "The key difference between participatory and other research methodologies lies in the location of power in the various stages of the research process" (1995: 1). Other scholars argue that in conventional research and extension, inappropriate recommendations have frequently followed from a failure to take account of local priorities, processes and perspectives (Agyepong 1992).

My colleagues from other social science disciplines like social work and community development strongly felt that we should use focus group discussions and Participatory Rural Appraisal (PRA) techniques such as Venn diagrams,

transect walks, gender analysis tools, seasonal calendars, and social mapping. Their main argument was that these types of data gathering techniques have been proven to enhance involvement of study participants within the research process. As a medical anthropologist I felt that these techniques were likely to bring out issues only at a superficial level but ultimately fail to facilitate participation in issues related to HIV/AIDS. Holloway argues that "having enough time to explore meaning and perspective is crucial, whether an encounter is spontaneous and informal or pre-arranged, formal and private" (2005: 176).

I suggested that a combination of participant observation and ethnographic interviews could enrich our understanding of the *emic* perspectives on the youth's experiences and perceptions of risk and vulnerability in the context of HIV/AIDS. These methods would help us collect data that may be different from what the formal archives and dominant discourses report as being the key drivers of HIV/AIDS infection among youth.

In the process of convincing my colleagues on the merits of qualitative methods, I acknowledged that PRA methods are useful in participatory research but that these would not be useful in the initial phase of the research process when we seek to understand the subject matter. With respect to research planning, it is imperative to start the exploratory process with ethnography to conceptualise research issues and clearly define research questions. After this phase, the PRA and other qualitative methods such as focus groups can be employed to obtain targeted information. I further argued that ethnographic methods should not only be used at the start of the research but throughout the investigation. The purpose of continuous use of ethnographic methods is to capture the dynamic nature of human behaviour, sub-cultures and social contexts of young people. This approach of transitioning from a thick ethnographic phase to PRA methods won approval from both our donors at SIDA and our technical advisors at SOMA-NET.

After holding a discussion on the limitations of participatory research; the debate between qualitative and quantitative data; and the need to address agency, representation, and power in participatory research, (see Agyepong 1992, Cornwall & Jewkes 1995, Sengendo et al. 2006) we agreed to employ a method where the potential study participants were given the opportunity to define the research issues, time the fieldwork activities, and adjust methods of data collection to their specific contexts.

After our research process was approved, my first task was to train the research team in ethnographic methods by outlining their basic theories and practices in preparation for fieldwork. The main ethnographic methods I taught were informal conversations, interviews, and participant observation. We conducted interviews and engaged in informal conversations while doing

participant observation. Our research took place at drinking joints, places of entertainment, trading centres, markets, landing sites, and sports fields. In our interviews we allowed the study participants to direct the interviews. Only when the interviews took a direction completely unrelated to the research topic, did we politely interject with pre-determined topics that could steer the interview back to our research themes. By allowing this freedom, the youth were motivated to talk at length about their daily experiences and frustrations with HIV infection among their peers.

Strikingly, our interviews raised new and important issues that we had not considered before. For example, the key assumption underlying a number of Uganda's policies and interventions in sexual and reproductive health (SRH) is that HIV/AIDS is considered to be the most significant problem. This is clearly demonstrated by the amount of human and financial resources spent on HIV/AIDS in comparison to other SRH problems, such as teenage and unwanted pregnancies and abortion. Policymakers and practitioners encourage young people to prevent infection from HIV/AIDS based on the assumption that they fear contracting HIV. However, when the youth frequently raised the issue of pregnancy during informal conversations, we began questioning the validity of the assumption that HIV/AIDS was their primary concern.

When we followed up with additional interviews we explored issues that we had previously overlooked. We then targeted key informants who were health workers, NGO staff members, and community leaders. Interaction with key informants helped us position the information generated through the informal ethnographic phase on the current discourses on HIV prevention among young people.

The other methodological challenge we faced was data processing and analysis. While in medical anthropology, data collection and analysis are interactive, the other social science colleagues regarded data analysis to be a completely separate phase that takes place once the fieldwork is completed. For example, when I was in the field I was always reviewing the data, using it to reformulate and refine my research aims as well as to identify new and more important issues that emerged from observing and listening to study participants. In addition, I was continually revisiting the data, writing notes in relation to the key research questions, and listening to transcripts all before the 'formal' phase of data analysis began. Thus the formal phase of data analysis was rather a re-analysis as Crang and Cook describe:

> What this formal stage of analysis is supposed to do, then, is to reconfigure this data, to look at it more carefully and critically, and perhaps to de- and re-contextualise different parts so as to be able to see new themes and pat-

> terns in it… It's not that separate a stage that takes place in a detached space. It's a connected and connective process… The themes that become such an important part of formal analysis usually start their lives in the data as it's constructed, then get scribbled on the margins of the data... (2007: 133).

It was a constant uphill battle to convince my colleagues to take fieldwork and data analysis as an interactive process. Still, I shared with them the emerging issues from what I conveniently termed 'preliminary analysis.' The nightly debriefings from my preliminary analyses eventually excited my colleagues to follow suit. The important lesson I learnt was to demonstrate the value of medical anthropology methods to convince reluctant members of a multi-disciplinary team to adopt anthropological methods.

After conducting interviews and participant observation, we held Community Dialogue Meetings (CDM) to clarify and deepen discussions on issues identified by the participants. CDM is a forum that draws participants from as many parts of the community as possible to exchange information face-to-face, share personal stories and experiences, express perspectives, clarify viewpoints, and develop solutions to community concerns (Canadian Rural Partnerships 2002). CDM emphasizes listening in order to deepen understanding. It develops common perspectives and goals, and allows participants to express their own interests. In the community dialogue meetings, we used PRA tools to enhance participation of young people in the research.

This CDM served as a community driven validation workshop for issues generated during the ethnographic phase of the study. Through this process we generated interest among the community members in the research. For the first time, they could see that their own concerns were actually part of the research agenda.

Medical anthropological approaches, such as informal conversations and participant observation, added value to the participatory research methods. They teased out issues that were later considered for further discussion using the common participatory research tools such as risk mapping and analysis, gender analysis, problem tree analysis, brainstorming, decision tree, open-ended stories, and social mapping.

Fear of pregnancy preceded the fear of HIV/AIDS

While analyzing the data, we found that the majority of the youth are indeed sexually active. This is despite the efforts to spread abstinence messages couched in religious undertones of sin and hell through media efforts, Faith

Based Organisations (FBOs), as well as some government policies and programs that focus on 'traditional' cultural values, namely the prohibition of premarital sex. The youth in this study engage in sexual activities for a variety of personal, sociocultural, economic, and environmental reasons. However, contrary to the popular belief that young people protect themselves against HIV/AIDS because of severe morbidity, stigma, and death, the study revealed that the youth were more preoccupied with preventing pregnancy than with HIV infection.

Premarital pregnancy was to be considered more stigmatizing than HIV because it is more visible within a shorter span of time. When we pursued this issue in another CDM with both young men and women, several participants made observations that confirmed this finding: "It would not be easy to know that some one has HIV as it is with pregnancy … Pregnancy causes shame … The boy responsible can deny the pregnancy, your parents lose trust in you, and it also shows you are immoral" (Summary given by male and female youth in the CDM at Budondo, Jinja).

The young men emphasized the legal ramifications of being responsible for a pregnancy, but showed little interest in the health consequences of HIV infection. "If you get a girl pregnant, it is a criminal offence … you can miss education … as for HIV, the consequences are faced after a long time …" (A male youth in the CDM at Budondo, Jinja).

Premarital pregnancy was also associated with moral punishment. A pregnancy is evidence of the fact that two people engaged in unlawful sexual intercourse. As a result, they can be taken to courts for punishment, although it is usually the young men who face the penalties for having impregnated the young women. The law gives parents the power and right to press for charges against the boy or adult man although cases of this nature are usually settled outside of the court.

In this study, we found that pregnancy resulted in being expelled from school. This meant fewer opportunities of re-entry into the school system and future employment. In addition, parents were described as being reluctant to pay tuition fees for young women who became pregnant:

> Even after giving birth, as a girl and a young mother it is practically impossible … to go back to school. At such a young age, some girls may be forced to marry the same men who tried to deny their pregnancies while others are forced to take responsibility of their children and condemned to a life of domestic chores (A female youth in the CDM at Kabembe, Jinja).

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Other critical losses included the lack of income and work skills, abandonment by fathers, dependence on parents for their own and children's upbringing, growing up too fast, embarrassment, and in a number of cases, expulsion from homes and harsh punishment from parents. Others feared being ostracized by their family and community:

> A girl in the neighbourhood became pregnant, she was barred from interacting with other members of my family at all; her father considered her a disgrace to the family. When it was discovered that she was pregnant, she had to drop out of school (Summary given by male and female youth at the CDM in Budondo, Jinja).

The study participants observed that in situations where the child would be born out of wedlock; the young woman was in school; or the father abandoned his responsibility, the pregnant girls often chose unsafe induced abortion methods, such as consuming herbs or overdosing on tablets such as malaraquin and chloroquine. In different CDMs, participants reported they resorted to abortion because they feared expulsion from their homes and schools, social stigma, rejection by the child's father, incompetence in raising a child, and risks associated with early pregnancy.

Discussion

Participatory methods need to be complemented by ethnographic methods especially when conducting research on sensitive and stigmatizing issues such as sexuality, pregnancy and HIV/AIDS (see Shoveller et al. 2004). Although CDMs enhance the level of participation of study participants, in a morally restrictive environment, they may only generate dialogue on the overt and popular issues. This may deny the young people the platform to bring out their most important concerns. Informal conversations and ethnographic interviews with young people taught us that they fear pregnancy more than HIV/AIDS because of moral restrictions. This issue had not surfaced in the predetermined research questions and objectives when we first designed this study, before we had incorporated the ethnography after much debate.

It was evident from the study that a good number of female and male young people engage in sexual activities. Paradoxically, moral restrictions have not been successful in stemming sexual activity among young people. Participant observation and ethnographic interviews helped us to understand that young girls have developed coping mechanisms to deal with the stigma asso-

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ciated with sexual activities. Secrecy about the girls' sexual lives enables them to manoeuvre between moral expectations and sexual desires. This may partly explain why girls fear pregnancy more than HIV/AIDS.

Shoveller et al. (2004) note that there are two central processes that alienate young people in their attempts to come to terms with their sexuality. The first is the pathologizing of sex and the second is the silencing of meaningful discussions on sex. This is, however, not accompanied by education or support on how to respond to sexual desires in a way that protects youth against the negative consequences of sexual activity. Instead, young people are blamed for failing to adhere to the norms and values held on sexuality. The focus is on generating fear rather than helping youth to manage their emotional and sexual feelings. It does not, however, stop young people from having unprotected sex, which makes them vulnerable to unwanted pregnancy, unsafe abortions and sexually transmitted infections including HIV.

The study's findings demonstrate that it is impossible for girls to hide pregnancy but relatively easy to hide HIV/AIDS because the symptoms are delayed and are similar to other diseases which affect the entire population. For young people, pregnancy is too visible and harder to cope with in the short-term. The threat from HIV/AIDS was perceived as more distant than the daily struggle of coping with a pregnancy in a social environment where sexual 'trespassers' are openly shunned by their family and the community.

Yet, despite their fears of being shamed and ostracized, most young people continue to be sexually active. Demographic health surveys indicate high levels of teenage pregnancy at 37% (UBOS & ORC Macro 2001). The fear of pregnancy has not prompted young people to avoid unwanted pregnancies and unsafe abortions.

Conclusion

The anthropological approach in this research revealed unexpected and contradictory views and practices on HIV/AIDS and unwanted pregnancy among Ugandan youth. Anthropologists should promote the strengths of their methodologies while working in multidisciplinary teams. There are many opportunities for anthropologists to influence the research design, redefine key research issues, and analyse the findings. A combination of medical anthropology approaches with those of other disciplines will enhance the quality and acceptability of the overall findings and conclusions.

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Chapter 4

From revelation to reality

The struggles of a doctor trained in medical anthropology

LAURA CIAFFI*

The reasons

I am a medical doctor, trained in Italy with a clinical curriculum and an academic approach. During my postgraduate studies I was a resident in an HIV clinic. At that time, the lifesaving therapy for HIV was not yet available and the work of a doctor was very much that of accompanying patients through a history of repetitive diseases, feelings of imminent death and a lot of social problems. Therefore the social and 'human' aspects of medicine were a large part of my work and I was confronting the limits of a biomedical approach on a daily basis. After my studies in tropical medicine, I decided to work with a humanitarian organisation. When I left to work in a foreign country, I did not really know what I was going to face and that was probably part of the fascination. I worked in Nicaragua, in a very remote village in the Northern part of the country. Practicing medicine in a resource poor setting, with very young but experienced local health workers, in an isolated community, was exciting but also puzzling – not only in terms of professional practices but also the exchanges I had with the local doctors. The most amazing part for me was finding another way of looking at things, of deciding about priorities in life and of managing the harshness of daily living.

My training did not prepare me to explore 'health' dimensions through different eyes. I could not understand why a women who already had ten female children would try to become pregnant again just to deliver a male child,

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Thanks to all those who have guided me through this revelation. Special thanks to Modeste Deffo, a Cameroonian anthropologist who tried to push me beyond my 'egocentrism'.

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putting her health (already weakened by past difficult pregnancies) in danger. Or why were people coming to the health services for problems with minor symptoms, while others were presenting very late?

Returning home, I had those strange feelings that many people face after having been through this kind of experience: questioning your own culture, your relationships, and the way of life of those around you. I discovered later that this was called being 'thrice born'.

I left again, after few months of rest, for West Timor-Indonesia. There we worked on a program on the prevention and management of sexually transmitted diseases and HIV. The program had to be opened and the strategies decided.

I had the chance, and now I would say the clever insight, to rely on the advise of experienced people from local organisations and from the community. In fact the most successful part of the program was the community work. Organising outreach programs to the most vulnerable groups with people from the same communities allowed us to modulate the messages and to better understand their needs and the strategies required to improve communication.

All of this work meant that I had to be in contact with many actors whose roles and interests I had to understand. Needless to say, this was difficult. I remember the beginning: sitting in long meetings where everyone spoke in *bahasa* Indonesia, and not understanding a word, but trying to learn who each actor was and what were the issues at stake for each of them.

I stayed for 14 months; I learned the languages and got acquainted with the ways of communication that initially appeared mysterious to me. I say that I was getting acquainted, because at least I had avoided offending anyone, creating misunderstandings or spoiling relations. But I was far from understanding the hidden ways of 'real' communication. I remember, near the end of my mission, speaking with one of my colleagues about some of the strategies we implemented and was given a critical comment on some of decisions made in the past. "Why did you not tell me before?" I asked. "I did," was the response. But during the beginning of the project, I had not understood, because I did not know how to read between the lines of a non-direct communication.

That was just the one example of a series of experiences that made me decide that I could not go on with my work without having some tools to ease my way through another context, another culture, and people different from those that I grew up with and was used to in my home country. I decided that I was going to study medical anthropology.

It was clear to me then that not only were people different but also that we would have try to understand and adapt to local contexts – which is obvious to anyone who works abroad. I needed to learn how to 'read' these differences and make use of this understanding to improve the services I was supposed to

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help establish. I attended the Amsterdam Master's in Medical Anthropology (AMMA) program and I experienced a sort of revelation.

The studies

It was difficult. My first challenge was switching from a very 'scientific' way of thinking (i.e., cause and effect, biological phenomena, proof by controlled experience) to a new way of looking at things. The readings I had to do seemed too literary, using different categories, and a different language than I was used to. I felt I had to reset my mind to a new way of looking at reality. Some authors did not help; Clifford Geertz and Michel Foucault were very poetic but difficult to grasp. Others, Byron Good and Arthur Kleinman, were so clear in their thoughts and expression that they allowed you to easily enter another world where different thoughts and behaviours are just different responses to the same human needs of survival and desire to explain what is going on in their life.

Learning different anthropological approaches led me to understand that there are also different ways of explaining events, depending on the way you look at life and human beings.

I was now familiarising myself with a world that allowed me to revisit my past experiences, not only in 'tropical' countries, but also in my 'domestic' country. It was difficult, however, because medical anthropology analyses western medicine and shows how biomedicine and diseases are culturally constructed. This may sound trivial to students coming from other disciplines, but that is not the case for those coming from medical studies. In addition, as a medical doctor, I realised that what happens in our practice and with our patients occurs within an established, non-neutral relationship; it is also not only a professional interaction, but there is a whole context at play in those moments of great intimacy between a doctor and a patient.

I was reminded of the incomprehensible behaviours I observed in my patients, and recalled these past experiences from a different perspective. These memories were given new meanings and the purpose of my work become clearer.

While the course continued, I became more and more convinced of the added value that an anthropological approach could have on my profession and in medical programs in developing countries where sufficient understanding of local cultures is often lacking. Anthropology could make these programs more effective, acceptable, and adaptable to the context. But I was also realising how this approach could enrich my personal experience while working in different settings.

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I wondered how it is that anthropology is not included systematically in the training for people who work abroad? How did others in my medical profession experience all of this? And what about those who had the opportunity to study anthropology: how did they manage their feelings about going back to the 'field'? How much do they contribute to the diffusion of different perspectives? Perhaps I more easily understand anthropological concepts when the anthropologists are also doctors.

Back to work

What is left of this amazing experience? As at the end of the day I am still a medical doctor and work as one. After another four years of working in the field, in programs providing care and treatment for people living with HIV, how many times was I surprised by people's behaviours and ways of thinking? How many times was I puzzled, trying to understand their choices, decisions, management of conditions, and problems that were very far from what I would anticipate? Descriptions of symptoms, histories of illness, uses of western and traditional medicine, and religious healing – there are many things to understand about behaviours and choices that people make when they are sick.

I applied an anthropological approach to my work, trying to understand the 'insider' point of view to gain perspectives on different stakeholders and frame all those inputs into the broader cultural context. I am sure that anthropology enriched my background while observing local practices as well as when I was discussing with patients, authorities, and colleagues. I questioned more, I tried to meet people from very different backgrounds, and I consulted with local anthropologists. All of this helped.

Where was the struggle then? In medical programs, solutions should be found quickly; there is no time for extensive ethnographic research, especially when you are not there to be an anthropologist. Projects have a specific time frame, which often relates to the funding provided, and obstacles should be worked out with quick assessments and practical solutions.

At the beginning of one of the first projects providing antiretroviral therapies in Cameroon, we were surprised by the high number of patients refusing the new available treatment. We organised some focus groups to discuss with the two groups of patients, one of which refused and the other accepted the therapy. The results helped us to change the messages we were giving to patients about the treatment, which had probably centred too much on the risks of side effects than on the benefits of treatment. In addition, we became aware of the 'rumours' that were circulating in the communities of the people

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living with HIV/AIDS about antiretroviral treatment, which were fuelled by the 'politics' of South Africa with the collaboration of their Ministry of Health and rising suspicion of the high toxicity of these drugs.

But the institutional framework, the attribution of responsibilities (a medical coordinator is not supposed to work as an anthropologist) did not leave enough time to analyse, to study, and for sure, to notice one of the many details that would have allowed us to better shape the messages to the patients and the approaches we could have taken in our delivery of care.

The struggle

During my professional experience in the medical humanitarian world, I had the opportunity to observe how the role of anthropology is perceived and when anthropologists are needed. I witnessed the use and abuse done to anthropology and how anthropology struggles to establish itself in the medical world.

While coordinating a training session on HIV for humanitarian health workers from different countries, I defended the need for a session on the anthropological aspects of the HIV pandemic. The objective was to provide a glimpse of what is behind the patient coming in for a medical consultation and what shapes the community's perceptions of HIV and their reactions to the epidemic.

It was very difficult to have a successful session. We had brilliant and experienced anthropologists who presented their fieldwork and offered possible approaches to analysing the context. The health workers, however, were very unhappy, rating the insights as useless or considering anthropology to be too theoretical and not adapted to 'field reality'. They were confused by the use of categories foreign to medical culture, and were bewildered by the references to concepts very far from the 'disease', unable to grasp the suggested insights. At the same time, the anthropologists may not have been used to dealing with an audience that is not their usual one: the academic arena. They read their notes and referred to authors unknown to the majority, and made little effort to translate their language for people with different levels of experience with anthropology. Nobody is to blame, except the separation that exists between two worlds that constantly struggle to understand each other and collaborate.

I tried to promote interest in an anthropological approach to analysing the context and problem solving, but I was often surprised by how little understanding existed of what anthropology can bring to a medical intervention and by the superficial expectations that medical people can have.

Anthropologists are often sought out when after having done what is medically expected, the results are unsatisfying. In these cases, cultural aspects are

suspected to influence the outcomes. For example, in a HIV project in Northern Mozambique, patients with HIV were disappearing after a few consultations, and half of those who did not meet the criteria to start treatment for HIV (ART) completely stopped returning to the clinic. Even before analysing the set up and organisation of the care, 'culture' became the suspect cause and an anthropologist was called upon to propose solutions. The anthropologist found that the HIV clinic was too isolated and too identifiable from the rest of the hospital; there was little support for the patient who is not in need of ART; the types of messages that were passed to patients by health workers and counsellors were off-putting. An anthropologist with no experience in HIV and little experience of Africa was able to produce these finding within three months.

What can we learn from this? Sometimes anthropology is used as a way to divert attention away from our own limits of humanitarian medicine: where medico-technical logic is paramount, emergency is prioritised and action comes (and probably should come) before the deep understanding of the context. On the other hand, there is also some disappointment caused by the few efforts done by anthropologists to clarify what they can contribute.

Quick assessments and superficial conclusions, often drawn from some interviews and focus groups, without further analysis of the discourse and behaviours bring little to the discussion and understanding. Something is always gained, however, when you know more about the context and ask colleagues and patients questions. Medicine does not need an anthropologist to explain that HIV carries stigma and that gender relations influence decision-making.

Medicine and medical anthropology despite being pieces of the same puzzle have great difficulties with fitting together. Human suffering is often caused by biological processes, but it is also embedded in individual and group experiences and social conditions that need to be considered, studied, and understood as well as the biological phenomena causing ill-health.

Anthropological insights should be 'vulgarised' to penetrate medical thinking, and anthropologists should frame and make clear what added value they can bring to medicine. Health workers refer to anthropologists when they think that there are 'cultural' problems that hinder their intervention. Anthropologists can and should provide more than this.

Comprehension is easier to achieve through direct experience, therefore anthropologists have to find ways to let health workers participate in the process, in discovering the other world where illness becomes a human experience. This was my discovery while studying medical anthropology and it needs to be shared with others.

Simplification of some research methods and provision of some practical tools will allow direct experience of the anthropological research to medical

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people, opening the door to 'revelation' for them. Anthropological research should aim toward providing clear and practical insights on the missing parts of the puzzle, not only providing knowledge, but also practical solutions. Anthropologists should be ready to take the responsibilities of the implementation of their recommendations (Hemmings 2005).

Doctors should make the effort to adopt a different frame of mind, to accept the limits of the biomedical approach, and to give space to another discipline. Medical organisations and institutions (including universities) should adapt their frameworks of knowledge and intervention to include the anthropological approach in practice. Space should be given for a true 'cross fertilisation'. An anthropological analysis is useful, but its application to real problem solving, the anthropology *in* medicine (Shand 2005) will allow a further step in the work of medical anthropologists and to the medical intervention in practice.

There are examples in medical anthropology history in which the two approaches have been used for the good of the patients: some prominent professionals tried to create a bridge among the two disciplines, including Paul Farmer and Arthur Kleinman. We have to analyse their strategies and see if there are lessons to learn: did they manage to do it only in the academic world? Did Paul Framer have to create a private NGO to apply the two approaches, as it was not possible to do in other ways? What can they say to other doctors who are struggling? Which insights of theirs were put in practice?

Conclusion

But after all this theory, where am I? I am still working as a doctor, and probably I did not struggle enough to make these two worlds of medicine and anthropology come together. Medical anthropologists who are also doctors should make the most efforts to bridge medicine and anthropology, as they know the language and the methods of both disciplines. This competency should be recognised and used by the organisations that really want to make the difference for the people they want to serve.

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Chapter 5

Medical anthropology and HIV prevention

Analyzing the use of condoms among gay men in Chile

CARLA DONOSO ORELLANA*

In this paper I share my experience as a researcher in the participatory research project called 'Social and cultural factors that influence the use of condom among homosexual men and men who have sex with men (MSM)'. This research was carried out during 2004 and 2005 in Chile by two NGOs working on HIV/AIDS: The Unified Movement of Sexual Minorities (MUMS) and SIDACCION (an organization for HIV prevention among homosexual population), both with remarkable trajectories in the fight against HIV/AIDS and recognized advocators for the human and civil rights of homosexual men. The research project had the financial support of CONASIDA (Chilean National Office for HIV/AIDS Prevention) and United Nations Global Fund for AIDS.

In order to contextualize the HIV epidemic in Chile some epidemiological facts must be mentioned. In Chile 12,574 people have been infected with HIV (CONASIDA 2003), and 3,860 of them have died. About 10% of the total number of notified cases are female. Although CONASIDA estimates the real number of cases is 19,479, *Vivo Positivo*, the National Organization of People Living with HIV, based on UNAIDS guidelines, estimates at least 40,000 people infected. According to CONASIDA, sexual transmission accounts for 93% of the notified cases. Until 2003, 89% of cases corresponded to men. Even though a process of 'feminization' of HIV has been reported, self-declared homosexual

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and bisexual men remain the group mostly affected by HIV, accounting for almost 70% of the notified cases.

The first case of HIV in Chile was reported in 1984. In 1990, along with the first democratic government after Augusto Pinochet's dictatorship, the National Commission for Prevention of AIDS (CONASIDA) was created. Since its creation, CONASIDA has launched several campaigns to raise social awareness about HIV/AIDS, and carried out focused intervention projects among groups considered more vulnerable to HIV, such as youth, sexual workers, and men who have sex with men (MSM). In addition, CONASIDA has improved the quality of health care for people living with HIV, particularly through increasing access to antiretroviral treatment to reach universal coverage nowadays. However, many problems remain unsolved. The official response to the epidemic in Chile has been weak and unable to deal with cultural resistance to open promotion of safe sex. For instance, it is worth mentioning the systematical opposition of Catholic Church and conservative media to HIV prevention campaigns that openly promote the use of condoms. Furthermore, they have launched their own campaigns promoting love, fidelity, and sexual abstinence before marriage as the only safe ways to prevent HIV.

Since 1987 several NGOs' projects related to HIV prevention among homosexual men have been implemented in Chile. These projects usually encompass awareness raising activities such as condom distribution in places where homosexual interactions take place, distribution of information brochures, and other sensitization activities. As a result of these interventions, homosexual populations have deeper knowledge regarding HIV prevention than the general population; nevertheless this does not imply that homosexual men use condoms properly and regularly (CCHPS 1997).

