

Theory and action are closely connected in medical anthropology. Theory frames the way for finding pertinent meanings and making intelligent interpretations that open the door to relevant action. Kurt Lewin's maxim that there is nothing so practical as a good theory is well known. Theory is practical because it produces the questions that matter in medical anthropological research.

This book contains 37 essays and one poem. All of them address prominent issues in present-day anthropology and medical anthropology in particular. The contributions focus on people who are excluded or marginalised because of their age, their illness, their 'madness', or violent circumstances. Others are oppressed because they do not fit in the dominant societal discourse. The essays show, however, that people are not solely victims of marginalisation. They have impressive agency and resilience, often driven by their determination to remain connected with their loved ones. Although there is much pain, fear, loneliness, injustice and violence in the contributions, there is, fortunately, also hope, friendship, care, spirit and humour.

'Theory and Action' is a gift of friends to Els van Dongen who had to resign from the University of Amsterdam because of serious health problems. 'Theory and action' reflects the main concern of her life as an anthropologist.

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THEORY AND ACTION

Essays for an anthropologist



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Preface

The plan for this book started when Els van Dongen left the University of Amsterdam after two years of severe illness. Since she joined the Medical Anthropology Unit in 1996, Els has been one of our most gifted and popular teachers in medical anthropology, a creative thinker and an extremely productive scholar. She was at the peak of her career when cancer struck and forced her to cross the boundary about which she had spoken so often. She turned from a researcher into a patient; from a theory expert she became an experience expert. Or rather, we should say that she added her personal patient experience to her anthropological expertise.

To show our admiration for her person and her work, and to express how much we miss her as a colleague at the university, we decided to make a 'book of friends'. We wrote to about fifty colleagues in (medical) anthropology and related fields and invited them to write a contribution to the book. Some were colleagues at the University of Amsterdam and other institutions in the Netherlands and abroad with whom she had worked over the past years. Others were former students who had been supervised by her and become personal friends.

Els's condition has worsened during the last few months and time became an urgent factor. We allowed the authors only three weeks to hand in their contributions. We asked them to write about one of the many themes that are prominent in Els's work, such as 'madness,' psychiatry, care, communication, silence, older people, migrants, exclusion, bereavement, social memory, narrative, and violence.

The enthusiasm and loving concern that erupted after our mail was astonishing. Thirty-seven people managed to submit a text, some could not but intend to send their contribution via another way, and some could not be traced. The book contains 36 essays and one poem. Some of these were produced in the most extraordinary situations: during holidays with the family, in trains and airplanes while travelling, during fieldwork far away, in the late hours of the night, or in moments stolen from the family at Christmas. One author ended the message that accompanied her paper: "And now I pack my computer in the box". She was moving house.

This volume wants to be more than an idiosyncratic book of friends. In it a wide range of issues are presented and discussed that are not only Els's interests but are also prominent in present-day work and debate in medical anthropology. The contributions focus on people who are excluded or marginalised, because of their age, their illness, their 'madness', or because they are living in violent circumstances. Others are about people who are oppressed because they do not fit in the dominant discourse: people with HIV/AIDS, victims of (sexual) violence, refugees, and migrants.

At the same time, the essays show that people are not solely victims of marginalisation; they have a lot of agency and are remarkably resilient, as is shown by their active resistance and mutual help, their communication, and their self respect. Care, in its widest sense – not just health care – is a key term in many contributions. Social memory plays a role in the discussion: how, when, and with whom to communicate, and how to cope with uncertainties in life. In traumatic situations, forgetting is often the only strategic option, but forgetting is impossible without remembering.

The need of people to remain connected with loved ones and others comes up in several contributions. People are, therefore, selective with sensitive information or keep silent, as there is no trust – an essential aspect of communication – or there are no listeners. Sometimes the anthropologist is the only listener. Communication takes place in narration, a single gesture, or, indeed, in silence. There is much pain, fear, loneliness, injustice, and violence in the contributions, but fortunately also hope, friendship, care, resilience, and humour.

The title of this book 'Theory and Action' is the name of a famous core module that Els taught in the Master's of Medical Anthropology and Sociology. In an address that someone 'else' presented on behalf of Els in 2008, she stressed that theory and action are closely connected in medical anthropology. "Theory helps us to bear our ignorance of facts," she quoted George Santayana. Facts, she continued, acquire their meaning from what people do to them, in this case anthropologists and the people they are working with. Theory provides a way of finding pertinent meanings and making intelligent interpretations that open the door to relevant action. She then cited the famous line from Kurt Lewin that there is nothing so practical as a good theory. A good theory is practical because it enhances understanding and produces the questions that really matter in medical anthropological research.

In her module, Els discussed with the students how problems of ill-health and suffering should be regarded in their historical, political, and economic contexts, and how larger social and political forces shape relations and actions and cultural imagination at the local level. The necessary – but

often difficult – cooperation between anthropology and health workers received special attention. Questions that were addressed during the course included: Why do we need theory? Which theories are relevant? How can we link macro, meso, and micro theories with practical work?

‘Theory and Action’ constitutes both medical anthropology’s ambition and its weakness. The frequent criticism that medical anthropology receives from those who work in the heat of the day confirms that, unfortunately, much academic work remains largely or totally useless to ‘actors’ in health care. Nearly every contributor in this book struggles in one way or the other with this dilemma and with the challenge of proving the practical relevance of theory.

The contributions in the book have been organized following more or less the alphabetic order of the authors. No attempt has been made to force them into specific categories or overarching themes. The book starts with a recent article on the magic of ‘managing’ unbearable suffering written by Els. In this text she applies the two perspectives: of anthropological observer and reflexive patient. The book ends with a poem. In between, 36 essays touch on a wide variety of very topical issues. Ample room has been given for paintings, drawings, and other illustrations. They echo Els’s own artistic work. The cover shows one of her paintings that expresses care in South Africa. No less than five different languages appear in this book of friends, purposely, to pay tribute to Els’s large command of languages. Unfortunately, one medium of her anthropological approach is missing in this collection: novels. Literary writing is usually more effective in describing and interpreting human conditions of suffering and resilience than anthropological accounts. Clearly, this book is not complete...

We want to thank all those who made the production of this book possible: the authors, the English editor Zoe Goldstein, the desktop editor Hanneke Kossen, and the publisher Ben van den Camp. The Department of Sociology and Anthropology, the Amsterdam School of Social science Research (ASSR), and the Amsterdam Master’s in Medical Anthropology (AMMA) provided the funds for this project. We also thank Els and her partner Leo who at a later stage were informed about the book and gave us their full and enthusiastic support.

We have never worked on a publication that gave us so much joy and sadness at the same time.

Heemstede / Oud Ade, 5 January 2009
Marian Tankink & Sjaak van der Geest

Keeping the feet of the gods and the saints warm

Mundane pragmatics in times of suffering and uncertainty

ELS VAN DONGEN*

When it became known to my family, friends, students and colleagues that I had cancer that had metastasised, an unexpected process began to unfold. Dozens of postcards, phone calls, bouquets of flowers and visits flew into the lives of my husband, my children and me. It was not only words of encouragement, intentions, hopes or wishes for recovery that people sent or spoke. Their words also bespoke practices of people who were confronted with the pervasive uncertainties of cancer and the realisation that this illness often cannot be well controlled. In such times of suffering, doctors also often feel powerless. Patients, families and friends cannot rely on medicine and will-power to become more active to 'conjure evil'. They often rely on activities that, at first sight, do not seem to belong to the health domain. These activities show 'the pragmatics of uncertainty' (Whyte 1997) that medical anthropology has not often described in 'western' countries.

It was the third day after my operation. I felt pretty helpless and was a little dizzy from the morphine, but I was strong enough to get out of bed and talk with the people who visited me and to read the many postcards and letters I received in the hospital. One of them had sent me 'healing angels' to sit on my shoulder in order to manipulate the course of recovery. Someone else went over my body with her hands to pass on the power that came 'from above'. Some told me they would perform magic or a ritual to influence the illness process and to chase the evil away. However, the most common practice that many of my family, colleagues and friends told me that they performed on my behalf was burning a candle, at home or in a church. People wanted to do something. Doing is a cultural practice and activities such as biomedical healing, giving advice or using hands suggest that we can control our suffering.

* This article was first published in *Anthropology & Medicine* 15 (3): 263-269 (2008).

The pragmatics discussed here differ from other cultural practices, which are typical in times of suffering and illness, described as for example “health-seeking behaviour patterns” or biomedical therapies and rituals. Cancer disenchanters “the myth of control” (Kleinman 2006: 7). This myth, which so strongly suggests that the vulnerability and fragility of human life can be controlled, may even suggest that life can be protected and almost endlessly extended when people use the right medicines, techniques, regimens, food, etc., in times of life-threatening illness.

In this short paper I explore the social meaning of a simple pragmatics in the times of an illness that has an uncertain prognosis and no guaranteed treatment. I do not intend to present an ethnographic paper based on research and fieldwork. I intend to explore a mundane dimension of illness and suffering that has received scant attention by medical anthropology in western countries.

Confronting uncertainty

When I received my diagnosis, simple metaphors that are so often used when someone falls seriously ill suddenly became useful and true. How to stimulate my recovery in the best way? How to live with this illness? How to not be dominated by the disease? How to deal with my work? And, what is most important, what about social relations? Love? ‘You must go for it,’ many said. ‘It will be an intense struggle,’ others wrote. The well-known war metaphors did not make sense to me. Fight against whom or what? And if it is a fight, what kind of a struggle, swimming in a wild river, fighting in a war or, as a nurse described it, mountain climbing? Such metaphors must make sense to the suffering individual in order to do their work to support her or him. Although I have swum in rivers and climbed mountains, I felt that accepting the metaphors would make me feel lonely and disconnected from others.

Sontag (2001) has pointed out that the metaphors of empowerment that seek to enhance someone’s will to resist diseases such as cancer have an accusatory aspect, because they throw someone back on (solely) her own will to survive. Sontag resists the metaphors that were, according to her, punitive and false and contribute to the (further) suffering of people. She shows that such metaphors are ones of fear, perhaps existential fear of others and the patient, the fear of losing someone, the fear of contamination or the anxiety of the unknown and uncertainty. To this author, cancer is ‘just’ a disease that needs proper treatment. However, is the allopathic medical model of

disease, with its genes, cells and immune system in which the disease has an 'objective' cause and cure, not as metaphorical as any other model? Sontag starts her book with a metaphor; she speaks of the kingdom of the ill, a separate world mystical but nevertheless realistic. This world is like the painting by Ilja Repin, *The Surgeon J.V. Pavlov in the Operation Room*, a world where the patient is excluded from normal life by a circle of doctors around her or him. Did I belong to this kingdom? Or to the 'village of the sick' (Stoller 2004)? And what would this citizenship mean to me and others?

There are other metaphors that people devise to arrange their experiences in a meaningful way. A well-known one is the universal journey metaphor often used to examine the authenticity of the patient's journey (Reisfeld and Wilson 2004). Lakoff and Johnson (1980) argue that metaphors give direction to our thinking, experience and actions. However, it is the transformative action that is important for people in illnesses such as cancer, which are infused with uncertainty and life threats. This transformative action changes the patient into a member of a social group. The action is about pragmatic knowledge that enables the person to deal with it. Stoller (2004) shows how in the US cancer is seen as a war, while in West Africa illness is an ever-present companion, which is to be mastered through acceptance, pragmatism and patience. By using the knowledge passed on by a Songhay sorcerer, Stoller tries to deal with his cancer and the liminal and lonely position of a cancer patient. He tries to deal with this situation by rituals to maintain control. Those rituals are performed by the sick person. However, one is never sick alone. Others are involved in the process. Being ill is essentially social and others also will perform rituals.

It is not my intention to further elaborate on such metaphors of illness and on their work in people's lives. Those metaphors can direct us in ways that sometimes cause more suffering than is needed. But, as with all metaphors, they are ambiguous. They also express another dimension than accusation and punishment. One of the first experiences I had was if ever there is a kingdom or a village of the ill, it is a kingdom that is strongly intertwined with other 'kingdoms' and villages. It is a knot of social relations that are connected via the patient. For example, a hospital is not a *huit clos*. Artefacts and people bring the outside world and vice versa. In other words, being ill is essentially social. Being ill sets in motion all kind of social processes that are not only medical but also belong to the people's quotidian activities.

I experienced that cancer is considered to be a misfortune, a fate that blows in the face of all who are involved, and leaves us with deep uncanny feelings of uncertainty. Doctors may believe that they can never say what the course of the illness will be, how many months or years we will have to

live or how we will react to the treatments. Others may believe that cancer-like other illnesses-is an illness that reveals the limits of medicine and the limits of humans in general. In such times, many of us realise that we are confronted not only with the limits of life but also with the uncontrollability of death. Uncertainty in cancer is an intrinsic and irremediable aspect of the illness.

There are many studies that deal with uncertainty and its management (see Steffen et al. 2005). Steffen et al. mention the classical anthropological studies of misfortune, studies of risk and uncertainty, and studies of the management of uncertainty. In their book *Managing Uncertainty*, they contribute an approach that concerns individual agency and the human capacity to deal with situations of crisis to these studies.

Because of medical anthropology's focus on human agency and control, an important aspect may escape its attention, in particular in western countries. This is the exploration of controlessness. What if people know and feel that there is no control? That uncertainty cannot be changed into reasonable certainties or even illusions of certainty? Do people turn to gods or spirits? Do they have special rituals? Do they perform magic? We may transcend to another level where uncertainty becomes more bearable.

In the work of Whyte (1997) but also in that of earlier anthropologists, such as Victor Turner (1967, 1968), spirits as agents of misfortune are described in African countries, while in western countries 'medical high-tech' is the focus of studies of risk and uncertainty. Whyte (1997) argues that it is important to study such high-tech techniques in non-western countries. I want to reverse this argument and plea for an exploration of non-medical techniques of control, like religious pragmatics or magic such as the 'techniques' I described in the introduction of this paper, in western countries.

In classical anthropological theories one usually distinguishes two modes of reality: science and magic/religion (Malinowski 1948). However, my point here is to not make this distinction. In my experience the two modes of reality exist almost unproblematically together. For example, people who believe in the powers of medicine also use magical acts such as candle burning. Thus, we have to explore questions such as those Tambiah has asked (2000: 68). 'How we are to understand man's participation in at least two modes of reality, man's readiness to shift from one context to the other, and also how we are to see them as complimentary in relationship?' These questions-also relevant in the context of the theme of this article-can partly be answered by Good's concept of 'subjunctivity' (1994). Whyte understands subjunctivity in terms of situated concern: "It is the mood of people who care about something in particular" (Whyte 2005: 251). Subjunctivity "is

about the specific uncertainty that particular actors experience as they try something that matters to them-as they undertake to deal with a problem ... it is about action, and especially about interaction" (Ibid.: 251).

Activities like candle burning and similar 'little rites' are not very similar to the constituents of a magical performance described by classical anthropological theory. They lack the dramatic expression of emotions, the objects used are not impregnated with sacred words, and during the rite people often do not use particular words (although some may recite a prayer to the saint or god they burn the candle for). In general, magic is understood as something through which people influence supernatural powers. Often magic is perceived in relation to religion, but the concept can be used in a broader sense: magic is the human control of what usually lies beyond control (Van Dongen 2002). In magical rites such as candle burning, the meaning of the performance lies in the performance itself. "Through performance, meanings are formulated in a social space" (Schieffelin 1985: 707), and the rite invites the performers and others to reflect on social relationships and commitment.

Keeping the feet of the gods and the saints warm

I heard this expression of one of my family members. Often the candle is burned before a statue of a saint or god. The warmth of the candles keeps feet warm ... *

Candle lighting is a common ritual in many countries and in most religions. It has a variety of symbolic meanings, varying from the expression of hope, longing, commemoration to celebration. It may be a socially or individually performed religious ritual, or even a profane practice. People burn candles in churches, chapels and at home. Candles are used at special religious occasions such as the Jewish Hanukkah or the Catholic mass. They are used in particular periods of the year (often during winter in northwest Europe). The commonality of candle lightings is that they are used in times of physical or existential darkness. The lights may mean commemoration, inspiration, insight into our personal lives and connectedness with gods

* My colleague, Marian Tankink, told me another expression: "You have to keep your feet warm and must not burn your wings." It refers to the myth of Icarus. According to Marian, the expression means that we untie ourselves from rational thinking and direct ourselves to the spirits and gods, but not too much, so that we do not burn our wings and will not get cold feet.

and other human beings, but they may also indicate sympathy, anger and mourning. Burning candles may express the belief that gods or saints will perform a miracle. Often, people burn candles when they have no other way to express their dread, fear and other emotions, and when they are speechless and powerless. Often, these experiences occur when fate strikes unexpectedly and hard. Many of us are familiar with the custom of burning candles at the place of a murder of a well-known person or a child. Most of us are familiar with burning a candle when a family member or friend falls ill or is enduring hardships.

In such times, people experience loss of agency and certainty. However, they still want to 'do' something. This action may very well be candle lighting, a very simple pragmatics, perhaps not worthy of being the subject of a paper. Candle burning is a simple magical act that bridges the gap between traditional meanings of the act (for example in religion) and personal meanings. Therefore, candle burning is mundane pragmatics. However, when a patient is told that a candle is lit for them, it is a powerful signal that expresses a strong connectedness and compassion. Candle burning is a ritual that gives people comfort for themselves, but it also enables the sick person and others to transcend the stigma and lonely experience of having a serious illness.

It is as Whyte describes for Uganda (1997), but then in the Dutch way. This pragmatics shows some family resemblances to the strategies for reducing uncertainty that Whyte describes (1997: 229). Misfortune in Uganda and in western countries is connected to relationships. In Uganda, dealing with uncertainties involves two methods. The first is mobilising kin; they stand by to help maintain confidence. The second method in Uganda, "ritual speaking", differs from western countries. In Uganda it should clarify uncertainties. In ritual speaking, spirits may speak through a person or may be addressed. In this ritual "control of uncertainty is attempted by making relationships and intentions sensible in words and gestures of giving" (Whyte 1997: 229).

Candle burning and similar activities in western countries are not meant to let spirits or gods 'speak' or to search for causations, but in the case of crises and severe illness, they are meant to let the gods and saints 'work' when people cannot give a clear meaning to misfortune. It might mean: I have no power to alter the situation; you, saints and gods may control and give us certainty. It is a gentle pragmatics; gods and saints are not urged to do their work. As somebody commented: 'Keeping the feet warm'. Perhaps warm feet may result in more empathy from the saints and gods! In a certain sense, the pragmatics are not attempts to control uncertainties; they are expressions of hope. This is not the hope that needs the individual will to recover,

but the hope that others (i.e. saints and gods) will let the patient recover. In the Netherlands, there is a saying – *Baat het niet, het schaadt ook niet* ('If it does not help, it does not harm') – that people often use when they discuss these pragmatics. The verb *baat* means to better, cure, or help. The social aspect of the meaning is clear.

Candle burning is an indexical mode (Gaines 1984: 184-185). It expresses that the social and the spiritual is part of a person, and the person is part of the social and spiritual. Gaines relates the indexical mode to the "Latin Great Tradition". He attempts to break through the comparison we often tend to make between "the West and the rest". But we may even break down differences within cultures, especially when it comes to threatening events, dark times and "unmakings of the world". Persons with different cultural or religious backgrounds burn candles; pragmatics reach over such boundaries.

Although the lighting of a candle often seems an individual act, because many people do this at home or alone in a church, it connects the lighter of the candle to the gods or saints and the person who is ill. People may not know each other, but they are related through the patient. Of course, candle burning is not the only mundane but magical deed worth studying; I have experienced many actions, varying from private magic, prayers or sending powers to heal. Such pragmatics are expressions of an experience of misfortune affecting both the individual and the group, giving rise to practices, which go well beyond anything that may be regarded as belonging to the strictly medical field" (Fainzang 2000: 1). They relate bodies, religious or spiritual feelings and social relationships in a way that is an expression of connectedness and support, not only for the patient but also for others. It changes us from individuals into social beings.

Candle burning and other everyday rituals show that the disenchantment of the 'western world' is a myth (Gijswijt-Hofstra et al. 1997). We have to approach the idea of elimination of magic with caution (Van Dongen 2002). 'Science' and 'religion' are not opposed but intertwined in explanation and activities. They both belong in the repertoires of suffering.

Medical anthropology and the mundane

The pragmatics of this paper are not spectacular, nor are they exotic. They belong to mundane activities in human life of European countries such as the Netherlands so strongly that many of us take them for granted. Because of their taken-for-grantedness they reveal – when studied – our deep beliefs,

hope, vulnerability, powerlessness and commitment to each other and the world.

As I have written before, medical anthropologists tend to overlook these activities. When doing research in their own country, anthropologists may often focus on 'the west versus the rest' and elaborate on the distinction between biomedicine and other healing activities. They may even pit the two against each other, arguing that they are different realities: the land of the sick and the land of the healthy in which people do different things and without reckoning that both are intertwined in a complicated way.

Another issue with medical anthropology as it is now practiced is that the anthropologists' perspective is too much on the patient, who is then placed in the centre of the research. The patient's experiences, actions and reflections are important to understand, of course. But when we reverse the perspective and look at what others around the patient experience and do, we might better understand what illness is about: social relationships and the uncertainties of (social) life. Defining sickness, uncertainty and lack of control in only biomedical terms or in terms of the patient may lead to overlooking other aspects of the situation. It will probably ignore the pragmatics about which people do not talk so easily. Anthropologists should follow the mundane actions taken by all people involved. Candle burning and other little magics belong to daily lives and they reveal-when studied-our deep beliefs, hope, vulnerabilities, powerlessness and commitment to each other and the world. They give us a hold on and-perhaps-a feeling that we control or influence even the worst situations.

I have not presented an analysis of the cultural models of or the logic beyond such practices. With this small paper I want to draw attention to mundane pragmatics and practices that belong to 'social illness behaviour' and present the patients and others around him or her as social beings who express their desire to belong. Although the practices might sometimes seem ritualistic, they are essential and important, both for those who practice and for those who suffer.

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Body narratives of social suffering

LINA CRISTINA CASADÓ I MARÍN

Good Friday

It was 10 o'clock in the evening on Good Friday in my home town. Inside the church, believers and unbelievers, devotees and non devotees, were congregated in a beautiful and strange combination of tradition and modernity, spirituality and laicism.

The procession started in the church and went under the most absolute silence through the many narrow streets of my village. At that moment, a strange atmosphere of silence was in the air. This odd sensation was only broken by the music, solemn and gloomy, intoned by drums and psalms. Silence, sorrowful canticle, and all bathed with candlelight. Images of Christ lying dead and of the *Dolorosa* (Mary) dressed in mourning and crying were worn by hooded people from brotherhoods, while penitents walked barefoot, flagellating themselves through the darkness of the narrow, steep streets, following the procession.

I was seven years old the first time I went to a Good Friday Procession in my village, and without a doubt the memory that stayed with me the most strongly was that of the penitents. The image of half naked people, carrying crosses on their backs, their faces covered by white sheets, flagellating themselves, left me with mixed feelings of attraction and repulsion at the same time. I remember asking my mother about the meaning of such actions, and she answered that it had something to do with fulfilling promises and making amendments for wrongdoing. I must admit that I did not understand my mother's words. If I rummage around more in my mind I also remember a canticle that, more or less, said: "By your wound, by your wound, by your wound I'm healing, and through your blood my sin is expiated..."

What sense could all this make in my child's mentality, in my particular symbolic universe? Sores, bruised feet, heavy crosses on exhausted shoulders, blood emerging from stuck thorns on the backs of men and women... To tell the truth, I still wonder about the meanings of and reasons why people are involved in so-called bodily self-harm actions; maybe in a different way than I asked of my mother years ago, but engaging in a necessarily introspec-

tive exercise, I think I could find the origins of my interest in my childhood incomprehension of the matter of suffering, and in the desire to know the reasons why people become involved in self-punishing actions.

Eighteen years passed until the matter of self-harm burst into my life again. I was doing the last year of my degree in Anthropology when I had the opportunity to work on a research project about eating disorders, commissioned by the Women's Institute of Spain. As a nurse and almost anthropologist, I did not have many problems accessing the field.

One month later I had started the formal procedure of being admitted as an anthropologist in a mental health institution, and I started doing the fieldwork in an eating disorder unit in Barcelona. I also had the possibility of attending some therapeutic sessions and interviews, and to compile the experience of some girls who were being treated both in the in-patient and out-patient departments for eating disorders.

Even though the matter of self-harm was not an aspect of specific analysis in our project, from the girls' stories I was surprised by the high frequency of practices such as scratching, biting, and cutting that they explained (and showed) to me. From ten compiled stories, nine openly expressed the matter of bodily self-harm as a kind of reaction to heavy, emotionally stressful situations.

Once the eating disorders project was finished, those stories were piled up into a mound of papers, waiting for the precise moment that I would take them up again. I had to do it, and thus it was. Three years ago, in 2005, I dusted off those girls' stories and I started my own project, with the objective of saying something about, and to throw light on, the workings of a hypothesis that I had postponed years ago.

I began this personal reflection by explaining my childhood experience of the Good Friday Procession, and the turning point from which I started to become interested in bodily self-harm actions in young people. I did it not by chance; it allows me to think about the differences between penitents and people with mental health problems. About who decides the difference between the two: who's who? About why the same action could be legitimized or criminalized depending on the context. And about the dimensions of the madness construction.

Mental health and self-harm

Georges Canguilhem wrote that the boundaries between madness and sanity are vague and imprecise. He assured: "... what is normal here could be read as pathological there, and is also tempting to say that there is no frontier between sanity and madness..." (Canguilhem 1971: 195). According to Canguilhem, it is logical and even paradoxical that the rules of reason and insanity are implicitly written in societies. Once said, the following question we should ask ourselves should be: who constructs those arbitrary rules, and why?

From the Social Conflict Theory, in Neocapitalist Society the dominant social group is the one who sets out the limits between normal and deviant actions. This assumption, together with the Foucauldian concept of 'biopower' (1991) and the concept of 'meritocracy' proposed by Michael Young (1964: 56), allow me to think about why certain hegemonic patterns of behaviour which are created and imposed by certain social groups become incorporated in ourselves, are embodied into ourselves to the point that we consider that they emerge from ourselves?

From my point of view, the dissociation between patterns of feelings and models of life in comparison with one's own life is the reason for the increase of diffused afflictions and sensations of discomfort nowadays. Talk is out; in fact, the market of emotions and the management of discomfort is the area currently generating the most benefits for the pharmaceutical industry. According to data published in the National Health Report in Spain 2006-2007: "*One in four women older than 16 years old could have mental problems*" (ENS 2008: 11), meaning that 26.8% of women and 15.6% of men have "risks" related to mental health. Furthermore, according to a longitudinal study (2003-2006) carried out by the Consultant for Addictions and Mental Health from the Generality of Catalunya 2007, 30% of Primary Care users have Mental Health Problems. The most frequent disorder was depression, affecting 9.6% of patients, followed by anxiety (7%), phobias (6.6%), and alcohol addiction (3.2%). This survey remarks in general terms that 7% of men and 14% of women suffered from Mental Health Disorders (2007: 1-2). It is said that the most frequent disorder nowadays is neurosis. In practice the most frequent diagnoses that fall under the old term 'neurosis' are 'anxiety' or 'depression' and as we saw, women suffer the most.

Related to this, it is undoubtedly true that nowadays the market of affliction and uneasiness is penetrating our own bodies through different strategic campaigns, making us realize that we are not able to understand ourselves and that we are not equipped to interpret our own lives. To add

a note at this point, during the period when I was working as a nurse in a health care service in a rural setting in my country, I remember doing a lot of prescriptions for antidepressant and anxiolytics in practice. I remember with affection one morning when two women, a mother (80 years old) and her daughter (60 years old approx.), came to my office and the daughter asked me if I could prescribe the *I don't care pills* for her mother (the "I don't care pills" she was referring to were a well-known antidepressant brand that the doctor had prescribed for her months ago). When I asked her about her reasons, she told me that in the last few days she had found her to be "a little down".

Returning to bodily self-harm actions, in the DSM-IV the diagnoses that mention self-injury as a symptom or criterion are: borderline personality disorder, stereotypic movement disorder (associated with autism and mental retardation), and factitious (faked) disorders in which an attempt to fake physical illness is present. In addition, forms of self-mutilation (amputations, castrations, etc.) could also appear in psychotic or delusional patients.

The most common explanations for bodily self-harm from interviews with psychiatrists and psychologists during my fieldwork in mental health institutions were: 1) the desire to attract attention from others; 2) as an addictive action as a consequence of increasing endorphin levels; and 3) in response to blocked emotions, usually caused by sexual, physical, and psychological abuse in childhood.

These explanations from the psychologists and psychiatrists that I had the opportunity to interview were based on their experiences. In a review of the psychiatric literature I found eight explanatory models: 1) the biological explanatory model; 2) sexual sadomasochistic explanatory model; 3) the associated symptom; 4) the emotional regulation explanatory model; 5) the suicidal ideation explanatory model; 6) the expressive explanatory model; 7) bodily self-harm as a copy mechanism; and 8) the school stress explanatory model. Once I had studied all of these explanatory models, I felt I would like to include a new one that incorporates the social and structural factors involved in bodily self-harm.

Aiming for a multi-causal explanatory model

My modest contribution to the study of bodily self-harm in young people, through my ethnographic experience, is motivated from the perceived necessity to apply a *social-support-stress-disease paradigm* with the aim of approaching bodily self-harm not only as a psychological phenomenon but

also as a complex process in which social, cultural, and biological elements all take part.

From my point of view, the application of a multi-causal paradigm that understands the senses and meanings of this practise as a phenomenon, and does not depend exclusively on biological and psychological deviant criteria, could give us new, comprehensive elements to understand its meanings.

From my fieldwork experience, I would also like to highlight the *nocebo effect* (Cannon 1942) conditioned by the *diagnosis labelling*, that promotes a worsening and a tendency towards chronification of diseases in general, and of bodily self-harm in particular. It is well known that nowadays patients want to be informed about themselves – about their symptoms and prognostics – and this fact, related to the expectations of professionals, is contributing to the creation of a therapeutic dependence relationship that also contributes to the achievement of certain *prognostic prophecies* that increase the impact of such a prophesy, and in turn the vulnerability of one so prophesised, specifically young people.

To recoup the cultural and symbolic meanings hidden behind the action, I am sure that a hermeneutic position that goes in depth into the comprehensive and explicative meanings of bodily self-harm from *the native's point of view*, must allow us to interpret self-harm behaviour as an action that involves the body – because the body is where the action is done – and through the engraved words and cuts the anonymous body is turning into a text by itself with discursive abilities.

Picking up on the idea of the body as a social field (Csordas 2002: 58), the analysis of the “injured body as a subject” leads to an interpretative analysis whereby bodily self-harm actions can be understood as a form of agency, of transgression and divergence, in the face of hegemonic and normative patterns of bodies. Referring to that, the emergence and increase of bodily self-harm actions allows us to think about how, in the face of *neumatic* serial reproductions of behaviour and bodies like *Leninas Crowne* (referring to the perfect archetypal citizen from Aldous Huxley's novel *Brave New World*, 1932), some disruptive practises appear.

These disruptive actions to bodies – I include here the action of *cutting* (usually superficial cuts mainly on arms, belly, and legs), and the act of engraving words on the skin (like *I hate you, this one is for you, loneliness*, etc.) – allow us to take up again the idea of *the body as a field* from which it is possible to communicate and to express wishes, and reminds us that they usually emerge from buried emotions. The relation between *repressed emotions* and the body as the vehicle to channel discomfort appear frequently in the narratives with my speakers, where expressions of loneliness, pain,

emptiness, etc. appear not only in their speech, but also carnally engraved on their bodies.

From the narrative analysis of my speakers, most of them consider their actions as an alternative lifestyle. But their alternative lifestyle is read as deviant behaviour, and that difference makes us think about two issues: in the first place, about what is allowed and what cannot be represented using the body, and in the second place, about the reading of bodily self-harm as epidermic performance according to subaltern bodily codes that appears in response to homogenised paradigms of bodies and identities.

Ideas to conclude

From my point of view, bodily self-harm actions are carnal narratives that explain stories; stories that need to come up to the surface through the scars and through the blood. In this context, my position is to move into the symbolic and interpretative sphere, but from interpretations that appeared and were deducted together with my speakers.

The proposal which my work makes in terms of the interpretation of bodily self-harm is that it should not be analysed as an isolated symptom or action of deviant behaviour; rather, as actions that we must redefine and position within explanatory models and frameworks of broader significance.

Following Byron Good (1977), I think that we need to understand and to interpret bodily self-harm not only as a symptom, but also as a “semantic illness network”, as a symbol that emerges from experiences and feelings, condensed into a nebulous of significance. The links between emotions, experience, and individual suffering in terms of the considerations of the three types of body proposed by Scheper-Hughes & Lock (1987) have been useful to me in terms of deconstructing and analysing separately the meanings of suffering, disembodied bodies, and have led me to rethink the issue of the control and regulation mechanisms at work in the body. Their considerations have helped me to break down and provide a context to self-injury from a phenomenological and symbolic-interpretative perspective. Furthermore, in terms of explanatory theorising, their contributions on the different corporal dimensions have been useful for understanding bodily self-harm actions as expressions of suffering ascribed to the environment of the individual, but which appear in response to feelings of “disembodied self/selfless bodies” in regulatory contexts of politically and subversively disciplined or passively repeated bodily patterns.

This idea of the subversion of hegemonic bodies that I propose here, and which in some ways reconnects us with Foucault, is reminiscent of the work of Jean and John Comaroff (1992) in which they suggest that many subordinate corporal practices contain a message of protest and resistance, which necessarily have to be decoded and interpreted.

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Portraits de folie

Images, ethnographie et histoires

JOSEP M. COMELLES

Découvertes



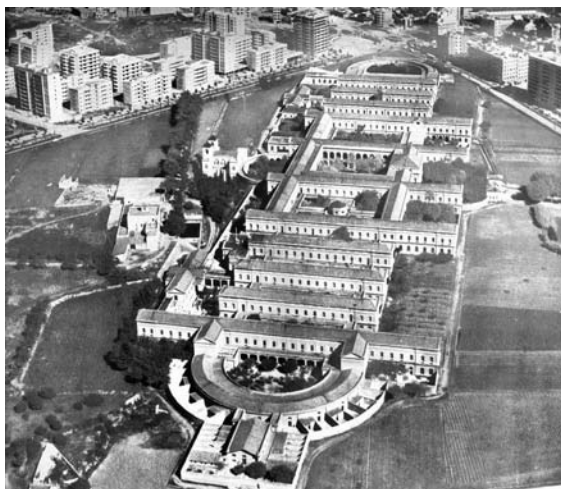
Vers le crépuscule de sa carrière, un Beethoven sourd découvrit la voix humaine. Il avait écrit un opéra, mais dans son œuvre symphonique ou de chambre, *Fidelio* est une exception, la voix humaine n'est présente que dans le dernier mouvement de sa dernière symphonie. Mahler en fit autant dans le *Chant de la Terre*. Pourquoi eurent-ils besoin de la parole? J'y songeais en réfléchissant sur ma particulière découverte de l'image et de son rôle dans le langage ethnographique. Musique et parole, ethnographie et image. Une ethnographie avec seulement des images est-elle possible?

Vieux cinéphile éduqué aux années soixante autour du post néo-réalisme italien, de la nouvelle vague française, du *free cinema* et du premier Bergman, avant de songer à devenir ethnographe, mon *désir* d'ethnographie, malgré quelques incursions – *Tabú* de Murnau, *Nanook* de Flaherty – dans le documentaire réaliste, ne pouvait se comparer à mes rêveries dans les mondes imaginés des romans réalistes, à *Fortunata y Jacinta* de Galdós, à la *Comédie*

Humaine, à Flaubert, Zola ou Dickens. Et puis vint Proust. Le coup de poing de *La Recherche* se construisit lentement, dans un *crescendo* dont le premier sommet fut le *Côté de Guermantes*, mille pages pour *décrire* une soirée au Faubourg Saint Germain. Sa description me *prit*. Un récit ethnographique, duquel Painter (1967) révéla les rapports avec le terrain vécu, comme les carnets d'enquêtes d'Emile Zola (1986) nous montrent le fondement de son ethnographie. Je lisais le *Côté*, fascinant récit d'un monde qui s'effondrait, à côté du récit cinématographique sur une autre soirée que Visconti sut mettre en images pendant trois-quarts d'heure à son *Guépard*. Impossible de penser que Visconti ne s'était pas inspiré de Proust. Connaissant bien Proust et Visconti, je ne pouvais alors réaliser les rapports profonds entre ces deux homosexuels, l'un juif et snob, l'autre Duc de Modrone, aussi snob dans la mesure où il se plaçait dans la production artistique sous l'appartenance au PCI. Je ne compris qu'une décade plus tard que les *Tristes Tropiques* de Lévi-Strauss étaient aussi une relecture de Proust (Boon 1992) et qui mettait en rapport l'ethnographie et la fiction. Où sont les limites entre ethnographie et fiction?

Ethnographie et cinématographie

J'ai raconté ailleurs comment et pourquoi je devins ethnographe (Comelles 2006). Venant de la médecine, j'abandonnais mon identité pour une autre, moins reconnue, modeste du point de vue social, richissime sur le plan personnel, autour d'une recherche sur les fous – qui sont les fous? –, la folie – qu'est-ce la folie? –, sur les asiles – qu'étaient les asiles? Une abandon résultant de mon expérience douloureuse comme psychiatre dans l'asile, si différente de celle de Els van Dongen (1994). Elle, ethnographe, pouvait se rendre au sein de la folie et prendre une place de folle. Elle voulait comprendre les fous comme producteurs de culture; moi, un gosse de vingt-trois ans, je voulais comprendre les gardiens de fous: médecins, éducateurs infirmières, et ma folie pour comprendre la folie des autres. Mais Els était ethnographe, moi un jeune psychiatre, à peine apprenti ethnographe, incapable encore de comprendre que le regard clinique pouvait évoluer vers le récit ethnographique. Pour Els et pour moi, l'ethnographie était un genre d'écriture académique. Trente ans auparavant, ethnographie était à peu près synonyme de vérité, mais dans l'ethnographie, la valeur de l'image ne se reconnaissait que comme *illustration* 'hors-texte' bien que Rivers (1912) ait écrit sur le besoin de l'ethnographe de faire des photos. En 1979, je ne songeais pas ajouter des images. Je ne fis pas de photos. Mes deux thèses (Comelles 1979, 1981) furent texte et rien que texte. Comme chez Els, *Gesprekken met psychotische mensen*. Rien que la parole.



Pourquoi un cinéphile négligeant l'image? Le paradoxe était que le psychiatre en avait fait. Pendant mon stage à l'asile (1973-1976) j'enregistrai, en *Super8*, sept minutes de film. Mon mentor en anthropologie, Claudi Esteva, me sachant psychiatre, m'avait averti: «regardez autour de vous et notez ce que vous voyez». Filmer c'est voir, me disais-je, et le matériel répondait à une ingénue volonté de sauvegarde d'un monde déjà condamné. Ce n'était pas de la '*cinématographie*', seulement une 'illustration' d'un des meilleurs exemples 'd'architecture morale' d'Europe. Ce film montre des espaces, des fous, une procession de vendredi saint, l'extérieur, les couloirs, les cours – pas les salles car la modeste sensibilité de la pellicule ne le permettait pas. Les fous, toujours pris de loin, avec trépied et téléobjectif, seulement des plans généraux. Un regard *etic*, distant, naturellement neutre. Pas un seul premier plan. Un regard extérieur, non intérieur. Les images restèrent oubliées trente ans. Aujourd'hui, je n'y reconnais pas l'œil de l'ethnographe mais elles sont un document ethnographique qui peut-être permet une cinématographie. Devenu ethnographe, ma seconde expérience avec le cinéma (1979-1982) eut un rapport très profond avec mon second terrain.