The fact that homosexual transmission accounts for a substantial part of HIV cases in Chile does not imply that HIV is encapsulated among homosexual men. In Latin America most of homosexual men regularly have serial or frequent heterosexual intercourses. This phenomenon has led to the use of the concept 'men who have sex with men' (MSM) as a way to focus the analysis exclusively on sexual behavior leaving aside the theoretical discussion on sexual and gender identities. The use of the category MSM is problematic and it has raised a substantial theoretical debate. From an epidemiological point of view, it accounts for sexual behavior regardless of any social identity, but at the same time some critical scholars point out that it neglects the social and cultural complexity of homosexual experiences (Díaz 1996). In the context of this research project, the use of the category MSM was imposed by CONASIDA as a way to address those subjects who may not feel part of the homosexual community. However the boundaries between MSM and homosexual or bisex-

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ual on the one hand, and between different ways and levels of identity on the other hand, are not easy to draw. Being aware of the criticisms against the politics of identity pointed out by queer scholars (Green 2002), we still find the category 'homosexuality' useful for social research. By homosexual men we mean those men who – taking into account their biological sex, sexual orientation and cultural patterns related to sexuality – define themselves not only as homosexuals but also claim a sense of belonging to a political community. According to Weeks (1987), beyond the sexological obsession with sexual identities, identity has become a way of differentiation and reassurance, "in a culture where homosexual desires, female or male are still execrated and denied, the adoption of lesbian or gay identities inevitably constitutes a political choice" (Weeks 1987: 47). However, in the Chilean context, homophobia plays a major role in making this 'political choice' more problematic and the fact that men acknowledge themselves as homosexual does not necessarily indicate public disclosure.

Nonetheless, a theoretical reflection on gender and homosexual identities is also crucial. Gender order has been established in many societies on women's oppression, leading to the exaltation of what is culturally considered masculine. This phenomenon is explained through the concept of 'hegemonic masculinity', which involves those features considered desirable for men (Connell 1997) and also influences the way homosexual identities are constructed on the basis of traditional gender patterns. Therefore, the construction of homosexual sexuality does not exist isolated from gender order and it encompasses cultural elements of hegemonic masculinity such as 'active, dominant and impulsive' sexuality. This means that homosexual men face the same obstacles that heterosexual men to develop HIV preventive behavior.

It is commonplace in social research done among Latino gays and bisexuals to point out that gender distinctions play an important role in the way homosexuality is perceived. In many contexts same-sex object choice is less important in the constitution of sexual identity than perceptions of activity (penetrating) or passivity (receptive), which has been traditionally understood as gender roles in sexual practice. In Latino cultures it has been found that the active role in homosexual encounters is not necessarily perceived as homosexual behavior, and may translate into a high degree of bisexual behavior without being transformed into a distinct bisexual identity (Lancaster 1988, Parker 1990). In addition, more recent social research (Carballo et al. 2005) indicates the important role played by gender stereotypes of masculinity and femininity in sexual behavior. For instance, Carballo et al. found out that among 'versatiles' (those who either take an active or passive role) the 'active' or 'passive' role was defined according to the way the sexual partner was perceived, those

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who perceived their sexual partner as being more masculine than they, based on his appearance, took a passive role. Conversely, versatiles reported a greater likelihood of taking the active role when the partner was perceived as more effeminate. However, in the Chilean context, what seems to be more important in the definition of homosexuality is the sex of the partner, and we found a considerable amount of flexibility in the way sexual roles are negotiated and performed.

Objectives and methodology

The main objective of this research project, as defined by CONASIDA, was to describe the acceptability of the condom use as a HIV prevention strategy among MSM and homosexual men; identify factors and relevant actions for promoting, and increase condom use among this population. Acceptability refers to favorable attitudes towards condoms, but it does not imply that condoms are rightly and frequently used. Therefore, we realize the need for identifying cultural and social factors that facilitate or inhibit the proper use of condoms. The use of condoms cannot be isolated from the study of sexuality and sexual behavior, thus HIV prevention and particularly the condom use should be analyzed as part of the wider phenomenon of the cultural and social construction of sexuality.

At the beginning of the research project, four interviews with key informants were carried out, two of them with social scientists who are experts in the field of HIV and sexuality research, the other two were conducted with health care providers working on STDs advising services in the Public Health Care System. The purpose of these interviews was to get initial information about the issues involved in the acceptability of condoms among homosexual men. In spite of the fact that the research team already had substantial knowledge in this field, the interviews were a requirement from CONASIDA to validate and give 'legitimacy' to the research. Because the research team was made up with professionals from two 'activist' social organizations, it was perceived by CONASIDA as not totally neutral and scientific, therefore its representatives decided that the opinion of other experts was needed in the methodology design.

The research methodology involved a qualitative approach, particularly by conducting focus groups and in-depth interviews. Eleven focus group discussions with homosexual men were conducted, some of them with men living with HIV and some with men who do not live with HIV. We also carried out 18 in-depth interviews, with a wide range of men ascribed to different social groups, including young men, homosexual, bisexual, HIV positive, and

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members of NGOs working on homosexuals' rights and HIV prevention. Focus groups and interviews were conducted in Santiago (the capital of Chile), and two other big cities of the country (Valparaíso and Vina del Mar). Both focus groups and interviews addressed middle-class men of ages between 15 and 50 years old. In the case of focus groups, variables as age and HIV status were taken into account in the production phase in order to have homogeneous groups. In both cases the sample was reached through snowballing and different entry points were needed (internet, personal contacts, visit to homosexual meeting places, among others).

Even though the utility of focus groups can be limited in relation to some research topics, when they are comprised of individuals within a minority community, they offer the opportunity to discuss issues of common concern. They can thus be specially useful in research on gay and bisexual men, as their shared experience offers a significant foundation for their interaction within the group (Parker & Carballo 1990). Focus groups allow the emergence of common discourses and shared experiences even though they are restricted to what is socially accepted in a particular setting.

In-depth interviews allowed an approach to homosexual men's narratives on their sexual biography. A narrative research approach presents the perception of experiences and events by the narrator, along with the meanings attributed to it by those who hear or read it. The narrative approach draws on the subject's ability to organize and explain life events in a way that is meaningful for himself/herself. The narrative conveys experiences and events that are related in a temporal dimension, suggesting an individualized type of causality that establishes a sense of order and coherence for the individual (Gergen & Gergen 1986, quoted in Gil 2007). The narrative approach did not overcome the discussion about informants' actual sexual behavior reported in the interviews, but allowed us to explore the way people describe and give meaning to their sexual experiences. The interviews were designed as biographical accounts that include the narration of the first sexual experiences, the discovery of homosexual desires, experiences with homophobia and current sexual behavior, including the use of condoms. The wider scope of the interview questions also allowed us to minimize the methodological problem of the socially accepted and expected answers, particularly critical when studying sexuality, because our informants were required to refer to their past and actual experiences as well as their beliefs and perceptions on sexuality without looking for any internal coherence. The high level in which they reported sensitive episodes in their life such as sexual violence may be an indicator of the quality of the interviews carried out. In addition, the interviews were conducted after analyzing the focus groups transcriptions. This methodological decision gave us the opportunity to think and design the

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interview questions, drawing on the findings from focus groups and looking for specific information to deepen the analysis.

Main results

Sexuality and romantic love

Regarding the interviewees' perceptions about sexuality, one of the most outstanding results was the importance they give to romantic love in their decisions regarding sexual behavior. To have a stable relationship focused on mutual love is highly valuable for the interviewees, because, according to them, a stable committed relationship leads to plentiful and satisfactory sexual intercourse. In opposition to our expected outcomes, this romantic view about sexuality is even stronger among younger men (less than 20 years old), who mostly said their main expectation in life was to find 'the one' or 'a charming prince' in their lives. Among those men who are involved in homosexual and HIV prevention NGOs, this view was less important and they have more positive opinions regarding casual sexual intercourse.

The importance of romantic love for the majority of the interviewees involves several expectations that influence their sexual behavior. For instance, they explained that casual sex was part of their search for true love: the more sexual partners they met, the more probabilities to find the 'right' one. However, they said that casual sex and 'express sex'* are less valuable and stigmatizing, even though they declare to practice sex in this way.

Casual sex is considered to be a negative practice even when using condoms. The devaluation of casual sex is the result of several cultural beliefs that see it as 'sinful', 'dirty' and 'abject'. While sex in the context of love is highly valued, casual sex is described as the result of a biological need (the urge for sex), but something they want to stop as soon as they settle into a committed relationship. This set of beliefs makes men ignore the fact that even when love is involved, there is a risk in having sex without condoms. Homosexual men tend to believe that whenever a romantic element exists in the sexual encounter – whether with a stable partner or not – the risk becomes lower, as if love itself would make sexual relations safer.

* In this research we used the concept of 'express sex' to refer to those sexual practices performed in public spaces, in a hidden and brief way, which have the purpose of giving immediate sexual satisfaction without much personal interaction or communication between those participating in the sexual encounter.

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In the case of men living with HIV, we found no variations in the way they perceive sexuality and love. The notification of their HIV positive status makes stronger the condemnation of both 'sexual promiscuity' and homosexual sexuality. In this sense, when notified of having HIV, homosexual men usually become sexual abstinent, and only after a long period that may take several years, do they look for stable relationships. They define this period as a process for the development of a 'healthier' or a 'more decent' sexuality. As a consequence, instead of incorporating the use of condoms in their sexual behavior after their notification, they incorporate a higher level of guilt and have their search for love and affection reinforced as the 'right way' to have sexual encounters. However, in both groups seropositive and seronegative homosexual men, the concept of 'sexually exclusive relationship' did not appear: whenever they talked about their relationship they referred to affective commitment with a given person, not necessarily an exclusive one. In this context, sexual exclusiveness is just an expectation, even though they admitted not to trust in their partners' faithfulness.

The expectation of love and stability in their relationships constitutes an obstacle to use condom properly and also it has a negative influence in their self-perception about risk behavior. It is interesting to note that there is no consistency between the information they have on HIV prevention and their cultural beliefs regarding love and sexuality. The way culture shapes their perceptions about sexuality seems to have more influence on their behavior than the fear of HIV.

Perceptions about homosexuality and identity

Most of the interviewees declare to have a homosexual orientation and some of them label themselves as bisexual. Regarding the meaning they attach to this condition, the majority named it as 'abnormal' or 'dirty.' Even though they acknowledge their homosexual desire for other men, they do not accept or legitimize it but see it as something wrong. Most of them said that if it were up to them they would rather be heterosexual; they reject their homosexual feelings in a process that brings them guilt and confusion. Those who expressed this sort of feelings, give several reasons to justify their homosexuality asserting that "it is God's will" or "love and affection is the most important thing between two people, no matter their sex." These explanations help them legitimize and value their homosexual orientation.

In addition, we found that most homosexual men have negative opinions about other homosexuals. For instance, they referred to the others' sexual lives as "promiscuous, unorganized and irresponsible"; furthermore, some of them

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mentioned that the others' lifestyle was "materialistic and superficial". They do not feel comfortable at publicly recognized homosexual places (such as bars or dance clubs), but they usually go there because it is their chance to meet potential partners. This discomfort with homosexual community does not imply a challenge to their own sexual orientation or to their personal sexual identity, but it means that they do not want to be considered part of any homosexual social group.

Therefore, they do not have a sense of community belonging, but they share the stigmatization and devaluation of homosexuality just as the rest of society, in a process that has been called 'internalized homophobia' (Caro 1997). When we asked about their gender identity, most of the informants emphasized their masculinity, which was put together with the rejection of the 'effeminate' behavior culturally attributed to homosexuality. They tended to define themselves as 'discrete gay', 'quiet gay', and 'normal gay' or 'traditional gay', as a way to explain that they were not socially perceived as homosexual because they did not display any female behavior in public spaces. In contrast, they perceived those homosexuals to be *locas*,* or as a distortion in the social environment, because of their anomalous and open 'effeminate' behavior, which elicits taunting, contempt and violence against them. In their understanding the loca is the most discriminated against because he is more visible and disruptive. The loca is also perceived as being more risky, in terms of HIV prevention, since he is supposed to be more promiscuous than 'discrete gays'. Those perceptions were found in both focus groups and in depth interviews.

Those who regard themselves as 'discrete' homosexuals stressed the importance of keeping their homosexuality as private matter, as a sign of 'respect' for society, avoiding any open homosexual behavior such as kissing, holding hands, or getting too close with their partners in public places. However, they asserted that in some cases, public affective behavior should be allowed between same sex couples.

We found a strong relationship between men's perceptions on sexual identities and the level of risk they attribute to having sex with a partner perceived as part of certain identity groups. For example, having a partner who is loca should be riskier in terms of HIV infection, than a partner who is a 'quiet gay'. This perception shows how strong the belief is that HIV has to do mostly with 'sexual promiscuity' rather than the use or non-use of condoms, and it also illuminates the way beliefs regarding 'promiscuity' are intertwined with gender constructions.

* *Loca* can be translated as 'mad woman'.

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Perceptions about condoms

When we explored the meanings attributed to condoms, we found several negative perceptions, even among those men who reported using condoms frequently. They mentioned several features of the condom that make it unpleasant and uncomfortable to wear. In their opinion, the condom becomes a barrier between partners, reducing spontaneity and personal connection in sexual intercourse, which is particularly rejected in stable relationships. What we found most worrisome is the lack of trust in condoms as a preventive method; the majority of the interviewees thought that condoms break too easily. Some also added that it was scientifically proven that HIV may trespass the condom barrier, so it was a mistake to think it to be an actual protective measure. This lack of trust in condoms can be partially explained as a result of the campaigns against condom use, led mainly by the Catholic Church and other conservative groups in Chile, which have raised doubts about the effectiveness of condoms, arguing the existence of several scientific tests that show its lack of safety. These messages have had an important effect in shaping homosexual men's opinions about the condom, as well as those of the Chilean population at large.

It is interesting to note that even though men have negative opinions about condoms, they use them frequently in daily life. Ironically, we found that some men who have a positive opinion about condoms, do not use them because they have a stable partner. These findings challenge the common assumption that there is a strong relation between attitudes towards condoms and actual use. In order to explain this apparent contradiction we realized the need to explore other cultural factors that may play a role in condom use. In addition, the search for intimacy and commitment may be one factor that prevents men from using condoms, as well as the belief in male sexuality as something inherently natural and irrational that cannot be controlled or self-regulated. Because sexual pleasure is perceived as the immediate satisfaction of a strong sexual impulse, the use of condoms is perceived as a 'too rational' behavior that does not fit with sexual pleasure. Furthermore, most of HIV prevention messages have emphasized the need for rational reflection about risk, meanwhile the use of condoms has not been placed in the language of pleasure or eroticization.

In the case of men without HIV, the argument for the refusal to use condoms is based on the assumption that their partners do not have HIV. Generally speaking, our informants said that they stopped using condoms after they confirmed their partners did not have HIV, usually after an ELISA test or after their partners told them that there was no risk involved. One of our main findings was the fact that some men view the stopping of condom use as a sign of commitment in their relationships, because it showed how much they trust

their partner. This gesture seems to represent how solid the relationship is, as one informant said, "It is like we started to wear a marriage ring when we stopped using condoms".

Conclusion

The moral panic raised by the HIV epidemic has led to the development of preventive strategies that condemn sexuality and impose self-care as a norm (Weeks 1995). This view tends to ignore the role played by sexual experiences, pleasure and love in the context of homosexual relationships. These elements have been ignored by major institutions when analyzing HIV risk behavior, as part of the biases applied commonly to homosexuality and homosexual relationships (Bolton 1998).

One of the main conclusions of this research was the need for the promotion of a cultural change to overcome the negative view that homosexual men have of their sexuality, promoting more positive perceptions about casual sex especially when the condom is used. We see a great risk in the belief that their sexuality must be covered with love to be socially legitimized, not only because it makes them think that there is no need for condom use in stable relationship (even though they do not believe in sexual exclusiveness) but also because the search for love legitimizes the unprotected casual sex.

We realize the importance of confronting cultural homophobia even among homosexual men, as part of a strategy to promote the proper condom use. We found that men who had a more positive view about their sexuality were also more likely to use condoms, as part of their self-care. In contrast, those who felt guilty about being homosexual were mostly those who did not use condoms, basing that decision on their love and commitment with their partners. That view attributes to love the quality of 'being preventive' in itself. We think that such a belief has to do with the Catholic cultural substrate of Chilean society as a colonial production (Nesvig 2001), as well as with Catholic-based campaigns that promote sexual abstinence and monogamy as preventive practices, that have also had a considerable impact on Chilean population at large.*

In order to increase the use of condoms, a serious effort is needed for it to be culturally accepted as a pleasurable experience. This process involves the development of a new cultural meaning for the condom use, which assumes

* For instance, one of the messages promoted by these campaigns was "love is life." A national survey about Chileans' sexual behavior (CONASIDA 2000) proved that 48,2% of people think that having sex only being in love with the partner is a way of preventing HIV.

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that sexuality is not a 'natural' phenomenon but it is the result of cultural constructions, just like other social practices.

The fact that practices and beliefs do not coincide in the case of Chileans' sexuality is also worth further discussion. Even though we found very strong negative opinions about homosexuality and casual and express sex, this does not mean that it is not practiced but that individuals feel guilty and see HIV as a punishment for their 'sinful' behavior. As researchers in the field of HIV and homosexuality, we did not expect to find such conservative views among homosexual men, particularly because they have been subjects of intense HIV prevention campaigns as well as campaigns in favor of homosexual liberation and 'gay pride'. The discourse of homosexual liberation seems to have reached a very superficial level of their experience, because at a more subjective layer we still find several conflicts and discontents with their homosexual desires and practices.

At a theoretical level there is also a need for further discussion on the concept of homosexual identity in the way it was used in this research and its ulterior outcomes. The use of the concept of MSM was required by CONASIDA, however in practice we found that men tend to define themselves as either homosexual or bisexual. We did not reach the MSM population, probably those men who define themselves as heterosexual but have occasional sexual encounters with other men, for whom the distinction between identity and practices may be applicable. We found a much demarcated distinction between individual identity and social political identity. As mentioned before, most of the informants define themselves as homosexual and bisexual because of their sexual desire towards other men as well as their sexual experiences, however they do not feel part of a community and do not feel comfortable with such a social identity. Cultural homophobia and their own negative views about homosexuality play an important role in reinforcing this distinctive level of identity. Homosexuality is still seen as a private matter that must be kept hidden and unnoticed by society.

Regarding the application of the research results, the promotion of a cultural change on homosexuality was seen as an overly ambitious goal by CONASIDA. They even mentioned that it was not a part of CONASIDA's role to encourage cultural changes, because they want to leave room for people's individual choices. Nevertheless, we found solid evidence to make the point that homosexual men who feel guilty about their sexuality do not have a wide range of options for having safer sex. Through this research we influenced the design of the last AIDS Prevention National Campaign. We strongly advised (together with other researchers working in this field) that the campaign should be exclusively focused on condom promotion, with explicit messages for homosexual

men. Unfortunately, the campaign was later strongly criticized by the most conservative sectors of Chilean society and also, it was not possible to assess its real effect on the homosexual men's perceptions on sexuality and HIV prevention. In spite of these issues, we still think that the very act of showing publicly homosexual practices in an AIDS campaign is a contribution to confront and reduce cultural homophobia.

In addition, during the research project we worked closely with the HIV/AIDS NGOs Assembly conformed by various social organizations. They gave us recommendations for a better development of this research and later on discussed the research findings, which undoubtedly improved the quality of our results. Also, the NGOs Assembly gave us the political support for influencing the National AIDS Campaign.

Finally, I would like to make a few comments regarding how my involvement in the Amsterdam Master's in Medical Anthropology program (AMMA) at University of Amsterdam helped or influenced the development of this research. I applied some of the skills learned at AMMA, particularly in terms of qualitative methodology, which enriched enormously the research process and its results. Reflecting on this experience, what I found to be the most valuable skill gained at AMMA was the ability to think wider in the construction of the research problem, taking into account the several levels and social dimensions involved in applied health research. Secondly, to hold a master's degree from the University of Amsterdam helped me lend more credibility and legitimacy to this research. As mentioned before, CONASIDA was reluctant to hire two 'activist' organizations (MUMS and SIDACCION) because they thought these organizations were biased in their approach to HIV prevention and they did not have the academic credentials for doing this kind of research. Thus, my training was crucial in validating the research and give it a 'scholarly' profile.

In a wider perspective, medical anthropology has much to offer to social research in the field of sexuality and HIV prevention. The inclusion of a cultural perspective in this kind of research is critical, particularly in cases where other approaches have failed or have had limited results. However, what I missed in my graduate education was more concrete public policy skills for more direct recommendations in how to apply the research results. I noticed the absence of a common language with policy makers in order to make the medical anthropology perspective stronger, which is just the reflection of an epistemological gap. Even though policy makers found the research results interesting and valuable, they did not fully believe that those results could be applied more concretely, and furthermore, they did not even believe in the possibility of a policy-directed cultural change. They also showed their concern about how representative qualitative results were, implying that informed public policies

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must always rely on 'numbers'. The role or contribution of qualitative research is still unclear for them, and it seems that qualitative research is chosen just because it is cheaper and it seems 'easier' and 'faster,' regardless the nature of the research problem and the state-of-art information.

In conclusion, in order to promote the development of medical anthropology research in the field of HIV, we must keep on unmasking the role that culture plays in health phenomena, as well as the fact that culture is a dimension that can be explored through applied anthropological research. In this regard, it is also important to emphasize the fact that culture is not a fixed abstract entity, but that cultural change can be promoted in order to improve the living conditions of those for whom public health policy is intended.

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Chapter 6

A bump in the neck

From doctor to patient to doctor

MICHAEL GOLINKO*

Arthur Kleinman writes toward the end of his book *What Really Matters*, "No time is easy; no life is as simple a progression as an academic vita outlines" (2006: 195). I echo Kleinman's sentiment when reflecting upon my experience going from a doctor to a cancer patient and back again.

No one who knows me now would guess that I had once aspired to be an astrophysicist, but then later changed my mind in high school only after reading an article in *The New York Times* that left me wanting to pursue medicine. Nor is it apparent that I didn't get accepted into medical school the first time I applied or that I almost went into psychiatry instead of surgery. My resumé, however, neatly enumerates the benchmarks of a young physician in the midst of surgical training, but there are several instrumental parts of my career that do not appear in the long list of accomplishments. One of these unknown experiences, however, is worth mentioning here. A major part of my story on becoming a doctor, but often omitted, is my experience with cancer.

Between my second and third year of medical school, I took a leave of absence to study medical anthropology. It was in that classroom, amongst my international colleagues, that I acquired a new vocabulary with which to define and articulate my experiences in medicine. In that classroom, I learned about symbolic healing (Kleinman 1978) and "illness as a form of communication" (Scheper-Hughes & Lock 1987: 15). As a medical student, I found the concepts of emic and etic useful in thinking about modern medical training.

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Could physician training improve after doctors themselves experienced being a patient? Could a patient heal faster if he was empowered to take charge of his own health? Laurence Kirmayer suggests a theoretical midpoint between these two poles at which healing is possible, "If we [the physicians] meet patients on equal footing, together we create a place where a personally and culturally meaningful process of healing can be co-constructed and enacted" (Kirmayer 2003: 270). But does the gold standard of 'equal footing' require the doctor to become a patient himself? Moreover, how is the transition from doctor to patient experienced by an individual? How is self, identity and purpose re-defined when illness strikes? These questions will be explored through the narrative of my own experience with cancer in the midst of my surgical training.

A bump in the neck

In May 2006, I noticed a painful bump in the left side of my neck. I thought it was a muscle spasm and would resolve on its own. When it remained, I consulted a close friend – also a physician – to offer his opinion. As he asked me to turn my neck to the right, the bump became more noticeable. Even though I could not articulate what I suspected, the simple concern of another person sent a chill through me.

If the bump did turn out to be something, it was the most inopportune time. I was planning to leave residency for two years to pursue research. These 'lab years' were often seen as vacation compared to residency, and in addition to doing research, I was looking forward to a nine to five job. I had also planned on a three-week trip to China before entering the lab. I had my visa, plane tickets, and a Mandarin pocket dictionary. This bump could throw a potential wrench in all of my well-laid out plans.

After consulting with my physician friend, I asked for an opinion from an ear-nose-throat doctor at the hospital where I worked. He was not particularly concerned, reasoning that I was a young male without any risk factors. It was probably just a benign cyst on my thyroid, he said. After all, most thyroid cancer patients are middle-aged women and many have had a history of head or neck radiation as a child – or lived close to Chernobyl. Even if it was thyroid cancer, I would feel less anxious than a woman may feel who discovers a lump in her breast or a man who feels a nodule in his testicle; while I treated numerous patients with breast, pancreatic, lung and colon cancer in the acute phases of their disease, never had I seen someone die of thyroid cancer. Nevertheless, at his urging, I had an ultrasound the next day.

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The next morning an ultrasound technician snuck me in for a quick exam before the regular patients showed up. As she scanned the left side of my neck she said, "Whoa! No normal thyroid tissue here." Curious, I asked to see the image. And there it was. Twinkling with calcifications in the firmament of the black ultrasound screen was a five cm mass surrounded by swirling fluid. I realized the bump was actually the fluid component, not the hard, solid mass that lay deeper still. Staring at the screen, it was hard to believe I was looking at an image of my own neck.

Action took precedence over thoughts and I left the ultrasound suite with a printout of the images and headed straight for the one surgeon who I knew could take care of this. With over twenty-five years of experience, Dr. A was renowned for thyroid surgery, and as one of his residents, I would have unprecedented access to his expert opinion. As I walked into the hospital to find Dr. A, I mentally reviewed what I knew about thyroid cancer from a biomedical perspective. The cure was surgical in the vast majority of cases – no chemo or radiation, so that was a relief. I also wondered if I was hyperthyroid all this time because of the mass. An overactive thyroid gland would certainly explain my personality. I knew that as a young male I was one of the approximately five men in 100,000 to develop thyroid cancer. Cure was clean and easy and I would just have to take a little blue pill for the rest of my life. For these reasons, I felt no urgency to tell friends and family until I talked to Dr. A.

Once in the hospital, I ran into Dr. A and the chief resident, who was also a good friend of mine. I showed them both my neck and gave them the ultrasound taken just moments before. The reaction was as subtle as the image they held in their hands. "Where the hell did this come from?" Dr. A. asked. My chief resident furrowed his eyebrows in confusion, felt my neck and uttered a four-letter word. These two surgeons, my teachers, my colleagues, soon to be *my* doctors, took turns feeling my neck then looked back in surprise at the ultrasound. Superstitiously, without saying the 'C-word,' they knew as well as I that it was cancer. Dr. A's face, rippled with disbelief just a moment ago, was now calm. With resolve he turned to me and said, "You know this has to come out, right? We can do it next week."

Though clinically, the mass was likely cancer, the next step was to have a fine-needle aspiration (FNA) biopsy of the mass to confirm diagnosis. After all, there was a chance it still might be just a really large cyst. I hoped for my parents' sake, and perhaps secretly my own, that it was only a cyst.

After the exam, I delivered the biopsy to the pathologist. On the way, I wondered, did this tube really hold cancer, *my* cancer? Was *I* a cancer patient and what did that mean exactly? I didn't feel ill nor did I think that my life or livelihood was threatened, so how would this change me, if at all? The bio-

medical trained part of me knew deep down knew I'd be okay, but another part of me worried that if the mass was responsible for my personality in some way, how would its removal affect me? How would taking replacement thyroid hormone affect me?

The thyroid gland may be thought of the gas pedal of the body. Increased thyroid hormone increases the amount of 'gas', i.e. oxygen and glucose delivered to the 'engine' of virtually every cell in the body. Hyperthyroid people tend to be thin, need little sleep, may appear anxious, while hypothyroid people tend to be heavier set and move at a slower pace.

Reflecting back on own personality, I never sat still. Far from passive, I always felt compelled to be active. I even won the coveted 'Energizer Bunny' award my first year of residency. So, perhaps it was an overactive thyroid that explained my personality trait. But as it turned out, my thyroid function tests were normal, so the tumor didn't even seem to have a functional effect on me. So how would this cancer, which I had seen taken the lives of so many others, affect my own life and my families'? Like an expectant father who knows his child will be born yet is spellbound nevertheless at the moment of delivery, I, too, witnessed the birth of my thyroid cancer on June 12, 2006.

I called the pathologist and got the result over the phone from the hospital clinic. "It looks like classic papillary-carcinoma; textbook actually," he said. So there it was. What I thought was a muscle spasm, turned out to be cancer in my neck. The words of the ultrasound technician scrolled through my mind like a giant LED news banner "no normal thyroid tissue…".

I can't say it was fear or sadness that enveloped me at that moment, but rather an utter sobriety. At once, the crystal clear image of my future became murky – what would my parents think? Would I still be able to go to China? Could I start my new research job on time? The ethereal thoughts and what-ifs of having cancer now fell from the sky like a lead brick weighing me down. These realizations were all the more perplexing as to me as I had never even felt sick.

From doctor to patient

As soon as I began to tell my family, colleagues and friends, I discovered that the dimensions of the tumor were far larger than those outlined in the ultrasound exam. My parents didn't know about the bump in my neck. Nor had they any idea I would be going for surgery to take it out next week. And certainly they never would have expected I would have cancer. I didn't know how much my parents and non-medical friends knew about thyroid cancer. Unlike

breast or lung cancer, thyroid cancer did not necessarily inspire a global crusade, pink ribbons, or national telethons. Because of my biomedical training, I delivered the news to my family and friends rather nonchalantly, though I quickly discovered I had seriously miscalculated my assumption.

The news took my mother's breath away. My father was simply floored. Neither of them had cancer and there was no family history of thyroid disease. Both were extremely supportive and loving but struggled with the idea that their son, a person half their age went from being a healthy doctor to a cancer patient who was about to have surgery – and all this within a span of ten days. I found it was easy to tell my non-medical friends about my diagnosis, but not easy for them to hear. During a typical phone call I would inform my friends by telling them about the *mass* – its discovery, dimensions, and the cell type, but not *me*. Many friends were speechless or awkward after I told them the news. I was perplexed as to why. It wasn't awkward for me to talk about it, so why should it be awkward for them? I knew this was no big deal. In a subsequent conversation with one of my best friends, I was describing this phenomenon and my confusion. He pointed out that most people don't really care what cell type it is, they just want to know whether I was going to be okay.

The reaction from my colleagues was of concern, but it did not carry the same level of emotional urgency I felt from my friends and family. They were relieved that it was papillary carcinoma (which carries the best prognosis among thyroid cancer), and as a result, were not particularly fearful about what would happen to me. Almost all of my medical colleagues responded the same: "Well, if you're going to have any cancer, thyroid is the one you want to get" – intimating at the knowledge we all shared of how dismal it was to get one of those other '*real*' cancers and how lucky I was in contrast.

Under the knife

With the full support of my friends and family, the day of my surgery finally arrived. I was about to become a patient in the hospital where I had spent so much time training to be a physician. I would have an intra-venous line, wear a patient gown, and stay in hospital bed. In a way, I was looking forward to the chance at gaining this insider perspective of the patient. As I sat in the pre-operative area with other patients waiting to go back to the O.R., I reflected on why my thyroid really had to come out. After all, my lab tests were normal and I was asymptomatic, save for the minor discomfort caused by the bump. The most frustrating aspect of this tumor was that it robbed me of my summer

vacation; what was I supposed to do all day? All summer? Just ten days after having my ultrasound, Dr. A. and my chief resident wheeled me into the O.R.

My very next memory after the surgery was that of the recovery room, after my surgeons spent four hours loosening the tumors grip on my windpipe. I felt like I was hit by a truck and spent three groggy days and nights in the hospital, experiencing among other things – unrelenting back pain, nausea and vomiting, and in general, a flu-like feeling. Lying in the hospital bed, I discovered I had lied to many of my patients about the details of their hospital experience. I used to tell patients as a resident, just weeks before, that the inflating/deflating leg stockings they had to wear to prevent blood clots was like getting a free massage. However, I found wearing them most unpleasant and nothing at all like a massage. In addition, I used to scold male patients who immediately having had surgery to stop attempting to get out of bed – while I myself found it almost impossible to do otherwise. By the third hospital day, my sensorium had cleared and I remember watching a TV commercial with a guy sipping a cup of coffee. Just the simple act of enjoying that cup of coffee unimpeded seemed all I wanted in the world. To me that simple image of being able to enjoy the aromatic vapors spiraling from the mug represented what it meant to enjoy good health.

Thyroidless, beeperless and residencyless: Liminal space

After my hospital stay I was discharged home and for the first time in my life, my only identity was that of a patient, and my only activities were the so-called activities of daily living. I felt as though I was in the 'liminal space' described by Van Gennep (1960) in his book on rites of passage. I too felt as if I was in an in-between state. First, I was a surgical trainee – a student of its principles, a disciple of its art and tradition, but was still far from being a fully trained surgeon. Lastly, the transition that I had prepared for was from clinician to researcher, not clinician to patient.

For this reason I did not experience some of the more identity-based reactions to becoming ill that some physicians report, that it is "the worst possible thing that could happen to them… If you have an illness, you become one of them" (Klitzman 2006: 547). It was not as if I was an established attending physician with a practice I was leaving behind, nor would I be creating more work for my resident colleagues, as I was leaving residency anyway. In some ways, the timing seemed ideal. My new mentor at my research laboratory was very flexible about my start date. My only job now was to rest, as most patients do when they are ill. But this was easier said than done for the 'Energizer Bunny'.

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Assuming the patient identity

I did share my struggle with the sudden change of pace with two elder colleagues who both also had cancer. As two physicians, one with non-Hodgkin's Lymphoma, the other with bilateral breast cancer and melanoma, they candidly reveal their experience:

> Having Cancer is not all bad… For one, it certainly grabbed our attention. As busy professionals with equally busy families, we tended to live like everyone else – from one task to another, without really stopping to consider the meaning and wonder in our daily lives (Tierney & McKinley 2002: 27).

For someone who lived life at full throttle, learning how to just rest was unexpectedly hard to do. Because I knew my wound wouldn't reach adequate tensile strength for at least six weeks, I limited my travel to the local grocery store. Navigating the subway and the human seas that swelled in Manhattan were out of the question.

At first, I tried to learn more about the biomedical aspects of thyroid cancer from my surgery textbooks to keep busy. My parents encouraged me at every turn to take it easy and watch movies, but I insisted on staying busy. I didn't feel like myself if I wasn't doing something, saying something, or socializing. Just resting, any more than the little sleep I needed, seemed unnatural and lazy to me.

I was also lonely. Being a resident was a fairly social enterprise, since I met and schmoozed with new people all the time. My only social interaction was with my two roommates. As a way to reach out, I used the internet and joined a thyroid cancer survivors group. Almost all those I corresponded with were older women. The nature of the email exchanges centered on the diagnosis and treatment experience, but not about what those experiences meant on a personal level.

Over the coming month following the surgery, the primary tension I encountered was an internal struggle between the physician within me – the one who had knowledge and skill, took action, and gave back to society and the patient – the one without choice, and though no fault of his own had to absorb society's resources to restore himself to health. Recalling the 'equal footing' of Kirmayer, I reasoned that if thyroid cancer wasn't making me 'sick' per se, then perhaps it had appeared to make me better, or that it had imparted some lesson for me as a doctor.

After considering my own clinical experience as both patient and doctor, I came to appreciate two distinct forms of uncertainty. One is primarily experi-

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enced by doctors, which is estimating what a patient's particular outcome will be from treatment or how long they will live or how well. Before the internet, doctors seemed to be the sole purveyors of this knowledge, quoting five year survival rates, in addition to a variety of metrics designed to provide some certainty, or at least some probability of what comes next for a particular patient. But in recent years, thanks to ubiquity of medical data on the internet, that gap in knowledge has rapidly closed. Patients often come to a doctor's visit armed with the latest studies and statistics, conveniently downloaded to their blackberries or iPhones. The reality is that doctors can offer no more reassuring or condemning statistics than the patient could find online. There is no secret cache of studies that is bestowed on a person once he completes his training as a physician. Whereas much of the separation and power hinged on doctors' specialized knowledge of what to expect, this knowledge is simply not so special any longer. This type of uncertainty can be the most aggressive aspect of cancer or any serious disease; for some patients, a threatened future can be more crippling than a severed limb.

The second type of uncertainty I encountered was the short-term uncertainty. My identity and knowledge as a physician spared me the first type of uncertainty of my physical future, at least statistically: less than five in one million with my demographic profile die within five years from thyroid cancer (Ries 2007). I was far more likely to be a traffic mortality. What is less accessible to the public is the nuts and bolts of treating a disease, such as a needle biopsy, ultrasound, general anesthesia, etc. I took comfort from the fact that from a technical aspect I knew the procedure down to where the clamps would be placed on my neck. I knew the doctors who would cut me, the nurses who would care for me, and I even knew the room I would wake up in postoperatively. It was the same room that I had tended to other patients dozens of times myself. Few people could have been afforded the degree of certainty and support I had. Without them, my experience would likely have been far more agonizing. Although I was a physician, my professionalization was incomplete. In some ways I identified and looked forward to my chance to be the ultimate insider, and to use participant observation to fully embrace the emic perspective of cancer.

As Scheper-Hughes and Lock (1987) suggest, illness is a form of communication and my new mission for that summer was to discover what my thyroid cancer was trying to teach me. For example, what lessons could I learn about myself? How had I approached the world in this cancer experience? Or, how was I to become a better doctor? Why else was I sitting around for two months doing nothing? Most people would be grateful for the time off, but I was not at ease with my new lifestyle of leisure and the vulnerability it entailed. My

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summer subsequently followed two paths, one explored the personal meaning behind my illness (which is beyond the scope of this essay) and the other examined how I resolved the struggle of doctor and patient – the struggle of the powerful and the vulnerable – the certain and the uncertain – which simmered within myself during this period.

Once I became stronger, I slowly began to emerge from the shell of my living room and venture out into the world, not as a physician but as a recovering patient on my newly started thyroid replacement hormone. Because I was not working in a hospital, and still had over a month until I had to start research, I felt compelled to reach out to my fellow-man, perhaps to feel like a physician again.

After a day of brainstorming about how I could contribute to society (and fight my boredom!) without being a physician, I embarked on several projects designed to reach out to New Yorkers (Golinko 2006: 2901).

These various activities were some of the most therapeutic activities I engaged in that summer. It allowed me to me to feel like I was making a contribution, making a statement in direct response to something was which was causing overt suffering. During those moments, I didn't feel like a vulnerable cancer patient, but rather empowered.

As long as I regularly took my thyroid hormone to replace the organ I lost, I was rarely confronted with the patient side of myself. It was not until my research years were coming to a close and the anticipation of entering residency again confronted me with the doctor-patient duality.

From patient back to doctor

Kirmayer suggests that a healer's authority comes from his own experience with illness. He claims that a healer's "willingness to remain in contact with parts of the self that are wounded or in pain allows the healer to engage the patient on this empathic ground" (2003: 251). Jung points out that this sensibility is important for the development of any psychotherapist (1966: 37). But what about the surgeon? The one who chooses his profession to specifically not intervene in the psychic processes but now engages with them each time he deals with a patient? Could I now be a more complete physician having been a patient? Moreover, once having identified with the patient role, in terms of how powerless I felt, and then desiring to regain my physician stature, how would this experience help my future patients?

When I re-entered residency, I did not have to volunteer my patient status to my colleagues because the large scar on my neck almost always drew inquir-

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ies. In routine clinical encounters at the bedside or before or after the operating room, I found that my patients did not warm up once I told them that I had experienced cancer and went through surgery. In the acute care setting, most patients were concerned with their own suffering and the torturous procedure I was about to inflict on them. Occasionally, I did encounter patients who did seem to open up more, and allowed themselves to express their vulnerability more openly once I informed them about my cancer. Yet my cancer was always discussed in the past tense – yes I had it; yes I had surgery; but I never really felt impaired, never felt 'sick'.

My identities as a doctor and as a patient did, however, intersect at the end of my third year of residency. As part of surveillance of thyroid cancer, I had to undergo a nuclear medicine test to scan my entire body for metastatic thyroid cells. The test involved discontinuing my thyroid medication for two weeks in preparation for this scan, effectively making me hypothyroid. My endocrinologist warned me that I would probably feel lousy – so I scheduled the scan at time when I knew my clinical duties would be light. The scan itself involved multiple blood draws, taking a bowel cleanser, five sequential days of taking radioactive iodine, and then proceeding with the scan. Throughout this entire process, I had made a point to disclose that I was one of the residents, signaling my primary role as a physician than as a patient. This was borne out of a desire to navigate the system faster and obtain quicker results than if I was a mere regular patient.

But at the same time, I noticed a peculiar side effect of announcing my physician role. Although I invariably received faster service and special scheduling preferences with regards to the tests I was undergoing, I found that there was selective communication on the part of the medical personnel. Although I have a medical degree and familiarity with thyroid cancer as a surgical resident, I was also not a master thyroid surgeon or endocrinologist. I found myself wanting more information at the routine office visit than was being offered. Once the medical personnel discovered that I was a resident, I would invariably hear a comment like, "Oh! Then I don't need to go through all these details." However, it would have been nice if they had verified that I indeed understood the nuances of what was going to be done to me and why. There was a tacit assumption that because I was a physician that I should have automatically known or not be fearful about what the next step was or what a certain test was going to be like. The assumption was that I had more familiarity with the disease process as a physician and therefore did not necessarily have the same fears, concerns or anxieties as a regular patient. As the day of the scan approached, as my endocrinologist had predicted, I was feeling pretty slow – and no matter how much sleep I got, I never woke up refreshed. Coffee did

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not help and I was too tired to exercise. I was also cognitively slower – people had to often repeat themselves when asking me a complex question. To put it simply, I was not feeling like myself.

In this state, I found it increasingly difficult to care for patients the more I felt like a patient myself. It was difficult to look past the changes in my own body and mind and be truly engaged with patient care. I could go through the motions and do what needed to be done, but at the same time, I could not empathize with them. The challenge was to assume both identities simultaneously – although I was expected to be the doctor, I simply was not acting like myself.

Implications for clinicians

What is health then? Is it merely absence of disease or something more? Who defines health and how is it measured? Does missing a particular organ, such as a breast or thyroid, define health? Or is it how we feel what really matters? Do doctors or patients define what it means to be healthy? Perhaps health is the subjective state of balance. Like a tightrope walker who uses a long pole to balance himself on the high wire; we, too, use ideas, identities, metaphors, and worldviews to balance ourselves as we move through life. When illness strikes, it is as if someone has cut that pole short, forcing us to discover a new equilibrium point to keep moving forward.

The Chief of Psychiatry at MD Anderson Cancer Center writes, "People have to reinvent a way to live with [cancer]. Even if treatment doesn't work and the cancer is spreading, if the person is going to live five years, that's a long time, longer than you can stay in a state of crisis" (Lewin 1991: A1). As for my own experience, having cancer emphasized how important it was to honor the capacity for healing and vulnerability within each human being. When I was recuperating from surgery, I found new ways to express myself because of the space the cancer experience had opened in my life. Moreover, trying to be a doctor when in reality I felt more like a patient, forced me to accept my limitations and appreciate how most patients sitting in their beds just want to feel like themselves again, even if it means simply enjoying a cup of coffee.

If the role of the healthcare professional is to guide the patient back to his or her center, then doctors must attempt to understand the forces that converge to achieve this. Disease is a perturbation to health, which may arise from a single source, yet often engages and simultaneously affects the physical, emotional, social and spiritual facets of the person's being. As Dr. Rita Charon, founder and director of the program on narrative medicine at Columbia

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University argues, "A scientifically competent medicine alone cannot help a patient grapple with the loss of health or find meaning in suffering. Along with scientific ability, physicians need the ability to listen to the narratives of the patient, grasp and honor their meanings, and be moved to act on the patient's behalf" (2001: 1897). Medical anthropology can offer the clinician techniques and methods to gain the 'narrative competence' needed to grasp the patients' entire illness experience and engage them at a therapeutic level, honoring the unique way that each patient bears his disease.

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Chapter 7

From participant observation to reflection

Notes on returning from the field

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At a panel during the 2010 American Anthropological Association meeting in Philadelphia, several accomplished anthropologists contemplated the task of teaching methods in sociocultural anthropology, particularly as teachers of students writing their dissertations. Judith Faruhar reminded the audience that writing is part of methodology; there is an ethics applied when choosing what one should record (conference paper, December 3, 2009). Charles Piot, serving as the discussant of this panel, suggested that the changes in how we write in accordance to what happens in the field (how long we spend in the field, where we choose to study, and how close we become to our participants) reflect new trends in theory, not methodology (conference paper, December 3, 2009). Regardless of one's position on writing as an extension of theory or methodology, it is clear that both the nature of fieldwork (long-term engagement) and the writing process (how we translate) are expressions of what we believe to be important – or not – either to ourselves or to others. We strive to understand local communities by investing time to solve problems; by writing, we attempt to direct others toward knowledge that seeks to change their view of the world. In this essay, I argue that despite the numerous and innovative methods and theories on data collection, conducting fieldwork over a long period of time in the field continues to be anthropology's enduring methodological contribution to the broader social sciences. In addition, the writing of this fieldwork process is where anthropologists can reveal their commitment to ethics and morals.

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Reflecting upon my own fieldwork experience over the span of 18 months in Argentina in 2008-2009, I learned the benefit of long-term engagement as an outsider living within a local community. While cultural anthropology is criticized for being too slow in solving social problems, or for presenting data in overly dense and jargon-filled language, I claim that employing anthropology's classical methodology of participant observation over a long period of time continues to provide perspectives and data that makes our discipline distinct and valuable. Though contemporary anthropologists have become reflexive – sometimes to the point of navel-gazing – in response to, and as an apology for, our discipline's origin as a positivistic, racist, and colonialist endeavor, I still believe that there is tremendous value in learning about human behavior through experiential methodology. Committing to spending at least a year in the field enables us to build trust, produce in-depth understandings of social phenomena, avoid premature conclusions, and allow for personal transformation. These are the qualities that make anthropological data worth considering and valuable, not only to our own discipline but to those beyond the walls of the academy.

Make friends

We seek to establish trust with people by essentially becoming a friend. Hortense Powdermaker's aptly titled memoir, *Stranger and Friend: The Way of an Anthropologist*, published in 1966, reminds us that even as we seek to become an insider, we always remain an outsider, and our goal lies somewhere between these two worlds. Establishing and maintaining this middle ground requires patience, dedication, and constant readjustment.

In my own research, I worked with *ex presos políticos* (former political prisoners) who strongly disliked the United States and distrusted North American researchers as potential CIA spies – and for good reason. During the Cold War, the U.S. supported and funded several government coups throughout Latin America to effectively end the growing popular leftist and social movements. The U.S. School of Americas, as it was called then, at Fort Benning, Georgia, trained military officers from Latin America in counter-terrorism techniques, which were put to use when they returned to their respective countries. These students became important leaders of various repressive regimes that have tortured and killed 'subversives,' or 'disappeared' those who allegedly posed a threat to national security. In Argentina, the 'terrorists' were university students, labor union members, revolutionary fighters, and intellectuals. The military employed torture methods created by the CIA, and as a result, many of the survivors blame the U.S. for the human rights abuses committed through-

out the Southern Cone. It is unsurprising then, that an American anthropologist, like me, had to work hard to gain trust from those who fell victim to U.S. foreign policy. There were many jokes made about me being a CIA operative – a young American woman who wanted to simply hang out with old people seemed at times slightly curious or downright suspicious.

Though participant observation often conjures up an image of an objective observer who is slightly removed from her subjects, this field experience required a specific kind of political alignment. There was no room to refuse a position on global politics among the ex presos políticos. I spent five months developing relationships and actively participating in their organization, the Asociación de Ex Presos Políticos de Córoba (Association of Former Political Prisoners of Córdoba, or AEPPC), before even broaching the topic of interviews. Building close relationships involves passing a series of small 'tests,' having several conversations, making coffee dates, showing up on time, and being patient. I observed the interactions among the ex presos políticos, learned their vocabulary, and kept track of personalities and conflicts, as they, too, were watching me. Having this time to build friendships and to prove myself as someone in solidarity with them was the first step in a yearlong journey that culminated with my being allowed to create the first oral history archive for the AEPPC, and later to my translating their first book of testimonies. But spending time with participants is not simply a matter of obtaining data; this process allows an anthropologist to get closer at one or several 'truths'. That is, we see more facets of a person and hear more privileged information thanks to the closeness of our relationships and our mutual trust. I am not suggesting that there is one truth, or that an anthropologist walks away knowing the truth. What I am suggesting, however, is that building trust is a fundamental prerequisite to gaining rich insights that are contradictory, complex, and nuanced, leading to a deeper understanding.

Build a mosaic rather than carve a stone

In a 1955 study that compared participation observation and survey data, Vidich and Shapiro found that while survey data was more representative and provided a broader picture, participant observation provided a richer interpretation of the data. Both methodologies reached similar conclusions, but participant observation gave the data additional layers of meaning because the ethnographer was able to draw upon language, habits, attitudes, values, and beliefs to explain how participants interpreted the research questions and why they answered them in the manner that they did (Vidich & Shapiro 1955).

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Nonetheless, surveys are complementary to, and sometimes better than, participant observation – depending on the question and the kind of data one seeks. What participant observation allows, however, is the ability to take into account multiple factors and sources of data, and then stitch them together. Problems are rarely identified as isolated events. In other words, human behavior is complex and obtaining information on one aspect of a person is a thin slice of the bigger picture. Considering multiple conversations, interviews, and actions enables us to compare what people say and how they act, as well as changes in the person's views and actions over time.

In my scholarly preparation for the field, I drew heavily from other scholars of 'transitional justice' – the field that examines how individuals and governments deal with legacies of human rights abuses when a period of mass violence has come to an end. The language of transitional justice consists of key words like 'healing' and 'reconciliation.' Yet, once in the field, I realized that no one within the human rights community used these words, let alone the phrase transitional justice. The Spanish word for healing – *sanación* – was never once mentioned. Instead human rights activists repeated the words *memoria, verdad y justicia* (memory, truth and justice). Reorienting myself to the local vocabulary also provided insights on how the ex presos políticos viewed their own organizational goals and of the past. For instance, while English-speaking journalists and academics may refer to the dictatorship as the 'Dirty War,' the human rights community strongly opposes this phrase. A dirty war implies that there were two equal sides, but the ex presos políticos believe the dictatorship was a major power that systematically oppressed minority political dissidents in secret *campos de concentración* (concentration camps). The disappearances and killings constituted genocide, not just violence, according to the human rights community.

If I had spent only a few weeks, even a couple of months, in Córdoba, I would not have been able to listen and understand the local vocabulary and the meanings of these terms as used by the people. Gaining a better handle of the vocabulary also unearthed ideas and opinions about the past. I discovered how locals determine the political identity of a person by how they referred to the dictatorship. I learned about the values held by human rights groups by paying close attention to the concepts on which they chose to focus their efforts: memory, truth, and justice. Setting up memorials is not for the purpose of healing, but to tell the truth by establishing who they are and what makes them victims. Advocating for trials against former military officials is called 'justice,' rather than revenge, and is in opposition to amnesty, which opponents of the trial view as reconciliation and trial supporters view as impunity. Spending time in the field enables anthropologists to revise their questions,

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their language, and to reframe their studies to match the perspectives of the local community. I learned that while the ex presos políticos publicly talked about truth, memory, and justice in specific relation to the dictatorship, they participated more generally in the community through art, labor unions, and community centers. They talked more about their *militancia* (militancy) in personal conversations, suggesting a broader vision of justice than found in the transitional justice paradigm.

Avoid quick judgments

Parachuting into a community to conduct quick interviews and surveys may generate the best kind of data when resources are time-constrained and limited, but how an interviewee feels one day versus the following one may severely shade his or her answer to the point that it can misrepresent another more consistent or truthful position. Person-centering interviewing (Hollan & Levy 1998, Throop 2010) is one particular method that requires a researcher to conduct multiple interviews with the same person over a long span of time. This method takes into account that people change, as does their environment and their opinions and thoughts about a particular subject. When I first arrived in Córdoba, the AEPPC faced few internal conflicts and made decisions through consensus. After a few months, a division emerged based on differences that were political, personal, and historical. This split affected the organization, the relationships between its members, and their projects. Eventually, the members resolved their differences and were able to work again, but a new division, completely different from the first one, developed in its place. Since the time I left in the field in June 2009, the old conflicts re-emerged and changed the dynamics of the organization once again. These kinds of changes in the relationships between members will continue to occur, but by having spent a long period of time with the organization, I better understood the alliances, the tensions, and the camaraderie between sub-groups of the larger organization. Had I only experienced, say, the first five months of 2008, I would have walked away with a very different view of the organization, the relationships, and the concerns of the group. If I had gone during the middle, I would have perceived the division to be much more significant and permanent. Committing oneself to long periods of fieldwork enables ethnographers to capture a fuller picture of the dynamics between people, and the changing nature of human relationships within a larger context.

Drawing premature conclusions is also a result of not catching the contradictions and possible complications that go unspoken. This is best illustrated

by my attempts to gain a sense of how prevalent physical and psychological problems were among the ex presos políticos. Torture and imprisonment is known to have long-lasting effects upon a survivor, effects that are often impossible to recover from. Thus, when I conducted initial survey research and formal interviews, the ex presos políticos claimed not to have had any health problems related to their torture and illegal imprisonment. However, these same individuals would speak about their problems with post-traumatic stress syndrome and physical ailments that they attributed to their time in prison in personal conversations and in meetings where I was present and observing. I focused on this contradiction and delved further during my quiet observations. The issue was not simply a matter of trust, since they confided in me in other settings about their health problems. Nor was it a matter of a conversation's being recorded, as other recordings included these confessions.

In my initial analysis, I found that the ex presos políticos were interested in painting a different life history in their oral history archive interviews. Their focus was not on the torture they endured; they did not want to be defined by torture and imprisonment. For them, the only attention paid toward them from outside groups focused exclusively on torture. The professional group willing to assist the survivors was made up of psychologists offering to attend to psychological effects of torture. In addition, visitors at memorialized former concentration camps inevitably inquired after the torture methods, rather than the political motivations of the captors. Thus, to speak about their effects reduces ex presos políticos to victims. Rather they maintained their political identities as activists and as idealists for a better world, and preferred to speak about the political motivations behind their actions and why they risked their lives for their idealism and political commitments. They are militants and are more interested in the larger political struggle than the physical and psychological suffering inflicted upon them by their torturers. A quick judgment could have led me to believe that I had not in fact built enough trust, or that the survivors were merely dishonest. Spending time with this contradiction of being healthy, yet seeking assistance for effects caused by torture, led me to withhold any quick conclusions.