Le *Rocio* est un pèlerinage au Sud de l'Espagne devenu aujourd'hui un des actes de masses les plus importants en Ibérie. Entre 1978 et 1984, mobilisant moins de monde, pendant mon terrain, il était marginal dans les médias. Pour moi, ressortissant de l'asile, ce pèlerinage avait le profil des 'terrains classiques' en anthropologie. L'asile étant peu reconnaissable comme terrain par mes confrères, le *Rocio* en avait tous les atouts: loin, distance culturelle, terrain intensif de longue durée, culture et religion 'populaires'... Si mon docto-

rat à l'asile fut mon initiation comme ethnographe, le Rocío me 'doctora', et allait jouer un rôle par rapport à ma cinéphilie. Mon ethnographie (Comelles 1984, 1998, 2000) était d'un matérialisme radical laissant peu de rôle au point de vue des acteurs. L'interprétation des données de terrain se fondait sur les stratégies d'appropriation économique de l'espace et du jeu et des contradictions entre les identités multiples en présence.

Au début, ma cinématographie au Rocío se voulait aussi *etic*, avec profusion de plans généraux, mais de temps en temps, caméra à l'épaule, je m'approchais des gens et cadrais sur des visages, des larmes, des gestes intimes. Mon ethnographie était synthétique, faite de plans généraux; ma cinématographie, de premiers plans. Dans mon ethnographie, je voulais être anthropologue; dans ma cinématographie, l'œil me faisait dériver vers un autre regard possible que je n'interprétais pas en termes ethnographiques, mais comme une influence cinématographique de la *nouvelle vague* et du *free cinéma* en un temps où les *camcorders* avaient besoin de trépied et les caméras de 16mm étaient lourdes et encombrantes. Seul le *super8* rendait possible ce que proposerait plus tard les cinéastes Danois de *Dogme 95* (1995): éliminer l'artifice de la mise en scène pour conduire la cinématographie vers une ethnographie. En 1981, l'ambiguïté de mon regard cinématographique, par rapport au manque d'ambiguïté de mon ethnographie du Rocío associée aux difficultés de l'édition de film et de son en 8mm condamnèrent les deux heures et demie de film et le demi milliard de photos au placard.

Mon principal obstacle pour comprendre le rapport entre cinématographie et ethnographie n'était pas technique, mais intellectuel. Mes référents ethnographiques venaient de Malinowski, et du *réalisme ethnographique* et de sa cinématographie – de Flaherty à Rouch –; ma cinématographie par contre, venait de la fiction. À l'asile, j'avais dû examiner, à tâtons, ce qui se passait quand l'ethnographe faisait partie du décor et devait se 'distancer' de son espace et de son identité, comme psychiatre et comme ethnographe.



* Voir Favret-Saada (1978) et Vidich et al. (1971).

Par contre ma cinématographie là était distante, *etic*. Au cours de ma thèse, je me confrontais avec deux identités en conflit: le psychiatre qui cherchait l'ethnographie pour comprendre et l'ethnographe qui cherchait une ethnographie qui ne s'éloignât que peu de l'orthodoxie académique de son temps. Au Rocío, je maîtrisais la distance ethnographique mais, caméra en main, je me laissais *prendre* par mon rapport de subjectivité avec mes sujets et mon intérêt était de montrer comment mon rapport était aussi intersubjectif.

La Madeleine

Finalement, je réussis à faire un livre de mon ethnographie de l'asile (Comelles 2006). Trente ans plus tard, je pouvais clore le débat sur mon identité duelle. Je découvris qu'en 1979, j'avais écrit deux ethnographies parallèles. L'une, d'un psychiatre, l'autre de son glissement professionnel pour devenir anthropologue. Je choisis le texte du psychiatre et j'abandonnai celui de l'ethnographe pour ma nouvelle ethnographie. Le premier me semblait plus sincère, plus vrai, moins artificiel que le second dans son ingénuité. Or, je me demandais où était la vérité du réalisme ethnographique, mise en question, pendant la décade précédente sur deux terrains, l'un précisément le Rocío vingt ans après (Comelles 2000), l'autre une unité de soins intensifs (Comelles 2001). Ma nouvelle ethnographie était une sorte de méta-analyse des deux ethnographies écrites au préalable par deux personnages différents –deux alias. Or, trente ans plus tard mon Je actuel voulait les convertir en personnages d'un récit auquel je voulais donner la structure d'un immense *flashback* entre un prologue et un épilogue, et une structure centrale déri-



vée de l'organisation de la littérature dramatique. Le Leitmotiv était, à la différence de ce que proposait le décalogue de *Dogme95*, ne pas éliminer l'artifice, mais le rendre visible comme un instrument de compréhension des limites de la vérité ethnographique. Or, si pendant l'écriture, le débat de *Dogme95* ne me fut pas présent, une fois l'ethnographie finie, je trouvais, par hasard une centaine de photos magnifiques.

Ma première réaction fut d'illustrer. Mais vint Sebald (2002, 2003). Ce romancier allemand écrivait des textes – littéraires, journalistiques, ethnographiques? – où l'image faisait partie intégrale du récit. Il me montra qu'image et ethnographie *pouvaient et devaient* se fonder, pour obliger le lecteur à contraster l'impression de vrai. Je plaçais les images dans mon texte, sans légende, je réécrivais le texte pour éviter celle-ci et éliminer l'idée de la planche hors-texte. Le résultat final me satisfait. Nombreuses images se firent pour illustrer la publicité d'une institution privée. Le luxe des installations dans les images ne correspondait point au récit de misères qu'est cette ethnographie. Le lecteur devait faire sa propre interprétation des contrastes et des raisons qui m'avaient motivé à placer les images. Si j'écrivais «La statue du fondateur nous regarde en entrant», on lit une chose; si j'y ajoute l'image, je ressens que j'ouvre une fenêtre ou le fondateur nous regarde, un effet miroir impossible sans elle. Or cet effet miroir, cherché dans le document ethnographique, est retombé, dans le cinématographique.



Réalité ou émotion

Invité à une table ronde sur art et folie par des artistes qui voulaient un anthropologue, j'adoptai une identité d'artiste en préparant une présentation des photos de l'asile que j'allais introduire en deux – trois minutes. Pour alléger le défilé d'images, j'ai songé à une illustration musicale de 10 minutes. Dans mes fichiers de sons, j'en avais deux. Je choisis le *Concerto de l'Adieu* de Georges Delerue (1990) et en écoutant et regardant le défilé des images, je n'en croyais pas mes yeux. La musique, élégiaque, pour la bande sonore d'un film de guerre, s'accordait à la fondation, la vie quotidienne et la fin de l'institution. Si je ne voulais montrer que la beauté des images, je compris qu'une cinématographie était possible et complétait le rôle que les images

fixes jouaient dans l'ethnographie écrite. Ainsi le livre et la vidéo seraient complémentaires et je pouvais y ajouter la musique dont il y a de nombreuses références – écrites –, dans le livre, le cinéma avec mes vieux *super8*, l'animation des photos. Pourrais-je condenser en 15 minutes l'histoire d'une institution avec la volonté de laisser parler les images et réduire l'information non visuelle à deux courts paragraphes et deux douzaines de textes écrits éparpillés ici et là? Le résultat final (*Stultifera Navis, The Barcelona Santa Creu Insane Asylum, 1886-1986*) me surprit. Si ma volonté était une sorte de vidéo historico-ethnographique sur un monde disparu, je compris qu'il était possible de rendre ma volonté de 'représenter' l'institution d'une perspective totale qui était déjà dans le livre, mais désormais libère des limites de la parole écrite et l'image sur le papier, ouvrant la porte à la possibilité, pour le spectateur, d'être enveloppé et emporté. Les premiers spectateurs parlèrent d'émotion. Les premiers spectateurs en salle obscure réagirent favorablement, le débat naquit. Emotion pour les uns, c'est la limite de cette cinématographie – ethnographie visuelle pour d'autres dans le cadre d'une réunion professionnelle. Le débat me sert à distinguer entre la valeur du document à l'état brut, et celui de sa manipulation ethnographique ou cinématographique. Dans les deux cas, cela exige de connaître le contexte et les intentions de l'auteur. S'il y a fiction en cinématographie, toute ethnographie est aussi fiction. Mais la fiction n'est pas nécessairement contre le vrai. C'est ce qui me rend à la vérité ethnographique du *Côté* ou du *Guépard*, mais aussi à celle de *Tabou*, *Nanook* ou *Hommes d'Aran*.

En 1973, psychiatre, je manipulais mes images derrière un objectif que je croyais vrai. Mais mon scénario était inconscient à partir d'une expérience cinéphile. Ce document naturaliste, matérialiste, devient aujourd'hui l'expression de mes émotions par rapport à un asile qui occupe une place dans ma mémoire personnelle et que je veux transmettre, comme je voulais le faire aussi dans la monographie. Téléchargé à *Youtube*, le vidéo est lu, à Barcelone, comme la découverte d'une réalité ignorée, d'un monde oublié. Il y a donc dans un document qui joue sur l'émotion, une lecture naturaliste malgré l'artifice de sa construction.

J'aborde maintenant l'autre volet du regard cinématographique de ma jeunesse, le Rocío. Je ne peux plus partir de l'intuition, car mon matériel est complexe a, long de deux longues heures de film, auxquelles il faut ajouter undemi millier de photos et surtout une ethnographie sur le Rocío, qui a évolué mais qui est restée fidèle aux dimensions économiques et matérielles qui tournent autour de la *Romería*. La cinématographie dont je dispose ne représente pas cette évolution. Prise entre 1979 et 1980, c'est le document cinématographique le plus complet onservé d'avant 1985. Et il y a aussi le

regard qui a dominé la prise de vue, contradictoire à nouveau coincé entre deux identités, celle de l'ethnographie, celle de la cinématographie. Est-il possible de faire un montage de la cinématographie purement *etic*, ou dois-je choisir d'expliquer le Rocío à partir de mon regard intersubjectif. Dans ma première tentative, je voulais récupérer le son et le montage original pour être fidèle à *Dogme95*. J'ai vite renoncé. J'ai fait une nouvelle expérience (*Almonteño, déjame que yo contigo la lleve*). Essayer de raconter les images à partir des chansons – sevillanas et fandangos – que, d'année an année, de place en place, des villages à la *romería* racontent: faits et sentiments, identités et différences. La voix est à eux, l'œil est toujours le mien.

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Touching in nursing practice

How does it work?

RIEKJE ELEMA



Riekje Elema 1999

Touch is a universal phenomenon which is handled in different ways depending on the cultural context. The experience of touching and being touched, often easily and rather passively accepted, can be complex and powerful in its effects. Touching, as physical contact, is unique to each individual located in a particular space and time. It seems simple and straightforward but one can wonder about its causes and effects; even more complex is the infinity of intentions expressed and meanings understood in the form of widely or narrowly accepted social rules that control the practices of touching within cultures and groups of people.

People's external senses are generally described as those of sight, hearing, taste, smell, and touch. Of all forms of sensory communication, touch is perhaps the only one that requires some kind of contact between the parties concerned. We can look at or listen to a person from a distance. When we want to touch somebody we have to ask permission or at least be sure that it is socially or personally acceptable, and sometimes we do come very close and intrude upon or invade another's personal space (Pratt & Mason 1981).

In Dutch society physical contact as a full and free expression of intimacy is fully accepted between mothers and their children, and between lovers. In other situations where there is physical contact between people, it may be controlled by rules and conventions. One of these situations is with health professionals, in particular nurses and their patients. The act of touching is very often a fundamental part of this contact, and nurses represent a group of individuals who touch people throughout their life cycles.

Generally, information about touching in nursing practice has a clear focus on technical issues; healing touch, touch as communication tool, task-oriented touch, comforting touch, caring touch. Little is written about the

emotional side of touching. Further, one might find literature about the emotions of patients, but hardly anything about the emotions of nurses.

This essay will explore issues around the act of touching in the nursing setting. It will start with setting a definition of touching, and will explore the different issues involved in the act of touching, such as personal space, bodily integrity, touch as a means of communication, and the complexity of emotions involved in the act.*

The meaning of the word 'touching'

Many different meanings are given for the word 'touching'. For the purpose of this essay the following definition will be used: touching is the act of making and having physical contact between two people. It can have both positive and negative connotations. Touching in this context does not include a psychological or emotional action or reaction, such as when one is touched when one sees something. It may also seem obvious, but the moment that the act of touching is carried out, both the person touching and the person being touched will react to it.

Personal space

Personal space is a term used to describe the area surrounding one's body, including the space and objects within that area. Thus, personal space is an extension of the body. Personal space is central to one's sense of comfort. Anxiety and discomfort are experienced when one's personal space is violated. The dimensions of personal space vary from culture to culture and from situation to situation (Hall 1982).

In his book 'The Hidden Dimension', Hall (1982) starts off with telling us that communication constitutes the core of culture and indeed of life itself. He suggests that verbal and non-verbal communication occur simultaneously on different levels of consciousness, ranging from full awareness to out-of-awareness. All of us are sensitive to subtle changes in the demeanour of the other person as he/she responds to what we are saying or doing.

* This essay was originally written as a paper for a module given by Els van Dongen during the AMMA 1998-1999 'Ethnographies of Health and Health Care in Europe'. Els and I discovered our common interest in 'touching in nursing practice' and I contributed to one of her articles about this theme in 2001.

Not all of us use the same senses to communicate with each other. Hall brings in the concept of territoriality, which is usually described as behaviour by which people characteristically lay claim to an area and defend it against others. Its purpose is broad and amongst others serves to create a safe place, though it still remains possible to communicate with others. Territoriality is also associated with status. In addition to territoriality, people are surrounded by something that serves to maintain proper spacing between individuals.

People's perception of space and distance is not static; it is related to action – what can be done in a given space – rather than what can be seen by passive viewing. Distances are defined depending on what activities take place and what kind of roles people play. The specific distance chosen depends on the transaction; the relationship of the interacting people, how they feel, and what they are doing.

Hall (1982) describes four types of distances:

- Intimate distance (0-45 cm). The presence of the other person is unmistakable and may, at times, be overwhelming because of the greatly stepped-up sensory input. Smell, heat, sight, sound, and feel of the breath all combine to signal that there is another body close. Physical contact is very clear in the awareness of both persons. Intimate distance is often the distance of comforting or caring in the nurse-patient encounter.
- Personal Distance (45-128 cm). At this distance (close phase) one can hold or grasp the other person. When two people stay inside this distance of each other, it shows they have a close relationship, or demonstrates in other ways how they feel towards each other. Keeping someone 'at arm's length' is one way of expressing the far end of personal distance. In a very real sense it is also the limit of physical domination of one person over another, for in taking a step backwards one cannot get hold of the other anymore.
- Social Distance (128-348 cm). Nobody can touch or expects to be touched at this distance. Depending on where one is within this range, normally this is the distance in which impersonal conversations are held. In the close phase there is more involvement than in this distant phase.
- Public Distance (385-infinite). This is a distance where there is no real involvement between two persons, and is normally the distance in which social talks happen.

Bodily integrity

Bodily integrity is one of the concepts used in the human rights domain. It is a basic concept on which universal human rights are founded. When defining bodily integrity as a whole, non-violated (undamaged) body, which includes physical, social, and mental wholeness, one assumes that the individual is autonomous and able to control his/her body. It is a concept based on the Western assumption of self-ownership of the body. People from other cultures have rightly criticised this concept, remarking that individualism and possession of the body, as well as the power dimension implied in the concept of autonomous control, are culturally biased notions inappropriate for many people coming from other societies (Correa 1994).

Bodily integrity is culturally defined and differs from culture to culture. One might say that bodily integrity is a very personal experience. The way one perceives the integrity of the body depends on the context in which one is acting. In the context of a patient-nurse relationship, bodily integrity can be defined and valued differently compared with other social situations, especially the boundaries of what is acceptable or should not be altered in a particular setting. A body may be more 'open' (van Dongen 1997). Boundaries are defined collectively (nurses, patients, doctors) and different meanings are given to bodily integrity. The 'closed' body, where everything that goes in and out is strictly controlled, normally seen in our culture, is important to a lesser degree. This implies that the social rules and values of the outside world may not be very significant in the nurse-patient setting. Nurses have to safeguard their own bodily integrity while dealing with patients, but also have to be aware of the integrity of patients. They have to treat patients with respect.

Touch as tool for communication

When people touch, the action is less likely to be misunderstood or misconstrued if the act is formally constructed by the clearly defined roles of each participant, by rationalisation, or through some other statement of intent. Thus, where the boundaries are drawn and understood, ambiguity and anxiety are reduced, security is increased, and the touching is fully accepted. Nurses in their tactile handling of a patient are able to implicitly communicate expressions of care, concern, and gentleness. The role of the nurse is clear and known beforehand (Pratt & Mason 1981).

The use of touch is such a basic part of nursing that it is frequently overlooked as a means of communication. Nurses and patients assume that nursing care means being touched, both to provide comfort and sometimes to cause pain, depending on the purpose or task to be done (Vortherms 1991). All touch conveys some form of message. Weiss (1979) has identified the language of touch as being comprised of six tactile symbols that define the meaning of touch to the individual: the interaction between the duration, location, action, intensity, frequency, and sensation of the touch experience affects how an individual will perceive touch. Vortherms (1991) mentions four different types of touch used in nursing practice:

- Affectional touch is the expression of caring attitudes, including concern, acceptance, support, protection, respect, and love. It is a form of non-verbal communication that may replace verbal comfort.
- Functional touch is interconnected with many other aspects of patient care such as bathing. This form of touching may be the most important because it is so extensively used during patient care. This care can be given in different ways, either in an impersonal, neutral manner or in a caring, sensitive way.
- Protective touch is used to protect the patient from physical harm or to protect the nurse physically or emotionally. It is said that this way of touch distances the nurse from the patient.
- The last form of touch identified is non-physical and occurs when a nurse enters into the patient's personal space. As already mentioned, one of the functions of personal space is to safeguard a person's safety. This comfort zone of proximity expands or shrinks depending on the individual situation. Nurses frequently enter a patient's personal space to perform nursing care, which may either give comfort but may also cause anxiety.

Clearly, touch in nursing has a double meaning. On the one hand, it is a utilitarian and technical activity in which the bodies of nurses and patients are objects; on the other hand, touching is intimate, emotional, and human, and the bodies of both actors are subjects. So far, studies have generally looked at the emotional reactions of patients but not of nurses. Touching in bodily care requires a constant listening to the body by both patients and nurses alike. Touching, and the meaning of touch, is not only constructed by the tactile action, however complex; it is also influenced and given meaning by personal, social/cultural, and environmental characteristics (Edwards 1998). It reflects ideas, values, and norms in a society. Touch is related to age, gender, power, and social relationships, which in turn influence emotional responses. When the emotional response of nurses to touch

is also taken into account, touching is developed into an art that recreates good contacts and human relationships in a medical setting (van Dongen & Elema 2001).

Nurses as performers

A nurse is not necessarily one total person with one self; there can be many selves. Nurses, like many other service providers, have to keep up a front. This front is very correctly described by Goffman (1959: 32) as the expressive equipment of a standard kind, intentionally or unwittingly employed by the individual during his/her performance. The more convincingly the nurse can keep up this front the better her performance will be.

If a nurse is playing a role, one could consider the setting in which the act of touching takes place as the stage. If there is a stage, there is also a back stage where the front can disappear. This backstage may be in the nursing station with other nurses, or completely outside the nursing setting. In the nurse-patient interaction, nurses have many roles to play, some of which are determined by the setting while others are flexible and can be changed. One basic rule, however, will always be present, and that is that nurses have to care for patients and they will do that to the best of their capacity.

Emotions

Nurses receive extensive training in the technicalities of nursing, e.g. how to wash, clean, and lift patients. Touching patients is such an integral part of nursing that it is very often done without conscious thought. It is seen as a task-oriented tool that the nurse is capable of handling. If touching becomes problematic for whatever reason, the nurse, in order to protect both her and the patient's bodily integrity, might distance herself from what she is doing. The patient as a subject suddenly becomes an object, something that has to be cared for. Women undergoing gynaecological examinations often describe this feeling of alienation. Others call it numbing or distancing (Carmack 1997).

Patients as well as nurses have very little physical privacy, yet they have to safeguard their personal space and freedom. As such, it is said that intimate distance does not create anxiety for patients. It even seems that patients experience comfort rather than anxiety from close physical contact. Though physical intrusions may be accepted, a patient's sense of privacy over their

thoughts, and control of what personal information is disclosed to others, may continue to be possessively guarded (Smith & Cantrell 1988). I think this is also applicable for the nurses. They, in their role as professionals, have certain tasks to carry out, and as long as they are in control of the situation they can decide what to reveal or to conceal.

As already mentioned, touching may be used to show that a nurse accepts, or is making an extra effort to accept, the patient with all his/her problems. It may derive from a feeling of empathy, closeness, and compassion, but at the same time it may also stem from a feeling of disgust, shame, guilt, or embarrassment. Even though the emotions in the last group are perceived as negative feelings, they also have a positive function. All these emotions have their own specific mechanisms; they all raise consciousness, they create awareness, and they all arise from the fact that nurses value their patients. They reveal limits of the self and bear witness to the involvement of the nurse with others (Schneider 1977). However, one has to realise that this group of feelings is also very often hidden, and it may be very difficult to accept that they exist. However, they are as valid as the positive ones. For example, disgust responses serve to reduce the sense of intimacy with others. The other person may not be dangerous themselves, but could be felt as a threat to another's present defence mechanism. As long as disgust flows in one direction or the other, interpersonal distance is maintained. It is used to maintain self-other boundaries (Miller 1993).

Miller also states that disgust, in contrast with shame and guilt, seldom causes deep pain. All three emotions, like compassion, commitment, etc. are based on moral values and embedded in a culture. Shame may have a deeper effect on a person in the sense that as an emotion, it is meant to conceal and to cover that which is vulnerable to a perceived threat. While shame is an emotion directed inwards towards the self, disgust is generally an emotion directed to the other. The function of shame is also to preserve wholeness, bodily integrity, and human dignity. It is said by Schneider (1977) that it is especially the sense of shame that protects us from the public observation of private experiences. It has a clear moral value. In general, nurses have a strong feeling of 'substituting' shame. When they are touching the patient's more private body parts, it will normally be done behind closed curtains, in a 'private' place.

The act of touching is frequently construed as having sexual connotations. In the setting of the nurse-patient encounter, this is often not an issue. Touching is permitted as part of the helping role of the nurse. However, sexuality can play a role in the act of touching. Physical or emotional (non)-attraction of the nurse to the patient and vice versa may complicate the act

of touching. The one thing a nurse has learnt is that the encounter between a nurse and a patient should always be a therapeutic one, and the patient's self should be respected.

Concluding remarks

One can wonder what touching in nursing practice implies. The act of touching in the nurse-patient interaction is not a simple straightforward one. It is complicated by the moral and social values and norms of both the nurse and the patient. It is made even more complicated by the way nurses are trained and are assumed to act in the view of others in a particular cultural/social setting. Nurses are supposed to care for patients, and they have to accept patients because the patients need help and depend on them. A basic nursing ethic is that of professional neutrality (being non-judgmental) which means that neither the patient's nor the nurse's personal beliefs should influence the care given. There are so many nurses in the world touching patients every day and so little is written about the emotional responses of nurses when touching patients.

One has to look at the emotions involved when relating the act of touching to the concepts of bodily integrity, personal space, communication, and performance in the setting of the nurse-patient encounter. Emotions affect the way an individual experiences what happens to him or her and in the end determines if the individual feels that bodily integrity and personal space have been abused or not, and whether they feel comfortable in the role they are playing. Scheper-Hughes and Lock (1987) mention that insofar as emotions entail feelings and cognitive orientations, public morals and cultural ideology, they provide an important 'missing link' capable of bridging mind and body, individual and society. They also suggest that they think that emotions and feelings are never free of cultural shaping and meaning.

I do think that it is important to study these interactions much better, especially given the situation that the world is changing and more and more people, both nurses and patients, from different cultural backgrounds, are interacting with one another. I believe that it can only help nurses to realise that many emotions, often very ambiguous ones, may occur in the process of caring for patients, and that it is very normal to have them and that one needs to accept them without guilt. As Laing (1976: 74) said, "The more aware we are of our feelings, the more competent we are likely to be in restraining them when necessary, and the more easily will we loosen them when circumstances no longer seem to require to."

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De la théorie à l'action

SYLVIE FAINZANG

La théorie en acte. Voilà une expression qui sonne clair aux oreilles des anthropologues, fort investis dans le débat sur les liens entre savoir et action, où s'inscrivent à la fois nos choix professionnels et nos options personnelles, et qui se pose pour chacun, à l'intersection de sa carrière et de sa vie.

Parmi les centaines de sujets sur lesquels nous avons échangé nos vues, Els et moi, je voudrais reprendre ici celui du lien entre théorie et action, qu'elle a si bien fait vivre à travers sa pratique de chercheur et son enseignement, à quoi le sous-titre de cet ouvrage cherche à rendre hommage.

Ce débat n'est pas celui de la primauté à accorder à l'anthropologie fondamentale sur l'anthropologie appliquée, débat qui semble dépassé, ne serait-ce que parce que la seconde se nourrit nécessairement à un moment donné de la première. Pourtant, n'a-t-il pas aussi à voir avec le bénéfice que peut apporter l'une sur ce que peut promettre l'autre ?

Dans son texte : « À quoi sert la recherche fondamentale ? Point de vue d'un astrophysicien » (*Sauvons la Recherche*, 13 février 2004), Régis Lachaume écrit : « *On n'a pas inventé l'ampoule électrique en perfectionnant la bougie, le téléphone en optimisant le tam-tam ou la calculatrice en peaufinant la règle à calcul* ». Cette formule percutante illustre le point de vue de nombreux chercheurs (dont les anthropologues) sur la nécessité de défendre la recherche fondamentale. Si, dans les sciences dites exactes au moins, elle a effectivement permis de découvrir l'électricité, tandis que la conduite de la seule recherche appliquée ou finalisée n'aurait permis qu'à améliorer la qualité des bougies, leur solidité, ou leur longévité, le même raisonnement s'applique aux autres disciplines, et les sciences sociales, elles aussi, sont susceptibles d'apporter des réponses à des questions que la recherche appliquée ne peut pas poser.

Dans ce contexte cependant, la place de l'action, quant à elle, n'est pas totalement résolue et la controverse sur le rôle de l'anthropologue dans l'action, voire sur son rôle militant, n'est pas épuisée. On aborde ici ce que certains revendiquent comme de la « recherche-action », une autre façon de décrire la théorie en acte, et que revendiquent les défenseurs de la posture militante.

Les recherches que nous menons ont toutes pour objectif premier de comprendre un phénomène, d'analyser une situation, de décrypter des mécanismes. Mais pour certains d'entre nous, elles s'assortissent également du souci immédiat d'œuvrer à la transformation du monde, de lutter contre les inégalités. Un tel souci est légitime, et ce n'est pas contre cet objectif que l'on peut se positionner, mais contre celui d'asseoir la construction de la recherche (la problématique et la posture épistémologique) sur cet objectif.

En effet, prendre parti a priori sur une question qu'on se donne pour objet d'étude, c'est risquer de biaiser ses recherches et de ne voir que ce qui sert ses fins, ce qui à terme revient à n'avoir de son objet qu'une vision partielle ou parcellisée. L'anthropologue ne doit pas construire sa recherche en vue de l'action, même lorsque, au bout du compte, il fait de la recherche dans la perspective d'agir sur le monde. Nombreux sont les phénomènes sociaux dont les anthropologues ne sauraient s'accommoder, et nombreuses les situations sur lesquelles ils souhaitent pouvoir agir. Le chercheur peut avoir une opinion sur notre vie en société et mener un combat fondé sur les valeurs auxquelles il croit, et le désir de la voir changer. Rien ne lui interdit d'agir dans la sphère publique, voire d'être militant, mais c'est alors en tant que citoyen qu'il le fait, et non pas en tant que chercheur, sauf lorsque son action se fonde sur les résultats de ses recherches. Car c'est lorsque la recherche est achevée, qu'il est en possession des éléments qui permettent de fonder son action, et qu'il est véritablement efficace, en tant qu'anthropologue.

Dès lors, ne pas agir n'est-il pas pour lui, au moment de la recherche, le meilleur moyen d'agir ? Cette formule paradoxale vise à séparer les deux temps du rôle de l'anthropologue. C'est par une recherche affranchie d'une finalité militante a priori, que l'anthropologue, en tant que tel, est le plus susceptible d'être utile (que ce soit à la Santé publique, à la préservation des droits des individus, à la lutte contre les inégalités, ou à d'autres causes). Il ne peut se prévaloir de son statut dans la science pour fonder son action tant qu'il n'a pas mis l'objet à l'épreuve de la recherche et donc à l'épreuve d'une interrogation scientifique, libre de l'action. C'est dire que l'action ne peut sous-tendre ni construire la recherche. Si c'est son but ultime, cela ne peut être son but premier.

La recherche doit donc s'affranchir de l'objectif de l'action pour être menée dans les conditions optimales de scientificité et, partant, d'efficacité pour l'action ultérieure. La problématisation et la définition de l'objet doivent tenter de s'abstraire de cet objectif, condition nécessaire à une meilleure compréhension des mécanismes sociaux ou des systèmes de pensée étudiés, et à leur théorisation. On ne saurait pour autant se livrer à une profession de foi positiviste (il est évident que c'est avec sa propre sensibilité aux choses et

avec sa subjectivité que l'anthropologue accorde de l'importance à tel ou tel aspect de la vie sociale), mais on doit convenir que l'analyse la plus objective est précisément celle qui a le plus de chances de servir la cause défendue.

Pour ma part, mes travaux se sont toujours efforcés de séparer la recherche théorique de l'action, dans un souci à la fois de connaissance et d'efficacité. Il s'est ainsi agi par exemple de comprendre les logiques symboliques et les pressions sociales auxquelles sont soumis hommes et femmes dans le cas de l'excision (Fainzang 1985) ou de la polygamie (Fainzang & Journet 1989), même si on peut espérer, par de telles études, agir contre la domination que ce type de pratique ou d'institution fait exercer aux premiers sur les seconds. On peut également tenter d'étudier le mensonge en tant qu'ingrédient incontournable de la vie sociale (Van Dongen & Fainzang 2005), même si l'on est conduit à montrer le rôle qu'il joue dans l'exercice du pouvoir ou de la résistance au pouvoir; ou encore, on peut étudier, sans les juger, les raisons qui sous-tendent le choix des médecins de mentir à leurs malades (Fainzang 2006), même si l'on peut souhaiter œuvrer à une meilleure information du patient. En l'occurrence dans ce dernier exemple, le choix d'agir au sein d'une association de malades ou au sein d'une équipe médicale pendant la conduite de cette recherche aurait rendu impossible la posture épistémologique choisie – à savoir de me situer à la fois du côté des médecins et du côté des malades – et aurait biaisé les résultats obtenus sur les mensonges respectifs des uns à l'égard des autres.

Pour prolonger l'image de la bougie, si l'on veut accroître l'efficacité de l'action, il nous faut l'éclairage plus performant d'une recherche fondamentale, c'est-à-dire qui soit libérée de toute finalité de recherche appliquée, ou que certains anthropologues préfèrent qualifier d'« impliquée ». Dès lors, si le but premier de certains chercheurs, soucieux de mener une recherche immédiate efficace, est de s'y investir pour le mieux-être des individus (que ce soit pour la lutte contre l'oppression, contre la violence, contre l'inégalité ou pour la défense des droits individuels), le but ultime de la recherche doit être d'abord de mieux nous éclairer, afin de mieux éclairer notre action.

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« Attente » (Vienna, 2005),
painted by Els

Giving voice to the lives of older persons in South Africa

MONICA FERREIRA

South Africa and its people hold a special place in Els van Dongen's heart. She cares about older people in South Africa in particular – and, like me, has been passionate about hearing their stories. It made sense therefore for she and I to collaborate on an ethnographic study, between 2002 and 2004, in which we encouraged older persons in residential areas around Cape Town to tell us stories of their lives: what life was like for them under 44 years of Apartheid rule, before that, and since the birth of the new democracy in 1994. We reasoned that our interviewees would comment on modern times as well: times in which they now find themselves – for better or for worse, through memories of the past. Memories straddle the past and the present, after all, and the past needs to be remembered to understand the present. It was fortuitous, and appropriate, to be able to conduct the study under the South Africa–Netherlands Programme for Alternatives in Development (SANPAD).

Fourteen years have elapsed since Apartheid ended, but South Africa is still undergoing social transition: shaking off the shackles of an oppressive regime; treading uncertainly in a new democracy. The majority of the country's older citizens lived a life mired in poverty and hardship, suffering and misery. Their lives were shaped by troubled and painful experiences – of dislocation and exclusion, inequity and iniquities, and a lost struggle over places of belonging. Their losses are inestimable; opportunities for a better life, and people, places and hopes slipped through their fingers. Their memories, in the new society – alas, have been silenced. It was apposite therefore that we try to awake some of those memories. Here are excerpts from poignant yet redeeming stories our interviewees told us.

Breaking the silence

For many of the interviewees, life had been tough. Mrs PM, originally from the Eastern Cape, did not go to school, “...because during our days, schools were few. Our parents used to say that if you [a daughter] were educated,

you would not bring cows [bride wealth] to them.” Educated brides might discourage the tradition and not accept an arranged marriage. Mrs MQ, also from the Eastern Cape, had taken a second husband with whom she had two children, but she had “...abandoned him, because I was suffering with hunger. He was not supporting me. My sisters took me back home.” She later moved to Cape Town to look for work to support her children. Mrs LG, who lives in Nyanga in the Western Cape, had watched her husband shot dead in the Black Power riots. She was badly wounded when she tried to save him. “I couldn’t save him because I was shot, and now I have six bullets in my body. The *boer* [pejorative term for a white policeman] shot me in the back when I tried to save my husband. The pain... The doctors say they cannot operate on me. These bullets damage my whole body.” Grace, from the Eastern Cape, had six children, but three had died of high fever and one was beaten to death in the streets. Her husband, who was not a ‘good’ man, she told, had died of diabetes and both her brothers had died. Her two surviving children had migrated to Cape Town, and Grace had visited them. But, she had had a stroke and was paralysed, and her children had taken her to a hospital and left her there. She was later discharged to an old age home, but her children never visit her. She lost all her possessions, left behind in the Eastern Cape. When Els interviewed her, she had no underpants to wear. “I feel naked,” she said.

The stories we listened to emphasised material and financial losses, and the loss of relationships and kin. They spoke of deprivation and hardship that people suffered. They had a homogeneity, in the socio-historical circumstances and context of the lived experience of the tellers. Disadvantaged across the life course, their lives had been shaped by the country’s policies and a lack of opportunities. Yet the long struggle did not end with democracy – and continues. Els’ master’s student, Allanise Cloete, interviewed older residents of Belhar, an historically disadvantaged suburb of Cape Town. Their stories told of violence in the area, and about the vulnerability and powerlessness of the older residents, who may have been victims of a robbery or assault, or feared they would. The violence of everyday life, she noted, that the social order brings to bear on these people.

How did our older interviewees review their life histories? How did they ‘break the silence,’ by ‘re-memembering’ for us? How did they reflect on their present situation? Curiously, they did not articulate how politics had determined their lives as such, but offered social commentary on their experiences. Yes, they told stories of children they had borne and raised; how they had followed their menfolk, with young children, to an urban centre; how some of their children had died in violent circumstances; about the

careers – or unemployment – of their surviving children; the geographic dispersal of their adult children now; the children with whom they now co-reside; children who exploit them – or with whom they have lost all contact. Although separation from, or the loss of a spouse was often met with equanimity in old age, not so fractured relationships with children, which were a source of pain to the interviewees.

Several referred to social problems in their community: poverty, crime and unemployment especially. Others commented on the social behaviour of the young, or indeed of their younger kin. “Our children do not support us any more. There is rampant unemployment and people would die of starvation if there was not the [social] pension. Robbery of older persons, physical abuse by uncontrolled youth...” “The alcohol drunk by the youth. They embarrass our dignity as old people.”

The stories told of how the interviewees had coped in good times and bad times. How they had employed strategies, like migration, to try to improve their life and the lives of their children. About their ongoing attempts to reunite family, or to stay in contact with family. How they had experienced frustration and suffering because of neglect and abuse from family. How they had struggled to keep their pride. About their losses and disillusionment. By connecting different episodes in their life, their memories became moral comment – on the behaviour of, and their relationships with others.

Some referred to present-day politics in the country – and noted that little had changed. “When Mandela came into power, we said ‘hallelujah,’ and thought this was our moment, but the opposite has happened. People talk of democracy, but there is no democracy here. We don’t see it. Have our lives changed for the better? I don’t think so.” And, “That hasn’t happened. When we voted in the first democratic elections, politicians promised us everything, but nothing has changed. Actually, the rich get richer and the poor get poorer.”

It was a harsh time for our interviewees – across their life course. A hard time for families; a hard time for love and marriage. Families dissolved. Many storytellers had not only to struggle with an unfaithful and itinerant spouse, but also financial problems, alcohol abuse, displacement, violence.... Yet the majority felt that the past had been a ‘better’ time for them than the present.

Sorrow, resilience, hope

Despite the loneliness, sorrow and neglect we detected in the stories, they brought resilience and hopes to the fore. Indisputably, many of the tellers had suffered grievously under Apartheid – and continue to suffer. Some

were now frail and had no one to care for them; they were in an old age home, where young and underpaid staff wash and feed them, but ignore their psychosocial needs and treat them as objects. They are forced to accept a status accorded to them, within the institutional culture; they are twice silenced – and lack a voice, again.

Many of the stories were about loss of material possessions, relationships, psychological well-being and self-esteem. But the tellers remembered both the grievances *and* pleasures of their life: they reflected on paradoxical memories. Remembering had ambivalence: the act of doing so was a struggle, an uneasy alliance with their present life. Yes, it is in the nature of human beings to remember the beautiful times and things, and to try to forget the uncomfortable ones. But, with good memories, bad ones surface inevitably. How, then, could the people we spoke with say that things were better in the past, when the narratives were filled with violence, abuse, submissiveness and oppression? Perhaps they re-created a past with issues that are important to them in the present?

The act of remembering was difficult. “It is difficult to think. Everything comes through. Everything comes back and I have to cry.” “It was just finished and it happened to me. But sometimes it comes back to me again.” “...but we must forget the past to live in peace.” “You made me thinking; everything comes back, but it is good to remember, you must get rid of it.” Sometimes they felt they should forget the horrifying past. Many had definite ideas of what should be remembered: the nature of relationships in the past, the absence of violence. The past order dominated their memory and moral commentary on the present. Many now silenced their memories, as a tacit but radical break with the past.

Hence, the stories opened up a veritable Pandora’s box – of silent conflict, in post-Apartheid South African society, that continues to struggle with an identity and new democracy. In a South Africa where the youth are revered and the old are marginalised. The stories of older citizens have little interest and value in the new society. The narratives enabled us thus to explore connections in the multi-cultural society: between the past and the future; between diverse people and places; across a time of great change.