Be open to change

Perhaps it is cliché to speak about personal transformations while in the field, and going beyond the sardonic phrase 'going native.' Ethnographies rely upon the researcher, the pathway to knowledge is an experiential one. Our goal as anthropologists is to understand and view the world from the local perspective,

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rather than to judge it. We engage but we are not the arbiters of the truth. One's immersion into a community takes time and an incredible amount of work, not only to build relationships but also to stay engaged. Doing so not only brings an ethnographer closer to research ends, but also enables her to see the world in a new way, specifically from the perspective of those around her. The practice of suspending one's sense of the world, rules, and reality and adopting another's is a basic practice that we should all engage in, whether or not we are anthropologists. If we can assume that culture is not a bounded thing that is transferred, but rather a sum of many symbols, beliefs and behaviors, and that culture involves socialization, or enculturation, then we acknowledge that the local and unique environments shape the worldview in which one is raised. Anthropologists seek to work against ethnocentrism by recognizing that one's own socialization in the world is not the only way, nor is it the right way. The best way to use anthropology to fight against colonialism, dominance, and dominant powers is to embrace our discipline's goal to continually re-evaluate what we take as the norm by immersing ourselves in new cultures.

What long-term ethnographic fieldwork means for the bigger picture

In an attempt to solve social problems and apologizing for the shortcomings and sordid past of our discipline, anthropologists can put themselves at risk of overlooking the value of human understanding through meaningful human interaction. In an increasingly globalized world, the basic goal of understanding other cultures remains an important task for all people. Anthropology enables us to do it systematically, building upon past experiences and research to produce data that is not only useful for the problems we are trying to solve, but also for making us better global citizens. Speculating upon the future of anthropology, Jane Desmond claims, "Anthropology's commitments to actually talking to people, engaging with communities on a daily basis over a relatively long period, and committing to understanding their languages (all or some of which can often be lacking in 'cultural studies' work) are, I suggest, essential for generating a respectful depth of understanding across cultural, political and institutional boundaries." Anthropological fieldwork inherently takes time. Trust is built over a sustained commitment of friendship. With this trust also come responsibilities and challenges because the stakes are higher in how we, as anthropologists, choose to represent the people we work with and anticipate how others may use our data for and against the people we met in the field. This pause also what makes for more ethical research. These are the

moments in which we decide how we will apply our anthropological contribution to the larger moral and ethical issues, and the ethical way in which we research and write.

Step II: Turning the ethnography into a narrative

If we agree that the way we conduct fieldwork leads us toward questions of ethics and morality, then our writing reflects these concerns. Methodology in sociocultural anthropology may be traditionally seen as being restricted to field research, but it also incorporates the ways in which we analyze and translate our findings. Anthropologists are, in the most brute terms, conveying truths of human experience. Codes of morals and ethics often emerge in medical anthropology writings, as most of the scholarship touches upon experiences of illness, death, violence and social suffering. In his Tanner Lecture on Human Values at Stanford University, Arthur Kleinman posits that human experience is inherently moral "because it is the medium of engagement in everyday life in which things are at stake and in which ordinary people are deeply engaged stake-holders who have important things to lose, to gain, and to preserve" (1998: 362). In distinguishing the ethical from the moral, Kleinman describes ethical discourse as "an abstract articulation and debate over codified values" (1998: 363). Thus, while the moral is culturally and historically specific to local worlds, the ethical component attempts to produce, or gesture toward, general principles. Kleinman suggests that an ethnographer's contribution can be found in the translation and infusion of the local moral experiences into the global ethical discourses, and vice versa, to "make moral theory" (1998: 416). Anthropologists are constantly dealing with both the moral and ethical aspects of their observations, experiences, and writings. Considering the 'emic' perspective, treating participants on an equal level, making the research available to participants, putting the interests of participants before all others, and using a bottom-up approach are all morally infused values that create an anthropological ethical discourse (see Barrett 1997).

Arthur Kleinman's book, *What Really Matters* (2006), states that every community has a local moral order in which to judge actions as 'good' or 'bad', and that ethics are of a more personal nature, shaped by general human values (i.e. freedom, life, liberty, etc.). Kleinman reminds us that the type of work we do is rooted in personal experience, in mentors, in life-changing situations in a world that he describes as being filled with uncertainty and danger. In an attempt to answer the question, 'How do we deal with the world and build ourselves as moral agents?' (2006: 26), Kleinman shares stories from his years

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of work as an anthropologist, physician and China scholar, about people who made an impact on him, the 'anti-heroes'. These are people who are not famous or saintly, but are real and complicated and continually face challenges and make moral decisions.

One of Kleinman's anti-heroes, Sally, was diagnosed with HIV in 1997. Sally was an injection drug user, and had contracted HIV from an infected needle. But her chronic disease radically changed her view on life; she went from using drugs to donating her time and money to fight AIDS. Sally wasn't always this giving – and this is key in Kleinman's book – all of the people he profiles are flawed in some way. Earlier in her life, due to her drug use, Sally neglected both her children and her marriage. Kleinman writes: "Her selfishness, she argues, is powerfully conditioned by hyper individualism, narcissism, blindness to the unjust human conditions surrounding us, and deafness to the call from our local world to do something to remedy and repair those inhuman conditions" (2006: 147). Sally now believes that life is about doing things for others, and she regrets not having had better relations with her children and husband. According to Kleinman, Sally's notion of moral action is tied to her identity: "We become who we are, Sally insists, because of the way we engage with the very real dangers in the world" (2006: 155).

The most important lesson that can be learned from Kleinman is that the type of people we are, the people we choose as mentors, and the commitments we make, inform our ethical and moral stance in the world. What we choose to focus on as anthropologists reveals our own moral and ethical commitments. Furthermore, we can interpret an anthropologist's values by what she thinks is important to write about, both for herself and for the people whom she studies, regardless of the topic and where each person comes from. To illustrate, I will compare three ethnographies by three American medical anthropologists – Paul Farmer, Nancy Scheper-Hughes and Cheryl Mattingly – and examine how their use of narrative reflects particular priorities.

Three types of moral and ethical narratives

In *Infections and Inequalities: The Modern Plagues* (1998), Paul Farmer uses narrative as a diagnostic tool to consider how structural violence made his patients in Haiti and in Boston vulnerable to infectious disease and how their survival depends on their access to biomedicine. Narratives are analyzed not in order to find cultural difference but rather to determine how a patient's life story is connected to history and political economy, which are the two key analytic tools to understand one's position in society. Clinicians treat a curable

infectious disease while understanding the sociopolitical factors that affect an individual's quality of life and ability to survive infectious diseases. Farmer considers psychological aspects only to the extent that his patient-informants explain the existence of sickness through witchcraft. His project is not one of 'subject-making,' and the patients' psychological attitudes or subject-making projects are not his priority. For Farmer, infectious diseases require biomedical responses that only physicians can offer. Anthropologists, on the other hand, find ways to increase access in order to 'socially diagnose.' Farmer encourages fellow anthropologists to find ways to address barriers to health, not to investigate the meanings of disease.

In the ethnography by Nancy Scheper-Hughes, *Death Without Weeping: The Violence of Everyday Life in Brazil* (1992), we read narratives from mothers living in Brazilian *favelas* (shantytowns) who present a radically different orientation toward life and maternity than the one found in Western culture. Mothers in this *favela* accept the fact some of their infants will die in the face of abject poverty. In these *favelas*, it is the norm to witness three out of ten children die, and furthermore, it is inappropriate for mothers to express public grief and sorrow toward an individual child's death. This is 'death without weeping.' Scheper-Hughes uses this to demonstrate that maternal-infant bonding theory is not universal. The narratives she collected are evidence of how divergent worldviews can be. Ideas of structural violence demand for a 'pre-cultural' ethic of engagement to reduce inequality. At one point, when faced with local morals that dictate that mothers should not weep for their dead children, Scheper-Hughes intervenes to save a child (an act that was considered problematic by her critics) – because for her intervening in this case is a demonstration of a pre-cultural ethic. Unlike Farmer, Scheper-Hughes is not calling for increased access to healthcare. Instead she critiques the medicalization of hunger. Until there are substantial changes in the distribution of power and wealth, Scheper-Hughes argues, international health agencies offering powdered milk formulas and pills only obscure the larger sociopolitical structures perpetuating starvation and poverty. Furthermore, Scheper-Hughes considers local moral systems while working to improve local conditions. The purpose of her project is not only to examine how people struggle for healthcare and basic needs, but how they have a different attitude toward infant death, one that is cultivated by their environment and individual subjectivities, rather than the Western disposition toward longevity and maternal-infant bonding.

Contrast these two ethnographies with *Healing Dramas and Clinical Plots* (1998), which is Cheryl Mattingly's study of patients in a Western clinical setting. These patients are not only kept alive after severe accidents but are rehabilitated and expected to show a desire to continue living. Mattingly considers

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narratives to be a form of therapy or healing within the interactions between occupational therapists and their recently disabled patients. The success of this rehabilitation process between occupational therapists and disabled patients lies in the therapists' use of dramatic narratives. Unlike their other clinical counterparts, occupational therapists treat the whole person and engage in narratives to draw in the patient and imbue everyday tasks with a heightened sense of drama in hopes of empowering the patients to remake their world, in light of their 'new' existence as disabled persons. The narrative is reflective of psychological and emotional commitments toward life, bodies, and time. The psychological commitment to live and overcome new physical challenges is a necessary component of healing and rehabilitation. Even though the therapists and patients are not conscious of the narrative-making, Mattingly suggests that the reason occupational therapists are able to help patients is because drama bridges narratives with lived experience. Since a patient must change her orientation to her body, life, and the clinical atmosphere, making a patient's medical and therapeutic encounter meaningful enables the patient to become independent again, and to adjust to her disabled body. Narratives are not used to understand the physical and psychological symptoms of a sick body – but as a form of healing in themselves. History and political economy are not as fundamental to this analysis as are the concepts of temporality, truth, and meanings of existence.

Different from Farmer's universal call for an ethical-moral stance toward the poor, which is primarily aimed at treating the physical, Scheper-Hughes and Mattingly demonstrate how the psychological will to live is morally specific both culturally and individually. Unlike Farmer and Scheper-Hughes, Mattingly's use of narratives is more directly engaged with the lived experience and less on the broader sociopolitical issues. All three of these authors have chosen to focus on what they believe really matters, to borrow Kleinman's phrase. What each of these sees to be at stake morally and ethically drives their medical anthropological perspective and determines how their work is applied.

Let me explain by proposing a hypothetical topic where I imagine how each of these anthropologists might approach it. Take for example a person living with HIV as a way to compare these three anthropologists. Farmer would argue for equal access to antiretrovirals, and would more than likely insist that we have an ethical/moral obligation to ensure health as a fundamental human right. Scheper-Hughes might conduct ethnographic work where AIDS has ravaged whole communities and where early death has become normalized. She would argue that there exists a 'pre-cultural' ethic to engage, and would press for a closer examination of how people's psychologies are influenced by larger sociopolitical structures. Mattingly would consider the clinical interaction

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between a social worker and an HIV patient who may or may not want to live with the stigma of having HIV, and must cope with the changes in her body – weight loss, thrush, sarcoma, etc. Building drama when the person living with HIV must carry on the same mundane tasks with her newly sick body may be the link between narrative and lived experience. Narratives, in this respect, reflect not only different questions, but also direct us toward the morals and ethics of the ethnographer. Infectious disease, hunger, and disability all affect one's body, they are all changes to and assaults on the body, sourcing suffering and pain, questioning what quality of life means, and how one measures it. But for Farmer the ethic is to intervene, for Scheper-Hughes the moral is subjective but still demands a response, and for Mattingly, to live is the moral choice, and the therapist uses dramatic narratives to encourage and assist her patients to choose in that way.

Finding the narrative of ex presos políticos in Córdoba

In order to explain my own process of finding the narrative to express my fieldwork findings, some background information is necessary. In transitioning from a number of several military dictatorships that rule Argentina between 1955 to 1983, to a stable democracy, the country has confronted memories of 'disappeared' persons and state violence, particularly of crimes committed during the last military dictatorship (1976-1983). The Argentine government and its citizens, specifically human rights groups, have maintained these memories of past violence, disappearances, and imprisonment in the public consciousness through testimonies, marches, memorials, and archives. As stated before, I came to Argentina to study transitional justice from the perspective of survivors of state terrorism among the members of the AEPPC.

Formed in 2007, the AEPPC formed considerably later than other human rights groups in Argentina. Though many ex presos políticos joined other human rights groups or continued working with labor unions and community-based social organizations, the vast majority faced the difficult task of reestablishing their lives after having been illegally imprisoned without a trial or justice. In other words, the family-based human rights groups suffered the losses of their family members, but the majority of them did not suffer long periods of torture and imprisonment, and do not suffer from latter-day their psychological and physical effects that persist among torture victims long after the torture has ended. The ex presos políticos, who had to deal with the guilt of having survived or not knowing why they survived, and could not speak out about their experiences even after the fall of the dictatorship due to social

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taboos. They faced discrimination from neighbors, former bosses, friends, and classmates who feared association and often would cross the street at the sight of an ex preso político. Many were separated from their young children and spouses for several years, or returned to deceased or ill parents. The majority of the ex presos políticos were between 18 to 25 years old when they were taken by the military, interrupting their schooling, and professional development. Despite all of these hardships and economic barriers to accessing stable employment, they were distrusted by other human rights groups for having survived, and were not always considered to be victims. The focus of human rights groups remained on the permanently disappeared and not on helping survivors obtain jobs, health care, and resume their education. In these ways they were not only denied their victim status but also were denied the ability to socially reintegrate.

Throughout my fieldwork experience, I have brought to bear the insights of Farmer, Scheper-Hughes, and Mattingly on what I have found in Córdoba. Through their life stories, I saw the various social, economic and political obstacles that have affected ex presos políticos– their lives forever impacted by a comparatively short but violent period in their young-adult lives. I also saw an opportunity to record their narratives, as many of them have never told their stories before, and because as a group, they aim to pass on their memories to Argentine youth. Being able to speak out, under a government sympathetic to human rights, enabled them to exchange stories from prison, to indulge in black humor, and to find meaning in their survival through shared activism. Though I do not perform the same role as occupational therapists in Mattingly's ethnography, I participated in the making of narratives through conversations with ex presos políticos. My presence, as their first foreign ethnographer, is a small testimony to their importance to recent Argentine history.

In addition, it is by documenting and emphasizing their survival that I take on Scheper-Hughes commitment to seeing the world through the eyes of who we study. In the interviews, the ex presos políticos did not talk about torture or its consequences; they instead talked about their *militancia* (militancy) both in the past and present. They developed their own sense of morality by continuing their work as labor organizers, community workers, and political party members. In other words, while nearly all members face economic hardship and suffer long-term consequences of torture, they rarely speak of their own struggles and instead speak about the needs of other ex presos políticos and of the community's poor and marginalized. In transitional justice, concepts of peace and reconciliation are prioritized. However, by listening to and following the priorities of the ex presos políticos I came to know and interview. I understood that their moral sphere demanded much more than just prosecuting the

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people who tortured prisoners. Instead, the morality came through a revival of the dreams sought in the revolutionary movements of the 1970s. Scholars assume peace and reconciliation to be the moral imperative of transitional justice, but these survivors present a different paradigm. Their paradigm upholds revolutionary change for social equality as their moral cause.

Overall, as I follow the AEPPC in their four main projects – serving as witnesses in current justice trials, teaching youth about social justice today by telling them about their experiences in the past, lobbying for universal pensions for their fellows survivors who face economic hardship, and serving as tour guides at memorialized sites of former concentration camps – I am able to see the various ways in which the ethnographic narrative can be told. I could choose to focus on and write about the various barriers that the ex presos políticos face, or how they make meaning of their imprisonment, or the ways in which they develop culturally specific moral systems. This reflection after fieldwork is the period in which we decide how to present our narrative, and it is in the writing process that we demonstrate our own morals – through our analysis of human action – and our ethics – through the way we represent our relationships and the people we recorded. We write for and against something. As Scheper-Hughes observes, "In the final analysis we can only hope that our time-honored methods of empathic and engaged witnessing – a 'being with' and 'being there' – as tired as those old concepts may seem – will provide us with the tools necessary for anthropology to grow and develop as a 'little practice' of human liberation" (2002: 375).

Rethinking the transitional justice narrative

I believe that the work of Argentine human rights groups toward justice, reparations, and memorials is important and necessary. At the same time, I knew that the damage and suffering the ex presos políticos and other Argentines endured can never be undone. I am frustrated by the fact that no form of transitional justice will ever repair what was broken, taken, or destroyed during military dictatorships. We cannot bring back disappeared people; we cannot heal an entire generation terrorized and broken apart. The military, police, non-uniformed professionals, large company executives, and landowners all collaborated together to make disappear, torture, and terrorize people who were suspected of 'subversion,' of being Communists, or of subscribing to ideas that the dictatorship deemed subversive (collaboration, socialism, helping the poor, etc.). And the majority of those guilty of crimes committed during the dictatorship will never be brought to justice.

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I am working with people who have lost family members, friends, and communities, as well as important years of their own lives to state terrorism. I support – as they do – the efforts to bring perpetrators to trial, to memorialize former clandestine torture and extermination camps, and to create archives for educational purposes. But I do not believe that any amount of post-conflict work can truly heal scars or bring about reconciliation in Argentina, or in any of the other Latin American countries that experienced similar dictatorships, disappearances, mass killings, and violence. The ex presos políticos in Córdoba are now in their 50s, 60s, and 70s. Justice came thirty-one years later, and was welcomed, but it did not bring back what they lost, and few outside of this small community, and even fewer outside of Argentina, understood what this meant for victims and society.

My research experience convinces me that what we need is a sharper analysis of past and current events to *prevent* further or continuing violence, of all forms. While I believe it is still a worthwhile and noble effort to invest in reparations, memorials, truth commissions, and trials, this fieldwork experiences have taught me that we must work harder to arrive before the crisis/dictatorship/war occurs, because we can never truly and completely heal scars left by torture, war, and political repression. In this way, the frequently repeated phrase *Nunca Más* (Never Again) underscores that the importance of doing memory work and telling history is to remain vigilant ourselves against ongoing or future instances of violence – be it low-grade or extreme.

Bridging together Argentina's past and present

The irony of my project is that while I sought to study the past, I have really been preparing myself to understand present-day political and economic conflicts in Argentina. As I reflect upon my fieldnotes and begin to write, I realize that one of the biggest challenges facing human rights groups today is overcoming the widespread public opinion that the military dictatorship is something of the past, and that Argentina must move on by focusing on 'new' issues – like 'insecurity' (meaning crime, petty violence, economic instability, etc.). The discourse of insecurity is in fact now new, but rather the factor for government overthrows throughout Argentine history. Swinging between democratically elected governments and military dictatorships, the military was traditionally viewed as maintaining order and security when democratic governments lost control of the masses. For this reason, many Argentines allege that it was safer during the last military dictatorship because there were no crimes, robberies, and street violence. The military and police regularly patrolled the streets,

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and perhaps there was less visible crime, but the entire society was also living in fear. Thousands disappeared, were tortured, and disposed in mass graves through clandestine and massive networks.

Despite the recent progress of justice trials and the establishing of several new spaces for memory at the sites of former concentration camps, not all parts of the Argentine public are equally invested in reckoning with the events of the past. Human rights groups call what happened in Argentina during the last military dictatorship a *genocido* (genocide), and they argue that a democratic society cannot function without a justice system that punishes those who commit crimes against humanity. And while hundreds demonstrated at the sentencing of eight former military officers in Córdoba on July 24, 2008, thousands more poured out in the streets to protest against the government in 2008 in support of the *campo*, a powerful group of agribusinessmen who control the country's agricultural output – which makes up most of its GDP. Three months after Cristina Fernandez took office, the farmers staged several strikes to protest against the high export taxes the government wanted to levy on their crops. In response, the government called the campo and their middle-class supporters *golpistas* (coup-plotters). Human rights groups attempted to explain to the public the connections between the military dictatorship's economic policies and the growing inequalities today, but popular opinion remained highly critical of Fernandez. Campo supporters viewed the Fernandez's policies as stealing money from the hardworking farmers, that although she claimed stating she would redistribute wealth, she, in fact, would use the tax revenue to fund her power monopoly. Conversely, human rights groups mobilized in support of the government, and particularly focused their attentions on the most important and powerful of the agricultural lobbying groups, *Sociedad Rural* (Rural Society). Sociedad Rural had financially and politically supported the last military dictatorship, and, not coincidentally, during the military's rule, the economy was transformed from an industrial economy that manufactured products for domestic consumption (in which labor unions dominated) to one based on exports of agricultural raw materials.

The Sociedad Rural and the campo in general has long been made up of Argentina's wealthiest citizens, and they have promoted an image of themselves – widely believed by the country's middle class – as hardworking farmers being unfairly taxed by the government amidst rapidly rising inflation. Thus, while human rights groups see the campo's protests as another assertion of their long-standing power over Argentine society, the government opposition see the campo differently, and they believe the right-wing claim that the country is descending into chaos, and that Argentina needs more 'order' and 'security.'

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It is unlikely that Argentina will see another coup d'état; today's political context is radically different than that which existed during the Cold War. However, the most important issues facing Argentine society at the moment – the taxes on agricultural exports and *inseguridad* – resonate with rhetoric of the past. Throughout Argentine history, during times of economic crisis, and amidst rising rates of crime, the military would allege perceived incompetence on the part of the government, step in and restore order through a coup d'état. The last military dictatorship was particularly cruel in their highly systematic system of disappearances and illegal detention of thousands, but initially, there was no indication that it would be different than previous dictatorships. The ex presos políticos argue that the key lesson for younger generations to learn is not about the torture, but rather about the economic plan that the dictatorship sought to implement by terrorizing and killing its opponents. By prohibiting all meetings of more than three people, the dictatorship sought to erode social life and communities. When victims were kidnapped and tortured, members of the death squads interrogated them for names of their family members, co-workers, and friends. As a result, people no longer took part in social groups for fear of being taken by the military, or putting others at risk. Neighbors and friends avoided anyone suspected of being a subversive. These changes in society created the myth that those disappeared 'must have done something' and by knowing nothing, seeing nothing, people would remain safe. The political repression in effect created a form of individualism and apathy; the dictatorship terrorized people into cutting off social relations. Human rights groups argue that this political repression fostered a culture of individualism that allowed for the dictatorship and subsequent governments to implement the neoliberal policies of a capitalist economy.

In a meeting after the trials in Córdoba had been stalled by the early (and forced) retirement of one of the three judges for his ties with the former military, AEPPC members urged one another not to be disappointed by the failure of the justice system. Instead some *compañeros* (comrades) believe that true justice will come from organizing the *pueblo* (the 'common' people). Justice will be achieved when the people in their communities stand in solidarity with the ex presos políticos to fight for better working conditions, social benefits and redistribution of wealth. Though they recognize that times have changed from the 1960s, 70s, and 80s, many of the same battles remain – over how to redistribute wealth, over the role and strength of labor unions, and over the levels of investment in Argentine industries that should come from Argentines, instead of from foreign companies. Considering both the past experiences of the ex presos políticos and keeping a pulse on current day events, I believe an ethic of social prevention to be even more relevant to my anthro-

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pological endeavors: these efforts are valuable, but only insofar as they serve as prevention work by reminding society what happened in order to shun it. Thus, the priority in the construction of my own ethnographic narrative is describe how the visions held by the survivors – then and now – provide us with one avenue to underscore the importance of knowing the past to prevent future forms of violence, for that is the true lesson to be learned from the ex presos políticos.

On latent forms of violence

In their edited volume on violence, Scheper-Hughes and Bourgois (1999) argue that violence should be conceptualized as a spectrum, rather than as a dichotomy between war and peace. Peace – they argue – is a fragile state that must be vigilantly protected, since the quiet and insidious forms of violence can easily swing a society from a state on the peaceful side of the spectrum to one on its other, darker side, to prevent their taking more extreme forms: genocide, mass violence or humanitarian crisis. If there is no true peace, if every stable region is only tenuously stable at best, we must always be on guard.

My research experience suggests that we should practice what I call 'an anthropology of prevention,' broadly defined as one that promotes basic human rights and democracy, with the purpose of addressing social problems around the world, but paying special attention to situations that have not yet turned into fully-fledged humanitarian crises. This is not to say, for instance, that anthropologists should ignore war zones. Indeed, Marcia Inhorn (2008) drew attention to the lack of anthropological research of war and she rightly called on anthropologists to get more involved in this topic. We must continue our work to stop ongoing genocides and wars, as well as attend to those living through current violent conflicts. But the proposed anthropology of prevention recognizes these as places where we have failed, as anthropologists and as human beings. Though I study issues of memory and work with ex presos políticos, the political analysis that I bring to my work relates to present-day Argentina. I worked as full-time activist with the AEPPC not only for my own anthropological research, but to engage in a political process that seeks to support democratic institutions and to bring attention to the deepening inequalities within Argentina as well as in the global economy. In this way, I follow Scheper-Hughes's model of engagement. If past military repression and economic policies that benefited the few are the root causes of social problems suffered by the many today, then what I am studying now is not simply the political activities of the ex presos políticos. My research is an ethnography of a

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group of ex presos políticos engaged in prevention work to stop the worsening situation for the poorest and marginalized.

Conclusion

In this essay, I began by discussing the importance of participant observation that is conducted over long-periods of time. I argued that this commitment to understanding the communities we immerse ourselves in enables us to build trust, which leads to richer conversations that reveal deeper insights than if we were to conduct a survey with a complete stranger. Spending time in the community, paying close attention to the subtle behaviors, learning the slang used to describe local phenomena, and acknowledging the contradictions that emerge between what is said and what is actually practiced are all actions that bring anthropologists closer to understanding the broader political, economic and cultural context. Through fieldnotes, we track changes over time and monitor our own increasing amount of knowledge of others, the community, and the problem we hope to solve. Fieldwork is the process in which anthropologists transform themselves into the primary research tool, where we seek to suspend our own preconceived notions and adopt new ways of viewing the world.

The purpose of beginning this article with a discussion on participant observation was to illustrate that how we conduct research also shapes the way in we narrate other people's stories. All of these processes of participant observation, if done with ethical concern and intention, guide us through our writing process. Choosing what to write involves not only data analysis, but also a careful consideration of what we consider to be the most important aspects of our research and of value to our readers. I wrote about three well-known ethnographies to demonstrate that there is a practice of ethics and morals in anthropological fieldwork. But we do not accomplish this only through our narrative style, but by the choices we make as soon as we begin our fieldwork. What we choose to study and ask our research participants will later fill our pages. The methodology, however, does not end with transcription and coding, but in the reflection and narration. We must bring the same level of care and self-awareness that we possess standing in front of our interlocutors as we do when we are alone, and sometimes far from the communities we studied.

As a novice anthropologist, I have learned the importance of our discipline's contribution through the practice of ethnography. Before conducting my dissertation research, I was skeptical of what anthropology could provide that other social sciences could not. Now, after having completed my fieldwork, I view participant observation as an incredibly significant contribution to our

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discipline because we work to understand another's view and the role context and socialization play in shaping those views. Though living within a community takes time and is often harder than expected, building a high level of trust not only brings us closer to a 'truth,' but also enables us to make visible the networks in which social problems are embedded. Remaining in the field also stopped me from drawing conclusions too quickly, and encouraged me to pursue the multiple contradictions and puzzles that surfaced as my investigation went deeper as the months went on. Using ourselves as the tool to obtain knowledge, while imperfect, allows for personal transformation and human connection, which in many ways reflect our commitment to seeing the world through the eyes of others. As Powdermaker starts her book, "To understand a strange society, the anthropologist has traditionally immersed himself in it, learning, as far as possible, to think, see, feel, and sometimes act as a member of its culture and at the same time as a trained anthropologist from another culture" (1966: 9).

The full potential of participant observation in our methodology, however, is only reached in our analysis and writing of our time in the field. Our translations of field data into full-length ethnographies reveal what we found to be ultimately true. The stories we choose to tell, and how we represent the community reflects our ethical commitment to those we built relationships with in the field. Learning these skills both in the methodology of collecting and writing data shape the kinds of anthropologists and moral agents we become, and ultimately how we eventually teach others the value of our discipline.

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Chapter 8

Thick and thinned description

How useful can medical anthropology be?

SJAAK VAN DER GEEST*

'Thick description', a concept coined by Gilbert Ryle (2000) and made famous by Clifford Geertz (1973), stands for detailed ethnography that provides a rich variety of relevant contexts, including the ethnographer's own presence. For the non-anthropologist, the adjective 'thick' may assume the same meaning as it has in connection with forest or thicket: dense and difficult to penetrate. Practical-minded people often see anthropologists as producers of highly complex and theoretical texts that resist 'translation' into concrete action. As a consequence, anthropological descriptions tend to be regarded as irrelevant and paralyzing to policymakers because they merely complicate matters. When anthropologists *do* study concrete practical problems, their analysis of the situation is usually a 'post-mortem' one and lacks useful suggestions as to how to solve or prevent such problems. Moreover, anthropological reports often appear many years after the facts, post-post-mortem one could say.

The miscommunication between medical workers and health policymakers on the one hand and medical anthropologists on the other tends to come from both sides. The former fails to capture the practical relevance of thick ethnography and the latter often regards 'applied medical anthropology' as a dilution of their profession.

After a brief retrospection on my own medical anthropological research over the past forty years I discuss seven considerations that may contribute to better communication between ethnography and practical work:

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1. Concern among (medical) anthropologists about the practical implications of their research is not a dilation of their profession but a sign of theoretical insight and of reflexivity.
2. Cultural brokerage seems one of the most effective outcomes of applied anthropology.
3. Thick description needs to be 'thinned' resulting in transparency of the practical consequences of ethnographic and theoretical work.
4. One mode of 'thinning' ethnographic work is quantification of qualitative insights, an unpopular step in present-day anthropology.
5. Anthropologists should make more haste publishing the results of research that has practical relevance.
6. Research should from the beginning involve policy-makers, health workers, and anyone who has direct interests in the outcome of it.
7. Involvement of various stakeholders should be maintained into the period of writing and publishing.

Looking back on fieldwork

Let me start by looking back on my research experiences and my attempts to do something practical and useful with the results of that research. I am afraid that my achievements in applied anthropology are not impressive.

In 1973 I did fieldwork in Ghana about sexual relationships and birth control. One of the most worrisome findings was that young unmarried students lacked access to reliable contraceptives. In their attempt to prevent a pregnancy that threatened to put their whole future in jeopardy, some resorted to dangerous abortion methods that could damage their health, make them infertile for the rest of their lives, or even kill them. Others used harmless and ineffective methods and had their babies too early. Most of these girls never returned to school and indeed saw their future collapse before them.

The irony of the situation was that the official planning organizations did supply reliable contraceptives to married couples who were *not* interested in having contraception. Only the young and non-married were interested but were denied access on the basis of formal traditional and Christian rules of morality. My attempt to bring these disconcerting findings to the attention of those who had the power to change the situation was limited to writing a series of six articles about the situation for the popular weekly *The Sunday Mirror*. I have no idea what the impact of that series was. It produced one reaction, a letter to the editor by the director of the National Family Planning Programme (NFPP), indicating – rather implicitly – that his organization *did* allow unmar-

ried youngsters access to its services. His statement did not alter the fact that young people continued to avoid the NFPP because they felt they could *not* go there. A proposal by the Dutch World Broadcasting to broadcast a series on young people and birth control in Ghana based on my research and raise awareness about the plight of youngsters did not materialize in the end.

In 1980 I carried out research in Cameroon on the use and distribution of modern pharmaceuticals in hospitals, health centres, pharmacies and informed drugstores and market booths. It proved to be another delicate – and policy-relevant – topic. The outcome of the research showed that public health care institutions suffered from serious shortages of medicines. Health care in the public domain was officially free, but because of the lack of drugs, that free care had become an absurdity. People stopped visiting health institutions that had run out of medicines, or were forced to go and buy medicines outside the hospital, which resulted in them paying even more than those who sought health care in private institutions. The three main causes of the shortage of medicines were: (1) lack of state funding; (2) bureaucratic sluggishness of those responsible for the supply of medicines; and (3) theft and misappropriation of medicines that *had been* delivered. I added practical suggestions to my conclusions and was able to send a 200-page (too thick?) report in French to a hundred of institutions, organizations (including the Ministry), and individuals within a few months of the end of my research. One of the suggestions was that it would be better to make people pay a reasonable price for medicines and actually supply them than to pretend to give them free medication while in fact giving them nothing.

My recommendations did not fall on fertile ground, to put it mildly. The Ministry took offence of my harsh criticism and said they would never turn the fingers of the clock back, meaning: they would not give up the public right of access to free medicine. (Seven years later they did, when they signed the Bamako Accord, an agreement signed by African ministers of health under the auspices of the WHO to make health care more efficient, affordable and sustainable.) I realized – too late – that my approach had not been tactful and had antagonized the authorities. The title of my report, for example, already irritated them before they had started reading it: *La pathologie de services medicaux*. My love for literary style, such as paradoxes worked counterproductively and failed to entice the policy makers.

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From 1994 till today I have been involved in anthropological fieldwork among older people in the same community in Ghana where I did my first research. My practical bent in this research has been more modest. Although I do see tremendous policy-challenges in the case of care for older people in rural and urban Ghana. I have mainly limited myself to just writing about the joys and worries of older people, drawing attention to their achievements in life and discussing their relationship with younger generations. Older people do not want to disappear forever into nothingness, but hope to live on in the memories and activities of their children and grandchildren, as ancestors, as educators, as builders of a house in which others can live, as givers of care and other good things they did for the next generation. By writing about them and showing them and their children what I wrote, I hoped to increase their happiness and contribute to their memory. By now all the old people of my research have died and I can only hope that their children have good feelings about the fact that their parents' names and achievements appeared in internationally renowned journals and on in the Internet, sometimes even with their picture. Together with two Ghanaian friends/co-researchers I made a small book with the most beautiful quotes of six elders about growing old and related topics (Atuobi et al. 2005). I distributed copies of the book among relatives and they seemed pleased (especially with the pictures). We hoped that this book would also find its way to other Ghanaians who take an interest in the wisdom of elders, but that hope remains slim. Most Ghanaians do not buy books, however cheap they are. They have other competing priorities and if they buy a book it is more likely to be about Jesus. Two years ago I started filming, largely with the same objective: to show portraits of older people to people in Ghana and to the rest of the world.

Behind this short-term 'application' of enhancing older people's happiness and memory, *are* long-term policy-objectives, however. The Ghanaian authorities claim that they will never give in to 'Western' practices of placing older people in institutions. The African tradition of taking care of one's own parents will not be compromised they assert, but one of the outcomes of my research is that they will soon face conditions that will make it impossible to hold onto their claim. Migration and employment outside their hometown make it increasingly difficult for the next generation to provide that traditional type of care. The reduction of family size is another factor posing problems to care of the elderly. Moreover, life expectancy among the older generation is rising, so everything points at a longer period of care needed versus a diminishing 'pool' of caregivers within the family. In other words, conditions such as in my own country, the Netherlands, appear to be in store also for Ghana, however loudly political and religious leaders decry the 'Western' system of elderly care. For

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them, our treatment of older people is the epitome of a cold and dehumanised society.* I have not – or hardly – raised that point, however, and I am still pondering how to broach this topic, respectfully and tactfully.

At this moment I am, among other things, involved in a research project on HIV/AIDS in Ghana, in particular on voluntary testing, counselling, and the distribution of antiretrovirals. In contrast to the earlier research mentioned, I am not the principal investigator. Two Ghanaian PhD candidates and one Dutch post-doc bear the brunt of the research. It is the most 'applied' research I have ever been involved in and I feel slightly uncomfortable. Will we be able to achieve our objective to improve conditions for people with HIV/AIDS? I am afraid that the complexity of the social, cultural and moral context of AIDS will resist clear-cut recommendations. Just describing that complexity in clear terms may turn out to be the best 'recommendation', *if* policymakers and others are at all willing to read our report and take it into consideration. The fact that the planning and programming of this research and the first findings have been discussed with Ghanaian scholars, policy-makers, health workers, and people living with HIV/AIDS makes it slightly more likely that they will take an interest in it than was the case with my previous research projects.

Let me now, in hindsight, make a few critical comments about my own attempts to do research that would be useful for those I did research on. Four critical analyses on my past research are presented:

1. Three of the four projects I conducted were entirely my own initiative. I did not consult the people concerned about what they wanted me to do (if at all). I chose topics that seemed interesting and relevant to me (although I was – and still am – confident that they *were* relevant also for them). My naiveté was that I ignored the fact that 'relevance' also has political, psychological and emotional dimensions. 'Relevance' that is imposed upon others may put people off (as happened in Cameroon and during my research on unwanted pregnancy in Ghana) or just keep them indifferent to anthropology.
2. Closely connected with the first point: If I failed to consult those directly involved about their ideas, needs, suggestions, I should at least have tried to 'sell' my ideas to them from the start. I did not. I entered through a backdoor,

* African critics of the West European system of elderly care often overlook the enormous financial 'sacrifices' the working population makes to provide security to the older generation. In Dutch politics, diminishing pension payments have proved to be an extremely sensitive political topic.

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settled, made friends, and did my thing. I felt people appreciated my presence and liked talking to me, but they did not expect results that could help them in their lives. At first, some did expect results and thought I would bring them medical or other facilities. I had to disappoint them and explained that I was writing about them so that others could do a better job helping them. Most did not quite understand, however, what I was doing, except for writing a book. But who would read such a book? In short, they found my presence quite puzzling but accepted me and tried to benefit from me in their own way. In the case of the older people, my conversations with them had a purpose in of themselves. The elders enjoyed conversing with me and if I failed to visit them one day, those who could still walk would come to my house asking why I did not come. They sat down to have a conversation after all; for them it was a welcome change on a dreary day.

People in authority and policy makers in Ghana did not even know I was around. It may sound strange, but I never submitted a research proposal to a Ghanaian official and never applied for research permission. I just went there to 'visit my friends'.* The authorities – whether in Ghana or in Cameroon – were not part of my network and I never discussed with them the purpose or results of my research. In fact, I presumed that they were not interested.

3. My readers have always been first and foremost colleagues in cultural and medical anthropology. The journals where my publications regularly appeared do not reach policy-makers, let alone the people themselves (unless I purposely sent them an off-print copy). Although I detest the obscure and complicated style of writing that some of my present day colleagues practice and try to write clearly and transparently, I am aware that most of my texts are not easily digested by policy makers as they are too long and 'thick' in the Geertzian meaning of the term. Even, if they read them, they would probably find them unfit for application.

4. Finally, most of my publications** appeared long after the facts, another sign that my main concern was not *doing* something to improve conditions but producing texts with interesting cultural data and interpretations. To give one example: I am now working on an essay about greeting in Kwahu (Ghana). A large part of the ethnographic material that inspired me to write this text dates

* Cameroon was a very different story. It took a lot of effort to get my first permission and I was – initially – refused a second one. I frequently had to present my permit when I went to a new place for my research and once the police picked me up from the street and took me to the police station to question me on what I was doing.

** A prominent exception was my Cameroon report (Van der Geest 1981). It appeared a few months after I had left the country but was badly received (see above).

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back to 1969-1973 when I was doing my first fieldwork in Ghana. It does not worry me that the data are 'out-dated'; in fact, I am convinced that nothing in culture ever becomes out-dated in the sense that it continues to be true and relevant. But policy-makers have different concerns than of the past.

Enhancing the practicality of medical anthropology

The above self-examination leads to seven remarks or suggestions for enhancing the applicability of research results in medical anthropology.

The theoretical import of practicality

Mainstream anthropologists tend to be rather sceptical about applied research, although this seems to have decreased somewhat over the past ten or so years. They regard applied anthropology as superficial and divested of theoretical reflection. It is 'thin' in order to please the non-anthropological parties that are responsible for policy and practical implications.

I agree to some extent: applied anthropology must refrain from long theoretical discourse when it wants to reach the policy-makers and others. But applied anthropology should not be superficial or entirely without theory. Practical recommendations are the outcome of intense theoretical reasoning. Useful suggestions for change require more 'theory' than cultural interpretations of meaning.

The paradox – and irony – of most policy recommendations is that they are based on insufficient theoretical insight. Many recommendations are naïve, because they do not take into account the complex political and social relations where their recommendations ultimately arrive. Theses of students I have supervised over the years sometimes end with recommendations that fill me with vicarious shame because of their naïveté and implicit insult to the intelligence of policymakers and others involved in the issue they write about and ultimately also to their own intelligence. Many times I had to convince them to drop all recommendations to prevent annoyance, or worse, irritating the practice-oriented readers. Allowing readers to draw their own conclusions is often a better route to application than offending them with platitudes.

Another irony is that recommendations are offered to those who have little or no interest in changing conditions, while those who would benefit from the changes remain uninformed about the suggestions and without any say in the decision-making. To ensure application of research results one needs co-researchers who are at the same time practical workers in health care (cf.

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Varkevisser et al. 2001), but I never had such co-researchers. Policy-makers and health care workers are connected to politically loaded linkages among different levels of organization; bureaucratic rules and power differences are likely to complicate or obstruct the application of new insights.

It may sound cynical, but we should realize that policy-makers see it as their main task to produce papers that merely contain words and intentions. It is the appearance of certain words in government documents by which they are evaluated, not by the actual changes taking place on the ground. Anthropologists who claim participant observation as their principal research tool should not be caught in labyrinths of paper trails when they submit their recommendations. They should instead think (theory!) of ways to circumvent the 'paper delusions' of policy-makers and speak directly to those for whom policy change really matters to.

In addition, anthropologists owe it to themselves to think practically when they reflect upon their work and position as researchers. Seeing themselves in the web of conflicting interests and contesting parties that constitute their 'field', they cannot afford to shrug off the practical implications of their presence in that field. Concern about those practical implications shows reflexivity and theoretical maturity. Clever reasoning about cultural and political dilemmas and about social inequality without rendering account about responsibilities in the affairs that have been described is not only questionable on ethical grounds but also problematic for reasons of theory. Thick description that excludes the epistemological and moral reality of the researcher's own presence, misses the point. Glasser, a medical doctor, criticised anthropologists for not taking a stand in their romanticised descriptions of 'traditional' healing practices:

> Do they believe that the indigenous healing practices that they report on are effective treatments? Do they exhibit degrees of healthy skepticism in their writings? Do they shy away from outcome studies because of technical problems in performing them or rather is it that they would prefer not to know the answers? … Do they think that the governments that house these cultures do not have an obligation to these people to supply them with the basic ingredients of sewage, potable water, immunizations, and proper nutrition? …. The problem is that there is an appalling lack of outcome studies comparing indigenous healers with Western healers. It is as if there was an unstated taboo amongst anthropologists to investigate this area (Glasser 1998: 384).*

* See also Hemmings (2005) for similar complaints.

The fact that medical anthropologists have written abundantly about indigenous healers and their practices but refused to get involved in trustworthy studies of the efficacy of those practices is indeed a worrying sign of anthropological superficiality and gratuity.

Cultural brokerage

The applicability of my own research was mainly in the way of cultural and social/political brokerage. It has become somewhat of a platitude among anthropologists to write that they want "to give a voice" to groups of people that are not heard in the wider world. But platitudes can still be true. I have written about the dilemmas of young people getting pregnant against their wish, about the false appearance of free medicines in a public health system, about the worries of older people, about the plight of people with HIV/AIDS living in a society that refuses to acknowledge their existence and about horrifying toilet facilities. In each case I have tried to transport information about life in one corner of society to other corners where people live who are not aware of those conditions, or pretend they do not know, or do not want to know.

By confronting different categories of people with information about each other I practised cultural and social brokerage. Every society is, in varying degrees, a 'pluriverse' of cultures (Weidman, in Van Willigen 2002: 132), or a collection of 'co-cultures' (Ibidem). Cultural brokerage implies bringing about communication, interaction and – hopefully – mutual understanding and support. *If* anthropology has usefulness, it is first of all this establishment of respect and understanding between different cultures or different levels of societal organization (Van der Geest et al. 1990). Kinsman (2008.), in a critical analysis of how research leads to policy in the case of Uganda's fight against HIV/AIDS, convincingly shows that conflicting views and interests regarding the disease at different levels of the country's political set-up account for ineffective interventions. Better communication and understanding between international agents, ministerial officers, health workers and people suffering from the disease would improve the quality of anti-AIDS policies.

An interesting example of social and cultural brokerage can be found in a research experiment with health workers in Bolivia. Initially, the aim of the research was to have an anthropologist explore the views and needs of the community regarding health care and report the findings and recommendations to the health workers. Then it was decided to have the health workers themselves do the research and experience directly the problems of the populations. The experiment proved to be a success. The health workers gained a much better understanding of the patients' points of view and applied their new insights

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in a more respectful treatment of the patients (De Boer 2004); an ingenious strategy of cultural brokerage.

Nichter (2008: 173-174, 184) speaks of 'translational research'; anthropologists can engage the public through ethnography but they should write in clear and understandable language to explain their observations to the wider 'lay' audience and thus make dialogue possible. Such 'translational research' would fit the 'democratic turn' in the understanding and application of science. Participatory research (involving all relevant parties) is most likely to achieve this translational quality.

Anthropology, finally, should stimulate cultural and social imagination, the ability to imagine oneself in the position of others, either in terms of social hierarchy or of cultural difference. Margaret Mead's (1964) optimism that anthropology may help to bring about a better world, through its promotion of inter-cultural understanding, still makes sense to me. The fact that the present era rather seems to head toward a 'clash of cultures' does not refute her vision. It seems to me an indication of the social and political insignificance of anthropology. Anthropologists have not been able to make themselves heard and to get their message across; they have failed their cultural brokerage. Has our writing been too thick and hermetic?

Thinning

'Thick description', as we have seen, may amount to inaccessible or impenetrable description. Cyrenne (2006), a political anthropologist, admits that he was 'swayed' by Geertz's thick description of Balinese cockfights but at the same time realises that this reproduction of the "blooming, buzzing confusion" of social life is not very helpful to those who expect explanatory conclusions from social scientists. Although I do not expect explanations from anthropology, but rather intelligent interpretations, I do agree that the enticing thickness of some of our ethnography may be lost to those who are concerned with more practical matters while reading our work. That is the reason that I propose intelligent 'thinning' of the thickness.

My use of 'thinning' differs from what Ryle and Geertz understand by the adjective 'thin'. They see 'thin' as superficial, ignoring social and cultural contexts and meanings, as they demonstrate in the example of the 'wink' (Geertz 1973: 7). For them 'thin' in a sense precedes 'thick' whereas I present 'thinning' as an analytical operation following 'thick' description. It would be an intellectual achievement and an act of braveness to proceed from thick to thinning. By 'thinning' I mean that the author lays bare the basic structures of a certain problem or problematic situation. 'Laying bare' implies vulnerability,

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as is the case for any form of nakedness. In the Dutch language exists the term *zich bloot geven* (to expose oneself; lit. to show one's nakedness), which means 'to come out of one's hiding', but also carries the connotation of 'committing oneself'. There is gratuity and non-committedness in thick description when it hides the author's position. The author cannot be called to render account. He is hiding in the forest of his text, like a poet in an obscure verse. Writing clearly, openly and with commitment does not violate the complexity of social and cultural situations. Complexity rather requires precise and unambiguous language, as Weber (1972: 123) rightly pointed out:

> Scharfe Scheidung ist in der Realität oft nich möglich, klare Begriffe sind aber dann deshalb um so nötiger.*

The art of writing 'thinly' is, therefore, not to smooth over and blur the ambiguities and contradictions but to show them by clear writing. 'Medical diagnosis' may suit here as a clarifying metaphor although I invoke that metaphor with considerable hesitation. Making a good diagnosis in a clinical setting is the art of reduction. Reduction is a suspect concept in anthropology as it is usually taken to mean that context and complexity are overlooked. I do not agree with that interpretation. Reduction works in medicine because the organ or function that is found defective is part and parcel of a total system of organs and functions. Reduction does not overlook or forget context but rather assumes it, depends on it. Successful reduction is the art of spotting what is decisive.

I admit that social scientists have a much harder task to reach effective reductionist insights, which I call 'thinned description', but we should not run away from it. My inkling is that a sound theoretical underpinning is a successful reduction in disguise. Nothing is more practical than a good theory, the well-known adage goes.

Quantification

Quantification is another concept that is suspect and unpopular in anthropology. Tables are rare in anthropological publications or hidden in an appendix. I would, however, like to call for more recognition of quantitative data in combination with qualitative ones. Providing sensible figures can be an efficient

* "Sharp separations are often not possible in reality, but clear concepts are for that reason the more necessary." My teacher André Köbben drew my attention to these inspiring words of the German philosopher.

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way of 'thinning' our descriptions and interpretations. Quantification becomes possible after we have succeeded in what I called the art of reduction.

One way of quantification in particular appeals to me and I have encouraged several students to apply it. The central idea is that the most crucial and relevant insights that emerge from a qualitative research are 'translated' into unambiguous, somewhat extreme statements to which a larger sample of respondents may react with: agree or disagree (or no opinion). The purpose is to establish whether the findings from the qualitative phase are likely to represent a 'trend'. When it concerns a sensitive topic (it often does), the statement will be formulated in such a way that the respondent does not need to reveal his personal views. He will be asked whether he thinks that others have a certain opinion or practice in a certain way. One example:

An Ethiopian researcher, Getnet Tadele (2006), conducted qualitative research on sexual behaviour among young people in the provincial town of Dessie, 400 km north of the capital Addis Abeba. The research focused on young men between the ages of 15 and 25 years, and were, in particular within two additional categories: school going and street youngsters. Like Paul Bukuluki in his essay in this book, Tadele observed that the street youth seemed little concerned about the dangers of HIV/AIDS. Their general insecurity due to poverty, hunger, and police harassment troubled them more. They faced so many problems to survive from day to day that HIV/AIDS became a somewhat abstract risk. They had other more direct worries.

The role of religion was another prominent theme that emerged during the qualitative research. During conversations with young people it was often suggested that religious activities such as attending services were an alibi for meeting lovers and having sex. 'Religiosity' was not an indication of stricter sexual morals.

	yes/agree	**no/disagree**
Some people say that religion does not have any effect on sexual behaviour of young people.	55 (20%)	218 (80%)
Homosexual practices hardly occur among young people in Dessie.	122 (45%)	150 (55%)
Masturbation should be adopted as an alternative sexual practice to ensure safety from HIV/AIDS.	72 (26%)	199 (73%)
Most young people of my age use condoms.	100 (36%)	174 (63%)

Use of condoms proved a topic about which the boys were very much divided and the researcher suspected that the boys did not express themselves openly on condoms. The same applied to homosexuality and masturbation. Many

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denied that such practices occurred at all, but the researcher had his doubts about these statements. He decided to ask the youngsters about these topics in a less personal way through a brief questionnaire that was administered to 274 of them. The survey was both a less threatening approach and an attempt to quantify his findings.

Tadele's mini survey was a fair attempt to give his qualitative data more prominence and relevance. Usually the anthropological case study makes little impression on non-anthropologists, because they want more solid assurance that certain observations or stories represent trends that deserve attention from policy-makers.

Haste

A simple condition for doing applied anthropology, as I already mentioned, is that we make haste in publishing the results of our research if they need speedy action. Urgent matters should not be addressed five to ten years later. Laxity in applied anthropology is self-defeating; it takes away the credibility of the conclusions. I fully agree with Streefland (1991) who in a plea for applied medical anthropology criticised his colleagues for their lengthy procedures. 'Thick' and fat research reports take the writer many years to produce them.

The beginning…

The beginning of much research predicts already that the outcome will not lead to any practical action, because no one of the interested parties was involved in the decisions and preparations that led to the research. My own experiences (see above) confirm this. Any research that is designed for action should from the outset be conceived and planned with, or rather *by* those directly affected by the outcome.

Involving others from the beginning is a matter of sharing 'ownership' of the research and its conclusions with the stakeholders. Ownership feelings are often a prerequisite for the willingness to take the research seriously, identify with its outcome and take action. The role of social, cultural and political brokerage cannot be fulfilled if the relevant parties dissociate themselves from the research. Involving others may not be easy and even require some rhetoric and 'marketing'. As long as the researcher is sincere about his intentions I regard such an approach acceptable.

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The end…

Finally, the end of much research is an alienating experience for the parties involved. Even if they became 'owners' when the project started, they still may experience acute dis-ownership when the researcher returns to his academic environment and – sometimes many years later – reappears with a fully completed text in which *they* never had a say. All preceding assurances of shared ownership turn out to have been fake, mere strategies serving the interests of the researcher. The willingness to accept and act upon the conclusions will melt as snow in the tropical sun.

The most obvious way to prevent this from happening would be to keep in touch with the key persons in the field and invite them to continue giving their input during the writing. Over the last ten years I have always kept in touch with such key persons and asked them to comment on or correct my drafts and add their point of view if necessary. The advantage of continued shared ownership is not only that the conclusions are more likely to have an impact but also – of course – that the ethnographic quality of the text will be better.

Conclusion

My soul-searching retrospection and the subsequent suggestions may not have been as 'thin' and unambiguous as I intended. I am aware that some contradictions will always remain.

Let me first, by way of conclusion, and in an attempt to reconcile some contradictions, evoke the figure of the journalist. Good journalism, based on careful research and solid sources and written in an accessible style could serve as an example for applied (medical) anthropology. The objective of brokering information and understanding between parties has more chance to be achieved by clear, short and attractive reportage. Anthropologists would do well if they learned that job from journalists.

Secondly, providing clear-cut recommendations, like prescriptions, may not be advisable. Such recommendations could even be counter-productive. Stakeholders may find the recommendations naïve or an intrusion into their field of competence. It may be wiser, therefore, to only provide clear descriptions and analyses of the 'facts' and leave it to readers to draw their conclusions. Everyman has his trade. Or the writer could phrase his recommendations more indirectly, for example as questions or modest suggestions. Much depends on stylistic skills.

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Thirdly, I am aware that applied anthropology, whether 'medical' or otherwise, is a hard task. I have tried to present some of the reasons: application is an advanced form of theory; thinking about solutions requires intense reflection; and writing thinly is a step beyond thick description.

Finally, and by way of brief epilogue, several colleagues have criticised me for being too modest and pessimistic about the practical use of medical anthropology. They pointed at my own work in 'pharmaceutical anthropology' and the training programmes some of us have organised for health workers and shopkeepers to improve their ways of medicine distribution (see Hardon et al. 2004). Members of the International Network for Rational Use of Drugs (INRUD) have repeatedly pledged their indebtedness to anthropological research in the field of pharmaceuticals; my colleagues at Health Systems Research have said the same. In an overview of their work over the past two decades Varkevisser and co-authors (2001) provide several examples of very concrete and successful recommendations, such as more effective referrals, use of maternal services and construction of pit latrines. I hope they are right but my experience is that there is rarely reliable information available on the long-term effects of anthropologically inspired interventions.* Whatever the 'facts' are, my pessimism is not without hope. I cannot believe that 'understanding the other' will not eventually lead to a more humane and efficient health care, as Hemmings (2005: 100) suggests. After all, most pessimism is optimism in disguise.