Many of our storytellers had difficulty in telling their stories – *because* of the politics of forgetting and silencing. Some preferred not to tell their stories; they were more concerned about the present situation, the here and now. Indeed, it would not have been possible for us to hear *all* voices within the historical-social discourse. And there would always be more silence than recounting of memories. But, was the silence we encountered a social act of forgetting and denial? Should older persons indeed be allowed to forget and

be silenced, where denial of their personal stories and histories is aimed at a break with the past, now that the young own the present?

Understanding the depth of their suffering was difficult for us: overall, our subjects only communicated their sorrows and misery in an indirect way, by telling stories of 'good' times in the past – and giving 'moral' comment on the present. We intentionally do not portray them as helpless victims of the past – nor victims of the social dynamics of present-day South Africa. To do that would be to ignore their resilience. Our interviewees are marginalised in the new society and have gradually slipped into a frozen liminal state, in which silence, submissiveness and compromise are strategies to cope with the misery. For many, a radical break with the past instigated by their family has affected their well-being – and silence has become a coping mechanism. Totally silenced, many have become dependent on the goodwill of others; yet they continue to live, survive, cope and play roles in South Africa's social fabric. To be old and live in an old age home does not mean that the residents are without hopes for the future, or dreams. A woman expressed a deep wish of older people to Els: to heal broken lives and to seek redemption. Another woman had a recurring dream: "My mother is always with me [in the dream]. When I am sick, she is sitting at my bedside." Thus, Els and I attempted, rather, to highlight older persons' resistance and agency. The narratives we recorded carry their voices into the present; the same voices that reached us from the past. Indeed, the voices can now serve as gateways between the past and the present, that lead to paths that others may follow in the future.

Acknowledgement

I have drawn liberally from an anthology that Els van Dongen and I compiled, based on stories we documented in our study. In parts, I have excerpted Els' words unashamedly. My intention has been simply to indicate and revere her profound depth and sensitivity, compassion and love and to honour and celebrate her unique and invaluable *oeuvre*. Els and I have previously acknowledged the generous support we received from SANPAD to conduct this study, but I express our gratitude to SANPAD's Amsterdam and Durban offices again.

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Death and the urgency of time

AMINA GADRI

Vie!

*Fragile, menue, elle ne tient qu'à un fil,
Car personne ne connaît l'heure du trépas.
A-t-elle de l'importance en ce monde immense?
Sait-on apprécier ce qui nous est donné?
Car tout passe, tout casse, ne laissant pas de trace
Joie, bonheur, écoute, amitié, un court instant qui passe
Vivre intensément, le temps fuit en courant;
On ne rattrape pas ce qui n'est qu'un moment.
Parfois, elle vous laisse des pleurs au goût amer,
Un coeur qui vous martèle, un coeur lourd de pierre,
Difficile à porter en cette humanité
Où chacun donne beaucoup de sa pitié.
Pourtant elle laisse à ceux qui sont lassés,
Un don, un don suprême, celui de l'Amitié.*

Valérie, Sept. 1999*

In 2001 I did research in a home for palliative care in Switzerland.” It resulted in a study about how people prepared themselves for their approaching death, how they «gave birth to death», as I called it (Gadri 2001). Dying is a social task.

The individual's body is a representation of time, space and identity, as well as a means to relate to others. Through this relationship, the whole attempt of a person is to make sense out of his life story, out of his suffering and to

* Valérie (pseudonym) lived in the hospice where I did my research. She wrote this poem during a previous stay at Rive-Neuve, in September 1999. The two of us spent some time to find her poems in the home's files, and read them together.

** The research, under the supervision of Els van Dongen, was part of my master's in medical anthropology in Amsterdam. All names in this essay are pseudonyms.

attain “self-fulfilment” (Rosenthal 1969: 90). This process can only happen by sharing stories, as Frank (1995) puts it. Sharing stories needs witnesses, companions, and beloved ones. The story of our lives is made of a perpetually alternating movement between the inside and the outside, as Murphy reminds us (1990: 227). The social nature of the human being is emphasised likewise by Marshall:

I find it useful to assume that people will seek to render their lives, including the end of their lives, meaningful; that this process is inherently social, that it is symbolic, involving the use of language, and that it concerns the social negotiation of identity – the sense of who we were, are, and will be (1980: 164).

According to Murphy, dying is fearful because of the loneliness that it entails in our society (1990: 63). It is not the physical death that is to be feared. Just as for dependency, the threat for identity lies not in bodily changes, but in alienation from others. It makes us afraid of dying, because the interaction with others is a necessity for the fulfilment of our autobiography, namely making sense out of experience, out of shared time and space.

Meaning is created through a process, and understanding of oneself increased gradually until the moment in which time, space and identity of a person merge together. This process was what Alexandre called “l’activité de penser” (the activity of thinking). Nevertheless, it occurred with the help of mirrors, for time, space and identity are relative concepts. It needed interlocutors, for language is the symbolic construction of experience. And it needed the presence of beloved people, not only to give confidence, but also because love is the feeling of meaning itself (De Hennezel & Leloup 1997: 18).

In *Last Chapters*, Marshall explains the process of building one’s autobiography as inherent to human beings, but becoming more urgent towards the end of life.

My metaphorical understanding of aging and dying is that we come to a point in life where we realize that time before death is short. As meaningful and meaning-seeking creatures, with a sense of autobiography, we can now locate the self in the last chapters of life (1980: 159).

For the individuals I met care home, this awareness of finitude had suddenly jumped into their life through their materiality, their body.

- I know that I'm going to die, I don't have a lot of time left. A few months at most.
- And you said that you are not anxious about it?
- No, foutu pour foutu...What annoys me is time. Not to know how much time I still have left. And it's too early to die. I am only 63 years old. I would have wanted to last a little bit longer. (Mr. F.)

Time was too short, and not knowing when one was going to die made preparation difficult. Materiality was both an enhancer of awareness and an obstacle to preparation. Preparing for one's death meant putting all papers in order, as Switzerland is a country where administrative formalities have an important place. The testament was the first formality to fulfil, and when there were problems with the family, it could cost time and energy. But the testament was not only a formality, it was also a way of thinking of others.

You have to prepare yourself, and to think about those who are going to stay. I made my will, I also asked my wife to make hers." (Mr. T.)

Preparation was also about putting one's things in order.

I am putting small things in order, archives that I never had time to arrange. But after two hours of this type of work, I am exhausted.

I am doing the assessment [of his life] (Alexandre).

Other persons were talking about important events in their life, or some achievements, reviewing their own story, trying to give coherence to it by making links with their values. Justice for Mr. T. and Valérie, sincerity for Mr. F.

Besides putting their things in order, what some patients still wanted to achieve were meaningful acts that reminded them of a part of their story, like a walk in the forest, seeing one's home again, eating seafood.

As a matter of fact, preparation was in the succession of losses and awareness, and in the mixture of hope, revolt and acceptance inherent to them. Death was the last and most difficult loss, the loss of materiality: the body, the possessions and everything that makes a humane being able to communicate with others, to relate to this world.

Trying to make sense out of one's experience was made difficult by the fact that, in most cases, religion was not considered as a means of coping with suffering. This tendency reveals that religion and spirituality are not as distinct as Walter seems to suggest when he states that religion binds indi-

viduals with an outer meaning, whereas spirituality binds each individual with an inner meaning (1994: 28). Mrs. L., who found support in religion, considered it as a way of living her spirituality that she described as something developing with the years: "It's a word, an exchange, a reading, a relationship with nature" (Mrs. L.).

For Walter the focus on the individual lead to a loss of links with others, for De Hennezel and Leloup (1997), as well as for Mrs. L., individuals bind together through their own experience, which could be called spirituality.

For our values are not rooted in dogmas and beliefs anymore. They are rooted in experience, and in particular in the experience of solidarity, of presence, of attention to the other, of discovering the reciprocal enrichment in each encounter. This is where the meaning of our existence and of our acts finds its source (1997: 22).

These considerations can explain what first appeared to me a kind of ambivalence towards religion and spirituality. After saying that faith was not helping her, Mrs. G. added: "I don't pray. Well, not very much." Alexandre: "Now, if there is something, it's rather the Orthodox Church. I am unbelieving." I asked if he believed in a superior force, he answered: "Yes, but not necessarily a God. Spirituality is important. I don't stand what is done in the name of religion. To massacre children in the name of God..." Valérie had the same feeling towards religion: "Since I am a child I say that as far as there will be a poor seated on the church's stairs and a golden ciborium on the altar, I am not going to believe in God." Nevertheless, Valérie was praying for a deceased patient, and asked for the minister when she was in a period of trouble.

The dominant religion in the area is Protestantism, so the minister was Protestant. There was an ecumenical 'time for sharing' every Friday afternoon. Sometimes a Catholic priest passed by, and an Orthodox priest came every month to perform a mourning ritual for the dead.

The ambivalence towards religion was part of a search for meaning and references, something that could reduce the fear of the unknown. Charlotte's sister cherished a souvenir from their childhood. "Are you afraid of dying?" she had asked her sister. And Charlotte had answered: "Yes, because I am not used to it". It summarises what is waiting for us at the end of life: a new experience, where the unknown is the only expectation.

The first time I met Alexandre, he told me that he regretted not being able to read anymore, as he had just bought a book about philosophy and was afraid he would not have enough time to read it. I suggested that I could

read it aloud, but he said that he preferred waiting until he would be able to read again. Two weeks later, right before dying, he expressed that he was ready for someone to read the book aloud. He said that he wanted to hear other voices than the family's voices. But he did not have the book with him.

In our successive discussions Alexandre, had told me about his origins, his illness, his despair, and his hope. He was in search of making sense out of his experience, his life. In the example of the book, I can see awareness besides loss, hope, and dying. It was awareness about his own limitations, with death as the last limitation, and awareness that others, as members of humanity, contribute to give meaning to one's life.

Giving birth to death is thus to accept death as a limit "appropriate at any time" (Marshall 1980: 188) and "to free oneself of the restraints of culture, to stand somewhat aloof from our milieu, and to re-find a sense of what and where we are" (Murphy 1990: 231).

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Sharing uncertainty in clinical encounters in a Dutch fertility clinic

TRUDIE GERRITS*

I think that if a doctor shows her limitations, that gives me a lot of trust. Much more than if they pretend that they know everything and that they can accomplish everything. If he is saying, “We are not yet sure about this, or this and that is not yet quite clear” ... Yes, if you recognize your own limitations that enhances my trust. (Woman, IVF 14, Interview 2)

Nowadays, it is widely acknowledged that IVF (In-Vitro Fertilization) treatments are not without medical risks, and that success cannot be guaranteed. Since the early introduction of IVF in the 1980s, these potential risks and the relatively low success rates – the uncertainties surrounding IVF – have become highly debated issues. Critics have questioned why medical doctors encourage women to take the physical and emotional risks involved in the use of advanced reproductive technologies, as long as there can be no guarantees of success (see summary of critiques in Van Balen & Inhorn 2002: 15). While initially these critiques and concerns were predominantly heard beyond medical circles, since the 1990s representatives of the medical field have also been expressing their concerns more and more about the risks involved in and the efficacy of IVF treatments, and have been actively seeking ways to improve the situation (see e.g. De Joode & Fauser 2001; Ten Have 1995; Weymar Schultz 2000).

Couples indicated for IVF at the Radboud fertility clinic^{**} are, as part of the clinic’s patient-centred policy to empower patients and involve them in

* When I was in the midst of the fieldwork for the study on which this contribution is based, I once briefly spoke with Els van Dongen about the role of doctors sharing uncertainty with their patients. We had agreed to follow up on this conversation, but unfortunately never managed to do so.

** This is the clinic where I conducted an extended hospital ethnography on which my PhD thesis (Gerrits 2008) and the current contribution is based. The full name of the clinic is the University Medical Centre St. Radboud, and is located in Nijmegen,

decision making, extensively informed about IVF success rates and the possible risks involved in the treatment. With regard to success rates, couples in this clinic are certainly not provided with false hope, as has been suggested in the past by some authors (Becker & Nachtigall 1994; Fauser 2002; Inhorn 2003); on the contrary, the limited success rate (20-25% per IVF treatment cycle) is emphasized again and again. Couples also learn about the risks, for example of ovarian hyper stimulation syndrome (OHSS), infections due to ova retrieval, the increased chance of having a miscarriage or an extra uterine pregnancy, and the risk of multiple (twin) pregnancies. In my thesis (Gerrits 2008) I show and discuss how couples visiting the clinic and participating in my study consider this information, and how it affects their views about and use of IVF. I found that in spite of the abundant information provided, it was difficult for them to assess exactly what these risks and rates entailed for their own situation. Multiple pregnancies in particular were an issue that people found difficult to think of in terms of risk, especially when they would be pleased to have twins. They found it difficult to weigh the increased risks resulting from the transfer of two embryos against the decreased chance of success by transferring only one. Further, as might be expected (cf. Becker & Nachtigall 1994; Becker 2000; Franklin 1997), risk perceptions were not only informed by the information provided by the clinic, but were constructed over time and in interaction with various experiences and influences (regarding self and others, from within and outside the clinic).

Overall, the decision to pursue IVF treatment should not be seen as one based purely on a rational weighing up of the information on risks and rates. People's individual risk perceptions, the lottery like features of IVF treatment, feelings of 'anticipatory regret' (Tijmstra 1987; Heyink & Tijmstra 1994), couple's strong wish for a child, the promising potential of medical technology which raises couples' hope, and trust in the medical staff, were all found to contribute to the fact that couples are inclined to start and continue IVF treatment, even when they feel that the success rates are not really promising and they are scared by some of the potential risks or side-effects.

In this paper, I focus on the importance of trust in the medical staff in terms of the way couples consider the use of IVF. In particular, I pay attention to how couples' trust in medical doctors is enhanced rather than decreased

the Netherlands. Besides doing ethnographic observations in the clinic, I followed 23 couples visiting the fertility clinic over a period of 1 to 2 years. I use fictitious names to refer to the women and men participating in the study. The numbering of the couples in the quotations (IVF 14, IVF 6, and so on) refers to the order in which the couples entered the study.

by doctors' openness about the uncertainties surrounding IVF. Uncertainty is said to be inherent in clinical medicine, and the expression of uncertainty is suggested to have an impact on patient-doctor interaction and decision making. It is also said that the need to cope with uncertainty is likely to increase as medical knowledge expands (Gordon et al. 2000). Quill and Suchman (1993) speak about the 'illusion of certainty' in medicine, which should come to an end, and they have forwarded a number of steps for how to share uncertainty with patients. This paper in the first place aims to highlight the impact which 'doctors sharing uncertainty' had in the actual clinical practice of a fertility clinic, namely that of increasing couples' trust in doctors. With this paper I also intend to trigger more scholarly thinking and research on this topic.

Trusting the doctor

In couples' considerations about potential risks, trust in the expertise of the staff seemed to play an important role. Several couples said they were convinced that the hospital would not offer this treatment if the doctors thought it irresponsible or too risky. Sometimes, I also heard doctors explicitly saying this to couples when they uttered their hesitations, for example in the following case:

It is not that we think this [ICSI – Intra CytoPlasmic Sperm Injection] is not a responsible treatment. If we thought so, we wouldn't offer it to you. We think it is responsible, but I can imagine that emotionally it is different for you. (Doctor, Pre-IVF consultation hour)

Occasionally, though, study participants expressed their doubts about such reassurances from the doctors. For some of the women, for example, the fear of the long-term impact of hormonal medicines (i.e. gynaecological or breast cancer) became stronger along the treatment trajectory, when they experienced the acute bodily impact of these medicines. Some of them explicitly said that doctors could not really reassure them about this, as "They [the doctors] do not really know much about the effect of this hormonal rubbish in your body" (Woman, IVF 10).

* ICSI is a variant of IVF involving a micromanipulation procedure in which a single sperm is injected directly into an egg to attempt fertilization, used in cases of serious male-factor infertility.

Most couples also felt that they were well monitored. Anne, who had had negative experiences in another IVF clinic, but fully trusted that she was in good hands now and that the doctors kept an eye on her, explained:

Concerning the risks, you are kept under control. Whatever happens, they intervene! That is based on my experiences [in this hospital], not only with IVF. I don't see that as a problem. ... This time they had adapted it [the hormonal doses]. If you know that beforehand, then you are not too worried about that. That was clearly agreed by our gynaecologist and the IVF doctors. (Woman, IVF 6, Interview 2)

Couples realized that serious side-effects may occur, but at the same time they trusted that the doctors would intervene in time if necessary. They also felt well prepared to recognize signs of risks. In particular, they had learned to be aware of the signs of hyper stimulation and they were advised to contact the hospital immediately if they suspected anything might be going wrong. Some of them stressed the importance of regular controls during the period that the woman is injecting herself with follicle stimulating hormones, as Tim, for example, told me before he and his wife started their first IVF treatment:

Yes. That is what I hold on to (*Daar houd ik me aan vast*). During a certain period she [his wife] often has to go for control, and I think that has to be controlled well. If there is any indication that things are not going well, we will have to stop, I think. That gives me confidence. That gives me more confidence than if they would say "Do it on your own, and come back for control once a week". But that is not how it goes. (Man, IVF 7, Interview 1)

Regarding couples' decisions to start treatment and accept possible risks, trust in doctors' expertise apparently plays an important role, though some couples also realized that they were not in the best position to judge the doctors' expertise. How could they know whether the doctor had given them the right information or made the right decisions? Henk, an organisation advisor by profession, was quite explicit about that:

That is typical about specialists... About their expertise, you do not know it. That is where you have to trust them. (Man, IVF 9, Interview 2)

Louise made a similar remark about her capacity to judge a doctor's expertise or skills:

That [a doctor being empathic] is a very strong component, and based on that you can say if you like a doctor and think she is okay. But in fact that doesn't make any sense at all, because whether someone performs a good follicle puncture or not, I really cannot say. (Woman, IVF 10, Interview 2)

As most women and men visiting the clinic with fertility problems are lay persons in this area, they do not have the means to assess the 'truth' of the information provided by the clinic. They largely depend on the doctors' selection and interpretation of information (cf. Sandelowski 1993). Of course, women and men visiting the clinic can and do search for information elsewhere (mainly from the Internet) and some of them do bring their ideas on alternative treatment options and procedures – like, for example, assisted hatching or different medicine routings – to the clinic. However, as I noticed when observing consultation hours in which such alternatives were discussed, doctors and patients (however well the latter may be educated and informed about the topic) were not equal discussion partners. In practice, couples – when they suggested an alteration of the normal regime – first listened to the doctor's explanations of why the clinic had chosen one option over another, subsequently they could come up with another question or concern, but then the discussion generally ended, as lay people simply have not read all the literature and/or are limited in their capacity to really assess the information provided. In such situations, they have no choice other than to trust their doctors' skills, expertise, and judgement. This trust in the doctors seems to be enhanced by a number of factors, such as the appreciated clinical practices (described extensively in my thesis), which create an ambience in which (most) couples felt well treated and their questions duly answered. Doctors' openness about the limitations of their knowledge, medical science in general, and IVF in particular, and the risks and uncertainties involved, was another factor that seemed to enhance trust.

Sharing uncertainty

The couples participating in my study were profoundly aware that the doctors performing the IVF treatments did not have everything in their control,

and thus could not make predictions about the occurrence of risks or the outcome of treatment. They could not, for example, predict how women would react to the hormones injected to stimulate the growth of the follicles. A small difference in the amount of hormones injected may make an enormous difference in a woman's reaction. Prescribing too many entities may lead to OHSS, which is considered a serious risk; prescribing too few entities, though, may lead to a poor reaction. Both OHSS and too poor a reaction may lead to the cancelling of a treatment cycle and thus a lost chance. The decision about the exact amount of hormonal entities is based on several factors, including the woman's FSH (Follicle Stimulating Hormone) level, her age, and former experiences (if any) with stimulation of follicle growth. A final decision is made the moment the woman visits the clinic for the first ultrasound control. The ultrasound shows 'small black spots,' the follicles that might develop later on. It is not rare to see an IVF doctor hesitating about the exact amount of hormonal entities to prescribe, or hearing her say that she wants to consult her colleagues before making a final decision. Doctors share this uncertainty with the women and men in treatment; sometimes it is even said explicitly that the first treatment is a kind of 'try out' to find out how the woman reacts to the treatment. But even then, doctors frankly admit that this does not predict how the next treatment will go, as women do not always react in the same way every time. Hence, most couples are aware of the uncertainty involved in this part of the treatment, as well as in other parts.

During my observations in the clinic I noticed that doctors regularly shared these and other types of uncertainties with the couples visiting the clinic, or I heard them hint at the limitations of medical technology in general. In the interviews, I therefore asked the couples how they felt about being confronted with the many uncertainties surrounding IVF. Most of the participating women and men indeed had also noticed this sharing of uncertainty; and they said they preferred to hear that things are not one hundred percent sure rather than have the doctors pretend that they knew everything. Sharing the uncertainty increased their trust, several of them said. One of the couples, for example, recalled in detail how positive they felt about the doctor's hesitation regarding the amount of hormonal medicines to prescribe. The man ended his reflections by saying:

Someone is just thinking "What shall I do – 150 or 200 [entities of hormonal medicines]?" That flash I had. And maybe it is a bit naïve, but I do trust people then. (Man, IVF 16, Interview 2)

Doctors sharing a certain level of uncertainty and unpredictability with their patients seemed to strengthen rather than diminish the trust couples had in them. Several research participants shared similar experiences. The below quotes illustrate what some others said about uncertainty and trust:

I rather prefer that doctors do not pretend as if they are 'half gods in white'. I think it is realistic when doctors show that they do not know and cannot accomplish everything. It makes them more human. I would not like it if they pretended that they had everything under control. (Woman, IVF 8, Interview 2)

I think it is okay when they present themselves as vulnerable at such moments. Because if they said that they know everything, then you are thinking that they have everything under control. And if it fails, then you can reproach them: "How is this possible? You knew how everything had to be done, and still it is not successful". (Man, IVF 7, Interview 2)

However, not all women and men involved in the study appreciated equally this sharing of uncertainties. A few of them were openly fed up about the lack of precision (they wondered, for example, why there were not more standardized guidelines to determine the amount of hormonal medicines), and a few others preferred not to be confronted with the doubts of the doctor as it made them feel uncertain as well. Only one couple could not recall the doctors sharing any uncertainty at all with them; rather, they were very much impressed by the achievements of technology.

Conclusion

Couples' perceptions of risks and success rates with regard to IVF are socially constructed: in various ways, couples visiting the Radboud fertility clinic and participating in this study were trying to make sense of the information they received about risks and success rates. Some of the medical information received is complex, and as most women and men in treatment are lay persons, not trained health professionals, they have limited means to really assess the 'truth' of the information provided by the clinic. To a large extent, they depend on the doctors' selection, interpretation, and explanation of information, even when they themselves actively search for additional information. Various authors have pointed to the limitations of informed consent in this and other medical contexts, where – as they state – problems and

treatments are often complicated and even professionals do not share the same opinions (see e.g. De Jooide & Fauser 2001). The finding that couples' decisions to pursue fertility treatment are, at least partly, based on feelings of trust in the health professionals providing the treatment, even when abundant information is provided, points to a dilemma in the application – or rather the meaning – of the notion of 'informed consent' within health care. 'Informed consent', I suggest, should not be considered the result of a purely rational and autonomous process of decision making based on a profound assessment and understanding of information provided. In fact, it might be more realistic to speak about consent based on information *and* trust in the medical professional. Considering informed consent in this way underlines its relational and interactional aspects, and at the same time points to its potential peril, namely the possibility of abuse of that trust.

In this paper I have shown that, according to the research participants, their trust in the doctors was strengthened rather than weakened by doctors' transparency about possible risks and the limited success rates, and by the sharing of uncertainties involved in IVF treatments. I do not, however, intend to suggest that sharing uncertainty is necessarily and always valued in contemporary medicine. The positive assessment of sharing uncertainty by couples undergoing IVF treatments might be related to the fact that most of them have a longstanding relationship with the doctors at the fertility clinic, under which circumstances it is easier to discuss uncertainty (as has been suggested by Gordon et al. 2000). In addition, sharing uncertainty might be more positively valued in a context where patients are generally satisfied with other aspects of the patient-staff interaction, as is the case in the clinic where the current study was carried out (see Gerrits 2008). One may thus question how context- or even culture-specific the appreciation of disclosure of uncertainty is? Finally, one may question how much uncertainty patients can endorse or endure: at what point does sharing uncertainty in order to promote realistic patient expectations (Quill & Suchman 1993) lead to a decrease of trust in medical staff resulting in unsatisfied patients?

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Literacy practices of female farm workers in the Breederiver valley, South Africa

DIANA GIBSON

'Literacy' is embedded in social and cultural practices, and its related practices vary from one context to another (Street 1993). An adherence to dominant literacy uses can result in the submersion of alternative literacy practices, like those of women, in relation to the more powerful mainstream practices (Baynham 1995: 246). According to Street women's literacy practices in the past often developed and were used within the female domain, i.e. the household, to take care of the family's budget, bills and other commercial matters, or for keeping track of family affairs, maintaining kinship ties etc. This paper is about some of the literacy practices of 'coloured' women on farms in the Breërivier valley.

In the early 1990's I spent a long time working on these farms. Els van Dongen subsequently visited and did research on these and adjacent farms as well (Van Dongen 2003). My own study was done on three farms, Dieprivier, Boesmansrivier, and Sukkes, situated in the Breërivier valley in the Western Cape, between the towns Wolseley and Worcester. These three farms were fairly representative of the majority of the wine farms in the Western Cape (Gibson 1996), which were owned privately, rather than by companies. Ownership of most of the farms in the area lay in the hands of a relatively small group of families, who had been dwelling there for several generations.

On all three farms vineyards and peach orchards were cultivated. On Dieprivier there were also onion fields. Small herds of cattle and sheep were moved between the two farms, depending on where grazing was available (Gibson 1996). With the exception of the farmers and managers, 98 adults (defined as over the age of 17 and no longer in school) and 67 children living on the three farms. Eighty of the adults were employed on the farms. The workers and their families lived in 35 houses. Eight of these houses were occupied by female heads and their families.

Farm women's literacies: The private domain

For the majority of women on the farms researched, literacy was used mostly in the home, in the shops and in the church. Women's literacy practices were closely related to perceptions of women's roles in the family and religious sphere (cf. Puckett 1992). Women reported that they helped children with homework and occasionally read stories to them. Women enrolled children in school, did the shopping, paid the accounts, and applied for disability and fostering grants. These literacy practices accordingly related to the gendered role of women in the household as wives who are responsible for and co-ordinate household duties, take care of children and who attend to the household finances and administration. A great deal of the reading done by women happened communally, as described by Bet Koen:

I read *Huisgenoot* and photo stories. I also take out books from the library, like love stories. I like to page through magazines and read what interests me, like recipes, or patterns, household hints, raising the children, I especially like the column which gives advice on business of the heart, you know, love and marriage and things. I do not read newspapers. When I read something I discuss it with other women, they will say: "Wait, look, read a bit what is written here." Then we send the magazine around and each one reads or comments. Some read out loud: reading is something we often do together, like with magazines.

Farm women's reading practices accordingly did not replace oral interactions, but rather contributed to it. Such reading practices often became social events and by their very content and nature were women's events as well (Puckett 1992: 141). Yet, because such gendered reading practices happened mostly within the domain and context of domesticity, it largely remained marginalised from the public sphere of especially the work place (cf. Malan 1996; Gibson 1996).

The impact of gender in the production of invisible literacies was also discussed by Horsman (1990: 258). She argued that the tendency to adhere to a narrow view of literacy, "silences and delegitimizes alternative forms of literacy, based on alternative life experiences". This trend was first discussed by Rockhill (1987), who has also shown that there were gender differences in the literacy practices of Hispanic immigrant men and women in the USA. As a result of the extant power relations between men and women, the literacy practices of the latter were mainly confined to the domestic sphere, where it remained 'hidden' and was not appropriately valued.

One of the literacies practised mainly by women on the farms was the writing and reading of family letters. There were mainly two kinds of letters, private and family. According to Lien Voorslag:

Family letters are sort of family property. Apart from the telephone it is a way to keep contact, to tell about the important things which have happened to the family. It is a bit like an ongoing conversation. We say things and ask each other things and then respond to it again. So if you read a letter, it will not always maybe make sense to an outsider. You have to know the story we have been telling, the things we have been discussing. I usually write over weekends. When I, or we rather, receive a family letter, from my aunty or my cousin or my sister I read it for the whole family. Or I read it and then I read parts of it and then one of the others also read it and we talk about it. We tell the news about weddings, about new babies, we ask about the children, things like that. These letters are actually something we women mostly do. We keep track of the family, of their joys and sorrows (*wel en wee*), we keep up the family ties.

And the men. Do they also write such letters? (DG)

Not really. They may tell us what to write or what to say or what to ask of whom. We read the letters to them or give it to them to read, but mostly we read it out loud to them and so we give that news about the family to the men. One can sort of say men keep contact with other people through the letters written by us.

A letter from a friend again (male or female) is private. For myself, it's my own. I read it in private, by myself, for myself. Maybe I will tell the others something from the letter, but they will never ask to see it.

Unlike private letters and love letters, which were written mostly by women, but also by men, the writing of family letters lay firmly within the sphere of women's activities and was a way in which they could maintain family and kinship ties. These letters were intertextual family narratives 'telling the story' of its members, picking up continuous conversations which, maybe, started over the phone and extended into letters. The various texts were interdependent (cf. Malan 1966), answering previous questions and exchanging news and gossip across letters written by different women. Such letters were also common property and was a way in which men could also access kinship ties through the writing of women.

Women's literacy practices in general, and family letters in particular were closely connected to "local conceptions of women's 'place' and cultural identity" (Puckett 1992: 141). These literacies were thus also related to the construction of their responsibilities and identities as lying within the domain of the family and the home, as wives, mothers, sisters, aunts, caregivers, cooks, etc. (Rockhill 1987).

Other research has also shown that the construction of identity is often linked to literacy practices (Street 1993: 137). Based on a study in a rural Eastern Kentucky community, Puckett (1992) argued that literate interactions were linked to symbolic values through the gendered division of reading and writing. Men's identities were not associated with specific literacy practices, and they consequently displayed minimal or non-literate behaviour. Contrastingly women's literacy practices allowed them to negotiate their social, religious and cultural identities. According to Street (1995: 5) writing involves:

many paralinguistic features, equivalent in some ways to the gesture, facial expression, intonation of spoken language – the choice of type of script, ink colour ... all signify meaning beyond lexical and syntactic means.

The way in which family letters written by farm women were presented, i.e. the quality of the writing, its neatness, lack of mistakes, the kind of paper used, equally had special significance. This was explained by Ella Smal:

A letter is not only about the news in it. It also has to be neat, on nice proper writing paper. I take great care when I write a letter, I write more slowly and neatly, I think what I want to say. It is different from when I make a shopping list for the house. Then only I or my sisters will read it. But a letter, and especially a family letter is different. For a letter to a special friend or a boyfriend you take a lot of trouble to show them how much you care. But a family letter can be read by anyone. It is on the one hand so other people can read it, but it is also about what, how people think about you. When your letters are not neat and carefully written, without mistakes and things, people will comment about it, they will think you are not a neat/ proper/ correct/ upstanding (*voorstandige*) person. Your letter is a little bit of yourself. The letter does not only say what is written in it, it also tells what kind of a person is this. Who am I who wrote this letter. Who is Ella, what kind of a person is Ella. Say something happens to me in town when I go to post this letter and someone reads it, then this person must not only be able to make out what I have written, but he must also get a feeling (*gevoelte*) about the

kind of person I am. If I read a letter which is sloppy, then I think that person is also careless/ sloppy (*traak-nie-agtig*) and that person does not care about things. It is somewhat (*nogals*) important for women to write neatly and well, especially when it's letters other people are also going to read. When I write for myself, it does not have to be like that.

The letter itself, the way in which it was presented, symbolically displayed the identity of the writer, it said something about 'what kind of a person' the writer was, it was representative of her. The handwriting had to be neat, clear and carefully executed and was, as aptly put by Puckett (1992: 143), "another valued woman's skill". These letters would be evaluated by others, mostly women, as indicative of the character of the writer, of her propriety and morality.

Although the majority of the farm women said that they increasingly preferred to use the telephone and consequently wrote letters less frequently than in the past, family letters nevertheless remained one of the most important literacy practices of these women. These letters were not only shaped by and in turn shaped the feminine and domestic identities of women, but its form signified meaning far beyond its content and utility.

The public domain

Women's family responsibilities required of them to often use their literacy skills in the public domain. They did shopping, filled in forms, enrolled children in school, fetched pensions and grants and put money in savings accounts. In these cases a specific kind of bureaucratic literacy was used.

Mothers of babies also had to be able to provide their children's growth- and inoculation cards when they visited the mobile clinic. As they found the medical terminology incomprehensible, even the literate women usually had to rely on the nurses to 'translate' this for them into ordinary Afrikaans. Official representatives of an institution accordingly acted as literacy mediators for them (Malan 1996a).

The local Women's club also gave women the opportunity to use their literacy. One of the local women was chosen each year as secretary, she had to take minutes at meetings and would read it to members at the next one. During the meetings women did arts and crafts, needlework etc. The Community Development Association sometimes arranged for volunteers to present demonstrations. From time to time a guest speaker was also invited to address the women on different issues.

Religion was nevertheless one of the most important sites of literacy practices in the lives of farm women and was largely based on essay text literacy. The importance of this kind literacy was demonstrated by the following women's comments:

Most of the reading and writing I do, has to do with the church (Katryn Jakobs).

I do not really read anything at home. Only in the evening before I go to lie down, I read a little from the Bible (Mina Voorman).

According to Kell (1994: 104) religious literacy is probably related to Heath's notion of 'hermeneutically oriented reading' rather than Heath's own description of reading the Bible as having the function of confirmation (of ideas already held). Kell (1994: 95) reports that the reading of the Bible was apparently the only sustained kind of reading her informants did. This was also the case on the farms (Gibson 1996).

Reading the Bible was very much a family activity, and some of the families regularly had 'huisgodsdienst' (a session of Bible reading and prayer of all family members). If one of the family members was 'illiterate', others would read the Bible for him or her. In this way women used their literacy to benefit kin (Ibid).

Women thus often publicly used their literacy skills in a religious context. Most of the farm workers belonged to the Dutch Reformed Church of Africa. Although the congregation was actually situated in Worcester, farm workers attended services in the local church hall most Sundays. Once every two or three months the minister would deliver a sermon locally. For the rest of the time services were led by the deacons and elders of the vicinity.

The confirmation of deacons and elders was a very public event in the church and happened in the principal, or 'mother' congregation in Worcester. This important religious event was attended by members of all the different branches and was a cause for celebration and felicitation. Becoming a member of the church council earned the office bearers a great deal of respect and brought about a variety of public duties involving literacy. Deacons had to write receipts, council errand members, lead scripture readings and conduct prayer meetings. Elders, in turn, became the religious leaders of the community and were responsible for the sermons in the absence of the evangelist or the reverend father. Interestingly, the majority of the deacons and elders of the local congregation at Botha were women. Here they practised the reading and writing of the church, in public performances steeped in sanctity.

Up till then Katryn Jakobs' use of language had been reminiscent of the local Cape dialect, using many pronunciations and expressions from the local vernacular. When she started to pray, however, both her use of language and the tone of her voice changed abruptly. She suddenly used a very formal, old-fashioned form of Afrikaans. As she prayed, her voice steadily rose in tone and cadence until she was speaking in an emotive voice which sounded like a combination sob and shout. She had started by giving thanks and ended with a long and increasingly emotional appeal for forgiveness for a multitude of sins. When we opened our eyes again, she wiped tears from hers.

In such sacred performances women constituted their identities as public guardians of morality, instructors and interpreters of religious text. It was a great source of power for such women who were seen as paragons of virtue, spirituality and rectitude. According to Puckett (1992: 145) public performances of Bible reading and its interpretation is:

a literate interaction in which God's word is God's voice, and in which scripture provides instructions, axioms, proverbs, parables, and exempla as perlocutionary discourse which women then use to direct family and other social relationships.

When a farm woman first became an elder, she often relied heavily on her literacy skills and practices to perform her task as spiritual leader and advisor. According to Anna Olifant, who had been an elder for three years, she had initially spent many hours reading the scriptures, selecting the appropriate verses and accompanying hymns. She would also write up 'a little sermon' to guide her during the service.

As these women had become increasingly steeped in the sacred literacies their spirituality was signified by the command of Biblical metaphors. They also acquired a specific 'perlocutionary force' (Puckett 1992: 139) or ability to use sacred text to make utterances to bring about specific affects on the congregation "within particular speech event configurations or circumstances" such as a service (Ibid: 146).

The local Witness/Testimony Action (*Getuienisaksie*) consisted mostly of female members who visited families to give witness of their faith and to help with religious counselling. The women attended a course stretching over a couple of weekends offered by the church to do this. Every six months a minister visited them. If they had problems with their evangelisation effort, they wrote it down and discussed it with him. Women were accordingly highly visible and very active in church affairs, fund raising and public speaking.

The passing of time

The farms on which Els and I have worked have since been sold and the old people with whom she had done research have died or moved to old age homes in Worcester. Yet women still write letters in careful and tidy script and play an important role in the church.

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On the temporality of epilepsy

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Biomedically defined as a chronic disorder characterized by recurrent seizures, epilepsy manifests itself as a series of incisions in time. Its defining feature, the epileptic seizure, cuts the flow of life of a sufferer into a sequence of more or less disruptive events. Lay people may notice a short 'black-out' of a few seconds when they witness somebody having an *absence* seizure, or they may be shocked by the forceful spasms of the whole body and frothing at the mouth during a *grand mal* seizure. Whatever one may focus on in this regard, the seizure itself certainly stands at the centre of one's attention. In contrast, for those who suffer from seizures, this only partly applies.

When I asked people with epilepsy to describe their seizures, they usually shrugged and stated that they cannot say anything about them because during a seizure they lose consciousness, they 'are not there' and thus do not remember anything." It was only when I broadened my questions to cover the situations before and after seizures that their answers took on a kind of shape. My interviewees experienced a seizure as a 'gap in consciousness' (*Bewußtseinslücke*), as one person expressed it, making seizures accessible only through its situational before and after, its past and future – and above

* This text is a shortened version of a paper which I presented at the 'Sociology of the Body Group' at the Faculty of Social and Political Sciences, University of Cambridge, in spring 2000. Epilepsy and temporality was the topic I was working on when I first met Els van Dongen at the end of the 1990s. Our discussions on chronicity not only helped me to clarify my thoughts, but also started our engagement as teacher/student, as colleagues, and not least as friends. Taking up this topic here again is to express my gratitude for this. My paper also profited from comments by Andrea Stöckl, Bryan Turner, and the participants of the Sociology of the Body Group.

** Most of the ethnographic material used here was collected in conversational interviews with 31 adults suffering from epilepsy and their significant others in Austria between 1995 and 1999. My informants, 18 women and 13 men, were in the age range 18-73 and had a history of epilepsy of 3 to 69 years. Most of them suffered from generalized and/or secondary generalized seizures. Among other reasons, this is why I leave the highly complex matter of simple partial seizures out of consideration here, which are not connected to the loss of consciousness during a seizure.

all through the accounts and reactions of others – rather than through actual experience. In effect, although the question of having or not having seizures is indeed crucial to epilepsy sufferers, it is not the seizures *per se* which trouble them most, but their actual and possible effects on their everyday lives. As I will argue in this short paper, these are intrinsically bound up with the bewildering temporal ramifications of epilepsy, which not seldom contribute to a profound mismatch between what is usually expected to be a ‘normal’ world shared by others and the world in which people with epilepsy find themselves.

The problem of unconsciousness

It is rather obvious that occasions in which people lose consciousness are neither rare nor socially or culturally irrelevant – bear in mind medical anaesthesia, a stroke, a short collapse, and not least epileptic seizures. However, the topic of unconsciousness has hardly found any attention in anthropological, sociological, or philosophical literature. It is even missing in approaches which are explicitly based on an understanding of consciousness as gradable (e.g. Schütz & Luckmann 1994[1979]). Philosopher and physician Drew Leder (1990) has perhaps come the closest in calling attention to the paradox of embodiment which is posed by the inescapable presence of the body as the existential and experiential ground in our lives, and the body’s simultaneous absence as thematic object in our experience. Leder explored in detail the disappearance of different bodily regions and functions from direct experience. Leder’s main focus of argument, however, rests on those aspects of the absent body which can be discussed without much reference to temporality. He analyses the absent body mainly on the premise that the conscious and experiencing self is present *at the same time* as the body is absent. Only when Leder arrives to discuss the phenomena of sleep and birth does he supplement the relation between bodily absence and the experiencing self with a more diachronic dimension. During sleep the body in its entirety withdraws from experience – until we wake again. This is an important point for my argument: in order to discuss the phenomenon of sleep, Leder needs to introduce a temporal frame which covers the oscillation between sleeping and waking, and in which the temporality of the experiencing self is acknowledged. It is the sleeping body *of the past* that withdraws from the experiencing self *of the present*.

In his description of the temporal depths, Leder comes closest to the issue of unconsciousness, but without really touching it. Like Husserl, Schütz,

Merleau-Ponty, and others before him, Leder takes the *conscious* subject as his axiomatic basis, which subsequently tends to lead our attention away from the phenomenon of *unconsciousness*. It seems that the social sciences and philosophy need *conscious* subjects, at least to a minimal degree and in whatever forms and mediations, in order to have a subject at all. Perhaps it is still the Cartesian Ego which becomes manifest here and which refuses to be de-centred as the primary reference point.

What is missing in the view of the primacy of the conscious self and the logic of the absent body is that the conscious self too can be – temporarily – absent from itself. As my interviewees insist, it is not so much the body which they feel as being absent during a seizure, but rather they themselves, their conscious selves. This was clearly expressed in statements such as “I was not there” (*Ich war nicht da*), “I had stepped away” (*Ich war weggetreten*), or “I was away” (*Ich war weg*), which my informants frequently used to refer to their being unconscious during a seizure. Correspondingly, their regaining of consciousness was referred to as “Coming to myself again” (*Wieder zu mir kommen*), “Being there again” (*Wieder da sein*), or similar expressions. This sense of ‘being away’ is also contained in the very term *absence seizure*, denoting a common seizure type in which sufferers usually interrupt their actions for a few seconds of non-responsiveness, and then resume them where they had stopped. Often described as ‘black-out’, the term *absence* points at the fact that exactly at the moment when epilepsy powerfully makes its presence known, the person who it affects most is ‘absent’.

My point here is that the phenomenon of unconsciousness only comes into our view when the embodied self is recognised in its temporality, when we shift our reference point of the conscious self – which is thought to be synchronous to its experiences – to a diachronic self. For a person suffering from epilepsy, seizures always either have already happened or have not yet happened; they can be either recognised after the fact or anticipated; but they never happen in the *Now*, never have an unmediated experiential presence.

Experience and transcendence

The fact of being absent does not mean that seizures somehow happen outside of the world. On the contrary, the missing *Now* of seizures in the inner time of sufferers often stands in striking contrast to the all too real *Now* in the time of the world and of witnessing others. The spatial, temporal, and social resistance of the world comes painfully to the fore, at the latest

when a sufferer finds all his front teeth knocked out after a seizure, when he misses an exam because of a seizure, or when he loses his job as a salesperson because he had a seizure in front of his customers. It is precisely this paradox of being absent yet inevitably present in the world which accounts for many of the problems which people with epilepsy have to face.

In this regard, seizures are part of what Schütz & Luckmann (1994), in following Husserl and others, have called the *transcendence of the world*, referring to those shifting aspects and regions of the world which lie beyond our immediate experience, but which we nevertheless take more or less for granted in our *natural attitude* towards the everyday world. This taken-for-grantedness only becomes a problem to us when experience and transcendence cannot be adequately bridged, as is often the case with epilepsy. This concerns both the transcendence of seizures and the transcendence of the label epilepsy itself. Let us first consider the transcendence of epilepsy.

Although characterized by 'recurrent seizures', epilepsy is constituted not only by seizures, but also by that which lies between the seizures and gives them a before and after. Epilepsy is the alternation between seizures and times without seizures, and it becomes manifest only 'from time to time' when another seizure strikes. Perhaps in contrast to other chronic illnesses with more or less omnipresent symptoms such as rheumatoid arthritis, epilepsy thus has a rather puzzling presence. One man, now in his late 60s with a history of epilepsy since his adolescence, referred to this by comparing epilepsy to "A little devil (*ein Teufelchen*), who lurks in the back of my brain and who has to prove that he is still there from time to time."

The matter of epilepsy's transcendence is further complicated by antiepileptic medication, which does not cure epilepsy but can only suppress seizures or alleviate their severity, therefore having effects on seizures but not necessarily on epilepsy. When drugs are effective and seizures are stopped, epilepsy can no longer be easily diagnosed. After some time it may become doubtful whether the drugs account for being seizure-free or whether the epilepsy has gone away. Thus, epilepsy only comes into being after the occurrence of a few initial seizures. Over time, though, it may gain a form of existence which is not solely founded on the *actuality of past and present seizures*, but also on the *possibility of future seizures*.

As for the transcendence of seizures, it has already been indicated that seizures may have grave bodily and social effects. Most of my informants told me stories about serious injuries due to uncontrolled falls and bodily spasms during a seizure. Such stories involved fractured limbs and skulls, road accidents, severe burns, or near drowning in lakes or bathtubs. There are also a number of other possible signs which indicate that a seizure has

happened, including fatigue, confusion, a tongue-bite, aching muscles, or soiled clothes. Nevertheless, if nobody confirms the actuality of a seizure, its realness may remain doubtful or may not even be suspected at all, particularly when seizures are not severe and have left no physical injuries. Not all seizures are witnessed by others, for instance when a person has a seizure during sleep or while staying alone at home. It is therefore not only the label 'epilepsy' which needs social action to make it 'real', as labelling theorists have shown (West 1979), but also often seizures themselves.

Seizures and situations

It is of central importance in which particular situation a seizure takes place, for it indeed makes a difference whether one gets a *grand mal* seizure while sleeping in one's bed at home, while crossing a busy street, or at school in the midst of one's schoolmates. Of course, it is also important what kind of seizure one has. Due to the forceful bodily spasms, the frothing at the mouth and so on, *grand mal* seizures are certainly much more repellent to other people and more often lead to injuries than *absence* seizures or other seizure types. But dependent on the particular situation, *absence* seizures may also be profoundly disruptive in people's lives. One man, now in his 60s, who has been suffering from both *grand mal* and *absence* seizures since his early adolescence, recalled that one of the most distressing seizures of his life was an *absence* seizure which took place at the beginning of his career as handball player, in the middle of a match. The seizure happened exactly at the moment when he was to throw a penalty. He did not hear the referee's whistle, did not throw the penalty, and as a consequence lost the ball to the opposite team. He never played handball again.

This example also points to the fact that it is not predictable exactly when seizures will strike. My informants identified certain 'risk-factors' for triggering seizures, such as lack of sleep, forgetting to take anti-epileptic drugs, consumption of alcohol, or stress. Sometimes seizures are restricted to certain times, such as only during deep sleep, shortly after waking up, or only in connection with menstruation. But even within these limits, seizures basically can happen at any time and in any situation. Usually there is no *standard* situation in which seizures take place and to which one could adjust beforehand. Seizures break into situations to which they 'do not belong', as one interviewee put it. In effect, during a seizure, one loses not only the control over one's own body, but also over the situation. This basic unpredictability of the *when*, *where*, and *how* of the next seizure – or if the next seizure will

come at all – accounts for the more or less profound feeling of uncertainty, as reported by all of my informants and in other studies about epilepsy (Schneider & Conrad 1983; Good & Good 1994).

Another important aspect of the temporality of epilepsy is the suddenness of a seizure's onset. Seizures strike 'like a thunderbolt out of the blue sky', which is a commonly used metaphor in this regard, referring both to the abrupt and forceful onset of a seizure and to its total unexpectedness.^{*} The specific situatedness of a seizure is thus also defined by the mode of *how* the conscious self is turned away from the everyday world, and not only by the fact that it *is* turned away.

What brings all these aspects of the temporality of epilepsy together in terms of relevance for those affected by seizures can be described by the notion of *timeliness*.^{**} Although I do not think that any of my informants would find their seizures 'timely' as such, they would certainly agree to a graded untimeliness of seizures. When seizures cannot be avoided and the situation in which they take place cannot be adjusted (or only partially adjusted at the best), then seizures can only come as more or less untimely. In consequence, the relevance of a particular seizure for those affected can be said to correspond to the degree of its untimeliness: the less timely a seizure, the more problematic it is.

However, the potential untimeliness of epilepsy and seizures, together with their associated temporal peculiarities, in my view tend to change the worlds of people with epilepsy in a way which in many aspects mismatches the social world around them: one cannot rely on the specific givenness of the world at the next moment and of its longer term course, as other people may do. Epilepsy sufferers may therefore not engage in activities and projects which for other people might be more or less self-evident, such as such as riding a bike, using the subway, taking a bath on one's own, preparing a meal in the oven, travelling alone, or having children. The lives of epilepsy sufferers thus tend to get out of synchrony with their environment, both on a day to day basis and in the longer course of their biography. In my understanding, what is at stake for people with epilepsy is the constant struggle for re-building a socially shared world and time.

* I do not touch here upon the question of the *aura*, an 'announcement' of the seizure, which may take on the form of a strange smell or a feeling of nausea, among other symptoms.

** I am grateful to Bryan Turner for drawing my attention to this notion.

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Terms of engagement

Women's health concerns and new reproductive technologies

ANITA HARDON

Social studies of technology take as point of departure that innovators 'inscribe' a specific vision about the world into the technical content of a new object" (Akrich 1992: 208). In the design of new technologies, researchers anticipate the interests, skills, motives and behaviour of future users. As a result, representations of future users become materialised into the design of the new product. Adopting the view that technological innovation requires a renegotiation of gender relations and the articulation and performance of gender identities, Dutch and Norwegian researchers have introduced the concept of gender scripts (Oudshoorn et al. 2003).

In the past twenty years, medical technologies have been the focus of my research. In this essay I reflect on my engagements in controversies surrounding three new reproductive technologies. The controversies centre around the question whether these new technologies liberate future women-users, or reinforce unequal gender-power relations. Actors in the controversies are reproductive researchers and women's health advocates. I have studied the ways in which the women's movement framed issues of rights and safety and pointed to the possible abuse potential of two kinds of longer-acting contraceptive technologies, Norplant and the anti-fertility vaccines, and reproductive technology designed to protect women from HIV/AIDS, so called microbicides. I have shown how the women's health movement was successful in co-shaping these technologies. The gender-scripts changed (Hardon 2006).

Throughout these controversies, I participated in the women's health advocacy movement. I was concerned that women's health needs and interests were not sufficiently taken into consideration in the design of these reproductive technologies. I wore two hats, participating in debates as an activist (working for a women's health advocacy) and taking meticulous notes on the actions and reactions as a professional medical anthropologist. As an engaged anthropologist, my close colleague Els van Dongen inspires me: she challenges us to be clear on our theoretical standpoints, and to reflect on the terms of our engagement.

Setting the scene

The women's health advocacy movement is a broad movement with a variety of roots. The movement includes radical feminist groups calling for abortion rights, women's health organisations opposing medicalisation of women's reproductive functions, community-based health groups, feminist researchers and journalists. Women's health advocates would generally agree that they share a goal of empowering women to control their own fertility and sexuality with maximum choice and minimum health problems. They also have a common scepticism towards medical claims about the safety of the reproductive technologies.

In the industrialised world, the movement finds its origins in second wave feminist movements, which in the late 60s and early 70s rallied around the right to contraception and abortion and to express a growing concern about patriarchal control in medicine. Free contraception and abortion on demand were seen to be keystones of women's liberation. In 1980 the *International Contraception, Abortion, and Sterilization Campaign: Women Decide!* (ICASC) was launched (Berer 1997). ICASC organised the Fourth International Women and Health Meeting in Amsterdam in 1984; this changed the tone of international women's health activism. This meeting had as its slogan 'Population Control – No Women Decide!' It was there that the language for reproductive rights became international.

The meeting challenged the rationale on which population programs aimed at reducing fertility in developing countries were based – namely, that limiting family size as a societal responsibility has precedence over individual well-being and individual rights. There were reports on the way state population programs in countries such as India and Bangladesh aimed at reducing population growth by means of coercive family planning programs. Mistrusting their governments, women expressed concern about the safety of contraceptive technologies that were being made available in target-oriented family planning programs (Hartmann 1995). By framing their concerns in relation to reproductive rights, the women's health advocates had found an oppositional collective identity and a powerful counter discourse to that of 'population control' – as defined by the World Population Plan of Action (WPPA) and adopted at the 1974 Conference on Population and Development in Bucharest, and the subsequent 1984 International Conference on Population held in Mexico City.

In the second half of the 1980s, the global women's health movement gained momentum. Issues of concern relating to contraception were the adverse effects of the Dalkon Shield (which led to litigation against its

manufacturer, and a successful claim for compensation), the distribution of the hormonal injectable, Depo Provera, in family planning programs in the South, at a time the technology was still not approved for distribution in the United States, and the safety of the new long-acting hormonal implant Norplant (Hardon 1992).

Norplant and Depo Provera were opposed by some women on safety grounds and also because they were not 'user-controlled'. The DES scare had led to worries about the possible long-term effects of these hormonal methods. Women's health advocates preferred methods that could be used by women and men without the interference of health professionals, and had no systemic effects, i.e. condoms and diaphragms. An important argument was that contraceptives are taken by healthy women: this alters the risk-benefit assessment as compared to medicines taken by sick people with an aim of restoring health. Thus both the anti-medicalisation and the anti-population control roots of the movement framed the issues raised about new contraceptive technologies. By the mid 1990s, the women's health movement had become a strong global movement with several transnational advocacy networks. I worked for the Amsterdam-based Women and Pharmaceuticals project.

Responding to the advocacy, institutions such as the Human Reproduction Program of the World Health Organization (WHO) and the US-based Population Council in the 1990s increasingly involved women's health advocates and potential users in the setting of research priorities and in decision-making mechanisms. Illustrative of the trend toward greater involvement by women's health advocates in the contraceptive development process is the declaration from a symposium on 'Contraceptive Research and Development for the Year 2000 and Beyond' attended by reproductive research, managers of programs and women's health advocates. Among other things the symposium recommended:

Women's health advocates and potential users should be represented in all decision-making mechanisms and advisory bodies that are established to guide the research process, including definition of criteria for safety, determination of research priorities, design and implementation of research protocols, setting and monitoring of ethical standards, and decisions on whether to pursue a fertility regulation method from one stage to the next, especially decisions to move from clinical trials to introductory trials, and from introductory trials to introduction of a method into family planning programmes (Anonymous 1993).

The three reproductive technologies that I have been engaged with are: Norplant the anti-fertility vaccine, and microbicides. Norplant is a set of six hormone-releasing rods designed as a long-acting contraceptive, which is implanted in a woman's arm. The anti-fertility vaccine is developed to produce antibodies against human chorionic gonadotropin, a hormone which is necessary for the establishment of pregnancy. It also works as a long acting contraceptive. Microbicides consist of various chemicals which are designed to be used vaginally by women to protect them against transmission of sexually-transmitted diseases, including HIV/AIDS. The terms on which I engaged with these three technologies evolved over time.

Subaltern alignment in the Norplant case

In the mid 1980's when I worked both as an academic research (as a PhD student at the University of Amsterdam) and as a women's health advocate, I became concerned about the possible abuse of Norplant as a provider-dependent and longer-acting method in the context of coercive family planning programs in developing countries.

I had reviewed data from the Norplant clinical trials raising concerns about lack of data on long-term effects and the unknown risks of foetal exposure to the hormones. I pointed to the high percentage of women suffering from menstrual disturbances when using Norplant. Field studies initiated by the Women and Pharmaceuticals project showed that in Indonesia, Thailand and Brazil women had difficulty in having Norplant removed. In some cases health workers refused removal. In other cases the removal process itself was difficult, due to incorrect insertion of the breaking of rods during removal (Mintzes et al. 1995). Reproductive scientists testing the safety, efficacy and acceptability of Norplant largely disregarded the critique. They claimed that the menstrual disturbances were a minor side-effect not leading to health disorders such as anaemia. Removal problems they argued can be solved by better training. I saw as a basic failure of studies conducted on Norplant that they failed to discover people's own ideas about reproductive physiology, their own cost-benefit analysis in choosing a birth control (Hardon 1992). I was concerned that so little had been written about the consequences of the menstrual disturbances associated with Norplant in day-to-day life. I cited anthropological research that suggests that the consequences can be far-reaching. Menstruation is an important event in any woman's life. Delay or absence of menstruation is considered unhealthy in many societies; irregular menstruation is unclean and bad for one's health.

In addition I pointed to the need to consider how the technology affects the user-provider relationship, commenting that the trials testing Norplant did not look into this issue. Especially the reported removal problems in my view had to do be viewed within a framework of power-relations and diverging interests.

The terms of my engagement in the Norplant controversy is best characterized as one of subaltern alignment: as researcher I aimed at putting forward the problems the technology posed for women-users, in situations of relative powerless (faced by coercive family planning programs). The aim was to confront the authoritative medical-demographic arena involved in the development of the technology with the lived experiences of women, whose access to health care is constrained by power-differentials between health workers and patients.

Reflexive dialogue in the anti-fertility vaccine case

Subsequently, I became involved in extremely heated debate on the safety and user acceptability of the anti-fertility vaccines. Initial questions from a women's health perspective about the safety and acceptability of anti-fertility vaccines were raised at a 1989 WHO symposium on the safety and efficacy of vaccines for fertility regulation, which I attended with Judith Richter as consumer representatives on behalf of Health Action International (an international network of consumer, health and development organisations). We were the only advocates invited to this meeting. The aim of the symposium was to review aspects of present and past work on the development of anti-fertility vaccines, particularly relevant to the testing of their safety and efficacy (Ada & Griffin 1991). In a report on the symposium published in the WGNRR newsletter, I summarised several concerns with the anti-fertility vaccines (Hardon 1989). These included concerns about:

- the difficulty of 'switching off' the immune response (the temporary irreversibility is a problem for women who experience side effects, such as menstrual disturbance or auto-immune reactions);
- the unknown consequences if a woman is pregnant when given the vaccine;
- the risks of cross-reactivity and allergic reactions to the immuno-carrier.
- the vaccine's potential for abuse if distributed in coercive population programs (women could be injected with the anti-fertility vaccine without their consent).

We had studied the basic immunology underlying these technologies, to be able to engage in these technical debates on product design. Having rephrased the women's health concerns in technical language allowed us to engage in a reflexive dialogue with the researchers.

In response to our concerns, the reproductive scientists pointed to the ease of administration of a vaccine (one-time injection with long-term contraceptive efficacy) and argued that the adverse effects had not (yet) been reported in clinical studies. A vocal section of the women's health advocacy movement subsequently called for a ban on the contraceptive method that meddles with the immune system, they disagreed with the empiricist proposition that risks need to be tested in trials (Hardon 1997).

My position in this second controversy can be characterized as one of reflexive engagement. Other than in the Norplant case, I did not *a priori* align myself with one of the actors involved in the controversy, but rather reflected on the assumptions underlying both the positions of the women's health advocates and that of the scientists. I came to see that both parties were in fact heterogeneous, involving a variety of views and interests. Both women's health advocates and the reproductive scientist referred to projected user needs to support their positions. In the whole controversy actual users of the technologies were absent. This realization led to a third form of engagement, that of constructive collaboration, in which I sought for ways in which in the process of technology development actual users of technologies could be more closely involved in setting the parameters for the technology.

Constructive collaboration: microbicide case

In the late 1990s, in response to failures in promoting condoms to prevent HIV transmission, reproductive scientists with the support of some women's health advocates put forward proposals for the development of microbicides as alternative for women who are unable to negotiate safe-sex use of condoms with their partners. Microbicides are a wide range of chemical agent which are being developed to prevent/treat vaginal infections, and sexually transmitted diseases including HIV. Researchers involved in microbicides development were showed willingness to involve women in the research process, including definition of criteria for safety, determination of research priorities, design and implementation of research protocols, setting and monitoring of ethical standards and decisions on whether to pursue a fertility regulation method from one stage to the next. One of the vocal pro-

ponents of microbicides worked at the New-York Based Population Council, and agency which had taken the lead role in developing Norplant.

Having learnt from the Norplant controversies, the researchers at the Population Council decided to create a body to bring women's health and users concerns into the design of microbicides. A select group of internationally well known women's health advocates were invited to act as an advisory council. The group was called WHAM (Women's health advocacy on microbicides). I was involved as a women's health advocate and social scientist to propose methodological reforms in the clinical trial process which would enable user's views to be considered early in the development of the technology. The proposals emerging from the collaboration are unique: they suggest methodological reforms which allow experiential knowledge to feed into the biomedical routine of testing new technologies. We proposed that clinical trials become sites where safety and efficacy claims are negotiated between diverse groups of stakeholders, including medical researchers, end-users, and women's health advocates. We proposed complementary social science studies:

- 1 when the idea of a new product is born; is it likely to benefit users? Is it needed? (This question was not considered relevant by my counterparts at the Population Council; they said they had sufficiently argued that the products are needed).
- 2 when a prototype product is selected; which ones do users prefer?
- 3 when clinical trials are planned and conducted; what are user's safety and efficacy concerns?
- 4 when the product is introduced on the market; in what way can users be empowered to make sensible health care choices?

As said, my role in this controversy as one of constructive mediator. I had to reconceptualize clinical trials as sites for negotiations on safety, efficacy and acceptability of new contraceptive technologies. Issues of representation emerge; who can represent who in the process? And issues of power: whose values and interest count. In a pragmatic role of constructive mediation, such issues do not hinder engagement, but rather challenge the researcher to study the consequences of the reforms, and ways to overcome problems.

In conclusion: Dealing with dual roles: the activist and the researcher

This essay outlines the way an anthropologist and women's health activist have been involved in controversies on reproductive technologies. I have

shown how my role shifted from subaltern alignment, to reflexive dialogue, to constructive mediation. In describing the shifts in approach, I do not intend to argue that the latter modes of engagement are better. The first approach, subaltern alignment, is needed to give relatively powerless women a voice. It is possible once technologies are on the market, as I have shown in the Norplant case. However, such alignment should not simplify the issues. Views and need of women differ. They are context dependent and historically contingent. In presenting women's views, researchers need to acknowledge this diversity. The second, reflexive dialogue, can help in unravelling fundamental differences in standpoints of the actors involved. In itself this approach does not have much power to change the gender-scripts of technologies. It can however enable dialogue on contentious issues. Reflexivity led me to see more clearly the issue of representation. To whom do we grant power to speak on behalf of diverse users? Both reproductive scientists and women's health advocates were claiming to be legitimate spokespersons for future users. The problem in the anti-fertility controversy, the case in which I adopted this position, was that only few users were being confronted with this technology, i.e. only in the context of clinical trials. The third approach, constructive mediation, which I found myself adopting in the microbicide case, involves methods that enable researchers to explore diverse women's views and needs early in the development of new technologies. These methods allow for systematic consideration of women's views, behaviours, skills and interests early in product development

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Hole in the heart

Loss and bereavement among North Karelian women

MARJA-LIISA HONKASALO

My mother got a heart disease when she was working in the pulp factory in Joensuu [the largest city of North Karelia – M-LH]. She got first sore throat and angina and then a rheumatic fever and then she got a hole in her heart.

In the tip of her heart. And then she got a valve problem and they never operated her and then rhythm problems, for years, and then an infarct and then she died. And from my mother's side many relatives suffered from heart disease... both my brothers died from heart disease and then my sister.

And one sister got a stroke – no, two sisters of my mother got a stroke, the rest died of heart disease.

People are broken-hearted here, another woman said.

And broken winged, another added.

This is how some North Karelian women used to talk about their heart disease. Els van Dongen was visiting my field area in North Karelia when she attended our Nordic Medical Anthropology meeting in 2002. She came to know some of my informants during those early spring days with lots of light. After the visit we took a trip to the Russian Orthodox Monastery located in the area and had an unforgettable Palm Sunday dinner together. At that time, I had finished my year-long fieldwork in a village in North Karelia, in the easternmost province of Finland. The area is an emptied out 'cultural periphery', abandoned by the Finnish Government, as people used to say. The population of the village was a bit over one hundred, which is about one half of the population of the post-war period. The population in the municipality, where the village was located, was also less than half of the population as it stood after the Second World War. A fourth of the villagers are Russian Orthodox. The overall unemployment rate in the municipality was about one quarter of the labour force during the time of Els' visit. Dur-

ing my fieldwork, the largest industrial plant in the municipality decided to move its production to China, which meant either unemployment or a move for more than one hundred middle-aged, mostly married women with their families. If they moved, the care-taking of the elderly – their relatives in the more distant villages – would be abandoned.

The main interest during my fieldwork was the problem of heart disease, almost endemic in the area. I wanted to know how people made the situation meaningful, how they acted with the illness, both their own and their relatives'. On a deeper level, I was interested in the meaning of illness and the relationship between illness and culture.* In the situation of a long-lasting movement of people out of the area, my fieldwork interest focused on the lives of people who remained. Their motives for staying in the village were various. Women used to say that this was their home and therefore their reason to stay. Some remained because they considered they had no alternatives. Some had tried to work in southern Finland and had returned. Some wanted to stay because they had elderly parents to take care of. Several men said that they wanted to remain because of the possibilities for hunting and fishing in the huge forest areas of North Karelia. For them it was an important part of their quality of life, even though their salary would remain lower than in the city areas. Consequently, my sample is different from those in current *diaspora* studies, where the interest is mainly focused on (transnational) people who move, or are in motion, as refugees or exiles, in search of a new identity.

North Karelia

Finnish North Karelia is a gradually emptying social and cultural periphery, which has been constructed historically through layers of political acts. It has always differed from the more affluent parts of the country in terms of its high poverty, high unemployment rate, high morbidity and mortality rates for various illnesses, notably heart diseases and depression, but also for its high rates of violent death and suicide. According to historians and demographers (e.g. Turpeinen 1986; Kannisto 1947, 1990), people in North Karelia have been dying earlier than in other parts of the country since the existence of reliable statistics. The problem of an 'Eastern excess in mortality' (Koskinen 1994) – which is still about 50% among middle-aged men

* The study was published as a monograph in 2008, under the title *Reikä sydämessä* (Hole in the heart).

with respect to mortality in heart diseases, and 35% in connection with suicide and violent death more generally – is embedded in the ‘Eastern question’ of our country, as I would like to call it.

Throughout many centuries, until 1809, Finland was a Swedish province. The eastern parts, however, have been more or less influenced by the Russian empire while the western parts have had a more intense interaction with Sweden. Numerous recurrent wars between the two empires were carried out in the eastern areas of Finland, which, from the 14th Century onwards, constituted the border area of the two empires. As an outcome of the almost endemic warfare, this area was at times ceded to Russia, at times to Sweden. In the early 19th Century the whole of Finland was ceded to Russia as an autonomous area. Consequently, sources of livelihood have differentiated historically between East and West. Western Finland has developed more during times of peace and thus has become wealthier, and is still partly inhabited by a Swedish-speaking minority.

Finland fought two wars against the Soviet Union, the Winter War and the Continuation War. In the subsequent peace treaty with the Soviet Union, Finnish Karelia, the south-easternmost part of Finland, which comprised an area of about one tenth of the total area of Finland, was ceded to the Soviet Union. A little more than 10 percent of the Finnish population at that time, 420,000 Karelians, were evacuated from the area. Their subsequent resettlement in various areas of Finland was a national event, which markedly overshadowed the social life of Finland after the war; in fact, it still continues to resonate for many people and their families today. Even though the evacuated Karelians were distributed all around the country, some of them stayed in North Karelia.*

The mourning and grief over the lost region of Karelia is more than a two-generation-long national narrative in Finland. In the area of my fieldwork, the cultural wound was still both present and persistent. Since the peace treaty with the Soviet Union, the national border cuts across the area of the municipality, which was divided into two parts; one half ceded to the Soviet Union. The hills of this other half were clearly visible to the villagers, and the more remote areas were now called the ‘eastern villages’. Economically, politically, and culturally, the fate of North Karelia after the Second

* Because North Karelia and the eastern parts of Karelia consisted of a cultural and economic area with a long and lively common history, the Karelian problem touched people living in North Karelia in a different way than it did people in other parts of the country. More often the evacuated Karelians were relatives, friends, or colleagues of the people living in the North Karelian area.

World War is crucial. The economic and cultural ties and lively connections with Karelia were cut off and North Karelia became like a limbless torso, often desperately attempting to represent some of the lost Karelian culture.

Loss and heart disease

In their everyday theories of heart disease, local men generally used political tropes, but North Karelian women most often described poverty and overwork as the main causes of loss of immunity and resistance to illnesses. The woman that I quoted at the beginning described her mother typically as a woman whose life had been filled with too many children, and too much work and responsibility for others: children, relatives, and a sick husband. Poverty and strain wear away one's heart, they may cause a hole. But also other strains wear one's heart, like the slackening of social ties that are so important in the area. *Diaspora* has challenged the grounds of life precisely because it has questioned social ties. But diminishing possibilities to decide about one's life also make people weaker. The consequences of historical experiences are layered in the body: its resistance against illness becomes weaker. It is in this way that people become broken winged and broken hearted, women explained to me. Symbolically, the heart is the centre of the body and the site of life and energy. When there is a hole in the heart, in its tip, the heart is forced to do an impossible work: more power would be needed for every beat. The hole makes the heart ineffective, and a diminished amount of blood reaches the tissues with every beat.

This was how women talked about heart disease. In North Karelia, as everywhere in Finland (or western countries), heart disease is defined principally as a male issue. Consequently, women were most often talking about their husbands and their diseases, as was the North Karelian* health prevention project, with its specific aim to decrease *male* mortality from heart disease. In men's local theories, poverty, profound social structural change after the Second World War, and historical experiences of exploitation were the main causes of heart disease. They used political tropes for their theories. But the heart was also the site of pride and honour. The concept of a good life included a sense of pride as the result of work well done. Heart disease was, therefore, a sign of good life. Men used to draw the consequences of poverty and exploitation in two directions: they could be defined as a direct cause of one's heart disease and in these narratives one was at the mercy of

* North Karelian Project for prevention of heart disease, from 1971.

one' life; while in other tales men were strong – and became even stronger despite a hard life – “they could endure, but the heart failed”. Heart diseases were *natural* because they constituted a natural consequence of such a life. They were *natural* also in another meaning, pointing to the magnitude of good men in North Karelia. In both senses, heart disease shaped a local idiom through which it was possible to express important comments on society and life (cf. Good 1977; Nichter 1982).

In women's theories, nevertheless, loss of bodily resistance and immunity due to a hard life was an important reason for illness. Heart disease was not attributed to moral strength but merely to a gradual weakening of the body. Why? Heart failure seemed to be constituted to a great extent around *loss*. “Loss is a cause of heart disease and suffering,” they used to say, and in this way heart disease constituted a cultural idiom through which they were able to express their concerns. And at the core of what was lost, or what was threatening, were the social bonds. This, for them, was the content of the heart aches. When women talked about loss, not only spatial but also temporal dimensions became important: the causes of loss were not only embedded in the present *diasporic* way of organizing the family, but also layered within the history of the area. Illnesses can thus be understood as comments upon local history, or to put it in other terms, local history is embodied in the villagers' experiences (Skultans 1998).

But much like Mariella Pandolfi (1990: 261), I sensed that rather than tales or narratives of illnesses or suffering, what I encountered was a *memory* of suffering, “the imagined side of suffering that links the distant past to a present.” But how does one access the imagined side of suffering? How does one find ‘the origins’ of the cultural idiom, ‘ahas’, as women used to call it? Indeed, how things are remembered and how they are narrated can be portrayed against a local supply of stories. A collective reservoir of narratives may guide people's ways of telling (Ricoeur 1991). In addition to the present places and spaces and the multiple meanings of Karelia, the significance of loss is embedded in local memory also through the local folklore. In order to contextualise my study by local history, I used the lyrics of local songs* which constitute a kind of collective storage of memories and narratives of my informants. The song texts, along with incantations, runes, spells, and some

* The song texts – or lyric poems, as I also call them – are Finnish-Karelian Kalevala-metre lyric songs. They consist – as does the Kalevala, our national epos – of folk poetry cast in unrhymed, trochaic tetrameters. All of the lyrics I refer to are published in The Ancient Poems of the Finnish Folk, *Suomen Kansan Vanhat Runot*, abbreviated SKVR, in the three volumes of North Karelian poems.

ethnomedical data, were collected in the same area and more widely in North Karelia from the end of the 18th century.* The poems were collected over 150 years ago from the people living in the same village where I did my fieldwork; many of the singers at that time were the present villagers' ancestors.

What remains? Home and agency

For women, in the *diasporic* situation that threatens social bonds, home remained a crucial place and held a strong value, even though some of its essential dimensions and practices have changed. The home was a metaphor of the self and the centre of women's lives, which is why the altered situation was difficult for them. Through the home women were – and are – rooted in their world, and the home – even deficient now because of the *diaspora* – still held them there. The home served as a kind of axis that kept their world in place; it was a form of *appaesamento* (Pasquinelli 2004). A home brought together different spheres and layers of life and also connected this world to the other world. In Greek Orthodox homes, the holy icon with the linen shroud over its top were signs of the bridge between worlds. The connecting meaning of home was even more important in the *diasporic* situation of the families. The current threat of loss consisted of an insoluble conflict between the fragmented situation of the family and women's own home in North Karelia. For the mothers, a merely theoretical solution would have been to move closer to their children's families, but on the other hand, it was impossible to leave one's home in the village.

Located in the midst of North Karelian life, the home remained a self-evident centre both for elderly parents who stayed in the village, and also for those younger people who had decided to live in the area. In this situation, home became *a process* instead of being a mere place. For the mothers, home gained a new meaning of *receiving*, because the children who had left came back, at least for holidays. When young people married (and moved to the

* The Ancient Poems of the Finnish Folk contains 40 volumes of collected incantation, rune, and poetic material. From the North Karelian area alone there are three volumes. In the municipality of my fieldwork, over 1500 poems and incantations were collected, and about 600 from the village area where I did my fieldwork. In this article, I refer mostly to *Huolirunot*, lyric poems of various concerns and worries, which, collected in the North Karelian area, contain almost 600 poems (SKVR VII 2: 1725-2313). They are mostly sung by women. The code in the text refers to the number of the poem in the volume SKVR VII: 2.

south), they often created two homes, one with their own family in southern Finland, and the other, original and 'genuine home,' in North Karelia. The following quote is from a young, unmarried son:

Of course that home is our home. I don't call this place 'home,' usually I say that I live in Helsinki, not that I live *at home*. ... Every summer, immediately when the summer holidays start, we go back home – I mean back home in North Karelia.

Life in the *diaspora* contributed to a richness in children's lives. They acquired two homes, and new threads within their social bonds. For the mothers who stayed in North Karelia, the situation appeared more or less the opposite even though they considered the *diasporic* life of the children as a kind of good life. It constituted a good future for their children, more or less, and they knew that it was better than in North Karelia. The children departed, but they returned when the summers came, and the mothers and homes received them; a continuous movement of letting go, receiving, and of missing them. For the mothers, the process was about enacting loss by attending to the social bonds of the family and the village. At the same time it was about attempts to prevent a hole in the heart, a hole which would cost them their animation and power in order to take care of their own and others' losses.

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What is cultural validity and why is it ignored?

The case of expressed emotions research in South Asia

SUSHRUT JADHAV

A general problem plaguing research in the field of international psychiatry is the ignorance of cultural validity. Expressed Emotions (EE) research in South Asia is a classic example of this fallacy and difficulties associated with this research have been discussed at length (Bhugra & McKenzie 2003, Hooper 2004, Jenkins & Karno 1992, Kapur 1992).

Critiques of the International Pilot Study of Schizophrenia (IPSS) (Kleinman 1987) explicated problems inherent to Euro-American taxonomies and consequent methodological flaws in designing international mental health studies. Until recently, the field was dominated by debate over universality and relativism, but has now moved on to re-visit wider cultural and political forces that shape conceptualisation, design, interpretation and collaboration of such research activities (Williams 2003). In the process, a paucity of discussion about what is cultural validity and why is it ignored, have hindered further progress.

What is cultural validity?

If the validity of an instrument refers to actually measuring what it purports to measure with reference to the truthfulness of a theory, cultural validity extends to contextualise validity within the specific community being studied. It follows that theories and instruments need to be 'grounded' within that culture, if they have to be considered valid. Grounding implies researchers do *not* begin with *a priori* notions but instead develop theoretical constructs that reflect local concerns including indigenous theories, participant voices, priorities and values. For example, if tests on cognitive capacity, in a post capitalist society, privilege speed of response whereas in a Buddhist culture that values meditative reflection, scoring on tests will have to be in opposite directions and interpreted within each culture's norms. Similarly, the hierarchy of stressful life events in one culture might need to

be re-calibrated in another to reflect severity as perceived by members of that culture. Indeed locally stressful events may lead to either cross-culturally overlapping categories or generate an entirely new set of events. Studies on cross cultural aspects of body image distress might consider moving away from a focus on anatomical physical pre-occupations in European societies to instead, the value of 'grace' and 'poise' in South Asian cultures. These are superficial examples and the issues turn more complex when deploying research instruments that aim to capture local emotions and their relationship with disease categories. Consider for example, potent emotive idioms in a multi-lingual Indian setting, such as *Pyaar se chaata mara* (Hindi for 'I slapped him with love'), *Meetha daard* (Hindi for 'sweet pain'), and *Anpu* (a complex polyphonic Tamil term for a range of love related emotions). These emotions do not slot into neat categories of over-involvement, warmth, critical comments and hostility, nor can they be assessed by hour long EE rating instruments.