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* One that comes to my mind is a research by Ventevogel ten years after the much-heralded launch of a training programme for traditional healers in Ghana. The effects proved disappointing: the healers had not put into practice what they had so enthusiastically learned during their course (Ventevogel 1996).

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Chapter 9

Saving my soul

ELS VAN DONGEN*

In times of cancer, the integrity of the body and the person are deeply affected, and the world seems destroyed. The realities are not durable but fragile, confronting and conflicting. The question of how people deal with this complexity and variation and how they create coherence in their lives comes to mind.

Fragile medical realities

We, my husband and I, wait in front of the surgeon's office. We wait for two hours while looking at other patients who enter and exit, and we hear jokes for children coming from the small television screen above our heads. A nurse approaches, and then informs us that we will have to wait a little longer… She apologizes. We are in a regional hospital which feels familiar because the pace and tone of our life is also resonated within the walls of the hospital, and because we have been there before to play music during the Sunday services for patients. I have never been here as a patient. We say 'hallo' to people we know. This world is familiar and foreign at the same time.

We already know what kind of news the surgeon will tell us because we already had a long talk with our family doctor, who had received the results of previous tests and had told us that I had colon cancer with a big metastasis in

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This article is part of a longer text that was presented at the 2008 'Medical Anthropology at Home' Conference in Sandbjerg, Denmark. The full text will appear in the proceedings of the conference. We thank the editors for their permission to pre-publish this part here. One day after Els gave us the permission to include this text in the book she died after a long fight against cancer. We cherish her words as a treasure she gave us to keep (the editors).

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the liver. My prospects were bad. I received my status as an incurable cancer patient in my living room on a sunny afternoon.

The diagnosis took almost two months of visits to the hospital for examinations. I met radiologists, laboratory personnel and nurses, each having their own approach to patients and his dis-ease. One time I cried in the arms of a nurse-assistant in the radiology department; in another moment I laid on a bed for a liver biopsy. One moment I was a human being with emotions and fears; and the next, my body was an object where certain interior parts were visible on a screen, a vision the doctor and I looked at with great interest, but in different ways. My dis-ease changed with every meeting. My pain increased.

I had to walk my way through the diagnosis, marked with x-rays, scopies, biopsies and blood tests, each one making the cancer visible, and thus making my dis-ease real. But every time it was a little different. For the first internist, who specialised in diseases such as Crohn's, it was a 'process' because she did not find cancer cells in the colon biopsy. For the radiologist, the dis-ease was in my liver. To the surgeon it was my colon that mattered and required urgent action. In the meantime we had to deal with other realities outside the hospital. Our children, family, and friends gradually became to know that I had this disease, which is so often characterised by its fatal outcome.

Finally, the nurse who had profusely apologised eventually leads us into a small, sober room with a chair, a bed, and a computer. My husband and I sit on the bed leaving the chair for the surgeon. After awhile the surgeon enters. We shake hands. He starts the images of the CT scan: "Well, eh, I am sorry. I don't have good news; it doesn't look so well." He runs the images at high speed and I see the slices of the interior of my body: "Don't you see? It doesn't make sense to me. This is not typical for colon cancer."

Me: "Oh? So, it isn't colon cancer? They haven't found cancer cells in the biopsies of the tissue, you know." It is my hope that speaks.

"That's true, it made us uncertain, but this is more serious," says the doctor, showing slices of my liver, "a big metastasis, the biopsy showed that it is colon cancer."

Suddenly, I do not want to know the ins and outs of the slices; I do not care about the doctor's technical explanations; I get a flash of finality and the depth of grieve of my family and friends. All I can think of is, "Not now, not me, not us…" I want to know what can be done and start to ask questions as well as I can. My husband also has his own questions. All of this seems unreal to me.

"We cannot cure you. We can try to control the cancer. Perhaps you will have some years left. I will have to operate the colon as soon as possible, before

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I go on holidays… the liver cannot be operated, I know because I have done several of such operations in the academic hospital. In the meantime, you will have to make an appointment with the oncologist."

Holidays? Operation? A couple of years is the best scenario? At an academic hospital? The doctor makes his plan for the surgery. I feel my husband trembling. We shake hands with the doctor again and leave… We sit in front of the secretary's desk to make the appointment for pre-op examinations and wait again, totally confused and silent. She phones a colleague and tells the story of her holidays and pregnancy. It is bizarre but we do not say a word; we have our own misery, which now slowly starts to unmake our common daily world.

In a few weeks, I would be on the roll for surgery. We also visited the oncologist. His story was different from that of the surgeon. From our conversations I had the impression that he wanted to know what kind of a person I was. He asked what kind of work I did and we talked about medical anthropology. He asked me to bring something to read about this subject the next time, which I did. (I would rethink my work and that of my colleagues many times during the episodes of my illness, wondering if the claims medical anthropology makes were just.) He discussed the different options I had and stressed the 'free choice' I had. I was also offered the chance to participate in a trial. The latter caused us trouble. Should I participate? I felt morally obliged to give my little contribution, but I felt desperate after I read the side effects of the chemo. I could not decide. The oncologist made the final decision not to participate, saying, "You have done enough." But what did I do?

I had surgery on my colon. The operation went well and I received a permanent marker on my body that would remind me that I belonged to 'the village of the sick' (Stoller 2004). Perhaps it is an odd thing to write, but I remember this time in the hospital as a good time. Of course, I cried a lot; I had my fears and – in particular – I worried about my family, seeing them sad, tired and uncertain. I could not bear to have friends near my hospital bed, but my refusal caused me moral problems too. But the nurses tried to do everything to preserve my integrity, my weakness was respected and they tried to give more than just physical care. Whenever they had some time, they came into my room to talk or just to sit; they allowed my husband to come early in the morning to help me shower and with the new rituals I had to learn. Sometimes my room resembled a 'normal' living room. I lived in two worlds: that of the sick and that of the healthy.

In the regional hospital as well as in the cancer clinic visits, examinations, controls, MRI scans, etc. are never a lonely enterprise. They are social events. There would always be at least one family member or friend accompanying the patient, sometimes more. The examination rooms and offices of doctors have

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at least two extra chairs. The crowded waiting spaces made you fear that waiting times could be long, but with every visit at least two persons went into the doctor's room.

After two weeks we had to visit the oncologist again. We told him that we would "go for the Lance Armstrong-variant," that probably would bring strength and endurance. We would like to have the best possible treatment. The oncologist frowned at this prospect but put me on a schedule for several rounds of chemo. Then, we received an unexpected phone call from the surgeon from a cancer clinic in Rotterdam. It turned out that the surgeon of the regional hospital had sent the CD with my scan pictures to this clinic. He was not as self-assured as he pretended to be. This phone call turned our world upside down again. The surgeon told us that he could operate my liver when the chemo worked well. It did. I received two different kinds of chemo, stumbled through the days of nausea, weakness, tiredness, felt social isolation and strong emotions of uneasiness.

The liver operation went well. Within six days I was at home and tried to do my daily walks again. When we met the surgeon for a control visit, he told: "We took half of your liver. Most of the tissue was necrosis with just a few cancer cells. We also took you gall bladder. The glands were clean. The part we took from the liver did not function anymore. So… drink your wine after a couple of weeks." Which we did. My brother came from France with a bottle of champagne. We had to learn to be healthy again.

However, after a couple of weeks I began to experience terrible pain. Again I had another round of examinations: a CT scan to see if there was a new tumour – there was. I had more radiation and chemotherapy to reduce the size of this tumour, a MRI scan to exactly locate the tumour, and finally an operation. I discovered first hand the terrible pain that unmakes the social and moral world, as Scarry (1985) writes. It made me indifferent to what happened outside and even inside myself. It was a difficult time for many, in particular for my children and my husband.

We went in and out of the cancer clinic for weeks, every day during radiation, and I started to feel better; the pain disappeared. "You will have to have trust in yourself," the surgeon had told me when he had explained the operation to us, responding to every remark I made with the fact that I would have to trust him. During this entire episode others continuously let me know that another reality was waiting for me outside the hospital. I underwent a complicated operation, recovered slowly, and went back to work.

So, I lived in different realities that were fragile and contradictory. I received bad and good news. My 'healthy' state after a treatment could change into disease and sickness in a short time. I had to cope with uncertainty and distrust

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toward my body. But I had 'to trust myself'. I had to surrender and to resist. I had to make sense of the different medical stories about my disease. I lived different lives that came with 'the ontologies of medical practice' (Mol 2007: 181). The consequences of living such a life reached far beyond the illness per se.

Saving one's soul and integrity

When I could stumble from my hospital bed to the shower, I would wrap myself in a kikoy and cross the corridor to say "Good morning!" to a man and a woman who suffered from similar cancers. The nights were often long, the lights in the corridor sometimes kept us from sleeping, the footsteps of the nurse made us aware that we had constant care; there was snoring, coughing, restless turning, silent crying, and sometimes there was a terrible noise of an emergency when someone suffered serious bleeding or became extremely sick. We had enough time to think, to reflect us through the night. During the day we were engaged in examinations, controls, visiting hours, etc. No wonder our morning conversations did not revolve around illness, actions or treatments. Patients find themselves in the same position as Job, the biblical figure who faced serious challenges of misfortune, yet, nevertheless tried to save his soul.

Mrs. Job said: "I do not speak with my children about this terrible illness. I don't want them to see worried, they are still young."

"But they see you here, very ill and sad?"

"Yes, but during the visits I try to be more or less normal, you know. To be a mother, to show affection and interest in their days. You know, it is so frustrating to feel yourself so indifferent to other people sometimes."

Mr. Job: "You know what is sad? I have lost so many friends. This disease makes you lonely, it can make you bitter. But I cannot be good companion now. This night I had a terrible bleeding in my stomach and they brought me to the main medical centre in an ambulance. Even when I feel anger and sometimes – forgive me – hate, I don't wish what happened to my worst enemy. But this loss of friends made me worrying about my own feelings of friendship."

The struggles and dramas of keeping one's integrity or being a moral person (Kleinman 2006) began to unfold in the early morning under the clattering of the breakfast car. Integrity is a concept used in nursing. Usually it is described with terms such as self-respect, dignity and confidence of the patient (cf. Widäng & Fridlund 2003) that nurses have to respect. Integrity, as a state of being undivided and coherent is constantly under threat. However, I consider

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integrity as also having a social dimension, related to the 'soul', to me the social skin, the boundary between the 'self' and the person.*

I had to struggle with questions such as: what about my commitments to my family and others and to my work? Could I maintain my integrity that conflicted with my situation during the time of several operations, radiation, and chemotherapy? I found myself trapped in a gap between my principles and my actions. When everything went well enough I could promise to give a guest lecture in my own module on theory and practice of medical anthropology, but after some time, I had to withdraw. I would plan a trip with my husband, but then would have to cancel. 'To be clean' is more complex than to have an active tumour. You believe that moral and social obligations have to be fulfilled. Others expect so too. The side effects of chemo and radiation fade, you develop an appetite again, you force the cancer into the background, but it is still there. People tell you that you look good. Your life has to be coherent again, but it is not because of the uncertain characteristics of cancer. Often there would be a split between how I felt and how I behaved. I deceived others and myself and experienced sometimes that when I told the truth, I did not tell it for the sake of truth, but for my own sake. I wondered how much of a burden I could be when I saw the devastating effects of my illness on the faces of my husband and children. I realised how difficult it is to remain a moral and social person.

I thought I had to stand with my family, with my friends, and with the PhD students; I had to recover because of a professorship that would enable me to work for human rights, justice, and well-being of refugees, something that appealed to my moral principles and professional success was an important commitment. A conflict between personal and social morality (cf. McFall 1987) developed. I was a Mrs. Job, who became doubtful about moral values, about others' and my own intentions. The art of being an integrated person is to remain a social person, to trust and accept that everyone has her own way of 'doing a disease'. When I wrote to a friend about Japin's book *De overgave* ('The Surrender') and cited the main person's words about telling stories, she told me that in this case, we as anthropologists, or professionals who worked in health care, could as well stop with our own work if I were serious about the citation. There would be no ground for communication. Perhaps she was right, but at that time I had my doubt about a core activity in anthropology: storytelling. I wondered if my work with psychiatric patients and older persons in South Africa, in which the focus was on storytelling, had made a difference. Not that

* Hacking (1995: 6) describes the soul as standing for a mix of many aspects of a person. One person speaks with many tongues. The body is the best picture of the soul.

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this rather cynical consideration was a new one in anthropology, but this time my wondering was more doubtful. "You can burden many people with your past, it is not a smaller burden on your shoulders. You may tell your entire history, so that they, when they leave, carry this story forever with them. But that is all they will carry. A story has no weight. You can tell about your life as often as you want, it does not become lighter" (Japin 2007: 114, my translation, EvD).* Did story telling really make a difference?

Dealing with fragility

In the beginning we got an almost biblical message from the oncologist: "Go and enjoy…". This message did not fall on deaf ears. We discovered we could still enjoy many things. This kind of advice is often given in cancer cases; it is also often received. I heard and read many stories of my fellow-patients who told how they went on vacation, how they enjoyed a good wine or a book; how they surrounded themselves with beautiful things. In the cancer clinic 'enjoyment' spatially expresses itself in the front of the building. The restaurant always was full and if you did not know better, it could be a place in the centre of the city, where people who took a break conversed and drank coffee. Taxi drivers came in and out, looking for their customers. At the front door patients and personnel smoked their cigarettes and talked. Right behind the entrance to the polyclinic there was a shop with scarves, wigs, books and shawls, all nicely displayed. Colourful paintings of local artists hang on the walls. People were nicely dressed and laughed or smiled. Sometimes it was as crowded as a shopping centre on a Saturday afternoon. But the good observer also could see people silently disappearing as fast as they could. This meant: no good news. In our culture, one is hardly allowed to express sadness in the public domain.

Cancer led me back into my life, and into personal reflection. I struggled to maintain the 'normal' daily routine. I answered my e-mails, read many books, tried to work on some papers, made some paintings and took little walks and canoe trips with my husband. These things helped us to live with the chaos of all the 'realities' we had to deal with.

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* 'Je kunt nog zo veel mensen met je verleden belasten, het drukt er niet minder om op je eigen schouders. Je kunt ze je hele geschiedenis vertellen, zodat ze wanneer ze vertrekken jouw verhaal voor altijd met zich meedragen. Maar dat is dan ook alles wat ze dragen. Een verhaal weegt niks. Je kunt over je leven vertellen zo vaak je wilt, lichter wordt het er niet van' (Dutch original) (Japin 2007: 114).

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We developed two projects that needed our energy and appealed to our feelings of responsibility. At that time it seemed the only possibility to be involved in the broader world. The first was a film about swans. Filming and editing the hours of shots were a remedy against disintegration and fragile realities. But most enjoyable were the encounters with walkers, older people, and people of the village who seemed to enjoy the presence of the swans. We made the film available for children who lived in the nearby village and we used it as an argument for preservation of a fine nature domain in our district. The other project was the making of a photo book of which the revenues were sent to a South African organisation for young children who were sexually abused.

I attempted to use my medical anthropological understanding to make sense of what friends and family did – they, too, were living with my illness. I reversed Susan Whyte's argument that it is important to study high-tech techniques in non-western countries (Whyte 1997) by instead pleading for an exploration of non-medical techniques of control, like religious pragmatics or magic, such as candle burning in western countries (Van Dongen 2008). Perhaps, this was more likely an attempt to be a part of a reality – an academic community – I believe I belong to, than to define a debate. It became clear how important and precious social relationships could be. Being ill is trying to remain a social being, to learn to accept friendship and support, and to remain interested in others' lives, to maintain sensitivity, integrity and a moral life that is good for the patient and her family. This was difficult enough, especially in times of pain.

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Chapter 10

We came, we saw, we misdiagnosed

How medical anthropology can enhance emergency medical relief programmes

VANESSA VAN SCHOOR*

Angelique arrived in the early morning at the clinic in Bin Houyé, a small town in Côte d'Ivoire near the border with Liberia. She heard that doctors had come since the fighting had calmed down and that health care was being offered free of charge. By 8:00 am, there were already 100 people outside the clinic cued ahead of her, mainly mothers with small children. The nurses, a mix of foreigners and Ivorians, were going up and down the line feeling the foreheads of small children and handing out red cards to allow some to go to the front of the line. One of the nurses approached Angelique and put his hand to her forehead.

"No fever. What is your problem?" he asked.
Eyes downcast, Angelique mumbled, "Body ache."
"You will have to wait," he said and moved on quickly.

Four hours later, Angelique was still waiting in line. It was 37° in the shade and she was wondering whether she had made the right decision to come. Her family might notice that she was not working in the field and start to ask questions. No, she would have to go home quickly.

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Côte d'Ivoire

I arrived in Côte d'Ivoire in early October 2003. Only two weeks prior I had graduated from the University of Amsterdam with a master's degree in medical anthropology. Armed with a few textbooks and new strategies, I was returning to resume my fieldwork with the emergency medical relief organisation, Médecins Sans Frontières (MSF). Since the early 1990's, I had been working with MSF in Burundi, Liberia, Mozambique, Burma, and East Timor. We did good work in responding to conflicts, outbreaks, and crises, but I was convinced that our interventions could be done better. By asking the right questions and taking more care with programme development, even our emergency interventions could be made more relevant.

Côte d'Ivoire had descended into civil war in September 2002, when a rebel group calling themselves *Les Forces Nouvelles* accused the government of discriminating against northerners and Muslims. The rebel forces mounted an offensive and almost succeeded in taking the capital. The French Army then stepped up its historical support to the Ivorian government and brokered a peace deal that pushed *Les Forces Nouvelles* back, ostensibly leaving the country divided and talks about concessions and power-sharing set to begin.

For three decades after independence, Côte d'Ivoire had been a model of prosperity and tolerance in Africa, a haven for those fleeing other regional conflicts. I worked for MSF in Côte d'Ivoire in 1997, but at that time it was to run a support base to bring logistic supplies and staff in for emergency medical operations linked to a civil war in Liberia. We even hosted colleagues from Sierra Leone when they were evacuated after violent fighting in that country. I never anticipated that a return to Côte d'Ivoire would be for any reason other than a holiday.

Prior to the conflict, the Ivorian Ministry of Health ensured medical coverage by assigning its doctors, nurses and midwives to hospitals and clinics around the country. With the onset of the fighting, most staff members fled to the capital and were unwilling to return to the north. Most of the northern hospitals and clinics were either damaged or destroyed, and any equipment or medicines that could not be used by fighters were thrown in piles to be baked by the sun or to rot in the rain.

By the time I arrived in Côte d'Ivoire in 2003, the first MSF medical teams had gained access to the rebel-held north. The team I was to head had launched a handful of mobile medical clinics across the frontlines – we were working inside the rebel area, in the demilitarised zone and in government-held territory closest to the conflict. We were also trying to re-open a hospital near the Liberian border. Only a handful of Ivorian medical and para-medical staff who

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had families in the north had stayed behind, but they had very little to work with.

This was a typical context for MSF to get involved in, but for me, coming in after immersion in medical anthropological concepts and approaches, it was also an opportunity to see if what I had studied could be put into action and if we could improve our emergency medical relief programmes. Going in as the Head of Mission, I had the authority to not only drive programming, but also to influence authorities and donors. There were significant resources at my disposal, and more would follow if we could demonstrate an effective use of the funds provided and show that the interventions worked.

As I arrived in the clinic in Bin Houyé, I saw Angelique waiting in line. I had already been watching the flow of patients and noting their interactions with the consultants. With my anthropologist's lens I looked beyond the smooth functioning of our clinic operations and watched how patients respond to the services offered. A young girl, nervous, agitated and looking to leave, caught my eye. When I spoke to the triage nurse and asked what was wrong with her, it was clear that 'body ache' was not going to get her seen today.

I sensed there was something more to her story, so I asked one of the nurses to take her aside and help me in asking a few more questions. From the symptoms she described, it clearly sounded like a sexually transmitted infection (STI). It turned out that that Angelique's symptoms developed after she had been attacked by a young fighter who forced her to have sexual relations with him. We were so busy looking after sick children that we almost missed treating a woman who had survived one of the most heinous crimes of war – rape.

This was one person who was helped through nuanced participant observation, but how was I going to make it more than a drop in the ocean? A line from one of Paul Farmer's books echoed in my mind – "We came, we saw, we misdiagnosed" (Farmer 2001). I remembered how he had debunked the myth of poor compliance among people in HIV programmes in Haiti by showing that poor adherence to treatment had little to do with poor educational levels and understanding, but more to do with security and economic factors preventing patients or caretakers from physically getting to clinics on schedule. In Côte d'Ivoire, we were seeing more than 200 people each day at every clinic site. Were we misdiagnosing through triage bias? Could an enhanced degree of cultural sensitivity and appropriate questioning be integrated to reach more patients?

When starting an emergency programme in a conflict zone, the first thing is treating war-wounded patients. In reality, though, very few people can be reached in this phase as they are either too badly injured or too scared to come into a medical facility. By the time that doctors can safely reach the patients, there may be only a handful left who can be helped.

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Internal displacement and its effects are often more significant in scope and severity. During the fighting many families flee into the bush, leaving behind their food and water, sleeping under mosquito-filled skies and having nothing to nurse wounds acquired either in an attack or while tripping through the undergrowth. Small children, the elderly and pregnant women are the most vulnerable. This is the group that MSF teams focus on first.

Health care can be conceptualized as a three-legged stool that is based on staff, medicines, and a facility to work in. MSF teams enter with the intention to prop up at least one of the damaged legs until the government can regain its capacity to take care of its own people. In Côte d'Ivoire all three legs were damaged, which meant that there was a lot of work ahead of us. Our headquarters acknowledged that we were not going to see many cases of war surgery and that the people displaced in the bush were going to be of primary concern. We had our manuals for rapid assessment and setting up emergency services, but in this intervention I wanted to use my newly acquired anthropological skills to ensure that we were responding and adapting to the changing needs of our patients.

Staff

With the onset of fighting, people flee for safety. As many of the Ivorian health workers were not from the north, or at least not from the towns where they had been assigned, large numbers moved out quickly. By the time of the cease-fire, most health workers had regrouped in the capital, Abidjan. The Ministry of Health had no formal access to the rebel-held north and could not force its employees to return to insecure zones near the frontline. They also could not re-assign everyone to posts in or near the capital. As a result, a large number of medics were sitting around with little to do.

Further north, some of the healthcare workers were from local villages. Their families remained and they did not want, or could not, move them down to the capital. Some supported the rebel faction and the fight for more rights and resources for people in the north. Some of the nurses, lab technicians and medical assistants were also committed to their patients and their profession and tried to continue working in the midst of the violence and displacement. These were the people we wanted to work with.

As an international medical organisation volunteering to go into war zones and with accords negotiated with all parties to the conflict, we seek out respect and recognition for the neutrality of our medical staff and the impartiality of our actions. It may be that they think we are crazy or that they fear international

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condemnation in hindering our work, or it just might be that some fighters do have an understanding and respect for the Geneva Conventions.* Regardless of the rationale, MSF teams gained access to the north and had assurances that teams would be allowed to operate and move around in relative safety.

We went to the Ministry of Health to help us identify staff willing to work in the north. Most of the best-qualified staff had already negotiated to be posted in Abidjan. Initially we found only one junior doctor willing to work with us, and only recent nursing graduates were stepping forward to take on the jobs we offered. There was some concern about the lack of experience among these new recruits, but we saw the opportunity to ensure that these staff would be trained well. They were going to be the future of healthcare in Côte d'Ivoire.

When we travelled up to Danané, Bin Houyé and the surrounding villages, we met with the handful of health workers who had remained. We made deals to pay them incentives to complement their government salaries if they would work with us. They knew the terrain, the local dialects, the disease patterns and many of the patients. For me, they were essential to the success of any operations we would try to launch. They were going to be the backbone of our operation. My job was to ensure that our international staff and the young medics who had been recruited from Abidjan were also going to take the time to listen to and work with them. Cross-cultural understanding and acceptance were going to be key in the make-up of the mobile teams, in the choices of who would head departments in the hospital, and in getting the more experienced Ivorian medical staff to be willing to learn from the experienced Australian midwife who spoke only a smattering of French or the young German doctor who was initially terrified about treating adults, but had so much to teach about paediatric emergency care.

Medicines

Government supply lines are often short and erratic, even in the most developed countries. In Côte d'Ivoire, and especially in outposts along the northwestern border, providing health services was not a priority. Patient numbers were already low due to the fees demanded at government clinics. Private pharmacies flourished even before the conflict. With the civil war, hospital and

* Some of Les Forces Nouvelles and Ivorian military officers were trained by ICRC in International Humanitarian Law. Some of the soldiers were even running training programmes in International Humanitarian Law (IHL) for their men before the civil war started.

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clinic stocks were looted for materials that could be used by combatants to treat their own. Some items were probably taken by community members for private use or re-sale. Items that were of little use to anyone were strewn across clinic floors, dumped outside or sometimes even set alight. When MSF teams arrived, there was very little that could be salvaged.

In an operation like this MSF brings in its own medicines, intravenous fluids and bandages. This ensures that standardised stocks and quantities will be available for the medical teams to begin working immediately. It also ensures that the quality of the drugs is guaranteed as they come from known tested reputable manufacturers. In West Africa, many items are produced locally or imported from poorly regulated countries like China where the production may not be up to standard or where some suppliers are extremely adept at forging packages and filling them with a mix of compounds that range from benign to dangerous. In addition to overseeing our supply chain, part of my job, and the one that I was going to push my teams to regularly monitor, was drug sales in local pharmacies and markets in the towns where we were working.

We were not only providing free health services, but we were also providing the treatment free of charge. This can impact local markets. It can also lead to items disappearing from our shelves and turning up for sale in private shops. Patients themselves have been known to take their prescription medications and re-sell them. Walking through the markets, I saw antibiotics sitting out for days on end in the hot sun – these pills lose their effectiveness under these conditions. But I also saw some positive aspects, such as birth-control pills that were not our brand and that were not yet expired and available for sale. Basic painkillers were in abundance and vitamins were also already readily available. This was a region where people actively sought out health care from both western and traditional practitioners. People were in the habit of looking for alternative sources when the government system did not fulfil their needs. We needed to closely monitor our stocks and people's understanding and acceptance of what drugs they were taking, while maintaining good relations with some local sellers and healers to ensure that patients did not over-medicate.

Facilities

The building and equipment that went into many of the Ivorian facilities was astounding. It was obvious that in some places, substantial investments had been made, but many were 'white elephants'. In amongst the hospital buildings that had been shot-up with AK-47's, the operating theatre that had been

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used for torture, the smashed up lab and the charred furniture in the clinics, there was still clear evidence that at one point in time, the government, or a rich external donor had substantially invested in the medical facility. The infrastructure was there, but the staffing and medical supplies, we were told, had never followed. The big hospital had largely stood empty.

Rural clinics had been designed with a standardised layout. Most buildings had four large rooms for consultations and a pharmacy, a central corridor for waiting patients, and housing for the nurses or midwives assigned to the facility. Some of the clinics were beautifully tiled and looked as though they had never been used, while others had chipped paint and cracking foundations with little to no maintenance done since construction. There was almost no equipment left in any of the structures.