Validity of Expressed Emotions research in South Asia

The Expressed Emotion findings from the much quoted Chandigarh study (Leff et al. 1987) raise several issues. Although this unreplicated research is now over two decades old, this study remains to date, the sole evidence demonstrating the causal role of Express Emotions in the relapse of Schizophrenia in South Asia. Yet the implications of findings from this study are profound. They constitute received wisdom. This is chiefly achieved through the texts that are exported to most low income nations and endorsed by local mental health professionals, who seek to *comply* with the tacit demands of their western counterparts. Indeed, ethnographic research suggests that this rhetoric of 'compliance' with international governance is perpetuated and projected by local Indian clinicians onto their patients (Jain & Jadhav, in press). The published Chandigarh study states that the team of researchers had initially developed concepts of Expressed Emotions in South London, operationalised their instruments and trained (read socialised) all data collaborators to ensure reliability. Not surprisingly, the study could only discuss findings with respect to problems with inter-rater reliability. Variations on inter-cultural differences that showed up as problems in inter-rater reliability during the preparatory phase, were technically fixed by altering the thresholds of ratings. The consistently lower ratings achieved by one of the raters (AG, a bi-cultural psychiatrist) on the over-involvement scale was left unexplained from a cultural perspective. Similarly, for warmth and positive

comments that were found to be significantly higher amongst the Chandigarh sample compared to the London findings.

Why is cultural validity ignored?

So, why did the Chandigarh study design not consider developing indigenous concepts of emotions expressed in their full range? Why were local emotions and their attending theories not mapped out and then examined for goodness of fit with professional constructs? Had this been done, the operational mode of 'measuring' emotions might not have been restricted to a long verbal interview that relied on assessing emotions expressed through a predominant visual mode, and one that was more salient in London. What about assessing the complexity of emotions in India that include: women behind a veil, lovers who have never met, the role of food in substantiating feelings, and distressing letters from a mother-in-law, etc? (Kapur 1992).

The consequences of demonstrating that Expressed Emotions in Chandigarh was lower than London and yet predicted relapse, are twofold: 1) It gives false credence to universalising the concept of Expressed Emotions, creating a conceptual problem of "predicting without understanding" (Jenkins & Karno 1992), and stifling much needed theoretical enquiry within the discipline of cultural psychiatry; 2) Clinicians who intervene in Indian and non-European families to 'reduce' presumed 'toxic' (in an English context) emotions might be taking away the very glue ('nourishing' emotions in an Indian context) that holds a family together, and thus negatively impact on the course of the Schizophrenia.

These issues raise questions that go beyond the debate of validity to that of cultural, ethical and political concerns for both South Asians and the local UK Black population. If, as Jenkins argues, the Expressed Emotions bandwagon has turned into a "most thoroughly examined psycho-social research construct", it is indeed surprising that there is not a single study examining the role of Expressed Emotions amongst the British Black population, despite concern over the extensively re-examined nine fold high rates of schizophrenia within this ethnic group, as compared to base rates of the white population (Jarvis 1998; Littlewood 1993).

Given the infancy of the new cross-cultural psychiatry at the time of the Chandigarh study, these invaluable insights may have eluded the researchers. As the field has now moved onto more sophisticated terrain, it might be worth cautioning both researchers and clinicians to 1) re-consider the role of culture as a valid construct central to any research in the field of interna-

tional mental health, and 2) to reflect before intervening in high Expressed Emotion non-European families until the discipline establishes more firm theory that is predicated upon local cultures.

Thus, it would be premature to conclude that EE intervention for Schizophrenia is effective across cultures. The reported usefulness appears to more favour academic careers of international mental health professionals than help the culture being investigated (Jadhav 2005). In this present state of affairs, clinical work to reduce Expressed Emotions is simply dangerous outside Euro-American families unless locally validated. The past decade of research in medical anthropology and cultural psychiatry has continuously argued that the discipline of psychiatry might benefit from a fuller re-examination of its own cultural premise, rather than focus on how cultural variations in constructs such as Expressed Emotions in different societies could be better explained. Considerable efforts have focussed on researching how stigma, family support, rural lifestyles, and tolerance towards the mentally unwell, might favour better prognosis for Schizophrenia in low-income nations. Clearly, a great deal of effort and money spent would be better rewarded if researchers would also address why the course and prognosis of Schizophrenia is poorer in western countries. It would also appear that a fundamental re-education of western psychiatrists is necessary in order to stem the proliferation of spurious diagnostic categories that then find their way not only into official international systems of classifications (as these can be more easily rectified) but also into the minds of international researchers in the field. In conclusion, it may be hypothesised that a new diagnostic category of '*cultural iatrogenesis*' within future nosologies may help researchers generate some awareness of the sheer scale of institutional trauma generated by deploying 'branded' (manufactured in Euro-American cultures) scales and instruments. Returning to the case of Expressed Emotions in low-income nations, the development and application of such research methods, instruments and scales appear to be not just a matter of cultural insensitivity or about category errors. These are indeed instruments of violence (Farmer 2004).

* Abstracting local explanations of suffering to the level of a psychopathology constitutes 'cultural iatrogenesis' (Jadhav 2007).

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The caregiver

ARTHUR KLEINMAN

Most of what we know about caregiving has to do with the practices that constitute it, like feeding, bathing, toileting the seriously ill and disabled, or results from studies of professionals and patients. Lay caregivers are configured, almost as a caricature, as ‘burdened’: financially, emotionally, morally. What the caregiver experiences, other than burden, has been both understudied and distorted.

Based on research in China on how the elderly die in Shanghai, on my career-long interest in the failure of caregiving in medicine, and especially on my experience as the primary caregiver for my wife, Joan Kleinman, who suffers from Alzheimer’s Disease, I have come to understand caregiving as an embodied experience of ‘presence’. By this I mean the quality of being there for and with a loved one in the fullness of one’s humanness – alert, engaged, responsive, resonant, supportive – as a foundational existential act of protecting, assisting, emotionally supporting and morally sustaining the other and one’s relationship with him or her as the grand arc of a life bends inevitably toward diminution and death.

How this existential condition is inflected and reworked by culture, gender and other social realities in different local worlds has hardly been examined and remains a great question for history and ethnography and cross-cultural comparisons. But even in the absence of detailed studies, we can see that constituting and sustaining presence in professional settings is by definition extraordinarily difficult to achieve. Hence, how can it be surprising that professional caregiving by doctors and nurses seems to be characterized by the absence of ‘presence’. It is impressive when we see busy and distracted professionals find a way of being there for their patients. Because lay caregivers are there for their loved ones, it is not impossible to achieve this with families and friends and the care receiver, him or herself.

One of the sources of insight for me into the importance of presence in care has been the work and paintings of Els van Dongen which possess a rare and remarkable quality of both expressing and exploring a deep humanity. Her paintings seem almost haunted by both the presence and the absence of the caring other. I take the interpretation of this enchanted quality to be an object for further research.

Surprisingly, the performative turn in anthropology has not contributed much to the study of caregiving. The theory greatly outstrips the research on the lived experience of caregiving and care-receiving. William James referred to the 'moreness' of experience as that which got at the truly human qualities that seem to escape classical psychological research categories like cognition, affect, behavior.

Much the same can be said about the recent anthropological turn toward 'subjectivity'. The writing seems to lack a fundamental appreciation of what it is that makes us human. Surely, caregiving is one of those things, and presence in caregiving brings us closer to what it is in lived experience that is lively, vivid, overflowing, and that elicits deep feeling in others. It is a quality conveyed by the way the caregiver looks at you, with curiosity mixed with experience, with affirming words, acknowledging gestures, and the ability to cast feelings and ideas into the intersubjective space ahead, as a provocation to others to live forward. This is what the phenomenologists said is how the responsive self is positioned, as if to say, I am here for you. I care. We are all caregivers. At least, we should.

Sterven in het psychiatrisch ziekenhuis

HUUB BEIJERS

Dit is de Dood, helaas, die troost geeft en doet leven;
De allerlaatste hoop – want doel van ons bestaan –
Die ons als een elixer in een roes laat zweven,
En ons de moed geeft tot de avond door te gaan;

Uit: De dood van de armen – Charles Baudelaire

Acht of negen jaar geleden werkte ik enige tijd in ‘Wolfheze’, een psychiatrisch ziekenhuis in de buurt van Arnhem. Verscholen tussen de bomen, in een van de hoekjes van het terrein trof ik op zekere dag het kerkhof van het ziekenhuis. Een verwaarloosde begraafplaats met kleine betonnen paaltjes met daarin nummers gebeiteld, her en der een stèle daartussen, meestal ook ten prooi gevallen aan de tand des tijds, omgevallen of scheefgezakt en overwoekerd. Ik besloot de graven te fotograferen en deed dat vervolgens ook in enkele andere psychiatrische ziekenhuizen. Sommige van die ziekenhuizen hebben een eigen begraafplaats andere begraven hun patiënten op de gemeentelijk begraafplaatsen in de buurt. In totaal heb ik acht ziekenhuizen bezocht, in het westen, oosten, midden en zuiden van Nederland, vrij willekeurig, plekken waar ik beroepshalve kwam. Van vier ziekenhuizen heb ik foto’s gemaakt. Wat kan er worden verteld over sterven van psychiatrische patiënten in de psychiatrische ziekenhuizen aan de hand van deze foto’s, en wat is daarvan nog actueel? [Foto 1: c.](#)

Begraven op het inrichtingsterrein

Beginpunt en maatstaf voor mijn rondgang was de begraafplaats van het psychiatrisch ziekenhuis Wolfheze. Dit ziekenhuis is in 1906 gesticht door de *Vereeniging tot Christelijke verzorging van Krankzinnigen en Zenuwlijders* in Nederland. Deze vereniging werd opgericht door een aantal vooraanstaande christenen, die diep begaan waren met het droevig lot van de krankzinnigen en op grond van hun godsdienstige overtuiging het als een plicht van barm-

hartigheid zagen om daar zoveel mogelijk verbetering in te brengen (Hofsink 2004). Deze 'Vereeniging' kocht een terrein van 86 hectare bos in het zuidelijke deel van De Veluwe. Tegenwoordig maakt het ziekenhuis deel uit van 'De Gelderse Roos, een instelling voor geestelijke gezondheidszorg (GGZ) met vestigingen in Arnhem, Rivierenland en de Veluwevallei. Foto 2:

De begraafplaats, achter op het grote terrein, is slecht onderhouden. Omdat de natuur er vrij spel lijkt te hebben gehad, is het een idyllische plek, een stil dennenbos met grote rododendronstruiken. De graven zelf zijn vooral kleine betonnen paaltjes, die her en der tussen de bomen staan (foto 2) – meestal niet hoger dan 30 centimeter, verzakt en overwoekerd, met de nummers half zichtbaar (foto 3). Het is een vergeten oord, voor mensen wier naam er kennelijk niet toe deed. Een nummer volstond, verwijzend wellicht naar een register met namen van patiënten, met eigen verhalen. Her en der tussen de paaltjes ligt een groter graf, voorzien van een naam. "Rust zacht lieve Gon". Gon heeft haar naam behouden. Alleen haar voornaam met liefde uit het steen gebeiteld (foto 4). Kennelijk heeft familie zich hier verantwoordelijk getoond. Rechts naast het graf van Gon ligt 'nummer 702', een klein betonnen paaltje, dat zich tegen Gon lijkt aan te vleien, om iets van haar warmte over te nemen. Het graf van Gon staat fier overeind. Maar zij staat alleen, veel van de grotere graftenen liggen om of zijn verzakt en overwoekerd. In Wolfheze lijkt de begraafplaats sluitpost van de begroting.

Een vergelijkbare situatie als in Wolfheze trof ik aan in De Grote Beek in Eindhoven: de vele kleine betonnen paaltjes, in genummerde rijen. De begraafplaats van 'Voorburg', het psychiatrisch ziekenhuis in Vught, heeft conform zijn rooms-katholiek traditie, meer praal en kleur op de graven. Hier geen betonnen paaltjes, maar stèles van sober beton, eenvormig, maar wel voorzien van namen. Soms meerdere namen op één stèle. Hier liggen niet alleen de patiënten, maar ook 'de zusters', nonnen die vroeger voor de patiëntenzorg verantwoordelijk waren. Ook zij liggen onder sober en eenvormig beton. Net als in Eindhoven zijn ook hier de verschillen duidelijk tussen hoger geplaatst personeel en de gewone personeelsleden en onderaan de patiënten. Foto 3:

De dood is het einde van ieders leven. Wat van iemand blijft doorleven is wat hij of zij aan andere mensen heeft gegeven en wat in hun herinnering blijft bestaan (Elias 1984). Graven en begrafenissen maken de balans op van de waarde van de overledene, niet alleen voor de achterblijvers, maar ook voor de gemeenschap. Een goed verzorgde begravenis en graf van de rijken en prominenten bevestigt hun vooraanstaande positie in de samenleving. De eerloze graven van de armen doen het tegenovergestelde, ze tonen hun



Foto 3: Begraafplaats PZ Wolfheze



Foto 1

Een van de graven op de begraafplaats van
het psychiatrisch ziekenhuis in Wolfheze



Foto 2

Rij graven op begraafplaats PZ Wolfheze



Foto 4 Het graf van
Gon, begraafplaats PZ
Wolfheze

absolute uitsluiting uit de gemeenschap. “There was no shame in poverty, but great shame in a pauper’s funeral,” merkt Laqueur (1983: 109) op. Scheper-Hughes (2001) beschrijft hoe in het arme noordoosten van Brazilië het kerkhof het laatste oordeel velt over iemands individuele, familie- en sociale identiteit. Voor de overledenen zelf en hun familieleden is het van betekenis om ‘goed’ begraven te worden. Dat wil zeggen niet in een groepsgraf, zonder kist en onherkenbaar. Een goed graf is een vorm van postuum eerherstel en voorkomt dat degene die begraven is het stigma en de ellende van de armoede moet meedragen in een hiernamaals. Het respect van de levenden en het respect van de doden zijn beide in het geding. De ‘paupers funeral’, een armeluis begrafenis’ is schaamtevol en was in het verleden ook risicovol, omdat het lichaam kon worden overgedragen aan de medische wetenschap voor dissectie: “This was a terrifying ‘punishment’ for anyone not able to afford their own funeral” (Laqueur 1983: 125). Obductie ten behoeve van de wetenschap was ook in de Nederlandse psychiatrie een bekend verschijnsel.

Het leven in de inrichting

De vraag is of het verhaal dat de graven vertellen nog geldt voor de patiënten die tegenwoordig hun leven slijten in een psychiatrisch ziekenhuis. Het is moeilijk te zeggen op hoeveel mensen dit nu van toepassing is. Michon en Kroon (2002) komen op een getal van 15 tot 20 duizend personen die in voorzieningen in de geestelijke gezondheidszorg ‘verblijven’. Daarbij gaat het zowel om klassieke verblijfsafdelingen van psychiatrische ziekenhuizen als om woonvoorzieningen in de samenleving. In 1986 bestond 65,5% van de klinische capaciteit van de geestelijke gezondheidszorg uit voorzieningen waar mensen langer dan twee jaar verblijven (RVZ 1996). Nu is dat ongeveer 53%. In 20 jaar psychiatrische geschiedenis in Nederland is – anders dan in veel Angelsaksische landen – de vermaatschappelijking van zorg niet gepaard gegaan met een gelijktijdige afbouw van klinische voorzieningen. De Nederlandse GGZ is nog erg klinisch institutioneel georiënteerd. Foto 4:

Patiënten en hun direct betrokkenen hebben sinds de jaren zestig van de twintigste eeuw verhalen verteld over schrijnende omstandigheden, rechteeloosheid, en de ontkenning van het bestaan van mensen die langdurig verbleven in troosteloze inrichtingspaviljoens. Zo gaven zij zelf inhoud aan een emancipatieproces (Hunsche 2008). In Nederland heeft vooral Els van Dongen (1994) de verhalen van mensen met een psychose vertolkt en ook begrepen. Zij zegt daarover:

De verhalen gaven stuk voor stuk aan dat mensen zich slachtoffer voelden van onverschilligheid, sociale eenzaamheid, minachting, onrechtvaardigheid of sociale krachten die buiten hun controle lagen. (...) Er is geen gelegenheid voor gezamenlijk herinneren, sociaal herinneren van onrecht, van frustratie en pijn die de positie van psychiatrische patiënt dikwijls met zich meebrengt. (...) Als de verhalen geen luisterend oor vonden, omdat ze “buiten de alledaagse werkelijkheid” stonden, ze ondergronds verder woekerden en mensen zo niet angstig maakten, dan wel het idee bevestigden dat ze wel echt ‘gek’ waren. Of in sommige tragische gevallen: als de herinnering en het verhaal wordt afgenomen, betekent dat soms letterlijk de dood van de verteller (Van Dongen 2001: 2-3).

Maar eenvoudig is het niet, als lezer een lijn in het verhaal te vinden. Van Dongen vraagt een grote inspanning van degene die van een emic naar een etic perspectief wil overschakelen. De verhalen vertellen vooral dat de vertellers zich niet kunnen lossnijden van een verleden dat heeft geleid tot een vorm van ernstig en langdurig psychisch lijden en van ontbering in de schraalheid van het inrichtingsbestaan. De inrichtingen zijn plaatsen van transformatie van het verhaal van de patiënten. Dat kan ten goede zijn als het een vorm van herinneren, vergeten en hervertellen betreft van het verhaal, waardoor de ervaring past in een verhaal waar de patiënt mee kan verder leven. Als dat echter niet lukt en behandelaar en patiënt niet synchroon zijn en verleden, heden en toekomst in een gezamenlijke werkrelatie aan elkaar kunnen verbinden, versteent het verhaal. Er ontstaan ‘tragische contradicties’ zoals Van Dongen dat noemt, die het bestaan als patiënt chronificeren en het verhaal van de patiënt vastzetten in een eindeloze herhaling van retoriek. Voor de buitenwereld is die retoriek niet meer dan dwaasheid. Maar, zegt zij, deze herhaling is een vorm van vitaliteit, een voortdurende poging van de patiënt om het verleden te laten herleven en de ongezone aspecten van onze cultuur, die de psychiatrie als een zware last op de schouders van de patiënt legt, aan de kaak te stellen. Van Dongen is een authentieke verteller en vertaler van deze verhalen en geeft daarmee inhoud aan de antropologie van de psychiatrie.



Foto 5 Begraafplaats De Grote Beek

Niet alleen de symbolische ontkenning die Van Dongen beschrijft, ook het dagelijkse leven van psychiatrische patiënten is ontluisterend schraal. Het is “een keten van lege zondagen” waarin elke dag vergelijkbaar is met een zondag waarop je tot niet veel meer komt dan op bed liggen, eten, koffie drinken, roken en misschien een korte wandeling of kijken naar tv. Nog geen 5% (45 minuten) van de tijd wordt besteed aan face-to-face contacten, terwijl de standaard uitgaat van minstens 97 minuten per dag. Van dagactiviteiten wordt weinig gebruik gemaakt, gemiddeld 50 minuten per week, tegen vijf tot tien uur volgens de standaard (Wijngaarden et al. 2001). Het feit dat dit soort standaarden het leven van mensen regeert laat zien op welke ‘moderne’ wijze er tegenwoordig over levens van psychiatrische patiënten wordt beschikt. Dat die normen niet worden gehaald, lijkt vergeleken daarbij een. *Foto 5*

Herinnering

De begraafplaatsen en graven van psychiatrische patiënten getuigen van dit lege leven. (cf. Scheper-Hughes 2001, Laqueur 1983). Ze behoeven geen naam, zijn vergeten, afgezonderd van de anderen, zonder eigen identiteit, achtergelaten en eenzaam. Hun nagedachtenis heeft geen recht op onderhoud, hun graven worden verwaarloosd en vergeten.

De graven laten zien dat de dood al is ingetreden voor het feitelijk fysiek overlijden. Ze vertellen het verhaal over mensen wier leven geen waarde had: een leven dat dood is. Sudnow (1970) noemt deze situatie ‘sociale dood’: “de omstandigheid dat een institutie een patiënt, als voorbode van een naderende dood, (...) behandeld als een lichaam, als ware hij reeds dood.” Vanwege belangen van de ziekenhuisorganisatie en van de professionals verschaalt de zorg aan de sociale dode. Dit induceert een fysieke dood. Sinds Sudnow heeft het begrip sociale dood een ruimere betekenis gekregen (cf. Reidy 1993). Het begrip is los komen te staan van een naderende fysieke dood, maar refereert aan een proces van voortdurend krimpen van de wereld van patiënten, van losmaking van de sociale gemeenschap (social body), en van een leven dat bepaald wordt door zinloosheid van het bestaan (Van Dongen 2000, Helman 2001). Van dit proces van losmaking van de wereld en van verlies getuigen familieleden van langverblijfspatiënten:

Yet it seemed pointless to visit, since he seemed unaware and it was mainly depressing to see his decline. Our visits became less frequent, from twice a year, to once a year, to even less frequently. Every time we

visited, he was further gone from his old self. We experienced various levels of decline and loss over the years. Initially upon institutionalization, he was confused, but had some memories of the past and could converse with you in between his talking to himself. Then over time his memory was completely gone. He did not seem to recognize us. Next he stopped talking, except for an occasional outburst, sounding like a psychiatric patient. He aged rapidly and developed repetitive, nervous mannerisms with his hands. Eventually he lost his ability to walk. He ultimately died of an infection in his body” (Williams 2000: <http://www.losingtom.org/death/funerals.html>).

Het is opvallend dat dit proces van sociaal overlijden gepaard gaat met de waarneming van een versnelde fysieke veroudering. Dat is niet alleen bij Williams, maar ook anderen getuigen daarvan. In *The Independent* van 5 oktober 2008 spreekt Ana Galvin over haar 29-jarige broer, psychiatrisch patiënt, die sterft aan een hartaanval: “Watching him slowly deteriorate like an old man was horrendous. I can’t believe that in a civilised society this is how we treat people who are mentally distressed” (Lakhani 2008). De Nederlandse Eveline van Dijk vertelt in de documentaire die zij maakte over de suïcide van haar zus: “Ze ging kliniek in kliniek uit, en zag er intussen een stuk ouder uit” (Van Dijk 2008). Foto 6:



Foto 6 Begraafplaats ‘Voorburg’, Vught

Een chronisch leven in de psychiatrie is een proces van sterven dat uiteindelijk tot de dood leidt. De fysieke dood is daarin niet meer dan een transitie waarin het lichaam (in het verleden) ter beschikking kwam van de wetenschap, en verdween. Juist door die verwaarlozing is het mogelijk de graven en het leven van deze mensen in beeld te brengen en de herinnering te bewaren.

Die herinnering krijgt steeds meer aandacht. De Symfora groep, GGZ-instelling in Amersfoort, pleitte onlangs voor het bieden van betere palliatieve zorg aan langverblijfspatiënten. De zorg zo beschrijft een van de verpleegkundigen schakelt, als reanimeren geen zin meer heeft, op enig moment over naar terminale zorg. Laatste wensen worden ingewilligd en aan de begrafenis wordt extra zorg besteed, ter nagedachtenis.

Bezoektijden gelden niet meer. Je laat een deel van je verpleegkundige waarden en normen schieten (...) We richten de slaapkamer van de stervende in, halen een scherm-lamp uit de huiskamer, een schilderij uit het magazijn. We plukken verse hortensia's, zetten de radio van de nachtdienst naast het bed: (...) Soms redt iemand het toch, dan gaat alles weer terug" (Sluiter 2008: 28).



Foto 7 Gedeelte van het monument voor de naamlozen.
Begraafplaats van De Grote Beek in Eindhoven

Het leek alsof ik mijn broer had teruggekregen”, zo vertelt een familielid van een overleden patiënt. Deze palliatieve zorg is een vorm van individuele rehabilitatie, van eerherstel, die de dode tot leven wekt, om hem te kunnen laten sterven. Ik denk echter dat dit niet volstaat.

Eind 2008 stuitte ik op een persbericht over ‘een monument voor de naamlozen’, dat op initiatief van patiënten was opgericht op de begraafplaats van ‘De Grote Beek’. Dit monument wil de 1800 begraven patiënten hun naam teruggeven. Het is een publiek getuigenis en een vorm van postuum sociaal eerherstel (foto 7). Het monument is een glazen structuur met vier vleugels, als het ware wijzend op de vier verre windrichtingen, waar patiënten vandaan kwamen. In het glazen dak zijn de namen van de naamlozen gegraveerd. [Foto 7](#)

Op die wijze is aan de patiënten die zijn achtergebleven een naam gegeven. Herinnering is echter niet tijdloos en abstract, maar krijgt betekenis in een context en wordt gemaakt in een actief proces van herinneren, van actieve getuigenis en verzoening met de manier waarop de Nederlandse samenleving in het verleden met de levens van psychiatrische patiënten heeft gesold. Voor heling van de levens van psychiatrische patiënten is een openbare getuigenis nodig, publieke erkenning en bereidheid tot luisteren. Het afleggen van een getuigenis is heilzaam voor de gezondheid van mensen, vergroot het vermogen om lijden te verdragen en de zaken die het lijden veroorzaken ter discussie te stellen (Van Dongen 2001: 4).

Het is de vraag of het monument in Eindhoven zo’n plek kan worden. Verzoening is alleen mogelijk als we een gedeelde taal of gedeelde beelden vinden, in dit geval om de verhalen van de patiënten te verlossen van hun dwaasheid en ze begrijpelijk te maken (cf. Van Dongen 2001). De ongemakkelijkheid die dat oproept, die wij daarvoor nodig hebben, wordt, beter dan door het monument voor de naamlozen, verbeeld door het kunstwerk van Reinier Kurpershoek. Kurpershoek heeft op het terrein van Sint Anna, het voormalige psychiatrisch ziekenhuis voor vrouwen in Venray 100 ‘geknakte kruizen’ neergezet, met daarop de overlijdensdatum van een patiënt, de diagnose en de doodsoorzaak, die hij uit oude patiëntendossiers heeft gehaald. Het kunstwerk werd gemaakt voor de tentoonstelling ‘De Waan’ in 2002 en leidt sindsdien een omstreken leven. Inzet was om de geknakte kruizen na de tentoonstelling in de openbare ruimte te plaatsen in Venray. Inwoners van Venray houden dat tegen. De kruizen veroorzaken ‘hinder’. Dat pleit voor het kunstwerk: een goed monument voor de naamlozen moet de ‘hinder’ veroorzaken die nodig is voor sociale heling. [Foto 8](#)



Foto 8 De geknakte kruizen van Reinier Kurpershoek

Noot

1 Alle foto's, uitgezonderd die van het kunstwerk van Kurpershoek, zijn gemaakt door de auteur. De foto's van de geknakte kruizen van Kurpershoek zijn van Stichting Odapark, Venray, op: <http://www.buitenbeeldinbeeld.nl/Venray/index.html>.

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Congolese paintings on suffering, violence, and trauma

RUTH KUTALEK

The Democratic Republic of Congo (DRC) is a traumatized country. Struggling with war, violence, and political uncertainty, it is an extremely resource rich country with a population living in bitter poverty. Rich is the DRC in almost everything: fertile soil, rare metals (coltan, gold), and precious stones. Poverty is apparent in economic and social uncertainties: an almost non-existing infrastructure (health care, streets, schools), hunger, and violence in many parts of the country. For many people in DRC life is a conglomerate of many forms of distress, including war, anarchy, and forced migration.

Popular painting in Central Africa started in the 1920s with schools in Lumumbashi, Kinshasa, and Brazzaville (Anonym 1992). The most important representatives of this art form, Bela, Thango, and Pilipili, were precursors for contemporary artists such as Moke, Chéri Samba, Bodo, or Chéri Chérin (Anonym 2003). Congolese popular paintings are more and more present in art exhibitions, galleries, and private collections (Anonym 2003; Brändle 2008; Hug 1996; Jewsiewicki & Plankensteiner 2001; Pigozzi & Magnin 2006; Wendl 2004).

The paintings described here were produced by young Kinshasan artists in 2008. They deal with pressing political issues, with social and economic inequalities. They are sarcastic, sometimes shocking in their unveiled directness. They reveal a life world of misery and uncertainties that finds few parallels in Western countries. The 'peintres populaires' are well aware of the causes of their misery – the West, especially Europe and the USA. The two recent exhibitions on modern Congolese paintings in Kinshasa in 2005 and 2007 (Anonym 2007) make it clear that these paintings first and foremost are political and socio-critical art. The paintings unmask the day-to-day fragility of life in Kinshasa. "We tend to think of dangers and uncertainties as anomalies in the continuum of life, or irruptions of unpredictable forces into a largely predictable world. I suggest the contrary: that dangers and uncertainties are an inescapable dimension of life" (Kleinman 2006: 1).

Sam Ilus (Mbombe Ilunga) was born in Kinshasa in 1979 and started his career in 1997. In his painting 'Kongo est le Berceau de l'humanité ou l'Afrique?' (Fig. 1) he depicts a young desperate mother, in ragged clothes and barefoot, sweating, carrying her baby on her back. She pushes a crib over a greenish ground scattered with the skulls and bones of humans. The crib is jam-packed with street children, starving, with bony arms and legs and bloated bellies. An unborn child, embraced by the second 'o' in the yellow painted word 'Kongo', seems to symbolize the beginning of mankind. The wooden board behind the mother says: "La pays Africain, qu'on avait Trouvé l'os le Plus anciens de l'Homme, ce n'est pas à l'époque du Royaume Kongo? Car jusqu'aujourd'hui Congo ne ne retrouve pas, ou va le Congo..."

Fig. 1 Kongo est le Berceau de l'humanité ou l'Afrique?, Sam Ilus, Collection Ethnomédecine, Vienna

In 'RDC Fini la recreation' (Fig. 2) Sam Ilus shows the contrast of what Western and African politicians and authorities promise to the Congolese people and what the actual grim reality is like. Central on the left, and taking almost half of the space of the painting, is depicted the face of a white man with dark sunglasses, holding a speech. His sunglasses dimly reflect the suffering of the Congolese people – violence, hunger, and distress. Among the listeners are Javier Solana, Secretary-General of the Council of the European Union; William Lacy Swing, Chief of Mission, MONUC, and Coordinator of United Nations activities in the DRC, and a bishop. They promise peace – symbolized by the peace dove, and a jet fighter suggesting protection – and prosperity, as shown by the sturdy worker wearing a blue overall, yellow hardhat, and a shining watch on his wrist. He proudly holds the national flag. In the background the population is cheering. The African Union, United Nations, and the European Community throw relief supplies from airplanes.

Fig. 2 RDC Fini la recreation, Sam Ilus, Collection Ethnomédecine, Vienna

Alfi-Alfa (Alafu Bulongo) was born in Kinshasa in 1967; he started his career in 1983. In his painting the central figure asks himself "Qui dirige R.D.C.?" (Fig. 3). A UN soldier injects medicine into the country. Out of the sleeves of his uniform emerges a boot with the United States national flag; it steps on blood-tainted contracts. A Chinese construction worker offers a handful of money for the country. A rebel fighter who is provided with ammunition by an anonymous source controls the country's natural resources: uranium, gas,

petrol, gold, diamonds, wood, and coltan. A desperate Congolese is sitting on a ladder with his back towards his country.

Fig. 3 *Qui dirige R.D.C.?*, Alfi-Alfa, Collection Ethnomedicine, Vienna

Tresor-Cherin (Nzeza Lumbu) was born in Kinshasa in 1980, and started his career in 1995. His painting 'Vice versa' (Fig. 4) illustrates the problems of migration. A young man, head laid in his hands, sits on top of a ship called 'Clandestinité'. Another young man, a backpack on his shoulders, longingly looks across the border to the West – at happy people, multistorey buildings, and paved roads. To get to this blessed land, a family with children is camping in front of a hermetically blocked embassy. On the lower right side of the painting, however, the future of the migrant is depicted: even if he will manage to reach the West he will be forced to do low-paid jobs such as cleaning windows. A white man with binoculars mistrustfully searches the horizon. The young African and the white man stand so close, they could touch each other. Meanwhile, back in Africa another white man takes possession of the African mineral resources.

Fig. 4 *Vice versa*, Tresor-Cherin, Collection Ethnomedicine, Vienna

Tresor-Cherin's painting 'Consultation' (Fig. 5) depicts the DR Congo as a starving patient. The white medical doctor with his stethoscope auscultates the sick and looks sorrowful. The medical prescription for the patient reads: peace and security, water and electricity, regular salary, health and education, employment, streets and motorways. Around the patient assemble representatives of China and Africa, the World Bank (pondering about the medical prescription), and the European Community (the 'e' of UE painted as €).

Fig. 5 *Consultation*, Tresor-Cherin, Collection Ethnomedicine, Vienna

These paintings in a way are 'narratives of survivors' (Das & Kleinman 2001: 5) of everyday survivors, as Kinshasa is one of the African cities where everyday life means everyday survival. Thus, through their paintings, the artists 'remake a world' and are able "to recontextualize the narratives of devastation and generate new contexts through which everyday life may become possible" (ibid.: 6). The Congolese paintings are critiques of structural violence. They disturb and startle. They show the shattered hopes of a country whose postcolonial future once looked so promising (Vierke 2004). How-

ever, even if the paintings show all the misery of a country and its inhabitants, they are not without a subtle wit and even hope. The vivid fresh colors, comic-like arrangement and narrative suggest a deeply optimistic attitude and the understanding of the human need for jokes in healing the wounds of war and neglect. "And yet in the midst of the worst horrors, people continue to live, to survive, and to cope" (Das & Kleinman 2001: 1).

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Mihidi's drawings

Sketches of Zande witchcraft

ARMIN PRINZ

Drawings, especially from children, are a well known method used in ethnographic research. The idea that informants may put more information into sketches than give through an interview makes sense, as people in many societies are not trained to reflect on their abstract notions verbally. I have never observed, for example, African schoolchildren having to discuss issues like religion, witchcraft, magic, or oracles. The results of this is that while everybody may have a more or less clear und uniform idea about these phenomena, due to their inability to express themselves properly, the verbal information will probably diverge completely.

For this reason, drawings may be a better tool to analyse the above-mentioned notions. Unfortunately, most of these drawings are highly symbolic and difficult to interpret. Critics may also stress that these interpretations are more likely to reflect the ideas of the researcher than the notions of the person who has drawn them.

Since Evans-Pritchard's (1937) famous work on witchcraft among the Azande, this issue has been a central theme of sophisticated discussions in anthropology. However, these discussions tend to become somewhat sterile because his fieldwork, done in the 1920s, has not been thoroughly reassessed up to now. To widen the knowledge of Zande witchcraft, the use of children's drawings as a method seems suitable, especially drawings which are not only to be interpreted symbolically, but which are also prepared in such a naturalistic manner that there is much less doubt about their meaning.

In 1983 I was fortunate to meet a 15 year-old boy, Mihidi Polokis, in Doruma, D.R. Congo (former Zaïre). He was well known as a talented drawer and he offered to do a portrait of me. When I saw it, I was so impressed by his talent that I asked him to also draw topics linked to witchcraft. I gave him paper, pencils, and coloured ball-point pens, and he left for several weeks to visit his old relatives and ask them about witchcraft (*mangu*) and witches (*aboro mangu*; sing. *boro mangu*). He returned with wonderful sketches, which not only confirm Evans-Pritchard's findings, but

which also enable us to gain deeper insight into Zande witchcraft beliefs. I used these drawings in several publications (e.g. Prinz 2002) and also as a teaching method in my lectures on Medical Anthropology.

In his self-portrait from that time, Mihidi shows himself as a handsome, nicely dressed young man. In his right hand he holds a portrait of a cute young girl (Fig. 1). This stood as quite a contrast to his real appearance; he was small for his age, not really handsome, and had contact problems with his colleagues. In the text he writes: "*Ici ce le pauvre garçon qui a dessiné ce dessin. Oui c'est justement moi, alors je m'appelle Mihidi surnommé Polokis. élève de Doruma ayant comme l'âge 15 ans*" (Here is the poor boy who has drawn this sketch. Yes this is exactly me; indeed my name is Mihidi, with the given name Polokis, pupil in Dorma, who has the age of 15 years).

Fig. 2 shows how Azande believe that witchcraft is activated by the social malpractice of the victim. "*Ici c'est un socier qui viens ensorcier celui-ci (Ila mangu)*" (Here is a witch who came to bewitch this one). He enters the homestead and cries "*Oli?*" (Is somebody here?), "*Olio*" (I am here). The owner of the homestead who is sitting in a deck chair is angry because his wife has just arrived with his meal. Among the Azande, hospitality is obligatory and one should always give food to a visitor if it is available. But the man orders his wife to hide the pot so that he can eat alone after the visitor has gone. "*Le propriétaire de la maison n'a pas voulu donner sa nourriture pour le socier*" (The owner of the house doesn't like to give his food to the witch).

While the visitor stays overnight, flames of witchcraft come from his mouth. They fly over the homestead and enter the body of the landlord. There they create some kind of metastasis of witchcraft and return afterwards into the mouth of the witch (Fig. 3 and 4). The title of Fig. 3 is: "*Le sorcier fait sa sorcellerie*" (The witch does his sorcery), and the text in the drawing is "*Ici pendant la nuit le socier ensorci celui qui n'a pas voulu donner sa nourriture pour lui et maintenant le feu de sorcier s'envahi pour aller attaquer l'homme à nourriture*" (Here during the night the witch bewitches this one who wanted not to give him his food and now the fire of the witch surges up to attack the man with the food). In Fig. 4 the title says "*Celui-ci est gravement malade*" (This one is seriously ill). The text continues: "*Il souffre de son poitrine encore sa tête e puis tout son corps ne se sent pas bien*" (He suffers from his chest and also from his head and then his whole body is not feeling well).

The transformation of witches into certain animals is a very common notion in witchcraft belief around the world. Mihidi shows in Fig. 5 the transformation from a *boro mangu* into the magical cat *dandala* by way of showing the intermediate being in the middle. Its face is half human and half catlike, its ears are growing, its skin starts to become spotted, and its fingers are partly transformed into claws. From the mouth of the *dandala* the flames of witchcraft emerge to harm the victim. They are flying through the night, drop down to infect the body of the victim, and return afterwards into the mouth of the witch. People believe that the hard and unfertile laterite clearings of the Nile-Congo watershed, *munga* as they are called, have been caused by the *aboro mangu* who meet here at night. The captions in the drawing explain: "*La pierre de munga*" (The stone of the *munga*) and in the middle: "*L'eau de Munga ici il se change à une bête appelez dandala*" (The water of the *munga*, here he changes himself into an animal called *dandala*).

The notion that witches consume the flesh of their victims is an integral part of witchcraft beliefs in Africa. In Fig. 6 the witch is roasting the flesh of his victim in his witchcraft fire. As soon as he has eaten it, his victim dies. The flames of *mangu* fly over the trees to enter the body of the victim. The notion that witches eat human flesh is so prominent among the Azande that the European travellers from the second half of the 19th century were certain that the Azande were cruel cannibals. The text in the sketch reads "*Toujour de la chaire*" (Still the flesh) and "*La chaire de son ami*" (The flesh of his friend); below is written: "*Cet homme ici est un sorcier alors il est maintenant en l'intérieur de sa maison il dort et tout à dorment il fait sortir le feu de la sorcellerie*" (This man here is a witch indeed he is now inside his house he sleeps and during his sleep he lets the fire of witchcraft come out).

But why do people not like to be operated on in hospital? As Mihidi shows in Fig. 7, a nurse has opened the belly of a sick person suffering from a hernia and has found strange things in the intestines. A small earthen pot with animals in it, which are linked to witchcraft: a turtle, an owl, a snake, and a toad. Millet, peanuts, cassava, and rice to feed these animals are also in the belly of the witch. "*Le sorcier est attaqué par la maladie appelez Ernie et l'infirmier lui a fais l'opération, il est parvenue à trouver la un petit pôt avec plusieurs choses là dedans*" (The witch is attacked by an illness called (h)ernia and the nurse operates him; then he finds there a small pot with different things in it); "*Tous ceci se trouve dans le petit pôt: millet, tortue, hibou, arrachides, du riz, crapeau, serpent, manioc*" (All these things are found in this small pot: millet, a turtle, an owl, peanuts, rice, a toad, a snake, cassava). This

pot symbolises the witchcraft organ in the belly from which the flames of witchcraft emerge. People are therefore afraid of being accused of being a witch if the operating nurse finds such a thing in their belly.