In the Danané Hospital, the operating theatre had our teams amazed with the high-tech sterilisers and the sinks that worked by pushing a lever with the knee. Incubators were found in storage cupboards. There was even an x-ray machine and dentist's chair. Unfortunately most of it was in disrepair and looked like it had been so for many years. The steriliser coil had burned out years ago, so could not be used. The wards had no running water so the sink was useless. The temperature gauges in the incubators did not work, so ran the risk of cooking any newborn placed inside. There were no chemicals for the x-ray machine and no instruments for the dentist. Still, we had a very solid building and personnel who could cobble together some basic equipment. We brought in the rest of the missing essential items.

Over the time I worked in this project, we repainted and repaired wards, beds, tables and lamps. We hired cleaners to get rid of all the needles and razors scattered around the hospital grounds, and we built a new waste disposal area with pits for organic waste and ash. We introduced new levels of hygiene that not only made the hospital a more welcoming place, but also helped to reduce the risk of nosocomial infection. We trained health staff to separate waste so that it could be disposed of safely – training and retraining everyone from doctors to cleaners in order to ensure the system functioned. Good hygiene practices are commonly overlooked at the start of an emergency operation, but hiring additional cleaning staff would prove to keep our mortality rates down. The capacity of the hospital had not previously been an issue as it never reached optimum use and occupancy, but as numbers grew, we introduced a covered waiting area for cuing patients, built a water tower to supply the hospital and restocked the equipment.

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Intervention

With the basics in place – staffing, medicines, and facilities – we were able to start providing health care. The first priorities were treating malaria and malnutrition, while cleaning infected wounds.

In clinics, like the one Angelique visited, there were initially so many children with fevers cued up that we trained our drivers to take temperatures and to perform malaria tests while patients waited in line. This allowed the consultants to focus and see the most urgent cases in the day. This was only possible due to a rapid diagnostic test that had recently been developed under pressure from groups like ours working in remote areas where microscopes or electricity were not readily available. Now, a finger prick of blood dropped on a plastic card and mixed with six drops of buffer could inform us within 15 minutes if the patient was suffering from Plasmodium Falciparum malaria, the most severe and deadliest form of this mosquito-borne fever. Alongside the blood test, we measured the Mid-Upper Arm Circumference (MUAC) of children and checked their height and weight to see if they also needed to be treated for malnutrition. In the early days, it was like a small factory operation putting through up to 250 kids a day and sending the sick ones home with a handful of drugs and high-energy protein biscuits. This was standard MSF practice, but was it effective?

From the start of this MSF project, I wanted to look at whether applying a medical anthropological approach to emergency medical programmes could enhance the activities and the patient outcomes. Was it enough to see 250 kids in a clinic each day and send them home with a packet of pills?

The anthropologist in me started noticing that because the children were going in to see the doctor or the nurse with the malaria diagnosis already completed and because we were trying to see so many children, the prescription for almost every child with a fever and a positive test was automatically Arthesunate and Fansidar. The consultant was not taking the time to really check if there was any additional reason for the fever or if there was a concurrent infection. We were also only treating the sick child who the mother had brought in that day, but we were not asking about whether other children were at home suffering similar symptoms. If the mother did bring in three children, we were prescribing for all of them. We were rushing people through the pharmacy so quickly, that it was unclear as to whether the mother fully understood the diagnosis or treatment, whether she knew which child was to get which drugs, or whether the treatment would even be followed. And we were really only treating the children. Were we sacrificing quality for quantity?

The teams started recognising that there were pregnant mothers among the children and that they also needed attention. We had predominantly male

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nurses working with us and most had little if any obstetric or gynaecological skills. I had to find female nurses or midwives to join our teams. When midwives started working with us, the number of pregnant patients increased dramatically. Demands for contraception also started. Word spread as these women wanted to regain agency. By looking beyond our main patient base, I made sure that the programme was adapting to emerging needs. We did not just add antenatal consultations to the list of our mail nurses responsibilities, but sought out trained women who would be able to address the needs of their sisters, including their more devout Muslim sisters.

This was only the beginning of a more careful look at how we were operating, what questions we were asking and how patients were responding to our treatment advice. The midwives started noticing infections among the pregnant women. They treated them with antibiotics, but then some returned for their next trimestrial visit still unwell. Had the treatment not worked or had the women become re-infected? We sat with the teams and had mini focus groups to discuss how we could address this in a culturally sensitive manner. We chose to ask women to bring in their husbands for a consultation. We had male nurses talk to the men about symptoms and pain, and we had midwives mildly chastising the men for allowing their wives, and potentially their children, to be infected. We were successful in our treatment and fortunate to be working in a context where sexual practices could be discussed quite openly. Attention almost had to shift to counselling midwives shocked by the number of men coming in and dropping their pants as they walked in the door.

But curing STIs was not enough; we wanted to get to the source. With the help of a new young male doctor, a young male nurse and another older male nurse originally from the community, we started tackling the STIs at the prevention stage. We encouraged men who came in, whether with their wives or on their own, to also bring in any other partners as alternative companions were found when wives were pregnant. We organised health education sessions at the start of the clinic while people were cued and our medical teams were setting up for the day's consultations. I used some of the sources I had discovered while doing my master's research and adapted ideas and images for presentations using the skills of local artists. The health educators had a general presentation for all ages and then developed separate sessions for adults only where we used pictures of discharges and infection to help them self-diagnose and to see the effects if infections went untreated. We had wooden penises made to show people how to use condoms and we introduced the female condom. We provided soldiers on both sides of the conflict with condoms and opened special evening clinics to make it easier for them to come for treatment, although we insisted that uniforms and guns be left at home.

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In the meantime, the malaria numbers remained high. An MSF team on the other side of the border had conducted studies indicating a resistance to Fansidar. Fansidar was used together with Arthesunate in a combination treatment (ACT) for treating malaria, but Fansidar was also the only drug that could be given prophylactically to pregnant women to reduce their chances of malaria, anaemia and low birth weight. We had to switch to a new combination drug, Amodiaquine, and convince people that the associated nausea was a necessary evil. We tried to facilitate the switch by also bringing in blister packs. Rather than putting the pills into a couple of little plastic bags with markings on the number of times a day to take the dose, the blister packs allowed for easy dispensing and marking of fixed combination treatments. They were designed with set doses for children, adolescents and adults, eliminating the need to snap pills into jagged segments to get the right dose. We added mosquito-net distribution to the first consultations of pregnant women and worked with another organisation to do a general mosquito net distribution for the communities so that not only just the pregnant women were protected. We invested in some social market research on sizes, colours and existing availability of mosquito nets to ensure that they would be used.

While the clinic care was improving, we had to reopen the hospital. There were too many patients seen at the clinics who needed follow-up care that could not wait until we returned the next week. The nearest referral hospital was bursting at the seams – they had 350 children in the Therapeutic Feeding Centre and patients on mattresses in hallways due to mass influxes, and they were almost an hour-drive away from our nearest clinic. We did not have time to make sure our paint was dry or our rosters completed, our doors had to open. Prior to the conflict, the average number of beds filled at Danané Hospital was about thirty patients at peak times. Due to the quality of care, displacement having brought more people to the urban centre and free care offered, our numbers kept increasing. There were 90 beds with a bed occupancy rate of more than 100%. We often had to put two children to a bed. Cots took up too much room, whereas a mother could stay with her sick child if we left a regular bed in place.

Another week I saw two children die due to complications resulting after measles infection. I saw a 14-year-old boy coughing up blood and was about to chastise the doctor for not doing more. I can still see the look in his eyes as he told me that there was nothing to do but to comfort him in his last days – the boy had Hepatitis and was coughing up his liver. It is incredible how horrific observations like this can spark action. Previously, I might have accepted this as part of the fallout of poor health systems exacerbated by conflict, but I now knew enough about epidemic spread and the value of immunisation. And, I

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was in charge of the programme. Not only did we organise mass measles vaccination campaigns, but we also re-introduced the Extended Programme for Immunisation (EPI), including hepatitis vaccines. Some of the mothers had already been asking when vaccination would start again, so I knew that this was one area where promotion was not going to present big cultural hurdles.*

Our Ante Natal Care clinics thrived and women came to the hospital for delivery assistance. We had difficulties finding midwives, let alone French-speaking expatriate ones, so I finally welcomed an Australian midwife into the team. Her French was atrocious but she compensated for it with her expertise in deliveries. In the first month there were ten complicated deliveries – twins, obstructed labour, eclampsia; in the second month there were twenty deliveries; the third saw forty and the pattern continued. Despite the challenges with the language, we found her a translator and her reputation drew women to the hospital to deliver. Some of the women came with cow manure shoved in up against the cervix to promote fertility – this only promoted infection and we had to find ways to dissuade its use. Others came with rice that was sprinkled on the bed to coax out the new baby – this was harmless, so not an issue to allow at the delivery. Those who wanted to take their placentas home were facilitated. Miscarriages, abortions, and family planning were dealt with in culturally sensitive ways.

Again, I was watching clinic activities and picked up on new frustrations among the midwives. They were sending women home, despite concerns about their pregnancies as delivery dates were still weeks away. I talked with some of the pregnant women about the distances they had to travel and knowing full well from my thesis research that the majority of contractions begin in the middle of the night when in Côte d'Ivoire there is no safe transport available, our programme again needed to adapt. A maternal waiting house was conceived and constructed for women coming from far away to be close to the hospital when the contractions started.

The workload was increasing and we could not have our lone midwife sleeping at the hospital every night. I had to recruit more midwives and expand the delivery room. The Ministry of Health refused to provide names of experienced midwives to work with us. We found a midwife from Benin who was licensed in Côte d'Ivoire, but not allowed to work within the government system. The Ministry of Health was graduating new nurses and midwives and while they had not enough places to assign them, they were willing to second them to us

* In a number of countries, like Nigeria or Pakistan, there are fears that vaccines are being used to sterilise or infect those injected with diseases like HIV. It has resulted in attacks on health workers, including some personnel killed.

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for their first year or two for practical training. It meant extra work for our staff to get students who had spent little time actually in delivery rooms, up to the level needed to manage patient care, but it afforded us the opportunity to ensure that they were taught good practices and techniques.

Referrals for complicated deliveries became problematic. Due to insecurity on the roads, I could not authorise our ambulances or our staff to travel at night to the referral hospital where an equipped surgeon could perform caesareans. In the early days, and if the family insisted, we resorted to putting women in taxis together with family members. No one was comfortable with this option. We analysed the data (the numbers, the types of cases, and the risks) and we proposed to donors to allow us to introduce surgical capacity to be able to manage these deliveries ourselves.

Introduction of surgery not only allowed for complicated obstetric cases to be better managed, but also gave midwives more time to support a natural delivery. Teams in the hospital and clinics were also able to ensure that recovery care was properly monitored for the post-natal infections we were encountering. New services came out of extensive observation of clinic and hospital functioning, discussions with patients and their caretakers, and careful analysis of the incoming data. The numbers, supported by impassioned case examples, allowed for a strong presentation of the arguments to the government and to the donors, leading to the extension of our services and staffing. Anthropology had again taught me the value of using both qualitative and quantitative data.

With the introduction of surgery, new demands arose for the creation of a blood bank. Concurrent with high levels of STIs in the outpatient clinics, we also started seeing potential donors whose blood tested positive for HIV. These were predominantly young 'healthy' male family members. 17% of donors had to be told that they were 'not a match' as we had no capacity for counselling or treatment. MSF needed to develop a new phase of the programme.

Our national staff members were adamant about wanting the ability to inform people about their HIV status. Even if we were not able to treat them right away, at least we could stop them from infecting others unknowingly. It was possible for us to just start our own programme, but I did not want to begin with something that no one would be able to take over when the emergency phase and funding ended. We started by first investigating treatment options already available in the country. There was a new government department for HIV diagnosis and treatment, and it was staffed by a dynamic group of young Ivorian doctors. We worked with them to set up a programme in Danané that would be able to transition into the National Programme once peace returned to Côte d'Ivoire and MSF eventually withdrew. While we would initially provide treatment free of charge, the Ministry was working on a plan

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together with international donors to make national drug supplies affordable – three months of treatment would cost the equivalent of an average daily wage. The Ivorian national team provided us with educational materials and we provided them with data. Some members of our staff were trained in Abidjan on counselling and our HIV/AIDS treatment programme was born.

In the meantime, malaria still continued to plague all sites. The government, however, was maintaining its ineffective Chloroquine treatment regimen. Using the research skills obtained in my master's programme, we pulled together a host of regional studies that showed the high levels of resistance and ineffectiveness of the drug in the treatment of malaria in West Africa. We found a problem with the government Central Pharmacy still holding large quantities of Chloroquine stocks that they wanted to be rid of before ordering the new and more expensive ACT. We compiled our data and that of our sister organisations in other parts of Côte d'Ivoire. Using data analysis and graphing tools I learned in Amsterdam, the power of powerpoint presentations, and a cost-benefit ratio analysis comparing hospitalisation charges required for treatment of complicated cases versus costs of treatment with the new drugs, we successfully lobbied the government to not only allow us to continue with our treatment regimen, but we convinced them that they would be saving money if they changed their protocol.

My drops in the ocean were starting to accumulate into a pool. From one girl at a clinic we changed triage practices to be open to more survivors of sexual violence; from one boy who died of hepatitis came the re-introduction of the vaccination programme; from a handful of STIs we introduced and HIV programme that would continue long after the departure of MSF from Côte d'Ivoire. I strongly believe that approaches and skills that I learned through my training in medical anthropology give me a means to better understand the populations we seek to assist, the tools to provide more effective health care, and the ability to communicate this to other colleagues so that they can also apply medical anthropological methods and approaches to improving care. In dealing with the staff, it is important to recruit effectively, to see the initial shortcomings in their abilities as opportunities for training, and to listen to their ideas in programme development. It is equally important to take the time to talk with patients about how they feel about their interactions with the staff. It is essential not to dismiss traditional caretakers, but to find ways that western and traditional care can complement each other. With the medicines, we need to regularly check that patients understand and accept the treatment prescribed, we need to act on the opportunities to work with governments on improving treatment protocols, and we need to look beyond the treatment to the source of infection and counter this where possible. In the facilities, by

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taking the time to watch the flow of patients, to renovate structures and to introduce appropriate technologies and practices, there is a greater chance that the effects of the emergency intervention will go beyond the critical phase. In emergency interventions, medical teams need to be sure to periodically evaluate and adapt programming to avoid bias and misdiagnosis, and they need to be prepared to take the qualitative and quantitative data and be able to present it to authorities and donors in order to convince them of investing in the needed changes.

When working with an international medical organisation like Médecins Sans Frontières, interventions take place in a wide range of contexts – conflicts, natural and man-made disasters, outbreaks and even in some areas of chronic underdevelopment. With the opportunity to start most interventions in the acute emergency phase, there is often an opportunity to mobilise resources rapidly and to engage quickly with the population. The downside, though, can also come with the speed of the operation where consultation with the community is rushed and templates from previous interventions are quickly introduced rather than adapted for the specific needs of the local context. Inappropriate staff and locations can be chosen if proper attention is not paid in the early stages to the reaction of patients.

A growing number of anthropologists are working with organisations like MSF. They are rarely found in the official role of 'anthropologist', but have read about and understood the importance of participant observation, cultural sensitivity, the patterns of disease spread, and health seeking behaviour. They are asking some of the right questions and using this together with their steady shift into positions of authority to direct programming and resources.

There are still serious dilemmas with finding the time to follow research developments and access studies, especially while in the midst of a crisis in a country or where the Internet is not always easy to access. There is also very limited time to write up findings or to look for publications interested in helping to mould the data. Linking findings into the latest debates or theoretical frameworks rarely find their way on to a busy fieldworker's agenda. Maintaining and strengthening these links is one of the greatest challenges, but absolutely essential if we aim to do as Paul Farmer did and break through the barriers of our institutionalised responses to get the diagnosis right.

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Chapter 11

Why medical anthropology matters

Looking back on a career

CORLIEN M. VARKEVISSER*

In retrospect I must admit that there was not much planning throughout my professional life. My career (*loopbaan*, 'the path one follows,' as we say in Dutch) was determined by coincidence and luck rather than by forethought, particularly in the beginning.

Like the majority of the AMMA students, I did not start out in anthropology. In 1957, I opted for human geography, which included a small course in anthropology – then a relatively unknown field. Professor André Köbben, who taught this subject, was young and enthusiastic, and in no time captured my interest with a monograph about the Basotho people in southern Africa (Ashton 1952). From then on, I took up studies in anthropology in addition to human geography. After my *kandidaats* (bachelor's degree), I decided to pursue a *doctoraal* (master's degree) in both human geography and cultural

* Corlien M. Varkevisser graduated in Anthropology and Human Geography at the University of Amsterdam (1964), where she also obtained a PhD (1973). From 1964 till 2000 she was employed by the Royal Tropical Institute of Amsterdam, which enabled her to conduct educational and Public Health research and consultancies in many – mainly African – countries. In 1981 she obtained a Master's of Public Health. From 1987 to 1992 she was based at the WHO Sub-regional Office in Harare to initiate Health Systems Research. After returning to the Netherlands she headed the MPH course of the Royal Tropical Institute and was appointed part-time Professor in Medical Anthropology at the University of Amsterdam. In 2001 she retired.

I am indebted to the Ministry of Development Cooperation in the Netherlands for its willingness to support me financially in most of my short- and long-term research and missions, and to the Netherlands Leprosy Foundation which financed the leprosy and TB part. The Royal Tropical Institute served as a supportive home basis; the Offices of the World Health Organization in Geneva as well as in Harare facilitated the HSR activities in the field, and the Medical Anthropology Unit of the University of Amsterdam provided a valuable environment for learning as well as teaching. I am grateful for the many friends that I found in these institutions and in the field.

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anthropology. I kept my interest in human geography because, in truth, I was unsure about the job prospects in the field of anthropology. Since I had gained some teaching experience at a primary school in my native village Katwijk, I asked permission to specialize in the anthropology of education in developing countries. Professor Köbben approved my specialization despite the fact that anthropology of education did not yet formally exist in the Netherlands, but he trusted I would find my own way.

Sukuma Land

As fortune would have it, another professor of anthropology, Jan van Baal, had a strong interest in education. Van Baal had just quit his position as Governor General of New Guinea where he had founded several primary schools. He was about to launch a Centre for the Study of Education in Changing Societies in The Hague. A month after I had contacted Köbben, van Baal approached him in search for a female anthropologist with an interest in home education. Köbben immediately thought of me, and within a year I finished my studies and joined van Baal's interdisciplinary team of five young scientists. We had to investigate how home and school education in Tanzania could be better integrated. At the time, in 1964, Tanzania had just gained independence from Great Britain; thus, the educational system was predominantly based on a British model. Our project concentrated on the Sukuma, a large ethnic group (± 2.000.000) living near Lake Victoria. My role was to gain a deeper insight into socialisation at home and its possible contribution to formal education.

When we were doing research in Sukumaland we had two resources at our disposal that graduate students have to compete fiercely for today: time and money. From the two and a half years (fall 1964 – spring 1967) of funding we had, I reserved nine months for general anthropological fieldwork in Bukumbi district, then still a traditional rural area about half an hour driving from the town of Mwanza. The remaining 21 months I concentrated on the socialisation of youngsters (0-16 years), fifteen months in Bukumbi and six months in Mwanza town, in order to compare socialisation in a rural and an urban setting and to capture the most significant changes. This comparative approach proved extremely useful. Even today I advise my students that a comparison of two extremes may provide a deeper and quicker insight into a topic than solely describing one phenomenon.

It is difficult to overestimate the importance of my first research experience in Tanzania and its impact on the rest of my professional as well as personal

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life. I learned more in those two and a half years than all of the time spent in school combined. I had to re-learn basic human skills: speaking (*kisukuma*), walking (at a much slower pace than I was used to), eating (with my hands), and joking (what to say and not to say). In addition to these basic interactive skills I had to familiarize myself with data collection techniques, the ethical issues involved with fieldwork, and the ordering and interpretation of data. These enriching field experiences amply outweighed the difficulties I encountered in the field. Some friendships that I made then in Tanzania have continued to this day.

Yet, nothing prepared me for the lonely struggle in making sense of the data once I returned to the Netherlands. Within a few months after our return, the team had to collectively produce a book. The deadline was well before I would have a chance to thoroughly analyse the data. This tension proved to be so frustrating that I hardly touched the data for three years *after* the summary book had been written. Fortunately, I met a young American writer, Donald Bloch, who encouraged me and offered to edit my English. Within two years, I published the book that became my PhD dissertation (Varkevisser 1973).

Tanzania and Kenya

One month before finishing my PhD, in 1973, Dr. Leiker, a leprologist and colleague at the Royal Tropical Institute where I was employed, approached me for a research project in Tanzania and Kenya. Leiker needed a social scientist to conduct research on the reasons for the low attendance of patients in leprosy treatment programmes. He assumed the reasons to be mainly cultural.

In the 1950s, the pharmaceutical industry had launched a promising new drug, Dapsone, to treat leprosy. Provided Dapsone was taken early and regularly over a long period (or permanently for those with the serious multibacillary type of leprosy), using this drug could prevent the devastating deformities caused by leprosy. For over 2000 years, these deformities had stigmatised leprosy patients. Leiker had initiated a leprosy control scheme in the same area where I conducted the education study. With a team of four social scientists, including a Kenyan sociologist (at the time it became a policy to include young scientists from the country where we conducted the study), we started a comparative study of the reasons for non-compliance with leprosy treatment between Sukumaland in Tanzania and the Western Province of Kenya. Not only did we compare patient communities in two different locations, we also expanded our study to include tuberculosis. The TB services suffered from similar attendance problems as the leprosy clinics, often with grave consequences for the patients.

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We had two tight years to complete this comparative project (1974-76). Contrary to what the doctors expected, the main problems were not culturally based prejudices of patients but rather stemmed from poor functioning leprosy staff at village level. The medical authorities, however, did not appreciate these findings, and as a result, the recommendations were shelved. Yet time appeared rife for this kind of applied anthropological research.

Botswana

In 1977 a doctor at the mission hospital in Mochudi, Botswana asked for my help in analysing the TB problem as she had the impression that many patients abandoned treatment, only to show up again when they were terminally ill. A Dutch student in anthropology, Marian Paape, asked me if she could assist me. As the Dutch Ministry of Development Cooperation (DGIS) had provided me with enough funds to survive and carry out a rapid appraisal of one month, I agreed. Together we analysed the TB records at Mochudi Hospital and found a compliance rate of only 50%. Subsequently we interviewed patients, their relatives and TB workers about possible causes of patients' non-compliance.

I had asked permission from the Ministry of Health to use a government hospital as the control site for the rapid appraisal on TB services in Mochudi. The Ministry of Health advised to chose the hospital at Lobatse in the south of the country where the TB case load seemed to be the highest. An analysis of the records showed that a compliance rate of 50% in Mochudi Hospital was still 'fair' compared to the shockingly low compliance rate of 20% in Lobatse Hospital. In-depth interviews and focus group discussions with patients, their relatives, community members, and staff revealed that the TB services had recently been decentralised from full in-patient treatment (in a hospital) to only two months of hospital treatment, followed by ten months of ambulant treatment in a health centre. This abrupt shift in policy caused most of the problems we were not investigating. The health centres gave no feedback to the hospital whether patients had reported for treatment at the health centre, nor did the staff have time for follow-up of irregular TB patients. The health centre staff had not been thoroughly trained and supervised, and patients lacked counselling in all facilities, whether in- or out-patient.

To counter these problems we developed, together with the Regional Medical Officer of Lobatse Region, a plan of action for the TB services, which we proposed to the Ministry of Health. We recommended an intermediary person between the Regional Medical Office and the health centres, a health assist-

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ant specialised in TB, who could support the Regional Medical Office with the training and supervision of health centre staff. Further we recommended more precise job-descriptions, especially regarding health education, more on-the-job training of staff, more patient-centred counselling, better referral procedures between health facilities and better record keeping. We managed to get our plan funded by DGIS. Marian Paape, who in the mean time graduated with a master's in anthropology, helped to implement and test the recommendations. In four years time the defaulter rate among registered TB patients decreased more than two third in Lobatse region (Varkevisser 1977). Our recommendations also spread to other regions.

Papua New Guinea

In 1978 an Indian anthropologist, Dr. Dhillon, who was a WHO staff member in the Regional Office for South-East Asia asked the Royal Tropical Institute for my assistance based on the research we had done on leprosy in East Africa. He invited me to conduct a three-month study on stigmatisation of leprosy in the highlands of Papua New Guinea. The leprosy services had been decentralised in 1976. The Ministry of Health had rather abruptly closed the leprosaria and patients were sent home under the assumption that in Papua New Guinea, there existed no stigma toward leprosy, a statement Dhillan questioned. Those still needing treatment had to present themselves to the nearest health centre. I had to form an impression on how the patients had been received by their communities and the general health staff who had been given a crash-course training session in leprosy treatment.

The mission proved to be quite an experience. The Highlands of Papua New Guinea were not completely safe due to sudden eruptions of tribal wars. With the help of key informants in the Ministry of Health and the Goroka Institute for Medical Research I selected Lufa District in Eastern Highlands Province and Minj District in Western Highland Province as research locations. The WHO provided me with a land rover – without a driver – which provided some protection against warriors but could not bring me to the villages on top of the mountain ridges. The research problem sounded familiar. As in Botswana, I wanted to interview leprosy patients, their relatives and community members as well as health staff, together with key informants in the capital about one hundred interviews.

I had to climb the mountains (with help of my interpreter's father, dressed only in a penis quiver). Health centre staff in the Highlands had witnessed that relatives and villagers not always welcomed leprosy patients as cordially

as former leprosaria staff assumed. On the contrary, some deformed people, anticipating that the community members would have thrown them from the rocks if they returned to their villages, had settled near the Mt. Hagen airport and refused to move. That fear was perhaps justified in the past but at that point in time, their fear seemed a bit exaggerated. Indeed, community members repeatedly aired their misgivings to me about the government sending all leprosy cases back to them when the government should instead *protect* them against further infection from leprosy. Relatives of patients also admitted being afraid, though they tried to hide their fear. Yet, only about 10% of the patients interviewed experienced some form of physical or social marginalisation, mostly by unrelated community members. Social distance appeared to be an important determinant of stigma, as was confirmed in later research on leprosy. The report was favourably received by the staff of the South Asian office of WHO, but when the chief editor of *Leprosy Review*, an international leprosy journal, wanted to publish our report and asked the Ministry of Health of Papua New Guinea for permission, the government refused to grant publication rights, still stating that no stigma existed in Papua New Guinea.

Intermezzo: Taking stock

The Papua New Guinea and Botswana experiences taught me several lessons. First, provided the research problem is well defined, research does not require years but rather months or weeks to complete, specify the major contributing factors and propose remedial action. Second, teamwork accelerates the completion of a research project. The work took longer in Papua New Guinea because I was on my own (though with a very valuable interpreter). Third, it is absolutely necessary to involve the health authorities and health staff in all stages of the study: the definition of the problem, feedback of preliminary results, drafting of recommendations. Fourth, using different quantitative and qualitative methods at the same time (triangulation) shortens the duration and strengthens the validity of the research. Finally, it seems useful if one of the researchers is in some way involved in the implementation and evaluation of recommendations made.