I have quite a lot of other drawings of Mihidi. Unfortunately, during my later travels I never met Mihidi again; he has vanished and nobody has been able to tell me what happened to him.

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Keeping secrets, lying, and strategic disclosure

Reflections on the imperative to disclose one's HIV-positive status

WINNY KOSTER

Walking around at my first International AIDS Conference in Mexico City in August 2008, I sometimes had the strange feeling of being left out of the 'in-group', a large, vocal community of HIV-positive people. This group was divided into various sub-communities of sex workers, homosexuals, drug users, and women. Many had their booths in the Global Village, physically separated from the scientific conference venue. They organized activities such as rallies, panel discussions, training, and cultural shows, and sold their handicrafts or other products for income generation. Conference participants rallied for global access to housing for people with HIV – the banners they made were all over the premises. People were wearing T-shirts stating 'I am HIV positive', 'Positive Living', etc. (These were in sharp contrast to the T-shirts I had seen in Zambia in the early 1990s saying 'A friend with HIV is still my friend', and picturing a sorry looking person holding hands with a caring, healthy person.) Representatives of these groups also took to the main stage in the scientific conference, claiming their rights as human beings, equity in access to health care, prevention, and counselling services, and sharing their difficult road to personal and group empowerment. The audience cheered, among many others, an HIV-positive judge from South Africa and a sex worker from Nicaragua who pleaded against the criminalization of people with HIV.

Mexico showed me that there is a strong global social movement around AIDS, with a central position being taken by people living with HIV and AIDS. In this context, people with HIV did not position and pose themselves as patients or victims who should be pitied. Being HIV-positive almost seemed an identity to be proud of, whereas before HIV had meant a stigmatized master identity: once known to be infected with HIV, people ceased to be farmers, housewives, secretaries, doctors, teachers, etc., and instead became 'Persons Living with HIV and AIDS' – a group so defined by the global AIDS discourse. In many if not most local discourses this meant inferior people

who had had immoral sex, were prostitutes, sex workers, homosexuals, drugs users, promiscuous, unproductive, unable to take care of their family, and doomed to die a terrible death.

A global AIDS conference is nowadays a stage where people with HIV are listened to. In fact, people who had attended these biannual conferences before said this was the first time this happened on such a big scale. The UNAIDS GIPA principle – ‘Greater Involvement of People living with HIV and AIDS’ – definitely seems to work here. This disclosure of status and involvement in programmes is considered necessary in the fight against AIDS, in which everyone should get tested, know their status, take appropriate action to prevent the spread of HIV, access treatment when needed, and adhere to treatment. Disclosure will be beneficial to the HIV-positive person in order to obtain psychological, social, and material support, as well as for public health. The idea is that if many people disclose their HIV and treatment status as widely as possible, others will realise that with wider availability of Anti-Retroviral Treatment (ART), HIV/AIDS is no longer a death sentence and that people can live their normal lives. This would reduce the stigma of HIV and AIDS in the community and motivate everyone to get tested. This general sense of disclosure seemed to be happening in places like the AIDS conference in Mexico.

Of course, my impressions from the AIDS conference of this positive identity, and of people being open about their status, are not representative for all HIV-positive people worldwide. Even those persons who were so open at the conference were probably unable to be so everywhere. I think that the African homosexual wearing the T-shirt ‘African, Gay and HIV positive!’ will likely take off his T-shirt as soon as he is on the plane back home. The colourful, exorbitantly dressed Indian transvestite will likewise probably change into something more moderate.

From talking to different HIV-positive persons, listening to some of them talk at the Dutch National AIDS Congress on December 1st 2008, and through the findings of studies into HIV and AIDS workplace policies in Uganda which I am involved in,^{*} I have come to realize that people with HIV

* The STOP AIDS NOW! (SAN!) project ‘Managing HIV and AIDS in the workplace’ in Uganda is intended to support 75 SAN! partner non-governmental organizations (NGOs) in developing and implementing policies on HIV and AIDS. Key issues in these policies are awareness raising, education, HIV prevention, stigma and discrimination reduction, promoting gender equality, and care and treatment. With these policies organisations make commitments to their staff to care for those who are sick or have less strength to work because of HIV. They arrange for ART, adjust work hours and responsibilities, give time off for accessing treatment, etc.

have their reasons for being open in some situations and to some people, for keeping it hidden in others, and also for lying about it.

In the rest of this essay I present some cases and reflect on why and where some people either disclose their status or keep it a secret, set against the discursive imperative of AIDS programmes to disclose. Theories and insights of Goffman about stigma (1963), of Douglas about risk and culture (1992), and Bok about secrets (1984), are implicitly used.

Keeping secrets and disclosing

A secret is something a person keeps private and hidden from others for different reasons, and it may cause different emotions for the person holding it. A secret may give a feeling of power, of knowing something that others do not, a sense of joy, and a sense that when revealed the secret will raise admiration or the happiness of others. A secret may also bring fear and confusion, and weigh heavily on a person, because it relates to shameful, immoral thoughts or actions, and if revealed would cause embarrassment or social repercussions and loss of respect (see Bok 1984). Being HIV-positive is usually a secret of the last type. The following cases illustrate how people deal with or think they will deal with disclosure when being HIV-positive.

Cases

Adolfo, a guest lecturer in the AIDS and Anthropology module which I teach, invited students to email him personal questions before the lecture, having assured them that there was nothing he was shy about. Answering the questions in class, he was open about his feelings of despair when finding out about his HIV status, his anger towards the person who had infected him, and his sex life as a married man and a homosexual. I noticed that some of the students were quite shocked by his frankness, with Adolfo showing them worlds they were not acquainted with. He said he was open about his status to everyone, was not ashamed, did not have self-stigma, and did not fear stigmatization. However, there was one person he would never tell: his mother. When he found out he was HIV-positive he did not want her to know he was going to die, as medicines were not yet available in his country Brazil at the time. However, even now that he is on life-saving treatment and feeling healthy, he still cannot tell her. He explained that it would only cause her sorrow and that she would blame him for not having told her before.

In the NGO workplaces I study in Uganda, 64% of 236 interviewed staff said they intended to disclose in the workplace if they found out they were HIV-positive, but only 11% of these said they would disclose to all co-workers. The AIDS workplace policy encourages staff to disclose to all, reasoning that with examples of staff living positive(ly) and being supported by the organisation, more of them would get tested, be open, and take preventative measures – thus following the global discourse about disclosure. However, in only a few NGOs have staff actually disclosed their HIV status to the human resources officer, and only very few to all fellow staff, whereas in many NGOs there are stories of staff members who have sadly died of AIDS without disclosing to the organisation.

In interviews and focus group discussions, workers explained the different risks of disclosure. The risk for single male and female staff is that it would mean more difficulties in finding a marriage partner. Nobody wants to marry an HIV-positive partner, and many churches require an HIV-test before church marriage and refuse to marry HIV-positive people. During the Dutch National AIDS Congress, a Ugandan pastor told me he advises against such marriages although he cannot forbid them. The risk for married men and women is being suspected of unfaithfulness, with women being more likely to receive the blame. Although not discriminated against in the workplace, small gestures and gossip by their co-workers will remind them of their negative opinion. Another risk of disclosure mentioned in focus groups was that HIV-positive staff may be accused of utilizing the benefits of positive discrimination: no other disease attracts so many benefits and people have already started complaining about this.

In one of the Faith Based NGOs that one of my students studied, she found very confusing guidelines. According to the human resources policy, staff members who are found to have had immoral sex (i.e. premarital or extra-marital) will be dismissed. On the other hand, the HIV and AIDS workplace policy states that this does not count for HIV-positive staff, the reason being that it can never be known for sure what the cause of the infection was. With 95% of transmission in Uganda being through sexual contact, the assumption of others will be that the HIV-positive staff member has been immoral.

During the National Dutch AIDS congress, two men and one woman were interviewed on stage about their experiences of living with HIV. You could tell the public was shocked to hear their experiences with stigmatization in the Netherlands. All three were active in organizations for people with HIV and were used to being open and giving talks in public. However, they also reiterated how, for different reasons, they cannot disclose to every-

one and in every situation. I take the case of Alice, a woman of Dutch origin, who explained how she had always been open to everyone, but started to be more reserved when she had children. She had already become alarmed by the experience that some of her closest friends had questioned whether it was ethically right for her to have children at all. Alice was afraid that once the parents of her children's friends knew her status, they would not allow their children to play in her house, and therefore she only gradually disclosed to some of them. Some of her and the others' experiences make one understand why they might keep their status secret to some people in the future. Consider Alice's experience with a dentist who asked her – as she did not obviously belong to any of the stereotyped groups with HIV – how *she* had become infected. Imagine strangers asking you personal questions about your sex life, a boss requesting you not to tell other staff or customers about your status, family members begging you not to tell the neighbours.

Disclosing can also be personally beneficial and provide opportunities: poor Ugandan villagers, interviewed by one of my students, said that being HIV-positive presented an opportunity for them to access the food and micro-credit support programme established for people with HIV. In South Africa, HIV-positive women who have a CD4 count below 200 get an allowance, whether they are feeling sick or not.

Strategic disclosure against the imperative to disclose

The cases above illustrate that people with HIV do not necessarily follow the imperative to disclose to all, but rather disclose strategically. People have different motivations for telling some and not others. Disclosing, hiding, or lying about one's HIV status depends on the perceived risks and anticipated benefits of doing so. Risks are constituted by the discourse on HIV and AIDS in society and within sub-groups. Dutch Alice did not run the risk of being considered a prostitute or an immoral woman when disclosing, as did the single female staff in Uganda. An African man with HIV does not run the risk of being called a homosexual, as may happen to a Dutch man.

Most people with HIV base their decisions about non-disclosure on the perceived risks. Not disclosing to all is to protect your identity as a professional, a mother, a productive member of society, and is to protect yourself from impertinent personal questions about your sex life. Not disclosing can also be out of protection of loved ones: protecting them from sorrow, as Adolfo did by not telling his mother, or protecting them from stigma by association, as Alice did for her children when she did not disclose to other

parents. The Ugandan cases show that not disclosing can also be to have a better chance to marry, to prevent being called immoral, or to avoid making co-workers jealous of the benefits received.

These cases show that the imperative of the global AIDS programme to disclose does not concur with what most individuals with HIV do. Some people with HIV dedicate themselves to the public cause and publicly disclose, to so motivate others to get tested and go onto treatment, to reduce the stigma of HIV and AIDS, and to fight criminalization and inequity. However, for the majority of HIV-positive people, the personal risks of public disclosure outweigh the benefits for the public cause, and they strategically disclose to only a few people. The most effective way to get more people to be publicly open about their status would be to address the perceived cultural and societal risk factors that make people decide against disclosure; not an easy thing to do.

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Das ‘kulturelle Problem’ oder der Versuch einer Einigung im ‘dritten Raum’

ANDREA KUCKERT

Seit einigen Jahren wird in den Niederlanden die Diskussion um den Prozess der Interkulturalisierung geführt. Es handelt sich dabei um die Anpassung des niederländischen Gesundheitssystems an die Bedürfnisse seiner Klienten. Interkulturalisierung wird in diesem Zusammenhang nicht als ein Ziel, sondern als ein Prozess verstanden, der die Qualität der medizinischen und pflegerischen Versorgung für Klienten mit einer biographischen Migration verbessern und diese in das niederländische Gesundheitssystem integrieren soll (RvZ 2000). Damit verbunden ist die Vorstellung einer Einteilung der Klienten nach ihren Kulturen und die Abstimmung des Gesundheitssystems auf die entsprechenden Bedürfnisse der jeweiligen Kultur.

Van Dijk et al. (2000) fordern darüber hinaus, dass sich nicht nur das Management diverser Gesundheitsinstitutionen auf die Bedürfnisse von Klienten mit einer biographischen Migration einstellen muss, sondern auch die Politik und die Versicherungen. Von ihnen muss der Impuls ausgehen, die Bedingungen für eine adäquate Pflege der Klienten mit einer biographischen Migration zu garantieren. So sind auch die Politiker vor allem im Gesundheitsbereich gefordert, Sorge zu tragen, dass allen, die auf öffentliche Hilfe angewiesen sind, der gleiche Zugang und Gebrauch des Gesundheitssystems garantiert wird. Darüber hinaus sollten auch Versicherungen die diversen Gesundheitsinstitutionen zu einer am Klienten orientierten Politik motivieren.

An folgendem persönlichen Fallbeispiel werden einerseits die Schwierigkeiten dargestellt, sich als ‘Fremde’ in einem Gesundheitssystem zurecht zu finden sowie andererseits einen Lösungsansatz zu diskutieren, der den kommunikativen Austausch der involvierten Akteure beschreibt. In diesem Gespräch werden letztendlich die zwischen den Beteiligten bestehenden kulturellen Unterschiede nicht per se als unversöhnliche Gegensätze wahrgenommen, sondern betrachtet, besprochen und ausgehandelt.

Auch wenn dieses Fallbeispiel fast 10 Jahre zurückliegt, hat es, wenn man sich die aktuelle wissenschaftliche Diskussion anschaut, an Aktualität nicht verloren (van Dongen 2005; Gerritsen et al. 2006; Kamperman et al. 2007,

Suurmond et al 2006). Pflegende und Ärzte signalisieren nach wie vor ein erhöhtes Bedürfnis nach konkretem Wissen über Kulturen, Religionen, Rituale und Handreichungen im Vergleich zu den eigenen Normen und Werten (Kuckert 2008, Oostrum & Seelen 2007, Wolffers et al. 2007).

Fallbeispiel

Mein Mann, Sohn einer Niederländerin und eines Deutschen, aufgewachsen in Krefeld, hegte schon lange Zeit den Wunsch, in den Niederlanden beruflich tätig zu sein und das Land damit nicht nur aus der Perspektive des Urlaubers, sondern auch eines tatsächlich dort Wohnenden kennen zu lernen. Seine niederländischen Sprachkenntnisse – er wurde zweisprachig erzogen – verwirrten viele Leute. „Sie sind doch Niederländer!“ war eine viel gestellte Frage. Ausgestattet mit einem Stipendium für die Amsterdamer Universität (mathematische Physik), zogen wir 1999 nach Hoorn, einer kleinen Stadt am IJsselmeer. Ich selbst Anfang 30, ausgebildete Krankenschwester und Studentin der Ethnologie (culturele antropologie) im dritten Semester, war zu diesem Zeitpunkt im siebten Monat schwanger und nahm nach unserem Umzug an einem Niederländischsprachkurs teil, da ich ab September 1999, nach erfolgreich bestandener Sprachprüfung, mein Studium an der Amsterdamer Universität fortsetzen wollte.

Meine Schwangerschaft war bis dahin ohne Probleme verlaufen. In Deutschland wurde ich, wie die meisten Frauen, von einem niedergelassenen Gynäkologen betreut, einem Arzt mit eigener Praxis, der nicht einem Krankenhaus zugeordnet ist. Regelmäßige Untersuchungen wie Ultraschall, Blutdruckmessen und Blutentnahmen vermitteln den Frauen das Gefühl, dass alles für das Wohl des Ungeborenen und seiner Mutter getan wird. In einem blauen Büchlein werden die Daten und Ergebnisse notiert, und mit Stolz zücken die Frauen in Gesprächen mit Freunden oder Familie das Dokument, wird es doch auch als Beweis gesehen, dass es dem Kind und der Mutter gut geht.

Glücklich in Hoorn in unserem neuen Zuhause eingerichtet, machte ich mich auf die Suche nach einem neuen Gynäkologen. Wir kannten noch niemanden in Hoorn, den ich hätte fragen können, die Familie meines Mannes wohnte in Alkmaar und Umgebung, aber der Kontakt war nicht so intensiv, dass ich in dieser Angelegenheit um Hilfe bitten wollte. Ich nahm die ‘Gelben Seiten’ (Gouden Gids) und hoffte unter der Rubrik ‘Gynaecologie’ entsprechende Einträge zu finden. ‘Grondwerker’ und dann ‘harden’, aber kein Gynäkologe. Auch die Suche nach einem ‘vrouwenarts’ lieferte kein Ergebnis.

Abends besprach ich mich mit meinem Mann. "Stell dir vor ...in Hoorn gibt es keinen einzigen niedergelassenen Gynäkologen! Wo arbeiten die denn alle und wo gehen die Schwangeren zur regelmäßigen Kontrolle hin?" Mein Mann nahm die 'Gelben Seiten', vielleicht hatte ich etwas übersehen, aber in dem aktuellen Branchenbuch waren tatsächlich keine Einträge zu finden.

Durch Zufall lernte ich in den nächsten Tagen eine Nachbarin kennen, fragte sie in holprigem Niederländisch, wer in den Niederlanden die Schwangerenfürsorge vornähme. "Je moet naar de huisarts!" Ich war überrascht. An einen Hausarzt hätte ich nun als allerletztes gedacht, aber vielleicht hatten die ja andere Befugnisse als in Deutschland. In London zum Beispiel beriet der Hausarzt die Frauen in Fragen der Schwangerschaftsverhütung und führte diese auch aus. Das war in Deutschland nur den Gynäkologen vorbehalten. Meine erneute Suche in den gelben Seiten, dieses Mal unter dem Stichwort 'huisarts' brachte wiederum kein Ergebnis. Ich fasste mir ein Herz und klingelte noch einmal bei der hilfsbereiten Nachbarin. "Waar vind ik een huisarts?" Ich könne nicht zu irgendeinem Hausarzt, ich müsste schon zu dem, der für unser Wohngebiet zuständig sei; und mit dieser Aussage drückte mir meine Nachbarin einen Zettel mit Namen und Adresse des betreffenden Hausarztes in die Hand.

Ich rief aufgelöst meinen Mann an der Universität an. "Stell dir vor," rief ich "ich kann nicht einfach zu einem Hausarzt meines Vertrauens gehen. Man bekommt einen zugeteilt. Und wenn ich den nicht mag? ... Ich bin schwanger, möchte zum Gynäkologen und muss nun zu einem Hausarzt, den ich noch nicht einmal kenne!"

Mein Mann versuchte mich zu beruhigen. Am späten Nachmittag liefen wir zu der entsprechenden Adresse, alles war schon geschlossen, und mein Mann machte den Vorschlag, am nächsten Tag mit mir zusammen zu der so genannten 'inloop spreekuur' zu gehen. Diese Information hatte er dem Schild über dem Namen des Hausarztes entnehmen können. Zwischen acht und neun Uhr konnte man ohne Termin bei dem Hausarzt vorsprechen. Voller Hoffnung saßen wir am kommenden Morgen bei einem Mann mittleren Alters, der in Jackett und Jeans gekleidet war – kein weißer Kittel, wie ich es eigentlich erwartet hatte.

"Zo als u kunt zien is mijn vrouw zwanger, begin achte maand en wij willen graag naar een controle," fleckenloses Niederländisch ohne Akzent. Der Hausarzt zeigte sich überrascht. "Sie sind bei mir an der falschen Stelle, Sie müssen zu einer Hebamme, einer 'verloskundige'. Er wäre nicht für die Schwangerschaftskontrollen zuständig, nur für Verhütungsmaßnahmen."

Etwas frustriert gingen wir nach Hause, und nachdem ich im Wörterbuch die korrekte niederländische Bezeichnung für Hebamme gefunden

hatte, schlug ich die 'Gelben Seiten' unter dem entsprechenden Stichwort auf. Tatsächlich fand ich zwei Eintragungen und erfuhr über den Anrufbeantworter, dass man zu bestimmten Zeiten die verantwortlichen Hebammen auch telefonisch erreichen konnte. Auf einen Zettel schrieb ich mir die niederländische Frage auf, die ich der Hebamme mittags stellen wollte und rief zu der angegebenen Zeit an. Nach einer halben Stunde Besetzzeichen erreichte ich jemanden.

"Ik ben acht maanden zwanger en ga begin juni bevallen. Kunt u me helpen?" Schweigen auf der anderen Seite des Telefons. "Waarom belt u nu pas?" "Warum ich mich jetzt erst meldete?" Ich verstand die Frage nicht und fügte holprig hinzu: "Ik kom uit Duitsland. Ik woon hier pas een maand. Ik ben zwanger. Ik moet binnen kort bevallen." "In welke week bent u?" Ich schaute schnell in meinem blauen Heftchen nach. "week 34," stammelte ich. "U bent veel te laat. U had zich moeten inschrijven aan het begin van de zwangerschap, ik heb geen ruimte meer!" Damit war das Gespräch beendet.

Ich rief meinen Mann an und erzählte ihm, was sich ereignet hatte. Er redete mir gut zu und versprach, die zweite Hebamme, deren Telefonnummer ich in den 'Gelben Seiten' gefunden hatte, anzurufen. Vielleicht lag es tatsächlich nur an meinen rudimentären Sprachkenntnissen, dass ich keinen Erfolg hatte. Am nächsten Tag meldete er sich nach seinem Telefonat mit der Hebamme. Er hatte letztendlich eine vergleichbare Aussage erhalten. "In den Niederlanden meldet man sich bei einer Hebamme an, wenn man weiß, dass man schwanger ist. Sie betreut die Frau und das Ungeborene dann auch während der gesamten Schwangerschaft und auch während der Entbindung, die oft noch zu Hause stattfindet."

Ich war sprachlos. "Aber ich wusste doch im September noch gar nicht, dass wir in die Niederlande ziehen, wie hätte ich dann eine Hebamme kontaktieren können" rief ich. "Was ist das für ein Land? Deutschland und die Niederlande sind doch Nachbarstaaten, gehören beide zur Europäischen Union und ich kann hier nicht mein Kind zur Welt bringen! Ich will nach Hause." Mein Mann versuchte mich zu beruhigen. "Die zweite Hebamme habe ihm erklärt, dass die Mehrzahl der Frauen durchaus noch zu Hause gebären würde. Man bekäme dann eine Frau zur Seite gestellt (kraamhulp), die sich um das Wohlergehen des Kindes und der kleinen Familie kümmern würde. Das sei doch eigentlich gar nicht so schlecht."

"Aber das hilft mir jetzt nicht, ich brauche keine fremde Person nach der Geburt in unserem Haus" rief ich. "Unser Kind kommt bald. Soll ich mein Kind unter dem Baum zur Welt bringen und die Nabelschnur mit einem Stein durchtrennen?" Am nächsten Tag beschlossen wir, doch noch einmal den Hausarzt auf zu suchen. Vielleicht wusste er einen Rat.

Wir gingen wieder zur inloop spreekuur. Er war überrascht uns zu sehen. "Wat is het probleem?" Mein Mann fasste kurz zusammen, was sich in den letzten Tagen ereignet hatte. Der Arzt lehnte sich zurück und meinte schmunzelnd: "Ik geloof er is sprake van een cultureel probleem! Wie werden eigentlich Schwangere in Deutschland betreut?"

Mein Mann schilderte ihm kurz die Funktion des Gynäkologen in Deutschland und der Hausarzt konstatierte lächelnd: "Sie haben doch sicher schon ab und zu vorzeitige Wehen! Ich werde Ihnen eine Überweisung zu dem im Krankenhaus ansässigen Gynäkologen ausstellen. Er wird Sie weiter betreuen und dort können Sie dann auch entbinden."

Diskussion

Ein kulturelles Problem? Was bedeutet das konkret? Was hatte meine Situation als Schwangere in den Niederlanden mit Kultur zu tun? Ging es um eine niederländische Kultur, in die ich nicht hineinpasste oder war es meine deutsche Kultur, die für Irritationen bei den Beschäftigten des niederländischen Gesundheitssystems sorgte? Kann man überhaupt von der niederländischen oder der deutschen Kultur sprechen?

Kultur wird in diesem Kontext als die Zugehörigkeit des Einzelnen zu einer Gruppe mit ihren eigenen Normen, Werten usw. verstanden. Bis zu dem Zeitpunkt unseres Umzugs in die Niederlande war ich nur mit dem deutschen System der Schwangerschaftsbetreuung vertraut. Etwas anderes kannte ich nicht. Ich war mir zwar der unterschiedlichen Formen der Betreuung bewusst, hatte jedoch Mühe, sie sowohl ausfindig zu machen als auch mich auf sie einzulassen. Das Sich-emotional-nicht-auf-etwas-anderes-einlassen können findet sich auch in der Kulturdefinition von Marcus (1995). Kultur ist seiner Ansicht nach nicht an einen festen Ort gebunden, sondern primär als kognitive und emotionale Ressource zu betrachten, die je nach ihrem geographischen Ort in neue Kontexte mal mehr und mal weniger stark eingebunden werden kann (Marcus 1995). Auch wenn Menschen mit einer biographischen Migration geographisch gesehen nicht mehr permanent in Bewegung sind, kann man den geographischen Ort ihrer Herkunft nicht nur hinsichtlich seiner nationalen, sondern auch und gerade hinsichtlich seiner lokalen Grenzen definieren. Dann gewinnt der Faktor Kultur als kognitive und emotionelle Ressource in Abhängigkeit des Kontextes, in dem sich der Einzelne bewegt, mal mehr, mal weniger an Bedeutung (Appadurai 1991).

In meinem alltäglichen Leben kam es zu keinen nennenswerten Problemen. Das Sich-einschreiben für einen Niederländischsprachkurs, die Imma-

trikulation an der Amsterdamer Universität und das Sicht-Orientieren in einer neuen Stadt waren Situationen, die mir nicht fremd waren und die ich in verschiedenen Ländern in der ein oder anderen Weise schon erlebt hatte. Die Schwangerschaftsbetreuung hingegen war für mich etwas Neues und mir bisher nur aus meinen eigenen Erfahrungen in Deutschland bekannt. Hier kam dem Faktor Kultur eine viel größere Bedeutung zu, als in den anderen Bereichen. Ich war Erstgebärende und konnte auch nicht auf ein soziales Netzwerk zugreifen, das mir mit Rat und Tat zur Seite stand.

Die verschiedenen Mitarbeiter des niederländischen Gesundheitssystems gingen von ihren eigenen Erfahrungen, Werten und Normen aus. Diejenigen, mit denen ich Kontakt hatte, fühlten sich nicht (mehr) für mich zuständig und waren aufgrund von Arbeitsdichte und eventuellen anderer Restriktionen nicht in der Lage, von ihrer aktuellen Politik abzuweichen.

Der von uns kontaktierte Hausarzt versuchte uns in erster Instanz an die entsprechende Stelle zu verweisen. Nachdem dies missglückte, setzte er sich mit uns für eine gemeinsame Lösung ein. Die kulturellen Unterschiede (*cultural differences*) wurden somit wahrgenommen, besprochen und schufen die Grundlage für einen vielleicht etwas ungewöhnlichen Lösungsansatz.

In diesem Kontext sind die Überlegungen von Bhabha (2000) hinsichtlich der Begriffe 'diversity' and 'difference' wichtig. In einem kontinuierlich stattfindenden Dialog zwischen Menschen unterschiedlicher Provenienz (Lat. Abstammung) gibt Bhabha dem Begriff der 'cultural difference' gegenüber dem der 'cultural diversity' den Vorzug. Während 'cultural diversity' hauptsächlich sowohl auf ethnische als auch klassenspezifische Merkmale ausgerichtet ist, verweist die Umschreibung 'cultural difference' auf einen kontinuierlich stattfindenden Prozess, in dem sich die Teilnehmer über kulturelle Kodierungen – also ungeschriebene Normen des Verhaltens an denen sich die Mitglieder einer Gesellschaft orientieren – auseinandersetzen. Dieser Prozess der Bedeutungskonstituierung verweist auf die Heterogenität von Gruppen, spricht kulturellen Gemeinschaften, die durch Differenzen gekennzeichnet sind. Damit wird das Konzept eines Nebeneinanders von Kulturen in Form sich scharf von einander abgrenzenden Gruppen hinfällig. Was entsteht ist ein Bild von sich überlappenden und durchkreuzender kultureller Zugehörigkeit.

In den ersten Monaten meines Aufenthaltes in den Niederlanden versuchte ich etwas Identisches zu dem zu finden, was mir vertraut und bekannt war. Die Suche gestaltete sich als schwierig und von meiner Seite kaum lösbar. Der Hausarzt auf der anderen Seite erkannte die Notwendigkeit, sich einer Sache anzunehmen, für die er eigentlich gar nicht zuständig

war. Diese Suche nach Kompromissen wird von Bhabha als der so genannte 'dritte Raum' definiert. Diese 'artikulierte Gegenwart' (Bhabha 2000: 178) kennzeichnet sich durch ein Ion-Interaktion-Treten von Menschen unterschiedlicher Provenienz, bei der sie sich gegenseitig viel mehr verändern, als das bei der bloßen Gegenüberstellung zweier Akteure vermuten lassen würde. Dieses Wissen um den 'dritten Raum' schafft eine Grundlage, in der die involvierten Akteure die zwischen ihnen bestehenden Unterschiede wahrnehmen, betrachten, besprechen und unter Umständen aushandeln können, anstatt sie nur als unversöhnliche Gegensätze wahrzunehmen.

Der 'dritte Raum' ist der Raum der Hybridität, der Durchmischung von Merkmalen, Auffassungen, Traditionen und Symbolen. Das dialektische Konzept bedingt dann nicht mehr die Ablehnung bestimmter Eigenschaften, sondern die Verhandlung als geeigneten Weg, die Welt zu verändern und etwas Neues hervorzubringen.

Anstatt mich noch einmal darauf aufmerksam zu machen, dass er als Hausarzt nicht die richtige Instanz sei, um meine Schwangerschaft zu begleiten, entschied er sich mittels einer Notlösung – bei vorzeitigen Wehen können Schwangere in den Niederlanden an einen Gynäkologen überwiesen werden – mich durch die Einrichtung betreuen zu lassen, die mir bekannt und vertraut war. Damit hatte ich einen nicht ganz regulären, aber doch adäquaten Zugang in das niederländische Gesundheitssystem gefunden. Schwangerschaftsbetreuung, Entbindung und Nachsorge wurden dann in dem Krankenhaus (erfolgreich) durchgeführt.

In Erinnerung an Bernd Kuckert (1968-2008).

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Working on the interface between psychology and anthropology

The culture-sensitive prevention program 'First Steps'

PATRICK MEURS

In this contribution, I describe our Flemish 'First Steps' prevention program in the field of child development and parenthood. This program is directed at immigrant parents with newborns and infants up to three years. It aims to promote more fair chances for allochtoneous children in school, and for greater participation by the parents within broader society. While we work concretely on the early parent-child relationship and the educational situation within families, we also focus on the future prospects of the participants. Language development, school participation, and social-emotional wellbeing for the children, as well as educational strength, societal participation, and the understanding of intergenerational familial and ethnic positions are the main aims of this program.

The First Steps program is now being implemented at several sites in Flanders and Brussels. The financial support from the Flemish government is an enormous support for the dissemination of this program. A long-term follow-up study has shown strong beneficial effects of early prevention on the quality of life of parents and on the school career of children who are mostly considered a risk group for learning difficulties and other associated emotional and behavioural developmental problems. Within this program, general principles of prevention are adapted in a culture-sensitive way.

I will focus on the culture-sensitive issues of the First Steps prevention program and show the interaction between prevention science within psychology on the one hand, and cultural anthropology on the other hand. It is most of all in this interaction that I felt inspired and encouraged by the discussions I had with Els van Dongen. I will describe how we include in this prevention program the focus on emic concepts of parenthood, prevention, and child care, and how we have translated general psychological concepts into culture-sensitive approaches that are attuned to non-Western life-worlds.

Dertlesmek: Sharing the joy and sorrow of raising children and other family issues

The groups in First Steps consist of six to eight parents and their children, meeting together every week for two hours. There are various types of groups:

- Parent/child groups (with mothers, fathers, and their children);
- Mother/child groups;
- Mothers' groups;
- Three generation groups (grandparents, parents, and children);
- Father/child groups

A major source of inspiration for this project comes from the initiative taken by the French psychoanalyst Françoise Dolto in parts of Paris, with the opening of *Les maisons (ou)vertes*: open houses where parents can come to talk about child upbringing and development. These houses are designed to be *des lieux d'accueil et de rencontre* (places of welcome and meeting), *des espaces jeu et loisir* (spaces for recreation and leisure), and *des espaces parole* (spaces for talking), where parents can converse in the presence of their children (*faire circuler la parole* – pass the word around) and can share questions, concerns, joy, and sadness about their children and parenthood – *des espaces de partage* (spaces for sharing).

Dolto's idea of parents sharing affectively loaded relational experiences is, moreover, highly suited for placement within a multicultural perspective. In Mediterranean or non-Western cultures, for instance, people commonly meet together as parents and chat about such matters. This takes place informally between mothers of approximately the same age, during daily encounters in the late afternoon in the village square (before the mothers return to their houses to prepare the evening meals), or more formally and weekly, in the inner courtyard, near the water source, in the house of an older, respected woman from their community. In Turkey, these meetings are referred to by the term *dertlesmek* (the sharing of sorrow and joy, and of complex issues and concerns about raising children) (Devisch & Gailly 1985).

Taimoëm: A way of prevention

Another element of cultural sensitisation within preventive programmes is the translation of the goals of these programmes into culture-specific categories. Prevention programmes nowadays aim to prevent further deviance

in children's developmental pathways as well as to promote adaptive developmental trajectories. In Moroccan culture, the concept of *taimoëm* is well suited for grasping both aspects.

Taimoëm refers to a small round ritual stone that is said to have a purifying strength. The stone is used by Moroccans in situations where they are not able to use water for purification rituals, for example in former days while travelling in the desert, or nowadays, while travelling from the homeland to the 'guest land' without having access to water. The *taimoëm* stone is also used for purification in a lot of situations that are not considered optimal for rituals of purification, and analogous also in a context of migration which is experienced as a 'non optimal, intermediate circumstance.' Many Moroccan immigrant families use this stone only at key moments in the developmental course of the child, marking the transition from one phase to another, like the circumcision of boys and the menarche of girls. At that moment, the child, the parents, and grandparents hold the stone in their hands, begging for healing from sickness, preclusion of mischief, and the furthering of prosperity in the future life of the child and the family. These core symbols within the culture of the participant families make it possible to apprehend the aim of the developmental guidance in First Steps, where cure and prevention from illness as well as promotion of wellbeing are considered of paramount importance. For example, a *taimoëm* can be placed nearby the hearth like in the house of Moroccan immigrants, symbolizing that the participants in the programme are protected against negativity and supported to find healthy pathways into the future.

***K'bir a-tay*: A space for welcoming 'the Other'**

The room is divided into three sections of about equal size: one for meetings between parents, one for children to play, and one for interaction between parents and children. Chairs are provided *for the parents*, with low benches in between which are customary in North-African countries bordering the Mediterranean and in Turkey. In between the chairs and benches are small, low tables with all kinds of bowls and tea sets. The set-up of the room is similar to the room in which guests are received in their own cultures; see for example the Kabylean concept of *k'bir a-tay*. The small tables can also serve as workbenches for the children, since they are low, if they want to draw, do puzzles, or play near their parents. In addition, the meeting room for parents also has corners where children can be cared for, diapers changed, or where they can be breastfed, if the mother does not want to do this in the group.

Most of the mothers we meet spend the summer holidays in their country of origin. They often like to bring back a gift and know that children's books, toys, or items and ornaments for the meeting room (bowls, tea sets, wall hangings, or little woven tapestries of oriental origin) are extremely welcome, as well as fruit and water – symbolising productivity and purity – which have been brought back from 'over there' and are generously shared with the group in the first session after the holidays. In this way, an intercultural mix is gradually produced, through the available toys and in the furnishing of the meeting room, which reflects the widely diverse origins of the participants in the groups (Benoist 1996).

Several play areas are provided *for the children*, equipped with toys suited specifically to various ages between zero and six. Each child also has an individual drawer where all kinds of items can be kept, for example drawings, clay models, and other things they have made or brought along. The toys in the children's corners include a lot of dolls, as well as human figures with widely varying clothing and ethnic features. The room also has a wall cabinet with children's books in various languages, as well as books without text. Reading children's books together or reading stories aloud is an important activity mothers and children can share with each other; illiterate Berber Moroccan mothers – who initially avoided the book corner – can also become involved in telling stories, using the books without text.

Between the play areas for the children and the meeting room for the parents – where parents and children are occasionally also present together – is a *transitory room for interaction between parents and children*. This is particularly where the mother/child bond during the first years of life is practised; it is a *potential space* (Winnicott 1971) for a reality of signs, words, meanings, and symbols that are shared between mother and infant, or have meaning within the context of their interaction, not belonging to either mother or child individually, but to both together.

The intermediate room is where *floortime* (Greenspan 1997) takes place: explicit attention is devoted to bringing about and maintaining communication between parent and baby. Stimulated by the 'developmental counselor' or 'guide', the parents learn to look at interaction with their children in a new way, in order to recognise the positive aspects more explicitly and to reinforce them. The intermediate space where this subtle interactional game takes place can be separated from the rest of the room by a low plastic tape that is inserted in the floor. Parents and children can feel when they transgress this border or boundary; they can go back and forth around this border, between the meeting space for the adults and the play areas for the children, without disrupting mother/child interaction during the *floortime*

or the interactional guidance. As a result of this three-level structure in the meeting room, space is provided for mothers and for children, while also providing an intermediate place – a transitional space – explicitly for communication between mother and child.

Working through the loss of the containing cultural system of meaning

Immigration is not a subject in itself in the group meetings. At the same time, immigration plays an extremely important role in virtually all aspects of education and development, so that this subject is always implicitly or explicitly present in the stories these mothers tell and in the questions they ask.

Grinberg and Grinberg (1989) describe immigration as a far-reaching shock or change, more specifically as a loss of cultural self-evidence. Culture as a supportive basis and as a symbolic system which imparts meaning – in brief, culture as ‘containment’ (Bion 1962) – is lost through immigration to a greater or lesser extent. Immigrants can process this loss in a creative way; the results of this processing have been described as the emergence of a bi-cultural (LaFramboise et al. 1993) or twin identity (Werbner & Modood 1997), a multiple, hybrid (Akhtar 1999) or mixed identity (Akin 2002). The less creative processing is expressed, on the one hand, in an obstinate clinging to everything from there-and-then (“rigid cultural container”, Grinberg & Grinberg 1989), which impedes any change in cultural identity. On the other hand, it is all too easy to be absorbed into a new cultural identity, without leaving room for putting down roots of the culture of origin (“manic reaction to loss and depression”, Grinberg & Grinberg 1989).

However, a key moment arises in the family cycle with the birth of a new generation, when even a very creative balance between continuity and discontinuity in cultural identity is itself again brought sharply into question. Among parents, for example, the question remains of how they will introduce both cultures to their children; in brief, with the news of the impending new life, inherent strengths and weaknesses at the level of ‘bi-cultural identity’ suddenly become more conflictive. We regard this as an issue associated with immigration processes in general.

Immigrant fathers and mothers in a trans-generational perspective

The cultural change caused by emigration has brought about certain socio-emotional vulnerabilities, both in young allochtoneous mothers who have grown up here and in ‘imported’ brides. These young mothers admit that they find insufficient identification possibilities in their mothers, who are of

the first generation. With respect to the dialogue between cultures, first and second generation mothers adopt a different attitude. This is partly a result of the fact that the first generation of mothers did not come here until they were on average over thirty years old, while the second generation have been here since childhood or birth. The mothers in the second generation admit therefore that they look elsewhere for identification figures, particularly among contemporaries in age: sisters, cousins, girlfriends.

However, here too the feeling often arises of being left to one's own devices: the impression is of being charged with the same task, but still having to find one's own answer. Moreover, these second-generation mothers have the impression that they would like to impart to their children aspects of their cultural background which they received from their parents at home, but that their children will inevitably be very different from them, so that they do not know if they are doing right or wrong in raising their children in the way they do. The second-generation mothers thus often feel that they are on their own, both intra-generationally and inter-generationally.

A point of identification between immigrant mothers of the first and the second generation emerges in the 'three generation perspective', when the young mothers realise that they are living with the same fear as their parents – specifically, the fear that their children will be different, that their children will not consider their parents in their quest for an identification figure. This is expressed, for example, in a high degree of uncertainty and indecision when the young parents have to make choices concerning school, language, or have to structure their children in several circumstances at home, etc. In conversations in the presence of grandparents, during sessions in the three-generation group, the young parents recognise, sooner or later, that these fears were just as evident in the previous generation, among their parents. Discussing this trans-generational transfer of concerns about the upbringing and development of children in the context of immigration, and of the impact which these fears and concerns can have on parents and children, turns the group meeting into an important event for those involved.

Another emotionally loaded topic for the mothers is that most of them – as a child – had seen their mothers leave for Europe while they stayed in their land of origin, or have felt how the first-generation mother was emotionally unavailable in the land of immigration. The young mothers of the second generation were able to live with this pain, until the birth of the third generation, when they have to work this through. This is also an important topic in the group work of First Steps, where the other mothers – each with their specific history – are able to recognize the pattern and to understand and support the emotions this issue raises.

The fathers face other problems. Those of the first generation were focused on going back, and in that respect, had no intention of showing their children or their wives the way into broader Western society. However, as soon as they realised that migration had become more permanent, it was not so easy for them to change course. The second generation fathers are not infrequently just as insecure, either because they could not make the grade in Western Europe or because, as imported bridegrooms, they have just arrived from their country of origin and need some time to find their own way in a different environment. The insecurities of immigrant fathers are often discussed in the groups within the context of all kinds of upbringing issues. These young immigrant fathers' insecurities are brought sharply into focus, particularly in their attitudes towards school, the choice of educational language, the representation of authority within the family, and taking structured action with respect to their children.

In the parents/child and the three-generation groups, extra attention is devoted to the strengthening of the father's position in the immigrant family. At the end of the meetings of the mothers' group and the mother/child group, mothers are asked to report the discussion to their partner or other figures that support their educational activities, yet another way of challenging the father or other supportive figures to participate more in educational/developmental/familial matters.

*Increasing the efficacy of developmental guidance
by a culture-sensitive approach*

The prevention project of First Steps has already been running for nine years now. Recent longitudinal follow-up research (Meurs & Jullian 2008) reveals that in Flanders, immigrant families do not find their way to public mental health care services. The figures for the participation of these immigrant groups in 'First Steps' indicate that we are making significant gains with respect to the problem of inaccessibility of mental health services for these groups. Over nine years, approximately one thousand families have been involved in 'First Steps'. By our centre-based group work, combined with outreach methods (we go to the services where more isolated families come and set up guidance facilities in these centres) we have also been able to contact the more hard to reach sub-groups of immigrants in Flanders.

Most important is to know that the mothers and fathers that participate in the program tell us that this early prevention works because they know now that support and help can be found and that society cares about them. That makes the difference: without this early experience of help, parents

would wait much longer when they need support, or they would not even dare to seek appropriate help.

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Theory in action?

Reflecties vanuit een huisarts-praktijk

ILJA MOOIJ

Het spreekuur van een doordeweekse dag afgelopen maand:

- | | | |
|-------|---------------------------|---|
| 8.00 | Dhr. E, 52 | Evaluatie nieuwe bloeddrukmedicatie: gaat goed, herhaalrecept |
| 8.10 | Dhr. B, 61 | Bespreken uitslag longfunctietest en longfoto: <i>blijkt longemfyseem te hebben, uitleg.</i> |
| 8.20 | Mw. V, 20 j | Heeft chronische blaasontstekingen sinds geboorte. Opnieuw veel vragen. Heeft wat kleine klachten: <i>Geruststelling / Uitleg</i> |
| 8.30 | Mw. B, 74 | 8 min te laat. Vragen over spataderen. Vindt ingreep door kliniek niet goed gelukt. Wat nu?: <i>Advies om terug te gaan.</i> |
| 8.50 | Dhr. S, 80,
20 minuten | Is bezig met behandeling voor polymyalgia rheumatica (aandoening spieren), prednison nu aan het afbouwen: <i>afspraken over afbouwschema.</i> |
| 9.10 | Dhr. V, 61 | Bespreken labuitslagen: <i>herhaling van een labwaarde over 3 mnd, verder goed.</i> |
| 9.30 | Mw. P, 48
20 minuten | Bepaling risico hart-vaatziekten n.a.v. te hoog cholesterol in lab. |
| 9.50 | Dhr. J, 69 | Evaluatie wijziging bloeddrukmedicatie: <i>eindelijk resultaat, afbouwen andere medicatie</i> |
| 10.00 | pauze | |
| 10.30 | Mw. D, 75 | Bespreken lab, uitrekenen nierfunctie: <i>alles in orde, herhalen over 1 jaar</i> |
| 10.40 | Dhr. T, 48 | Bespreken lab: suikerziekte zeer slecht ingesteld: <i>patiënt verschijnt niet op afspraak.</i> |
| 11.00 | Dhr. L, 2 | Hoest, graag longen luisteren: <i>geen afwijkingen longen, geruststelling</i> |

- 11.20 Mw. R, 52 Antibioticakuur tegen vaginale afscheiding heeft niet geholpen: *verwijzing gynaecoloog gezien ook wat bloed-verlies, terwijl baarmoeder is verwijderd.*
- 11.30 Dhr. K, 48 Erg hoesten: *geen afwijkingen longen-keel, geruststelling, neusspray*
- 11.40 Mw. K, 49 Blijft pijn houden van de buik ondanks tabletten: *komt vrij bizar over, spreekt als angstig kind, dit benoemd en oxazepam mee naar huis, belafpraak morgen.*

Wat is er in mijn dagelijkse werk als huisarts terug te vinden van hetgeen ik me tijdens de studie medische antropologie eigen heb gemaakt? Het is inmiddels elf jaar geleden dat ik de module kritische medische antropologie bij Els van Dongen volgde en acht en half jaar geleden dat ik mijn afstudeerscriptie bij haar afrondde. Waar is de antropoloog in mij? Doe ik mijn werk anders dan een huisarts zonder (kritisch) medisch-antropologische bagage? Vragen die ik me al langer stel en vragen die ook Els al eerder dit jaar aan mij stelde. In een brief aan haar, die zij citeerde in een lezing voor de vereniging van vrouwelijke artsen, gaf ik hier een spontaan – zeker geen empirisch – antwoord op, en tevens schreef ik wat de module die zij mij gaf met me deed. Ik had destijds veel onvrede met de geneeskunde studie en het gezondheidszorgsysteem / instituut waarin ik werd opgeleid. In mijn brief aan Els schreef ik:

Nietsvermoedend begon ik toen in september 1997 aan jouw module, die toen nog de uitdagende naam ‘Kritische Medische Antropologie’ had. Wat er toen met mij gebeurde was iets wat moeilijk te beschrijven valt: het was een soort van openbaring, een verlichting. Opeens viel alles wat ik altijd had gevoeld, maar moeilijk kon beschrijven op z’n plek. Waar ik me altijd heel eenzaam had gevoeld, was jij daar, en Annemiek met haar boek, en Kleinman en al die anderen die net zo dachten als ik. Begrippen als hegemonie, paradigma, biomedische wetenschap als verlengstuk van het kapitalisme, machtsverhoudingen – waarbij de patiënt altijd het onderspit delft ter meerdere glorie van het geneeskundig instituut, al deze begrippen gaven voor mij opeens het inzicht in mijn eigen frustraties, gaven de mogelijkheid om er iets mee te doen. En, heel belangrijk, de inzichten die ik door jou kreeg, gaven me ook de mogelijkheid om toch door te zetten en arts te worden, een arts die zich steeds bewust is van al deze ongelijkheid. Met de handvatten van de antropologie kan ik nu ook voor anderen deze ongelijkheid duidelijk maken. Eens per jaar geef ik les aan medische studenten over mensen-

rechtenschendingen, armoede, conflicten, en de antropologische inzichten helpen daarbij. In mijn dagelijkse werk nu, als huisarts, ben ik natuurlijk niet steeds bewust bezig met al die zaken. Een verkoudheid blijft gewoon een verkoudheid, in de routine van de dag. Maar ik denk wel dat ik veel van wat jij me hebt geleerd, heb verinnerlijkt, het is deel van mezelf geworden. Ik zie het onrecht en bestrijd het, ik kan de mens alleen als heelheid zien en niet puur alleen de ziekte die hij presenteert. Ik voel me er completer door en zou elke arts toewensen om ook iets mee te krijgen van de kritische medische antropologie.

Als ik nu kijk naar zo een willekeurig ochtendspreekuur, is dan wel waar wat ik zeg, dat ik de mens als heelheid zie? Ik lijk op het eerste gezicht vooral labwaarden, bloeddrukken en gezondheidsklachten van de mensen te behandelen.

Maar als ik terugdenk aan de gesprekken die ik gevoerd heb en de gedachten die ik in mijn hoofd had geloof ik dat ik voortdurend ook met context bezig ben. Dhr. E zit niet lekker in zijn vel, zijn vrouw heeft hem net aangemeld bij een gereformeerde geestelijke gezondheidszorg omdat de relatie niet goed gaat. Hij tobt duidelijk en lijkt ook wat somber. Ik probeer een opening te zoeken om het daarover te hebben en denk na over hoe hij op mij overkomt, maar hij wil het nu alleen over de bloeddruk hebben, kan zich wel voorstellen dat die stijgt door spanningen. Dhr. B schrikt van de diagnose, hij is fanatiek wielrenner en nu opeens merkt hij dat hij niet meer meekomt met de rest. Heeft weliswaar gerookt maar is al twintig jaar gestopt, wordt hij daar nu zo voor gestraft? De strandrace van het nieuwe jaar kan hij zeker wel vergeten? Ik besef hoe groot de impact is van mijn diagnose en vooral het uitspreken ervan op deze man die zich altijd zo fit voelde.

En hoe moet het zijn voor een jonge vrouw van twintig om van kinds af aan voortdurend in ziekenhuizen te liggen, jezelf dagelijks te moeten katheriseren, vrij klein te zijn gebleven? Ik kan me haar onzekerheid ook over kleine klachtjes goed voorstellen. Maar steekt er achter die vragen over groeven in haar nagels mogelijk ook een grotere vraag: waarom ik? En: ben ik wel aantrekkelijk? Is er voor mij een normaal volwassen leven weggelegd? Mw. B vindt haar benen zo lelijk en durft niet naar het zwembad, haar vriendinnen zijn allemaal zo verzorgd en daar wordt ze onzeker van. Leeftijd speelt dus helemaal geen rol bij zorgen over het uiterlijk besef ik. Ook iemand van 74 wil van haar spataderen af om er mooi uit te zien. Waarom hebben ze bij haar dan de traditionele therapie gegeven in plaats van de nieuwe techniek die veel succesvoller is? Dat ze wat warrig overkomt en nu ook haar horloge achter heeft lopen mag daarin toch geen rol spelen?

Mw. P. en Dhr. J.: bij beiden speelt etniciteit een rol. Na jarenlang iedereen dezelfde medicatie te hebben geven is men er nu achter dat er tussen verschillende bevolkingsgroepen ook een verschillen in gezondheid kunnen zijn, deels door sociaal economische ongelijkheid, deels ook door genetische factoren: Mw. P is van Hindoestaanse afkomst en heeft daardoor meer risico op hart/ en vaatziekten. Dhr. J reageert niet goed op twee standaardmedicijnen tegen hoge bloeddruk vanwege zijn Creoolse afkomst. Dit zijn empirische gegevens. Om dit aan de orde te stellen bij de patiënt blijft altijd wat lastig: hoe zeg ik het zo dat zij niet denken dat ik hen discrimineer. Gevolg is soms juist geheel averechts: door mijn gehakkel over afkomst krijgen zij juist de indruk dat daar iets mis mee is.

Elke arts moet zich bewust zijn van de context, maar ik denk dat er bij mij ook steeds een wat diepere analyse plaats vindt: wat betekent dit voor deze mens tegenover mij, is een vraag die ik mij onbewust steeds stel en tracht te beantwoorden. Hopelijk slaag ik er ook in om dit voldoende te laten blijken naar de patiënt zelf. Toen ik net startte als huisarts twee jaar geleden, gaf Els me mee: geef elke patiënt het gevoel dat hij of zij er toe doet, dat hij gehoord wordt en in zijn waarde wordt gelaten. Dat probeer ik.

Bad news gesture

GERHARD NIJHOF

Bad news is communicated through speech, sociologists believe.* At least, that is my interpretation having read many studies on this issue. This concept is anchored in our linguistic culture. Naturally, we believe that bad news takes place in language.

Therefore, medical sociologists particularly study how 'bad news conversations' take place.** Doctors appear to dress their message by an introduction and after word. But there are others who keep it short, who break the bad news instantly, without hesitation. Mine did it in a way I had never read about before, and also quicker.

People do not live in language alone. That was made very clear to me, heavily-handedly. I had been in this particular hospital before. A year earlier I discovered I was bleeding heavily when in the bathroom. 'That's it', I thought immediately, 'I'm gone'. When I came home from holiday twenty years earlier, the same news had reached me when calling my mother. Six months later she was dead.

I was referred to a surgeon, an assistant it appeared later. His boss was travelling for study in Japan, he explained. With a colonoscope, he examined my colon and concluded a burst vein in the intestine wall. 'Other hospitals stick a plaque on it', he said. 'We just leave it alone.' Fully reassured, I left the hospital.

A year later I was bleeding again. I wasn't particularly concerned. 'They will have to stick a plaque on though this time', I thought unsuspectingly. I visited the hospital again. The first person I noticed was the assistant of a year earlier. He noticed me too and disappeared rather shyly, behind some

* The conversation analysts among medical sociologists act like this by definition. They study the verbal interactions between doctors and patients. See for example: D. Maynard (1992, pp. 331-358). There are also observational studies on the bringing of bad news. For an early such study, see: D. Sudnow (1976: 125-126, 129).

** See for example: K. Taylor (1988) and see for an early analysis of bad news conversations: B. Glaser (1966).

filing cabinets. Boss surgeon examined me in the same way. On my knees and bent forward, resting on my arms, the surgeon entered a colonoscope into my colon. He was standing behind me. I couldn't see him. After five minutes, he finished his examination. He washed his hands. Walked past me. And squeezed my arm.

'That's a bad sign', it shot through my mind like electricity. 'You may get dressed again', he said. Just seconds after I got dressed, he stood in front of me. 'It's cancer', he said. I buried my face in my hands. 'We may be able to operate', I seem to remember him saying. I am sure he said a lot more than that. But I only remember getting lost on my way home. The hospital is less than 500 meters from my house. But I couldn't work out in which street I was, and in which direction I had to walk to get home.

My surgeon told me with a single gesture. Particular gestures suit particular situations. They are accepted in those situations. You know what they mean. A squeeze of the arm means one person wishes to encourage another, or console. My surgeon made such a gesture. But what did I need the encouragement for? Without accompanying words, this gesture in this situation meant 'cancer'.

Why are many medical sociologists oblivious to such gestures? Because we predominantly ask questions and listen, rather than observe.* Sociologists take interviews, record conversations. Seldom do we merely observe what is taking place.** Like most people in our society, sociologists are people of language, not gestures. We keep whatever is happening at a sufficiently safe distance. We rather ask, afterwards. When hospitalised many things remain unspoken, they merely take place and are to be observed. I became very aware of that as a patient, when I enjoyed very adequate training in the sociology of gestures.

Breaking bad news is breaking with the ordinary. Bad news is the caesura between the before and after. It transforms ordinary life into another, less trivial life. We enjoy change at times. Enjoy breaking the daily grind. And

* The dominance of survey research in sociological research leads to the overevaluation of listening in interviews and the underestimation of listening and looking in participating observation.

** Examples of such research: M. Berg (1992), M. Berg (1997). A classic study in medical sociology using the method of participant observation is Goffmans study of the careers of inmates of a total psychiatric institution (1961). Another participation study is the report of the handicapped medical sociologist I. Zola (1982).

take a brief holiday from life. However, sometimes such breaks result in life never being the same again.

Illness, unhappiness, loss, hospitalisation, imprisonment, divorce, are all violations of our lives and existence. Often these violations are just there. They happen. But sometimes they have to be told. That's a task. No one is good at it. A few have studied for it; policemen, vicars, doctors, bailiffs, teachers. However, for those at the receiving end of bad news, there is no school of discipline, it is always a unique experience. They are overwhelmed. For them it always implies a crisis.

People are empty handed when in crises.* What do you do when ordinary life is no longer ordinary? Then we get lost in our own, normally familiar, surroundings. Because we are no longer the same person in the knowledge of bad news.

From: 'Ziekenwerk; een kleine sociologie van alledaags ziekenleven' (The sick's work; a small sociology of everyday sick life), Amsterdam: Aksant, 2001, pp. 8-10. (Translation: Eva Nijhof)

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Torture, the photographic narrative and truth

JANUS OOMEN*

On becoming converted to medical anthropology I had to learn many theories in action, about matters I previously forgot to think through, or that I do not know what to do about; also that I should have realized long ago. For instance, there is James Scott's *Weapons of the Weak* (1985), there is that 'matter out of place', and many more things that are 'at stake.' My teachers, Els van Dongen, in particular, made a lot of effort to push my mind frame in that direction.

Some of the theories in action offered to me by medical anthropology relate to medical treatment of the effect of torture. This is a new discipline in the Western healing crafts; revealing authors are Basoglu (1992), Brogdon (2003), Peel and Iacopino (2002), and titles are *Medicine Betrayed* (1992), *The Medical Documentation of Torture* (2002), and *Care Full* (2006), the last featuring Medico-legal reports and the Istanbul Protocol, a guideline derived from the Manual to the United Nations High Commissioner for Human Rights (1999) and recently a basic document for professionals specializing in and caring for victims suffering the recent and late consequences of torture. In my estimation approximately 200 medical professionals in the Netherlands have those titles always within reach because they are regularly involved in professional dealings with torture victims.

I will try to explain my involvement by telling how as a medical anthropologist I came to view the physical marks of torture. Previous to that, as a physician, I had tried to teach myself reading those marks, grounding my attempts on how the medical profession is based on the visual. My desire to use the medical craft to improve the chance of refugees in gaining asylum, exploiting my learning, kept me away from the critiques commonly made from an anthropological perspective. Els van Dongen and Annemiek Richters, my advisors of past fieldwork on the torture narratives, made me reflect on my role as a physician. What is the data that you are drawing from? The case studies, what have they told you, really? I came to realize that the research

* The text draws on a 2008 presentation at the European Association of Social Anthropologists (EASA) conference in Ljubljana. Rebekah Park corrected the English.

was questionable, led astray by incomplete, hard to interpret, unqualified assumptions. The results were not useless, but not altogether truthful or complete. Not the whole story.

How to make the truth happen in a context of disbelief?

How telling are scars of torture? Can photographs grasp the evidence? The setting I describe is that of Dutch medical clinicians volunteering, on behalf of Amnesty International (Netherlands), to document the torture narrative and make photographs of victims because the immigration authority denied them asylum and threatened with extradition. Some tortures leave physical evidence, but many do not, and all victims have combinations of significant mental, physical and emotional scars they want to forget and try to avoid speaking about. In procuring safety and healing, however, story and scars are all they have for weapons; weapons, they do not want to use, but need to fight against. One immigration and Naturalisation Service (IND)* stipulation in the asylum procedure (Vreemdelingen-circulaire 1982) states that medical expertise cannot play a role or contribute to verification: an 'officialised' looking away from scars and narrative manifestations. The Amnesty medical documentation has to overcome the IND strategy of denying the asylum seeker the advocacy of expertise in support of the allegation of having been tortured.

A case history

Francis** was 28 years old when asylum was refused to him and now, four years later, he is still appealing against that decision. An appeal, by means of a second asylum procedure, was initiated by Amnesty, the outcome of which is still pending. I do remember him, and his tale, most vividly because he had a photograph taken of himself by a friend before treatment of his scars. The scars, were treated with an anti-inflammatory ointment two years after the IND hearing. The photograph shows extensive festering scars. When he was

* The Immigration & Naturalisation Department (IND) is the Dutch service assessing asylum requests on the basis of the Aliens Act (Vreemdelingenwet 2000).

** Not his real name; the photographs shown are with his written informed consent and in accordance with Amnesty's attempt to prevent him from recognition.

examined by us, volunteering Amnesty doctors, two years later, the scars had subsided and stabilized as a result of the treatment.

His story was that he had been detained in an African civil war situation, and tortured, belted and burned, by rebels, who had since moved into a government position, and still are. Their leader is now the vice-president of his country. Francis managed to escape because he knew the area better than the rebels. He fled to the adjacent country and from there, assisted by family and a travel agent, for a considerable sum, by air to the Netherlands. To his amazement his asylum request was rejected within 48 hours. His wounds were at that moment still fresh under his shirt. During the conclusive hearing he offered to take off his shirt and to show his wounds, but he was told this was not according to procedure. Medical expertise was not called in because it was 'irrelevant' according to the asylum procedures. Our findings on examination of the multiple scars, two years later, were interpreted as very consistent with the alleged whipping on his back (while blindfolded), and the pattern exactly matched that of the earlier photograph taken by his friend. Several coin-like bleached skin areas would have been difficult to interpret without that first photograph, but could now be explained as cigarette burns. Military belts with heavy buckles ('cordelettes') left distinctive scars on his back, a type described by Peel (2000: 12). Still other scars showed the 'tramline-contours' known to be caused by the sjambok (whip).

To the medical mind of the examining Dutch doctor, the IND procedures are illogical and unacceptable. In this case, what else could he have told the IND other than the truth? Why was his story rejected? A misunderstanding, perhaps, due to the poor translation by the interpreter? But both sides spoke in French and not in a dialect of an African language unfamiliar to the Dutch interpreter. Or an adverse event in the busy day of immigration work, caused by an exhausted officer? But then no one intervened to support his tale against this adversity, or uncovered his wounds and there was no solicitor present in the room. Another possibility: an overly imaginative empathic doctor from Amnesty, constructing a wild tale, devoid of logic, to emphasize his expertise. But how then to explain the scars and the resulting photographs four years later?

Photographs and description

The upper photograph is the one taken by his friend two years before the lower photograph, which was taken by our professional Amnesty photographer during medical examination. In the upper photograph the marks are

of two kinds: many brownish stripes and four whitish dots. The brownish stripes are unhealed whiplashes and the whitish dots are healing cigarette burn marks. As Francis told us: when the first photograph was taken, the scars were still active, itching and burning. After consultation with a general practitioner he had decided to try an ointment. Because he was an illegal refugee, he had no access to specialist treatment and had to pay himself for the ointment, which contained a substance (salicylic acid) active against inflammation and a substance active against itching (a local steroid). This, in medical concoctions, is a quite usual combination. The lower photograph demonstrates exactly the same pattern of marks but slightly healed after self-treatment.

These two photographs, taken together, tell the whole medical story of what is at stake. Without using any medical vocabulary, one can see and describe a pattern marking the skin of Francis' back. We were looking at an extraordinary picture. The consulting dermatologist and myself, together documenting his narrative by our professional observations, were shocked. Not only were these scars completely consistent with his allegations, they were also evocative of how severe his tortured condition must have been during the hearings by

the immigration official. From a forensic point of view, Francis had inadvertently complicated our work by his self-treatment: one can see that the ointment had considerably mitigated the scarring. By making that first photograph prior to the self-treatment, however, he had helped us in our task: there was no doubt whatsoever that these were the 'writings on the skin by his torturers.' The manifestation and verification of his tortures, during the asylum hearing, should have been convincing to anyone. Francis' truth was painful and brutal; still it was denied to him.



Background figures and images

In 1996 I volunteered as member of a 'scarring from torture' project group of Dutch medical professionals in Amnesty Amsterdam. Since 2002 the photography of scars was studied by our group as applied visual medical anthropology, bringing together a professional assessment on behalf of the victims

of torture during IND asylum procedures and a collection of visualized data from an ethnographic perspective. Before dealing with the ‘what is at stake’, I must describe more details of the Dutch context, exemplified by the above case, and outline the impact, individually and on an epidemiological scale, of torture refugee conditions in the Netherlands. “Scars are of no account” (Oomen 2001; 2007). The interrogators do not look at the scars, even when mentioned during the hearing. Their looking away from clearly visible signs is perceived by our group as an officialised denial of proper asylum proceedings.

Several non-government human rights organizations have voiced grave concerns about those policies. As one Amnesty refugee expert formulated: “Europe fears asylum seekers. For many years now they are the subject of a political discourse with the emphasis on their numbers and not the persons. Media are reporting daily on war and persecution in faraway places, but personal nearby narratives, of victims trying to survive that violence, remain untold. Some of those victims seek protection in our backyard. Their dossiers are stored in the Ministry of Justice” (Busser 2007: back cover announcement).

Only a tiny minority of torture survivors flee from their country of origin to the European Union to request asylum. In the Netherlands the overall number of applications for asylum in 2003 – 2007 is estimated to be 60,000, around 10,000 annually on a population of 16.5 million (UNHCR). The rates of admission are very low: less than 5% in the official procedure. The admissions to asylum are never argued. The rules governing asylum policy in the EU aim at restriction, notwithstanding the fact that all EU-members support the international asylum conventions. Within the period under review, annually approximately one hundred clients are examined by one or more physicians in the Amnesty group from a pool of fifty. The task of our two photographers, only if scars or handicaps are recorded during screening, is to document visually what the examiner has put in writing.

More often than not, during the hearing, the asylum seekers are initially unaware of what is expected, and unable to speak about the torture, due to the setting, the approach, or being in post-traumatic and cultural turmoil. Avoidance or denial of the torture trauma thus becomes mutual, because both the interrogators and the victims ‘collude’ to keep out the painful events, which have led to the asylum request. Consequently, it is only during the protracted procedure, after the negative decision, on instigation by solicitor, or by fellow-victims, refugee councilors and (para-) medical caregivers, that the person voices concerns ‘what narrative’ (‘what truth’) is key to asylum. However, Dutch immigration authorities refuse to hear these belated

narratives, keeping decisions as they stand on the principle that the 'truth' is to be given at first opportunity only. The judiciary actions to deny asylum aim at extradition, 'refoulement', forced return to the country where the torture occurred. The fact that the asylum seeker runs the risk to be subjected to torture again is the mainspring of the Amnesty intervention.

What is at stake

Torture is severely, most emphatically, 'matter out of place' (Douglas 1966: 35). When torture is brought from the private suffering to the public arena of asylum policies, it breaks free and threatens the habits and rules of citizenship in the privileged and civilized European community. Such a transgression is forbidden and should be discredited with all possible means. In this contest, the medical photographic documentation aims at a visualization of what was not observed during the asylum hearing, versus what should have been observed and can be ascertained during medical examination. Scars and handicaps become pictorial and cannot any longer be denied in the process of interpreting the individual trauma. Additionally, the physician is enabled to state in what ways the photographic truth consistently details the allegations about the torture. The reporting takes into account the guidelines of protocol, because of the similarity to scars and handicaps associated with similar tortures, which are referenced in the human rights literature and in the repositories of Amnesty and the centres for rehabilitation of the tortured (CRT's) and other forensic public archives.

In their introduction to *Lying and Illness*, Els van Dongen and Sylvie Fainzang (2005: 8) write: "The denial of the experience of the refugees can constitute a second trauma which can be sometimes more destructive to the person than the events in the country of origin ... they stress the serious consequences that the stigmatization of the refugee as 'liar' can have." Medical anthropology has contributed that theory to the action.

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Punctuating *Criollismo* in Barrios Altos

Nilda's ethnic/racialized investments

MARIA ELENA PLANAS

Since 2006, I have been doing ethnographic research in Barrios Altos, a multi-ethnic inner-city neighborhood in Lima, Peru, shaped by poverty, social marginalization, and an underground economy of drug dealing and thievery. My interest is in the everyday life of children living in Barrios Altos, and the salience and psychosocial relevance of ethnicity and 'race' in their politics of identity.

In order to explore children's politics of identity, and their personal and social predicaments, I have made extensive use of visual methods (e.g. photographic self-portraits), a choice I relate to my engagement with a more critical, participatory, and multimodal research. What I present here is a snapshot of one chapter of my dissertation. As the title suggests, I will reflect on the specific ways in which Nilda, a thirteen year old girl living in Barrios Altos, reproduces, challenges, and recreates ethnicity and 'race'. I understand that ethnic/racialized identification, rather than a fixed and singular identity, is the unachieved product of a series of cumulative, intersectional, and constrained investments, some conflicting or contradictory, offered by multiple, hierarchically organized discourses on cultural and phenotypical difference. Ethnicity and 'race' in Barrios Altos are sites of contention and strategic investment with very real (material and discursive) consequences in the lives of people. I will share some thoughts about Nilda's ethnic/racialized politics of identity, and will present her account as a counterpoint to *criollismo*, an ethnic/racialized discourse that continues to shape people's lives in Barrios Altos.

Criollismo in Barrios Altos

Ethnic distinctions in Peru, like in so many other places, are mapped through a language of geographical belonging (Valdivia 2002; Canepa 2007). Ethnicity, and thus cultural differences and similarities, are articulated in response

to the more or less literal question “Where are you from?”, which can mean: Where are your parents/ancestors from? Where were you born? Where do you live? Name the place and wait to get figured out: the identification or categorization of people in terms of their putative origin in certain places is, *par excellence*, an ethnic question (Wade 1997).

The relevant answers within this geopolitics of identity – if you are Peruvian and sit in Lima – are: “From Lima” (*limeño/a*) and/or “From the provinces” (*provinciano/a*). If you are from the provinces then you map your belonging replicating the three ‘natural’ regions of Peru: from the coast (*costeño/a*) and/or from the *Sierra* (Andes, *serrano/a*) and/or from the jungle (*charapa*). However, if you talk to a *paisano/a* or a neighbor, you might have to trace your belonging to the specific city, town, district, *barrio*, and block. You zoom in and out depending on who you are talking to, where you strategically want to locate yourself, and who you want to ‘other’. These investments in specific geographical boundaries instantiate, however, not only cultural or moral distinctions but also racialized ones. When you locate your belonging in a place, you are immediately judged as fitting or not fitting the racialized popular neighborhoods like Barrios Altos, was the political project that articulated an imagined community of *limeños*. If *criollo* was during colonial times a category ascribed by descendants of Spaniards born in Peru, ‘Popular *criollo*’ reinvented the narrow ‘imagined community’ of colonial white *criollos*, to include *mestizos* and blacks. It was an effort to facilitate “the link among people who, despite having felt different from each other before, shared *without knowing* ways of being” (Panfili 2001, my emphasis). Popular *criollos* were non-racialized people living in Lima who were supposed to share a similar culture and similar morals. Panfili suggests that the Popular *criollo* was a *mélange* of “Afro-Peruvian culture, Spanish wiliness and Mediterranean cultures [i.e. Italians in Barrios Altos] who arrived in Lima with the early modernization [and shared] a gift for witty and naughty remarks, playful linguistic turns, and exhibitionist spectacle” (Panfili 2001: 50). In the same vein, Portocarrero (2006) portrays *criollos* as nonchalant and cheerful people, who have a vocation for not submitting their enjoyment to the trimmings of the law. The supposedly humble, prudish, sanctimonious, and obedient people from the *Sierra* – Indians and *cholos* – were the antinomy of the emerging *criollos*. Within *criollismo*, the racial divide is undermined and Afro-Peruvianness or blackness is supposedly ‘positively’ incorporated in the *criollo* culture: music, food, and soccer.

Barrios Altos is seen as the cradle of Popular *criollismo*. To be *criollo* is to invest in being *mestizo*, and since most Peruvians invest in one of the various

available *mestizo* positions, this has been related to a paradoxical situation that makes 'race' both central and elusive:

... its elusive nature lies in the fluid and situational character of these differences: the fact that individuals can shift their position in systems of racial classification, the relative nature of racial identity that permits an individual to be simultaneously more Indian than a second and more mestizo than a third (Orlove 1998: 207).

Indeed, most people I encountered in Barrios Altos articulate 'race' in Lamarckian terms of environmental determination. It has been suggested that *mestizo* positionings and cultural politics are ambivalent: they resist and reproduce racism. Mallon (2005) has argued that *mestizaje* tends to combine elements from liberating, counter-hegemonic, and creative hybridity, with official homogenizing and exclusive discourses. Various ethnographies suggest that people invest in *mestizo* and 'fluid' positionings in order to deny non-modifiable hierarchies based on racialized phenotypes, and posit a locus of agency and social mobility. In the next section I will punctuate the *criollo* discourse from within the politics of identity of a thirteen year old girl from the *Sierra* who moved into Barrios Altos when she was seven years old.

Nilda's constrained investments

Nilda identifies herself very much as from the *Sierra* and *provinciana*, and a bit *chola*: white, black, from the jungle, from the coast, and from Lima. She feels she belongs strongly to the *Sierra* since she and her parents were born in Huanuco (Andes region), and because she lived there and now she enjoys spending her holidays there. Because her mother's father is from Tingo Maria (Amazon region), she is a bit from the jungle as well; the part of her that is from the coast and Lima is because she has lived already for years in Lima. *Criolla* though, she definitively is not: "*Nothing criolla*," emphasises Nilda.

Nilda argues that you can figure out somebody's 'race' by her customs, her way of talking (her accent and the words she uses), her character, and her skin (i.e. if somebody is from the Andes, her skin becomes damaged and peels because of cold weather). However, when I ask her overtly to define 'race', she keeps silent. When I ask her about her own 'race', she asks back: "*¿From the Andes?*"

For Nilda, people from the Andes have a specific character: “They come here looking for work, to be somebody (...) It’s their personality, they want to come far in life, they want to be somebody.” She herself wants to become ‘somebody’, that is, to be a professional. She wants to finish her studies and become a lawyer and a cook. She keeps in mind what her father often says: “Education is the only thing we can offer you,” and I can see that Nilda really wants to take the chance and become ‘somebody’. Probably, that is why she becomes so stressed when she does not do well at school, when she feels she is not doing her best. When I ask Nilda if she is happy with herself, she says: “Not that much; because sometimes I am not responsible with my homework; sometimes I am lazy and it makes me uncomfortable, it gets me angry that I don’t do it.” For Nilda, her dearest dream is to become a professional; anything else gets in the way, for instance boyfriends. Nilda agrees with the fact that she is not allowed to have a boyfriend: “It is a waste of time (...) [My dad] tells me that only when I become a professional, I can have a boyfriend.” Nilda also tells me that a strong motivation for her to become a professional is “... to be able to help people that have no place to live, people who live in the street, people who have nothing to eat... Because nobody likes to live like that.” I guess she relates being ‘someone’ with having the power to help others and change things. This is also what she meant when she decided to portray herself in front of the Congress (see Image 1).



Image 1

In the photograph Nilda is standing at the entrance of the Congress building, looking at the camera; not presenting the Congress but just being there with her arms relaxed at her sides. The picture is quite dark for she took it in the evening: you only see the gate, the bars, and have to imagine the building behind. She says:

I want to become a congress representative, because some congress representatives – sometimes it is shown in the news – they do as if they hire people and cash their salaries; I want to set myself in the congress to do something for everybody, that is why I pictured myself there.

When I heard these words during our first interview, I wondered if she really meant what she was saying. Was she making it up for me? Was this a tourist picture with a post facto comment? Was this a ready-made answer to satisfy my demand for explanations? I recognize now that her dream of becoming

"somebody, somebody to help others" is part of her moral self, of her being from the *Sierra*. By identifying with the Andes, she is making a moral statement about who she is and who she wants to be: a determined, hard working girl who wants to come far in life. She is investing in this position in this particular way: claiming a set of values and a lifestyle, and elaborating on a specific notion of self-respect anchored in her being *provinciana* and from the *Sierra*. At the same time, Nilda claims to be a bit *limeña*, challenging and reproducing the boundary that qualifies Lima as *criolla*.

This boundary of *criolla limeña* vs *serrana provinciana*, however, is being reproduced by everyday discriminatory practices and ideals of beauty. Nilda knows that if you are from the Andes, you will be teased because of your face and the way you speak. In the news and in the soap operas, she sees how people from the *Sierra* are discriminated against: "They are denied jobs because of their origin and ways of talking." What is more familiar to her, though, is the everyday practice of name-calling. At school, Nilda is called names and also calls other people names when she gets teased for being fat, for having a *mote* (Andean accent), etc. At home, she says, "My uncle keeps bothering me by saying: 'Black, what are you doing here; we are all white, who did you take after if the whole family is white?'" However, this is no discrimination for Nilda, as her uncle "is playing," teasing her.

Nilda tells of a constant fight which has been going on between two schoolmates since first grade. One teases the other because she is from the *Sierra*: "Duck face," "Your dad is ugly and looks like [Inca] Pachacutec," "Your mom lives in Cusco," etc. The other keeps calling her "chata" or "Smurf" because of her height. Although this story came up while I was asking her to narrate discriminatory events, Nilda says: "They are playing;" there is indeed a continuum between discrimination, name-calling, teasing, and playing. Nilda also says that there is no possibility of asking teachers to intervene, "Since they are both insulting each other, they are both to blame."

How do these teasing practices against people from the Andes condition her self-identification? While Nilda was narrating discriminatory or 'teasing' events, she laughed about it too. But at a certain point she said quite firmly, "We are all equal," and again, but this time with a vindictory tone, "People from the Andes are better than people from here [Lima] because they come to become somebody, not like people from here, they don't achieve anything, they don't do it." Then she added, "But not everyone from Lima is like this." Nilda is constantly qualifying her statements: "Not everyone from Lima is like this."

Talking about her skin colour, she says: "I am neither white nor black, I am more or less." The bit of white she is, she relates to her father: "He and

his siblings are all white". The bit of black she relates to her mother: "My mom is blacker than me." When I ask her how *chola* she feels, she answers, "A bit." She relates her being *chola* to her father being from Huanuco, from the *Sierra*. However, despite her bit of *chola* self-acknowledgment, she never uses the term *chola* to map her belonging; instead, she prefers to say she is from the Andes. *Chola*, white, black – unlike being from the *Sierra* – are more explicitly racialized descriptions that are not linked with her politics of identity, with her morals, with her dreams.