Nowadays these points are generally accepted and have been commonly introduced in the practice of shorter missions. In the 1970s, however, scientists were still inventing this wheel.

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Sudan

Immediately after I returned from Papua New Guinea, the Dutch Ministry of Development Cooperation requested my support for a study into the nature and extension of the practice of female circumcision implemented by the Medical Faculty in Khartoum, Sudan. I initially refused, as both the subject and the culture were unfamiliar to me. The Dutch Ministry, however, insisted on my participation because the research had already started and a female anthropologist with experience in public health was needed to improve the research proposal. I never regretted my reluctant acceptance of the mission, because from the beginning until the end the entire experience was highly instructive.

When I arrived in Sudan the nation-wide survey had yet to be conducted. The plan was to employ medical students on semester break to conduct interviews in Kassala region, but the fathers of the female students refused to let them go as safe lodging was yet to be found. The midwifery school in Kassala was an option, but the staff could not be reached as the midwifery students were on holidays and the school was closed. Two male students who saw their holiday earnings evaporate proposed to travel with me to Kassala (which involved two days of driving through the desert with a camion or ramshackle bus) to prepare the lodging.

During the trip I discovered that the problem had less to do with the quality of the survey but more with its implementation. Students were paid per questionnaire so they took five, at most ten minutes to finish the 85 questions covering the sensitive issue of female circumcision. Students interviewed participants of the same gender with different questionnaires for men and women. Unfortunately no attempt was made to cross check the data collected from couples. Women and men were sampled separately, so it was more difficult to recruit couples.

In Kassala, we found the midwife teachers in an empty school, and therefore welcomed a distraction from our medical students. When all twelve students and their female tutors arrived we discussed possible changes in the implementation of the survey and about rewarding students based on their work per day instead of per questionnaire. I gave them training in qualitative interview techniques as well. To make sure that interviews would indeed last at least an hour, that contradictions between men and women; husband and wife would be observed and followed up, and that students would not lose their enthusiasm for the study, I proposed some permanent assistance. The Dutch Ministry agreed to fund a young Dutch social scientist for the duration of the survey. (This Dutch student married one of the medical students who had escorted me to Kassala and has remained in Sudan ever since.)

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My successive studies and missions in public health reflected a transition toward a more medical direction where as an anthropologist I felt I could be useful. However, I knew my knowledge of public health was still rather haphazard. Fortunately the Royal Tropical Institute granted me a sabbatical year (1980-81) to obtain a master's in public health.

During that year, a colleague, the late Pieter Streefland and I founded a Primary Health Care (PHC) group at the Royal Tropical Institute, as well as a countrywide network of people interested or working with us. PHC generated world wide political interest since reaching the poor with simple but basic health care had become a key goal after the famous Alma Ata conference in 1978. The DGIS made available abundant funds for initiating the participatory PHC approach. The Royal Tropical Institute was then still completely subsidized by DGIS, so it was possible to stay for weeks in DGIS-funded PHC projects to evaluate and support them, to promote cross fertilization between projects and try out new approaches. I participated in virtually all DGIS-funded PHC projects in Francophone Africa (Benin, Niger, Mali, Burkina Faso), and in Angola, Mozambique, Tanzania, Sudan and Yemen.

Benin

In Benin, the PHC group of the Royal Tropical Institute engaged itself for several years (1983-1987) in a PHC project in the rural town Pahou where Beninese medical students conducted operational research for their masters while working at a model health centre. The doctors treated malnutrition at the health centre, but wondered how serious the problem was in the wider community. We proposed to carry out a Rapid Appraisal on the extent and causes of malnutrition. Interdisciplinary Rapid Appraisals originated in the agricultural field but they were a novelty in the field of public health.

Our interdisciplinary team was made up of fifteen members which included eleven Beninese and four Dutch doctors, nutritionists, agriculturists, sociologists as well as Beninese officials who were part of district medical staff, agricultural officers, and local PHC and agricultural workers who all had at least six years of primary education. The research method developed for working with such a big, diverse group was experimental as well. We first worked with the entire group, brainstorming to specify the statement of the problem and developing the research proposal. Then we split up in smaller interdisciplinary groups of four or five people to conduct research in three different villages.

These smaller groups measured the arm circumference of all children to detect the degree of malnutrition. Then we split up into pairs (that were still

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composed of different disciplines and professions) to conduct interviews with mothers on the possible causes of malnutrition. After two days in each village, we reconvened with the larger group for a day to discuss the results of each team, considered them in the light of the objectives and, if necessary, refined the tools. Then we returned for two days to finish the work in the same villages. In different compositions we set off for the next three villages. Data analysis went in the same way of alternating big and small groups for respectively, discussion and analysis/writing/feedback to the villages, complemented by additional data gathering. All participants and villagers seemed to enjoy it. Chambers (1983) also reports how exciting such a collective enterprise can be. Only editing the final draft for publishing was a lonely affair (Varkevisser et al. 1993).

This 'harmonica approach' (alternately convening in plenary sessions and breaking up in smaller groups) is one of the achievements of the Benin period that I cannot recommend enough as an efficient method for explorative research. With the harmonica approach the group acts not only as research team but also becomes aware of itself as a research instrument.

Southern Africa

When still involved in the last phase of the Pahou/Benin project (1986), Yvo Nuyens from WHO Geneva requested the Royal Tropical Institute to participate in a new enterprise: sounding the Ministries of Health and Universities in the ten countries of the Southern African Region if they had an interest in Health Systems Research. Health Systems Research, in short, aims at evaluating whether the health services cover the needs of the population adequately and in the most cost-effective way. All ten countries accepted the invitation and sent two delegates to the WHO Sub-regional Office in Harare, a representative of the Ministry of Health and a scientist from a university. Together we drafted a project proposal for five years of Health Systems Research activities and handed it in at the Dutch ministry, which agreed to finance it. The Joint Health Systems Research Project for the Southern African Region (referred to hereafter as 'Joint Project') was born with three parties: it fell under the newly founded Health Systems Research and Development Programme of the WHO; was implemented by the Royal Tropical Institute (delegated to me); and financed by the DGIS.

In the mean time the social climate was changing. The Royal Tropical Institute was one of the first institutions hit by the 'market approach', a management paradigm that in the mid eighties invaded European countries from the United States. The governmental subsidy to the Royal Tropical Institute diminished by

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one third and to fill the gap, the Royal Tropical Institute employees were now supposed to ask fees for their involvement in developing countries (before 1985 we worked without compensation). As a consequence, it became much more difficult to carry out research. In addition, the DGIS soon adopted the policy to separate project formulation from project implementation, for which other agencies than the formulating one had to compete by tender. I still think that the disadvantages of this policy outweigh the advantages.

I felt relieved that the Joint Project still fell under the old regulations. When formulating the Joint Project in 1986, we assumed that funding local research proposals would be a major activity but few decent proposals with quality research methodology appeared. As a result, we placed a priority on the *training* of Ministry of Health staff and researchers in operational research methods. My position at the Sub-Regional WHO office in Harare was favourable: I enjoyed all privileges of a WHO staff member, including having easy access to Ministries of Health in all countries of the Sub-Region, but as a the Royal Tropical Institute employee I was *not* subjected to the sometimes stifling WHO bureaucracy. The five years in Harare were extremely gratifying.

A first country visit to Zambia already convinced me that at the Ministry of Health authorities had no clue what Health Systems Research was. They referred me directly to the Community Health Department of the University where I found more interest. A doctor from the Community Health Department and I worked through all medical research projects carried out over the past ten years that might, from their description, have a public health component and attempted to find out if there had been contact with the Ministry of Health about the selection of the problem or implementation of the findings. This appeared to be the case in only four out of over a hundred projects, and nothing was reported on the project's outcome. We went back to the Ministry of Health with unsatisfying results and this time the Health Systems Research raised its interests because they became aware of the potential contribution Health Systems Research could make in the solving of their problems. We agreed to organize a meeting between high officials of the Ministry of Health and interested researchers from the Faculties of Medicine and Social Sciences where needs and human resources for operational research could be better matched.

In all other participating countries in Southern Africa, we conducted a similar situation analysis and needs assessment for Health Systems Research before we started working. Everywhere the connection between the Ministry of Health and University appeared weak or non-existent. This situation improved when the Ministry of Health, at our suggestion, initiated Health Systems Research Units within the Ministry. Invariably the Ministry of Health

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authorities mentioned the need for more training of medical staff in operational health research. The greater part of my five years in southern Africa was therefore spent on teaching, but in a very participatory way.

The training of adults who have little or no experience in research methods requires a special approach. Fortunately we had an example of eighteen modules, prepared by Harvard University for a similar purpose in West Africa, the so-called SHEDS modules (1983). These modules were well structured but we still found them to be overly academic for the district health teams who formed our main target.

With twelve medical and two social scientists from the sub-region we adapted and thoroughly rewrote the SHEDS modules, in the same alternating big-group-small-group fashion we had experimented with in Benin (harmonica model). It worked. With two cycles we had within two weeks finished a first revision of the twenty modules necessary to develop a research protocol. The modules constantly needed small revisions during the many workshops in Health Systems Research conducted in some fifteen African countries. District health teams selected their own research topics based on a problem found in their working environment. Local facilitators with an academic and research background who had first been trained in teaching the Health Systems Research modules taught the district health teams step by step until each team finished its own protocol.

It took the teams nine to fifteen months to gather the required data, because they had to carry out the study alongside their regular duties. Without exception they returned enthusiastic for the data analysis and report writing workshop of two weeks, for which we had developed another twelve modules, in a similar way as the previous twenty. All these workshops proved to be rewarding; the facilitators gained as much as the participants. Evaluations taught that the district health teams could implement roughly half of the recommendations to solve the investigated problems, and sometimes more, depending on the authority of the team members to carry out the recommendations and the blessing of the Ministry of Health (Varkevissser et al. 2001).

The modules merged with a Malaysian version that Dr. Indra Pathmanathan prepared for the public health training of Malaysian doctors. In 1991 WHO Geneva and IDRC Canada published the completed modules to which so many persons had contributed. The second revised edition appeared in 2003 at KIT Publishers in Amsterdam (Varkevisser et al. 2003). They have been translated in at least ten other languages. Many Medical Faculties (particularly those who taught public health courses) as well as Social Faculties in the Western and the Developing World use the modules. WHO and IDRC also made the modules available over the Internet. Lastly, in an adapted and shortened version they

make up a large part of the *Manual for Applied Health Research* that is used in the Amsterdam Master's in Medical Anthropology (AMMA) course (Hardon et al. 2001).

Amsterdam

After those challenging, busy but very rewarding five years in Southern Africa, it was again difficult to get used to the Netherlands. I had decided to return to the Royal Tropical Institute in January 1992 because I felt the need to reflect on my life-long work as an applied medical anthropologist and to update my medical-anthropological knowledge. Fortunately the Medical Anthropology Unit of the University of Amsterdam invited me to teach part-time in their Unit. In that same period the Masters in Public Health (MPH) course at the Royal Tropical Institute, Amsterdam asked my assistance as a manager. As over 75% of the course participants (mainly Public Health doctors and nurses) originate from developing countries it felt like a continuation of my assignment in Harare. I taught applied research methods to Dutch students as well as those in the AMMA master's course where, like in the MPH course at the Royal Tropical Institute, most of the students come from developing countries.

In 1994 I was appointed 'extraordinary professor' at the University of Amsterdam on behalf of the Royal Tropical Institute. My task was to promote 'Interdisciplinary Research for Health and Development.' The inaugural lecture 'Health Systems Research: *De knikkers en het spel* ('The marbles and the game') was a result of my reflection on twenty years of applied research and teaching on health and health care in the developing world (Varkevisser 1996). In that lecture I took stock of what research and research-based implementation had produced over the years. The conclusion was not encouraging; inequity in health and access to health facilities is still rampant. HIV/AIDS has made the situation more complex. Many of the problems I was asked to focus my research on have remained problematic or are again a matter of concern to communities, policy-makers, health workers, and researchers. History keeps on repeating itself. Non-compliance in medicine use, failing health services, stigmatisation, gender inequality, to mention a few of the problems I attempted to explore and fight during my life as medical anthropologist and public health consultant continue to be hot issues. That sobering conclusion implies a call for more participatory and interdisciplinary medical anthropology. No one can change the world but we can at least join forces to play our part.

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Looking back

These were some of my experiences in medical anthropology. If I had planned a 'career' my life would probably have been less varied and interesting. It seems the jobs to a large extent chose me, instead of the other way round. That is not so surprising; in The Netherlands female anthropologists willing to conduct longer periods of fieldwork were rare in the 1960s. Yet, in hindsight, I discovered consistency in my successive 'career steps'. Successful experiences, such as the 'harmonica model' when conducting research and writing with groups of people, were later used in subsequent assignments. As a rule I worked together with a variety of scholars from other disciplines and professions. It requires some effort to acquaint oneself with other disciplines but I found it very rewarding. Then, I always worked in operational research, not because I disliked theory, but because the nature of successive missions rather led me in the applied direction. This meant working in a participatory way with different target groups and learning from them. And finally, I tried to transmit research knowledge in simple terms to local medical staff in order to equip them better for analysing and solving the many problems they meet in their daily activities.

Looking back on my life as an anthropologist I realise that applied medical anthropology is not an impossible thing to do, nor a diluted or immature kind of anthropology. Risking to sound self-complacent I can only conclude that the many projects I have been involved in over the years prove that anthropology *matters*. Anthropology, and medical anthropology in particular, can make a difference. It is a conclusion that fills me with undiluted gratitude in my retirement.

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Chapter 12

Journeying with medical anthropology

SHAHADUZ ZAMAN*

This invitation to write about my journey with medical anthropology is an opportunity for self-drumming. As one of our Bengali novelists once wrote "Don't give your drum to someone else, he might break it up. If you want to drum, drum yourself." But before I start this drumming I must acknowledge the fact that although medical anthropology has become my destiny, I only became aware of the term just around the time the Amsterdam Master's in Medical Anthropology (AMMA) started. Before that I knew very well what 'medical' was but a little bit of 'anthropology,' but nothing about them when put together as 'medical anthropology.' I entered as a medical graduate from Bangladesh who went to Amsterdam and left as a medical anthropologist. AMMA was the twist in my life.

Bangladesh, where I come from, appears in the international media as a land of cyclones, famine, and floods. The outside world has a general image of Bangladesh as place where people spend half of the year on the roofs of their houses due to massive floods. Thanks to the Nobel Prize Committee and the game of cricket this may have changed. After the Committee awarded the Nobel peace prize to Dr. Eunus for establishing a bank for the poor and after our boys qualified for the super eight teams in the cricket world cup, Bangladesh now enjoys having some positive images. The world now knows that Bangladeshi people do other things than swimming in floodwater.

Still, Bangladesh is a low-income country loaded with political and economic problems. Poverty is a recurrent theme of any discussion concerning Bangladesh. Getting enrolled in a university is a privilege in my country. I was privileged to get admitted to a medical college. However, I was a reluctant medical student as my interest was in social science and literature. I wanted to be a

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writer. My parents thought if I took literature as my profession, I would starve to death. They were probably right. I followed their advice and got admitted to the medical college. I was a strange medical student, however, whose bookshelves contained novels by Dostoyevsky and Garcia Marquez among anatomy and pathology textbooks. I kept studying medicine but also maintained my interest in literature. I started writing short stories and published in literary magazines. Stories, I came to realize later on, are part of the doctor's business.

After graduating from medical college I took a less-travelled road for a medical doctor in Bangladesh. I left clinical practice and joined a rural primary health care project run by the Bangladesh Rural Advancement Committee (BRAC), a national non-governmental development organization. To my hardcore clinician friends, a public health physician is a 'lesser kind' of doctor. The 'successful doctor' in Bangladesh specializes in sophisticated subjects like cardiology and gastroenterology and aspires to work in a big city hospital that provides a lucrative income. Generally, to the doctors as well as to their families, a community physician who is working in the rural areas monitoring people's toilets, water supply and immunization, does not fall within the expectations and ideas of a doctor who has 'made it.' Though my family was initially disappointed, I was fortunate that they did not oppose my decision to go to a village to work. They were rather worried, how I, their urban-bred son, would cope with rural life, where I would be without a comfortable house, toilet, shower, telephone, television, and a daily newspaper.

My life with the rural health project was indeed quite different from the life I was used to. I did completely different things than I did in the hospital. I trained traditional birth attendants and community health workers, settled disputes with the villagers who were against immunizing their children (as they believed injecting vaccines into the blood that God created is a sin), discussed family planning with religious leaders and listened to herbalists who knew the names and uses of hundreds of medicinal plants. These experiences were not comparable with the attempt to hear the murmur of a myocardial infarction patient in the coronary heart disease ward, or to find the right forceps for the surgeon while assisting him at the operation table.

I was touched by the multiple facets of the rural people's simple life. I was moved by the level of poverty, helplessness, and oppression. I also found out that there were lots of things in the village that could take the place of showers, telephones and televisions. The hospitality and warmth of the people were more than a match for the impersonal behaviour of city dwellers. The rivers, village festivals, and majestic scenery offered a different pleasure and recreation. Spending a few years in the village was rewarding for me both personally and professionally. At a personal level this stay widened my view toward life.

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Professionally, I learned to look at people's health beyond medicine. What I learned in the village that I did not learn in medical college was how health and disease relate to culture, society, politics, and religion. After spending almost five years in the village I wanted to further my knowledge in public health and earned a master's degree in public health from Bangladesh. While studying public health, I came across a few articles written from a medical anthropological perspective. I was fascinated by the way the authors dealt with health and illness. I wanted to know more, but there was none around who could talk about medical anthropology. No institution in Bangladesh taught this subject.

But somewhere up in the sky there was a star that read my mind and sent a visitor from Amsterdam to see BRAC health projects, where I was working. I was asked to accompany this visitor to the field. While travelling in different villages with a car I was discussing various issues with this Dutch visitor who worked for the University of Amsterdam. At one point she told me that they were planning a Masters in Medical Anthropology at her university. "What a coincidence," I said to myself. The visitor whose name was Trudie Gerrits told me that, if I was interested I should get in touch with her colleague Ria Reis. Later on 'Trudie' and 'Ria' became household names.

That was how it all began. I contacted Ria, submitted my application and got admitted. But I had no funds to go to Amsterdam. Fortunately, around that time the BRAC Research Division was thinking of developing its capacity in qualitative research and medical anthropology. So BRAC agreed to sponsor my study in Amsterdam. In a quite dramatic way my own interest, BRAC's interest and the start of a new course called AMMA coincided. I got enrolled in the first batch of AMMA. That's how I left the circle of doctors to join the 'alien' anthropologists. By this time, my physician friends considered me to be a confirmed apostate. One even wondered whether I had become interested in insects, as he mistook the word 'anthropology' for 'entomology'.

At this point I must say something about BRAC that I have been repeatedly referring to. BRAC is a Bangladeshi non-government development organization. It has multisectoral activities including income generation, education, and health programmes for the poor. BRAC is the largest NGO in Bangladesh and probably in the world. It has about 60,000 regular employees, 40,000 schools, and its health programme covers more than 30 million people. BRAC runs programmes in Afghanistan, Sri Lanka, as well as in Uganda, Tanzania, and Kenya. BRAC runs a bank and a university. It has a research division with more than 100 researchers. In short, as an NGO, it is very big and functions parallel to the government. In the mid 90s after three decades of public health intervention experience, the policy makers of BRAC, felt a need to incorporate medical anthropological insights in its programmes. They realised that many

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donor-driven health projects did not sustain because they were not culturally sensitive. My enrolment in AMMA was part of that long-term plan of BRAC.

As it happens with first-borns, we the first AMMA batch enjoyed total attention and lots of enthusiasm from the faculty. In Bengali language AMMA means mother. The department nurtured us like a mother would. I believe they still do. Medical anthropology proved to be liberating. I found a subject where I could blend my interest in medicine, social science as well as literature. My training in medicine gave me the biological understanding of health, my experience in rural Bangladesh helped me to link health, society and culture, and my practice in literary writing helped me to understand the anthropological approach. While writing short stories I applied similar tools to understand life not knowing that I was in fact doing participant observation and taking ethnographic interviews.

Meeting with students from different parts of the world was an exciting experience too. And exploring Amsterdam was fascinating. The aquatic nature of the city 'rimed' with the rivers and canals of my home country and had an intoxicating effect. I visited almost all the museums of Amsterdam, starting with the famous ones like Van Gogh and the Rijksmuseum, followed by all those strange ones like the Torture Museum, the Sex Museum, and the Boat Museum. I visited tourist and non-tourist spots of Amsterdam and met all kinds of people. After returning to my country I published my 'Amsterdam Diary' (in Bengali), which received a lot of positive reactions in Bangladesh. You may be interested to read the book, particularly because there is a chapter on my tutor and friend Sjaak van der Geest. Meeting Sjaak in Amsterdam was a remarkable experience too. It is not a good practice according to our culture to praise someone in his presence, but I just want to mention that I learned from him how to be an anthropologist 24 hours. I have seen him keeping his anthropological eyes open even during his sleep. In fact he has now become interested in the anthropology of the night.

In my post-AMMA life I have some happy stories to tell but also some not so happy ones. But most are happy stories. As I mentioned earlier, my interest in joining AMMA coincided with BRAC's interest in medical anthropology. As a result, the ground was already prepared for me to apply the knowledge and skills I learned in AMMA. I got the opportunity to do anthropological research on and in BRAC's health programme and influence BRAC's policies. Let me give some concrete examples: I studied male perceptions on a women-centred community health programme, sociocultural dynamics of a BRAC community health centre, and the training of traditional birth attendants. Through this research I was able to acquire insights, which we couldn't find through other research approaches. Body mapping showed how indigenous vocabularies of

reproductive organs matter in sustaining the knowledge given in the TBA training. BRAC changed its TBA training curriculum accordingly. Later on I worked as a principal investigator of an anthropological research to develop a model for an urban tuberculosis programme, which will be implemented through out the BRAC areas. I mentioned earlier that BRAC has a research division with more than hundred researchers. As the tradition goes in the research world, the BRAC research division was dominated by quantitative researchers. The general principle was "If you don't count, you don't count." I was able to convince colleagues with Einstein's adage, "Not everything that can be counted counts, and not everything that counts can be counted." On my return from Amsterdam we started the Centre for Qualitative Enquiry, the first of this kind in Bangladesh.

Meanwhile I got the opportunity to do my PhD in Amsterdam. My friend Daniel Arhinful from Ghana and I submitted our proposals to WOTRO* at the last minute on the last day of submission. It was the first time I went to Den Haag but I didn't like the city as it hardly has any canals. We were both lucky to get funding. I carried out an ethnography of a hospital in Bangladesh. While I did my PhD, I had to travel between Dhaka and Amsterdam back and forth several times. Amsterdam became my second home. This city probably has thrown a spell on my family and me. My wife Papreen also had to spend a considerable time of her life in Amsterdam. She is also an AMMA alumna and later completed her PhD. in Amsterdam. Medicine and anthropology may be uneasy bedfellows, but two medical anthropologists are not.

After completing my PhD. I got involved in establishing the School of Public Health at BRAC University. The school which receives students from all over the world, took an innovative approach to public health teaching, with a strong component of community orientation and field exercises. One of the core modules of the programme is based on medical anthropological concepts. I am currently working as the programme coordinator of the school. Amsterdam has a strong presence in BRAC school and for the last five years Sjaak and I are jointly teaching the module 'Culture and Human Values in Public Health.' If you go to our website you will see lots of pictures of us riding a bicycle in Bangladeshi villages. Co-teaching with Sjaak is a rewarding experience for me. I also felt honoured when I was invited to teach at AMMA. I was not wrong when I said that Amsterdam has a spell on my life. The last four years I chaired the AMMA module 'Historical, social and cultural dimensions of infectious disease.' This was one of my favourite topics while I was doing my AMMA, particularly because of the fact that the 'famous' cholera epidemic

* The Netherlands Foundation for the Advancement of Tropical Research.

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in Europe in 1832, which transformed European cities including Amsterdam, actually originated in Bangladesh and was called Bengal cholera. The fact that a tiny germ from Bangladesh has played a role in making this beautiful Amsterdam fascinated me.

It may sound as if all I have to say are success stories but that is not the case. I also went through confusions, dilemmas, and failures in my work. My ethnography of a government teaching hospital, which was published as a book, was praised in one of the top international medical journals *The Lancet*. I translated the book into Bangla and published it in Bangladesh. It was listed in the top ten of that year in Bangladesh, but has this book made any impact on government policy or planning concerning hospitals? Not at all. I was not able to attract the attention of government policy makers, let alone influence their policy. Similar things happened with another painstaking research that I have done on 'community clinics' run by the government. In that study I raised some serious concerns about community clinics. But my voice never reached one concerned authority.

Should I just be happy with the fact that I was a pioneer in Bangladesh in starting hospital ethnography? Should I be content that I was able to sensitize people through my book? I am not sure. Probably one should distinguish between raising concern and having influence. The area of my concerns is wide but my zone of influence is limited. Should I have focused only on activities where I would be able to bring about change? I was able to make an impact on BRAC as the organization was behind me.

My PhD research based on my hospital ethnography generated many internal questions. I often wondered whether it was at all possible to practice anthropologically informed medicine in a clinical setting in Bangladesh where resources are so constrained. It was also emotionally challenging to conduct anthropology at home. I was continuously balancing between being at home and being lost in a strange world. As Rob van Ginkel remarked that the problem of the anthropologist doing research at home is how to get out of his culture while his colleagues working in a foreign culture struggle to get in.

While trying to be a professional stranger in the hospital, there were moments when I felt awkward and uneasy in the midst of acute, life threatening situations. I saw doctors saving lives of patients near death. The patients and their family members left the hospital with big smiles. For a moment, I missed clinical practice. As a public health practitioner and medical anthropologist I will never be able to receive such an instant smile from my client. But that is the choice I made. Instead of curing an individual patient I have decided to contribute to keeping a whole community healthy. The clinicians focus on 'shadows of reality' – such as X-rays, but anthropologists focus on the

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'reality of shadows' – meanings of health and disease. I have engaged myself in that complex job.

There is a traditional Bengali drama form called 'Zatra'. Despite of the difference in themes and stories, there is a constant character in all the Zatras called 'Bibek'. In the midst of the climax of the drama or a happy episode this character Bibek suddenly appears. He always wears a black robe, suggesting that he is actually invisible. He appears on stage and starts singing and telling everyone about the dangers of life. He kind of spoils the excitement of the other actors. The one who does not pay attention to Bibek's warnings suffers at the end. People have ambiguous feelings about Bibek; they like and dislike him. Working as a medical anthropologist in a development organization in my own country I sometimes feel like Bibek. My research findings frequently ruin the enthusiasm of the programme managers. But whenever I give lectures about medical anthropology to students, researchers, or public health managers who have not been exposed to this subject at all, I encountered the 'Aha' moment among them. Many students or participants of workshops told me that after going through medical anthropology sessions a window had opened up in their mind. Now they see different things and view things differently.

Enough self-drumming. This was a useful exercise to explore my journey with medical anthropology as a public health physician, a researcher, and a teacher. One thing I learned from anthropology in general and medical anthropology in particular is that I discovered so much about myself by studying others. Exploring others turned into exploring myself. My journey with anthropology brought me to a destination that proved familiar and new at the same time just as T.S. Elliot (1986) wrote:

> We shall not cease from exploration
> And the end of all our exploring
> Will be to arrive where we started
> And know the place for the first time.

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