Nilda does not argue her belonging in phenotypical terms, nor defines 'race' in terms of genetic determination, but does relate 'face' and 'skin colour' with being from a place, echoing Lamarckian ideas of 'race'. Living in a place makes you 'from' that place, for you are exposed to the environment and that influences your appearance (also phenotypical) and your lifestyle, character, way of talking, and customs. She certainly relates ethnic/racial belonging to culture, lifestyle, and moral character. She is willing sometimes to invest in a racialized position as long as it relates to a psychosocial characteristic. For instance, she explains to me laughingly that her being part-black is to be seen when she shouts: "I have a bit of black because I shout a lot". When I asked 'why', she said 'because'; I should instead have asked 'when', to address overtly the situational dynamic of her identifications and belongings. There is, however, a stereotype at play: black is shouting. Likewise, there is a stereotype of white is beautiful, and Andean traits are ugly. For Nilda, like for most girls and boys, the whiter you are the more beautiful you are; and probably that is why she chooses not to be 'vain', or invests in being from the *Sierra* and not in being *chola*.

When I asked Nilda in our first interview if she belongs to Barrios Altos, she answered that she does, "strongly;" when I asked her to explain to me why, she doubted and remained silent for a while, and only after my repeated insistence said, "I don't know, I think because almost all my life I lived here." I could interpret her silence as being related to a lack of 'affordability': how can a girl from the *Sierra, provinciana*, claim to belong 'strongly' to Barrios Altos, the cradle of *criollismo*? How can a *provinciana*, a migrant, claim a belonging to Lima? *Chola, serrana*, and *provinciana* are discursive positions that exclude *criolla* and *limeña*. How then to understand her subjective investment in being very much from Barrios Altos? The second time I asked her to self-identify herself, she answered the same way to all identification terms, except to "Being from Barrios Altos." This time, she laughed and said she was a bit from Barrios Altos, "Because sometimes I insult my friends, sometimes I *achroro myself*". That is, sometimes she says she behaves like a *choro* (a slang word for thief, note the masculine); sometimes Nilda

looks for a fight and is willing to be (physically?) aggressive. It is interesting to note that she describes the *choro* behaviour in quite the same way as she describes *criollas*. Spending time in a place is becoming somebody else, becoming like someone from that place. The part of her that is *barrioaltina* is the bit of her that behaves – sometimes – like a *criolla*.

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Misery and resilience among war widows in the North of Rwanda

Individual and social healing
through the mediation of sociotherapy

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As a follow-up of her research on trauma, remembrance, and wellbeing among older people in South Africa (see for instance Van Dongen 2004), Els van Dongen planned new ethnographic research on everyday mundane life in contexts of social and political violence and its aftermath. Thus she hoped to contribute to the development of theory on the transformations of 'social souls' in processes of restorative work. The resulting theoretical framework would, moreover, have to be useful to give direction to concrete community health programs. The locations for the comparative research should be communities in a selection of countries that (have) endured long-term social and political violence. Some of the sub-questions Els was interested in were: What aspects of culture and sociality are used to strengthen the resilience of communities and individuals? Will memories remain dormant until political and social situations make it possible to articulate those memories? How do individuals and communities remake their world in contexts where political and bureaucratic responses to the legacies of past violence often deepen and complicate the problems these responses are intended to ameliorate? What is the impact of government supported truth and reconciliation strategies on justice and healing, as perceived by traumatized individuals and communities? How do communities deal with returnees (refugees, ex-prisoners, soldiers) and what are the consequences of return for the wellbeing of all?

My contribution to this book for Els touches on the complex of issues represented in the research program she envisioned, and which together we intended to develop and implement, in cooperation with others. I will set the scene with the story of Seraphine, a woman in her late fifties, who

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lives in the North of Rwanda, a country that went through a long history of political, violent conflict, culminating in the 1994 genocide. I met Seraphine in 2007 in the context of research I was conducting about the impact of a sociotherapy program in the area where she lives' (Richters et al. 2008). Seraphine told me her life history in an interview that took place a few months after the sociotherapy group meetings in which she participated had officially ended.

Seraphine

Seraphine completed one year of primary school. After that she was kept home by her parents so that she could look after the cows. She married young. To escape the 1990-1994 war violence she and her family moved further south. However, during the genocidal period her husband and one of her six children (a 3 year old girl) were killed in front of her eyes by the *Interahamwe* ('Those who work/attack together' – the civilian Hutu extremist militia). When the militia wanted to rape her she successfully scared them off by telling them that Nyabingi (a goddess Rwandans used to fear and were supposed to appease with ceremonies) would take revenge if they harmed her. Yet, despite that escape, she was cruelly raped later on by three *Interahamwe* soldiers during her subsequent flight with her remaining children to a refugee camp in Tanzania. After two years of living there, she went home with three of her children, and the other two joined later. She found her house destroyed, and since she had no means to repair it, they had to live in it as it was. After some time, she was advised to have herself tested for HIV/AIDS. The test was positive. A local association provided her with medicine. However, knowing that she was HIV positive added to her misery. Her sleeping problems caused by the nightmares of the violence she had experienced and her worries about daily life increased. She "spent the whole night weeping". She was not a good Christian, according to herself, because she drank alcohol. She stopped her alcohol use after joining the Church; people in the Church assisted her. They told her that she should be patient and continue to pray and that God would help her. She followed the advice given to her,

* The program was implemented by the Episcopal Church of Rwanda, Byumba Diocese, in cooperation with the Equator treatment programme for traumatized refugees at the Academic Medical Centre in Amsterdam. It is financially supported by the Dutch NGO Cordaid. See for a description of the program Richters et al. 2008.

and life went on. However, she kept feeling isolated, and people continued to distance themselves from her.

One day, Seraphine was invited to join sociotherapy. She accepted, hoping that this may help her to solve some of her problems. In the sociotherapy group she started to feel safe and experienced a release of her heart. She was advised by the group members to forgive, and she wanted to follow their advice. However, she did not know whom to forgive, since she had not succeeded in finding out who had killed her husband and child. In sociotherapy she discovered that she was not the only one with problems. She learned to trust others. Others gave her peace in her heart. It was like vomiting; everything in her heart came out. The group helped her to overcome her problems of communicating with others. Now she can talk to other people, friends and neighbours, who are now also willing to help her. The neighbours see her interacting with others, so they also start interacting with her, and she with them. However, Seraphine states that she still suffers from trauma, headache, and nightmares. She can now share these problems with others, which is a big relief, but she needs more help. She continues to meet with her sociotherapy group members, but now in the context of the Association they started together. The Association is like a family for her.

Asked what makes sociotherapy so special, Seraphine responds enthusiastically: doing things together, the support, and the security. She could talk about her secrets and thus share them with others, knowing that those others would not gossip about it. She enjoys the strength of mind she has regained. The sociotherapist who facilitated Seraphine's group provided some additional information, namely that Seraphine's husband was killed because the military suspected that he was affiliated with the RPF (Rwanda Patriotic Front, consisting of predominantly Tutsi soldiers who had invaded Rwanda from neighbouring Uganda in 1990, intending to liberate Rwanda from a Hutu government). On Seraphine's return, even her own family considered her as someone affiliated with the RPF, thus they do not have a good relationship with her. Seraphine, as a Hutu, is not entitled to the support the government provides for genocide widows (Tutsi women whose husbands were killed during the genocide). Through the intervention of a local authority representative, however, she eventually received a cow from the government, which diminished the problems she was having of not being able to feed her children properly.

The representative for women in the village where Seraphine lives noticed a remarkable change in Seraphine. "I was the one whom Seraphine insulted as being useless to her. But after joining this program she came to ask me for pardon, she said 'I calmed down, sociotherapy has strengthened

me'. Before, Seraphine was always alone. Today she has morale. She came to invite me and I accepted her invitation and promised her that I will help her in some activities".

Another female local leader told us in an interview about the impact of sociotherapy on widows (including Seraphine) in her area: "Before, I considered them as pitiful outcasts, as they did not collaborate with others in common activities, arguing they were too poor. But today they are smart; they wear clean clothes, attend meetings, participate in many activities, and operate in associations in order to cultivate the land. You find that they broke out of isolation." Apart from Seraphine's Association, which consists of the members of the sociotherapy group for widows in which Seraphine participated, there are four other, similar Associations in the area. Nowadays, the women of the five Associations proudly sell their products (beans, sorghum, potatoes, cauliflowers, etc.), even to people who come all the way from Kigali (a distance of two hours' drive) to buy them.

Being a widow in post-war Rwanda

The life of widows has always been difficult in Rwanda. However, in the aftermath of the war and genocide the misery widows are facing has substantially increased, and in response, so has their resilience. Following Ferreira and Van Dongen (2004) in their study of older persons' lives in South Africa, I use the term misery more broadly than to mean only psychosocial suffering; it is also used to describe the structural conditions which are a cause of unhappiness and pain. These conditions for widows in the North of Rwanda include post-war social fragmentation of the remains of kinships systems, destruction and loss of property, increasing poverty, a society full of mistrust, and, if they are Hutu, no public space to commemorate and mourn the loved ones they lost during the war. In most of these cases their dead husbands, children, and siblings are not even buried or officially recognized as dead/killed.

In the sociotherapy program widows are singled out as one of the vulnerable groups in society which could benefit from the program. The husbands of the widows I met had died of diseases (before, during, and after the war), poisoning (the underlying medical cause of this 'poisoning' is frequently AIDS), and the violence of the war and genocide. Sometimes husbands never returned from Congo, where they sought refuge or joined the military. Widows have always suffered from hostilities enacted by their families-in-law. Now also their own family members and children can turn against them,

trying (often successfully) to take their property away from them, chasing them out of their own houses, and withholding material and social support. Often widows have lost family members and children during the war and genocide, which means an additional loss of (potential) social support. One woman said to me: "I am the only one left". She lost both parents and all nine of her siblings during the war and genocide. Her husband who survived the violence with her died of AIDS in 1996.

As before the war, a widow is still considered in Rwandan society as a weak creature without agency, vulnerable in particular to the whims of men. Men can come to her for sex at any time, since there is no husband in the house to protect her. A major problem for widows is that their number has increased substantially since the war, and so have orphans, another vulnerable group. In addition, there are a large number of women who are alone because their husbands are in prison. The whole of society is in disarray. Resources are limited and there are many needy people. This means that widows have to compete amongst themselves and with others for sympathy, social support, and men to marry or have sex with. Widows are blamed by married women for taking their husbands away from them. Looking at this phenomenon from another angle, widows are victims of poverty, loneliness, and lack of affection, and men tend to take advantage of all that. All these conditions add to the widows' suffering. Many widows, such as Seraphine, suffer from hopelessness, isolation, stigmatization, extreme poverty, losing their mind or going mad, and wanting to commit suicide but fearing death and being anxious about leaving children behind, uncared for.

In the vulnerability context in which widows live, some do show the ability to 'bounce back'. They enact, for instance, a strong sense of responsibility in raising and protecting their children, including orphans they have accepted to take care of. Another example is their engagement in work that used to be men's work, such as the construction of roads and brick buildings. In addition, there is an active resistance among widows to the culture of widows' sexual availability for men. There are, of course, also widows who do not bounce back and do not resist society's attitude towards them. Instead, they may reduce their sensitivity and make themselves in this way less vulnerable. To me, it seems, Seraphine was quite resilient, actively taking care of her children as best she could. As she said, in sociotherapy she met widows worse off than her, some of whom I met, among them women who

* For a discussion of the concept of resilience and related concepts, see the special issue of the Dutch journal *Medische Antropologie* on dimensions of resilience in contexts of health-related adversity (Niehof & Van der Geest 2008).

nevertheless bounce back, but also women who had fallen through the vulnerability threshold, at least before their participation in sociotherapy.

Healing of the heart and subsequent social transformations

Sociotherapy has proven to be one of the interventions that can help widows break through their misery, even in situations in which their resilience seems to be irreversibly affected. What people, including widows, participating in sociotherapy demonstrate by their behaviour and talk is that what they suffer from most is a loss of intersubjectivity. They confirm what Jackson (2006: 39), who was greatly inspired by the work of Hannah Arendt, wrote about violence: “violence, like storytelling, occurs in the contested space of intersubjectivity, its most devastating effects are not on individuals *per se* but on the field of interrelationships that constitute their life worlds”. The key of the sociotherapy method is its focus on the restoration of the intersubjectivity lost as a result of war violence and its legacies. What people like Seraphine appreciate in sociotherapy is being respected by others again, and being given the opportunity to speak, tell their stories, and be listened to in a respectful way. The socio-group functions for them as a family and a doctor at the same time. Before their hearts were like a stone; however, sharing their story with others, and listening and processing advice from them, unburdens their hearts and gives them peace and security. Sociotherapy interventions help people to start a process of coming to terms with experiences related to the violence of war. The healing of their hearts helps them to constructively confront the violence that is part of their present day-to-day life by taking the initiative to reconcile with others who have harmed them. Their identity as a victim gradually dissolves. As people often say: “Sociotherapy gave me my humanity back”. Social relations improve significantly, people come out of isolation, and all or at least a substantial part of people’s physical and mental health problems disappear. The concept of the heart is key in the way people describe how they feel, positively and negatively. By focusing on intersubjectivity, sociotherapy contributes to the healing of people’s hearts, which in turn helps to heal what is left of the social souls in their living environment.

Building blocks for theory development

Let me return to Els’ research questions, and give some preliminary, very brief answers related to the post-war context of North Rwanda. The answers

are not complete because of a lack of space here, but also because research is needed to provide the material for the kind of theory development Els was aiming at in her research program-to-be.

What people appreciate in sociotherapy is that it brings back what they valued in the culture of traditional *gacaca*, a local level institution that helped people to solve problems in a communal way. Sociotherapy differs from the modern, government controlled *gacaca*, in the sense that within sociotherapy people find the safety and trust they miss in the modern *gacaca* and in society as a whole. Instead of solving problems, for many people the modern *gacaca* – a kind of legalized truth and reconciliation strategy – deepens and complicates problems; problems which they had already started to solve by themselves on a community level before the modern *gacaca* was introduced. Christianity, which has become part of Rwanda culture, is integrated in sociotherapy and is experienced as consoling. Sociotherapy provides a safe social space where people can voice their memories about the war and violence. The majority of people in the North of Rwanda lived through the experience of internal displacement or of being a refugee in Rwanda's neighbouring countries. Furthermore, there was no host community for them to reintegrate into upon their return. Whether returnees (refugees, ex-prisoners, or soldiers) or not, all people had to reintegrate in a kind of vacuum, and fill that vacuum by each contributing to the restoration of intersubjectivity, and leaving their identity of victimhood, such as the identity of being a widow, behind. Sociotherapy contributes to a new kind of intersubjectivity that reminds people of the intersubjectivity they lost due to the social and political violence of the recent past and its aftermath. What people appreciate is that it also modernizes the intersubjectivity they know from the past by adding, for instance, the dimensions of democracy and equality to it.

As far as the contribution of sociotherapy to intersubjectivity is concerned, more detailed research is needed to study, for instance, the subjective dimensions of people's resilience, on which the program has been built and can build further. One of the many other issues we need to understand better is how such a relatively 'simple' and 'cheap' intervention as community-based sociotherapy, focusing primarily on restoration on the level of social and moral relations, can have such a strong 'sociosomatic' and 'civil society building' effect. And further, to what extent and why it possibly fails to be effective. Another issue of concern is the durability of its effect. The study of these 'theory in action' issues would definitely gain in value if that study could be done in the context of a country-comparative research program, as Els proposed it.

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Fear of AIDS

Moralizing youngsters in Kenya*

RACHEL SPRONK

AIDS, like many other diseases, is not merely an illness of a diseased body: it also has profound social implications. AIDS is an awful disease, as well as a source of (moral) fear. These realities are interrelated and both have an impact on the meanings of AIDS in dominant discourses. Fear is commonly thought of as a response to danger, a reaction to something, but it can also be a chronic condition and hence penetrate social memory. The sources of fear are often unclear as fear thrives on ambiguities. It is an arbiter of power – invisible, indeterminate, silent (Green 1994: 227). In this essay I explore the fear of AIDS – the social structure of meaning-giving resulting in processes of inclusion and exclusion – in Kenya, based on my research in 1997/98 and 2001/2.

AIDS as a phenomenon of fear is built upon the real life tragedies resulting from the disease. The destructive character of the pandemic has affected individual and collective attempts to organise daily life. For the bereaved the loss of loved ones through AIDS is more bitter than any other death because of the social stigma related to it. The families in which both parents have died, and in which relatives (and sometimes grandparents) must take care of bereaved children, find themselves experiencing additional social and economic burdens: elderly parents outlive their children and grandchildren; companies and universities demand HIV negative status before they invest in young and talented employees/students; insurance companies refuse to take HIV positive clients. The highest numbers of infected persons are among the most economically productive age group (made up of individuals between 20 and 45 years of age), suggesting a grim economic future for some families. The strain on both dependants and caretaker relatives increases with the progress of the disease, as it demands long term intensive care and increasing use of palliatives. People often say that 'AIDS causes suffering' and when

* This essay is based on a paper I presented in a seminar on social exclusion in Africa, organized by Els van Dongen.

speaking about AIDS, people's body language typically expresses how AIDS is, in many ways, a tragic disease.

Of the young adults I spoke with for my research on sexuality, only one woman was HIV positive, and she developed AIDS during 2001. About half of the group had had at least one HIV test; the other half had never gone for testing. More men than women had gone voluntarily for an HIV test, while women often elected to have an HIV test as part of a larger medical check up. None of the group's nuclear families (parents and siblings) was known to be HIV positive or to have AIDS, or to have died of AIDS, although about half of the group had lost aunts, uncles, cousins, and close friends to AIDS. Everybody reported knowing people who had died of AIDS, whether colleagues, friends, distant relatives, or acquaintances. When these young adults were teenagers they were warned against AIDS through invocations of the evils of (unsafe) sex and the importance of sexual abstinence before marriage. They had all been made aware of AIDS, its physical and moral causes, and its physical, emotional, and moral consequences. AIDS was a major point of reference in their lives, and both the disease and its consequences have been intertwined with their lives. One way or another, AIDS has become part of life in Nairobi.

Following the recognition of AIDS in Kenya in the second half of the 1980s, health education programmes were put in place aimed at enhancing public knowledge of the risks of HIV infection. Later on, measures for promoting safer sex practices were put in place. Information on the nature of HIV and AIDS was disseminated through posters, pamphlets, radio and TV messages, and through primary health care services, however this was done in a relatively ad hoc way because of the reluctance of the government to acknowledge the extent of the problem. Public institutions such as schools, colleges, and universities became targets for AIDS education. A little later, the whole population became included by way of work environments, places for social gatherings, and via the media. Nowadays, AIDS has become a common topic in the media. The central message is that HIV is transmitted primarily through (heterosexual) sexual intercourse.

In almost every meeting I attended in Nairobi – and on nearly every flyer or television programme that I saw on the subject – the latest number of HIV infections and AIDS victims in Kenya was a central point of reference. It is thought that the endless repetition of these alarming numbers will serve to prevent people from engaging in 'risk behaviour', that is, illicit sex, or sex outside the socially approved institution of marriage. The numbers themselves have come to live a life of their own, in their sweeping and frightening statements of death. The monotonous recitals indicating thou-

sands and even millions of 'HIV cases' or 'death cases', or, in the common phrase in town, "Every one out of seven Kenyans has it", create an unnerving atmosphere marked by implicit or sometimes explicit accusations. Discussions about AIDS became shrouded in demarcations of right and wrong, as in the following statement: "Long before I understood that AIDS is a disease like cancer, I knew it was bad, something to avoid, but, then I had no clue what to avoid!" (Alex, aged 20). For young professionals, like many other Kenyans, AIDS has become a phenomenon of fear.

According to Nzioka (1996), a professor at the University of Nairobi, the public response to the AIDS pandemic has been moral in essence. Half-way during the 1990s, AIDS provided "a golden opportunity for moral entrepreneurs to advocate for a return to 'traditional normal' sexual behaviour":

A rift has since emerged between what could plausibly be described as the conservative forces on the one hand, and the liberal modernists on the other. The conservative moralists, led by members of the clergy, and the 'traditionalists' see HIV/AIDS as a consequence of wanton and wild promiscuity, permissiveness, and moral decadence often associated with the adoption of Western liberal moral values. Despite the enormous conceptual difficulties of what could be termed as 'African' in a culturally pluralistic country like Kenya, the moralisation of HIV/AIDS has provided the conceptions of what they consider to be an 'African traditional way of life'. Generally speaking, the mysteries surrounding HIV/AIDS have opened the flood-gates for the traditionalists to call for the revitalisation of 'African' sexual culture; a heightened sense of Puritanism from the clergy who remain opposed to a liberal sexual culture that accommodates the use of condoms; political sloganeering of 'patriotic' politicians who enhance their popularity through anti-Western rhetoric; and a forum for voyeuristic journalism and sensational reporting by newspaper editors... (Nzioka 1996: 566).

From the beginning of the epidemic, AIDS became implicated in different social meanings beyond health matters. These moral responses are typical of the continuing debates about the origins of HIV infection, alongside more formal responses. Various notions of public ills are discussed and criticised in a sweeping moralistic tone from different platforms. Politicians address the people during *harambees* to reach the populace for political ends and to speak out about social and economic problems like AIDS, female incision, or marrying off under-age girls. The clergy alert the people about their religious plight and how the neglect of Christianity is a root of general 'immo-

ality'. Teachers in primary and secondary schools are regarded as important actors to discipline young people into being responsible citizens, and they focus their debates on sexual virtues versus vice. These debates operate in the public sphere trying to make sense of AIDS, and by extension, sexuality and cultural heritage in different, and sometimes overlapping, ways.

Sexuality is a domain over which various groups wield or try to wield authority, by invoking the dangers of AIDS in various ways. AIDS has therefore become a major frame of reference for debating sexuality. It is a catalyst inflaming discussions about sexuality even when AIDS is not the central issue.

The dominant representations of AIDS as the disease of 'immorality' loom as a shadow over people's lives. I often heard people saying that 'AIDS is a curse from God, because of these immoral days,' using the concept of 'curse' as an equivalent to that of chastisement. AIDS is generally perceived as a disease born of wrongdoing or transgression. AIDS is understood as a bad omen: a sign that the social environment is somehow disturbed, and it is commonly associated with 'sinful,' 'bad,' or 'immoral' behaviour. Whether in the form of a direct spell or a more systematic rupture in the social fabric, AIDS is clearly equated with misconduct. Furthermore, the relationship between sexuality and HIV generates a condemnation close to excitement, especially when discussing matters of sexuality outside the context of marriage. Talking about sex unrelated to the conjugal bond implies talking about 'irresponsible' and 'careless' sex. Irresponsible sexual behaviour is 'bad sex' under all conditions, and the causal relationship between being infected with HIV and 'bad sex' is regarded as obvious. Sex by nature is good, since it is considered the source of life. 'Bad sex,' however, signifies deviant behaviour regarding socially accepted values: it is anti-social. In general, the discussions about sexuality concentrate on notions of promiscuity, permissiveness, and moral decadence.

The unholy trinity of promiscuity, permissiveness, and moral decadence is the major source of inspiration for people employing the notion of 'immorality', which flares up from different angles within Kenyan society. People from all layers of society reproduce the same notion to validate the image of a decaying society in the globalizing world – and many of these comments about 'immorality' reveal a sense of powerlessness. This sense of powerlessness is an important key to understanding people's responses to AIDS in Nairobi, with people citing the postcolonial period as an era of cultural 'confusion' and 'chaos'. In the experience of chaos, sexuality offers, through the concept of 'immorality', a palpable medium through which to express anxieties and discontent. The statement by renowned scholar and author

Oludhe-Magoye that “Kenya has become a society inflamed by sexual desire” should be seen in this context. Prominent actors in the public sphere emphasise that sexuality has gone astray due to corrupting moral practices (which need not necessarily be related to sexual issues; for example, bribing is ‘immoral’ as well) resulting in ‘rampant immorality’.

Furthermore, AIDS is a disease of time: it is latent and therefore ‘looms’ in society. AIDS has an elusive quality that contributes to its uncanny connotations. It has come to stand for the disease of sexual perversity, promiscuity, and sexual licence, all of the qualities that ‘proper’ citizens eschew. The topic of AIDS is obfuscated by vague and evasive terminology like ‘be aware of AIDS’ or ‘AIDS is there’, that lay the whole topic open for suggestive meanings. The leading cause of AIDS – unprotected sex – touches a fundamental yet secret aspect of community. The power of sex is not discussed, but hinted at. AIDS shocks precisely because it transforms the very source of life into an occasion for fatal danger, and this gives rise to panic, moral crises, and the association of disease with individual moral corruption.

As a disease and as a phenomenon of fear, AIDS has brought the topic of sexuality into the public agenda through the notion of ‘immorality.’ AIDS serves to define the affected individual as an ‘immoral’ other because of the violation of social expectations. The AIDS-related stigma has given rise to its own discourse, a language of human relationships that relates self to other, normal to abnormal, healthy to sick, and strong to weak. It involves all those exclusionary and dichotomous contradictions that allow people to draw safe boundaries around the acceptable, the permissible, and the desirable so as to contain fears and phobias about sickness, death and decay, sexuality, and social chaos. A polluting person is always wrong, as Mary Douglas observed (1966). The inverse is also true: a person judged wrong is regarded as, at least potentially, a source of pollution. The fear of AIDS reveals a fear of the disease, as well as a fear of even more inflammatory sexual behaviour and the loss of control over youth by elders. As Nelson suggests, often when something is criticised as ‘morally wrong’ in Kenya, the point is not so much that it is considered ‘immoral’ per se but that it threatens the gerontocratic and moral authority (1987). The issue of sex centralises the issue of social control over individuals and their desires. For parents and religious and political leaders, the increase in the number of sexually mature young people outside the bounds of marriage is not only contrary to chaste morals but has become an issue demanding public regulation. Sex is a permanent lurking menace and a necessity (in terms of procreation) to the conventional order: the need to control it – as well as the fear of it – underlies social processes of communication and social construction in the Kenyan public sphere.

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‘A life story that cannot be told will begin to give off a stench’

MARIAN TANKINK

This is what Els van Dongen had written in her dissertation which she gave to me as a present, some years ago. At that time I had not realised that the (im)possibility of sharing one's experiences would become the central issue of my anthropological work, but the inspiring discussions with Els as my teacher and most creative colleague put me on that track.

Els is right; a story that cannot be told can become a kind of rotten ‘corpus alienum’ in a person's life; it breeds pain and that pain fosters silence (Wikan 2000). Being untold, those stories cannot become a part of an individual's personal history, and as a result, it can infect memories, daily experiences, and the future. The owners of those untold, often secret and/or traumatic stories are likely to be “isolated within their own physical and emotional conditions, deprived of any vehicle through which their experience can be meaningful, and therefore, sufferable” (Zur 1998: 248). Through narratives, cultures and lived experiences are brought to an imaginary coherence that is not present in reality. Narratives, in other words, inform you what gives life meaning, what is inspiring, but also what is dangerous, risky, or worth taking a risk for (Mattingly & Garro 2000).

People who experience shameful and traumatic events often prefer to live with the bad smell instead of talking, in order to prevent their experiences from leading to further destruction in their lives. Such people are riddled with a mistrust that frames and feeds their fantasies and fears of the existing narrative constructions that could lead to (public) denouncement. Take the example of Milka, a forty-four year old woman from Bosnia with a Muslim name, although she is an atheist. She went into exile because of the unbearable bombardments as well as daily suffering and threats she received at her university, because of her Muslim name. During her flight, two soldiers raped her at a roadblock. Milka has not told anyone about her experiences, not even her husband. She is convinced that her husband will divorce her or, at the very least, she fears he would misuse the knowledge during a domestic quarrel.

Milka keeps silent, because her private experiences do not fit in the cultural master narrative; the story in which we live. Every cultural group works to create its own cultural master narrative which is built up from cultural assumptions, trails of their collective past, cultural notions of femininity, sexuality, gender identity and roles, discursive and symbolic formations, and practices from the country of origin (Becker 1999).

The cultural master narrative is not a fixed, static entity but a creative activity in which ideas and notions are made and shared. It is a continuous process of dialogue between the individual and the group, full of paradoxes, contradictions, disagreements, and inequalities. But for individuals like Milka, the cultural master narrative seems to be an almost fixed framework, determining how to behave and how to judge experiences.

In the public discourse of the war in Bosnia are several, often conflicting, narratives. For instance, one strain holds that the women who were raped should be seen as martyrs, victims of the destructive war. Nonetheless, men confess that it would be emotionally very difficult to marry a woman who has been raped. As a man, they feel, they must marry a virgin. Milka knows those different stories. On the one hand she is hopeful that there will be a shift to where women are not to blame. But, on the other hand, she concludes that the old stories, in which women are responsible for being in the wrong place at the wrong time, still shape too much the emotional behaviour of people. The cultural master narrative in which women are to be blamed is still too much 'embodied'.

Due to her war experiences, Milka has lost the naturalness of life and the trust that her life will continue in a safe environment with people who are faithful. This trust, which is not so much a conscious state of awareness, has disappeared in tandem with the feeling of having control over her life. It is too risky for Milka to produce a counter-narrative of her horrific personal experiences in public, although in private and confidential conversations she has another story to tell. Speaking out in public is not an option for Milka, she is too hurt and her world is too dangerous for a story that does not fit into the cultural master narrative.

But even if Milka decided to talk, there would be no public space for her story and appalling events. There is compassion for women like Milka, who have experienced sexual violence in general, but there is little or no compassion for the women who give their testimony in public, there is no audience. The narratives are too uncomfortable and too threatening. No one wants to hear and no one knows how to handle those stories. Milka fears a social death if she were to bring her story into the public sphere, also because she thinks that it will be felt as an attack on the symbolic and normative values

women stand for in the cultural master narrative. By excluding the narrator or by not taking her seriously, this threat can be removed.

Therefore, Milka has had to keep her experiences separate and has not been able to make them a part of her (public) life history. This has two important consequences, which I would like to explain by using the Dutch word '*herinneren*' and the English word 'remember'. Els once explained this to me in another context. The Dutch word for remembering, '*herinneren*', suggests that the past will become again a part of our inner self: it is '*her-innerd*'. It is an internally focused, individual activity in which we try to become reunited with the past so that events or experiences will become part of our life story. This is an important part of therapy. However, another aspect of importance is expressed by the English word 're-member'. Our memories help us to become again a member of society. It is a socially oriented externalising activity. By becoming reunited with one's – especially painful – past, one can also become a member of society again.

Milka feels the (universal) need to be connected with other people, especially with her loved ones. The rapes have ripped an unbridgeable chasm between herself and her husband and other relatives. It has had a destructive effect on her relationships, because she thinks that her loved ones will condemn her. This potential, yet imaginary, threat of disconnectedness causes her deep distress. Milka needs, as a human being, a relationship with others as a buffer against stress in general and as a source for her personal coping mechanisms, even if the other does not offer practical or emotional support in a way she needs for her rape experiences (Baumeister & Leary 1995).

By keeping quiet, Milka tries to present herself in a way that will allow her to be accepted by the other. It is a dialectical process in which Milka understands herself from the attitude of the other; it is a constant internal dialogue between the 'I' and the 'me' (Ewing 1990). The 'me' represents the others in us. In Milka's society the emphasis of the self is not so much on the autonomous, separate aspects of the self, but on the mutual dependency and on the capacity to live in harmony with others (Mehraby 2004). The more a society emphasises the capacity to live in harmony with others, the less stress is put on autonomy and separation. Milka is not only concerned with her own position in society but also with the reputation of her relatives. Since identity is relationally determined, loss of reputation can lead to loss of the capacity to live a normal life, for herself, but also for her husband, children, or other relatives. As long as Milka can continue her self-presentation in interaction with others, she is able to feel a kind of continuity despite the existence of other, not-integrated self-presentations. Experiences are felt on the intersubjective level (Jackson 2004). Therefore, Milka is convinced

that she has to keep her horrific experience secret. If she were to attempt to narrate her story in order to make it a part of her life story, as an attempt to 'her-inneren', she risks condemnation and even *dis-membering* instead of *re-membering*.

Milka is unable to reinterpret her experiences in a way that it can be 'her-innerlijkt' (become a part of her self and her life story) and also be 're-membered', in a way that she will still remain a member of her community and restore the intimate bond she used to have with her husband. She is constantly torn between a public and a private reconstruction of different concepts of justice, shame, and disapproval in order to give meaning to what happened to her (Foxen 2000). In an attempt to keep the feeling of connectedness, she partly isolates herself from the world. Talking, she thinks, will lead to devastating further destruction of her social life and the social life of her family. The feeling of belonging is possibly the most important and least recognised need of human beings (Weil, in Jackson 2006: 12). By keeping her experience private, Milka is deprived from other very important and essential aspects in life, namely to be heard and acknowledged (Arendt 1998; Jackson 2006); but the stench of keeping silent and being isolated with her suffering is for Milka, as for most women in her situation, more bearable than the unendurably foul stink of having the feeling of being disconnected and *dis-membered*.

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The uncut knot

Medical anthropology not exactly at home

DEANNA J. TRAKAS

After some 15 years in a research position at a children's hospital, I finally got the chance to try my hand at introducing medical anthropology to Greek academia. The very first department of social anthropology in the country decided to include the course in its curriculum. From an early age Greek ethnography had been narrated by foreign anthropologists and characterized by a discourse on the 'honour-shame' code and the 'ours-foreigner' (insider-outsider) distinction embedded in gender, kinship and patron-client relations.* The members of the new department set their sights on creating an 'anthropology at home', an indigenous Greek ethnography. Although I had conducted fieldwork in Greece as had my fellow faculty members, in my case it was as an outsider – at least initially. Further, I brought a second foreigner with me – medical anthropology. When I stayed on ('went native') and Greece became home to me, the matter of the insider-outsider was a favourite focus of debate whenever the issue of medical anthropology at home (or anywhere else) came up.

Surprisingly (or predictably) solace came from a colleague from afar. This is a story intended to recapture those times. I have taken the liberty of revealing some of the notes I kept from our late night emails. My quests continue to be much the same. Her midnight messages still hold true. If I kept them private it would be like holding back precious gems. Or, better ... special pebbles found by the seashore.

* The fieldwork of anthropologists in Greece during the 1950s to 1970s, mainly from universities in the US (Friedl 1962) and the UK (Campbell 1964, Du Boulay 1974) were primarily responsible for identifying these central motifs in Greek culture. John Campbell provided the prototype of honour and shame // male and female; Herzfeld (1985) is largely responsible for elaborating the principle of 'ours' – foreigner, and later, for his work on issues of manhood. Jill Dubisch (1986) and Peter Loizos (1991) have brought together a series of articles about gender.

Taking a few steps back, my research experience with physicians was actually quite benevolent. They had a tolerant, even amused attitude about what an anthropologist was doing in a children's hospital research centre. Even though the Institute of Child Health is a multidisciplinary research enterprise, the continual query of 'why an anthropologist' belies the underpinnings of a medical hegemony. I was concerned about presenting a *Proper* and *Clear* picture of medical anthropology – and particularly its *Usefulness*. Every question was an opportunity to begin an introductory lecture about the breadth and depth of the field, not only to physicians but to social workers, sociologists, psychologists, dieticians and any other innocent bystander who happened to pass by.

Attempts to justify my presence and, indeed, the *raison d'être* of medical anthropology need not have been so compulsive. My nocturnal emails suggested that "a little mystique around medical anthropology might contribute to its status ... after all, it seems to work for medicine ..."

Stop quarrelling with other scientists about the validity of anthropological research, about the possibility to make generalizations (from a small body of informants) or to predict. Stop with all those *hubris*. The alliance between medicine and anthropology may be uneasy and even a *folie à deux*, but that's time wasted. I want to play *quatre mains*. (Els van Dongen, email communiqué)

In comparison, the world of anthropology in Greek academia felt much more brutal, perhaps because I had expected to be able to finally go home to a family of fellow anthropologists. Instead I discovered that half of my kinfolk viewed medical anthropology as a panhandler, a poor cousin – trying to gain a place in mainstream, theoretical anthropology. It came as a shock to hear a fellow faculty member use medical anthropology as an example of applied anthropology. This was an insult for most anthropologists of my generation; our introductory courses had discussed how the financing of fieldwork had a clearly applied intent which served colonial relations.

My complaints about the coupling of medical anthropology with applied anthropology had results: My colleague announced that medical anthropology might be a type of public anthropology; e.g., an ambassador which would set up a dialogue with professionals outside of academia ... such as physicians. I was trapped between amusement and outrage – both a result of getting a good look at the same audacity to declare what medical anthropology was or was not (in ten words or less) – applied or public – without consulting with the only medical anthropologist in the county. I saw a denial

that medical anthropology would ever be part of the inner circle of 'real' (theoretical) anthropology. Never mind that several ethnographic studies of health and illness, life and death, reproduction and birth, the body and suffering in Greece^{*} as well as elsewhere had already contributed to the theoretical wealth of social and cultural anthropology. Remember, Greek society ... and probably Greek academia functions by the 'inside/outside'.

The failure of anthropologists to recognize the theoretical contributions of medical anthropology to the mother discipline was not unique to Greek academia. I had already seen it happen some 20 years before in the US when medical anthropology was newly baptized and gained a reputation for its elitist aura. In the 1970s, anthropological research with a medical dimension attracted funding at a time when grants for classical ethnographic fieldwork were undergoing budget cuts. Dual faculty appointments were set up for medical schools and anthropology departments in experiments in public health, community medicine and health education.

Mainstream anthropologists responded by viewing their medical anthropology siblings as frustrated medical school applicants unable to pass the entrance exams. The image was completed in teaching hospitals where anthropologists went on rounds with doctors, thus gaining the dubious distinction of being 'cultural brokers'. And there was always the friendly jab in the corridors of the anthropology department if seen with anything that looked therapeutic (a box of aspirins, a cup of hot soup, a packet of herbal tea): "Ah – does this mean that you're a medical anthropologist??"

In the meantime, medical anthropologists did not make many overtures to separate themselves from the medical profession. In fact, the medicaliza-

* Blum and Blum (1970) began their compendium of 'folk' medical beliefs and practices in rural Greece in the 1950s. I began my own research on illness in rural Rhodes in 1976 (Trakas 1981). Amy Blue (1991) completed her ethnographies of the practice of psychiatry in Greece in the late 1980s. In the same year Nadia Sememataki published her work on suffering and death (1991). In the area of reproductive health, Heather Paxson published her 1990s study of pregnancy, birth and motherhood (Paxson 2004) and Eugenia Georges has been working in ethnographies of reproductive health dating to 1990 (in press). However, except for me, none are actively involved in teaching medical anthropology in Greece; e.g., they are in other academic spheres outside of the country. Fortunately there is an entire new generation ready to teach the field. Some universities have begun to teach the Anthropology of Health and suggest that his title replace that of medical anthropology. I disagree: Either keep the classical name (medical anthropology) which is understood worldwide or move on and think about the 'anthropology of well being'.

tion of new anthropology students was well underway by the time medical anthropology celebrated its first decade (e.g., circa 1982). It is probably not by chance that medical doctors were able to make a significant impact not only on the development of medical anthropology as a field, but on professional modern medicine as well. True, in their early years, medical anthropologists did tend to label themselves with a little more bravado than did anthropologists who were trained in other thematic areas such as kinship or religion. On the other hand, these were the bread and butter of mainstream anthropology and had little need of publicity. Even those who added titles of theoretical areas to their sub-topical identity (e.g., cognitive, symbolic, materialist, marxist) were reserved about their use. Indeed, there did seem to be something going on with this upstart medical anthropology that had the potential to bring out the prickles between colleagues as well as cultivate aggressive thorns toward biomedicine.

The development of medical anthropology in the US – and the ease with which it was introduced into anthropology departments may have been related to the inclusion of both archaeology and physical (biological) anthropology in the same department with cultural anthropology. Here it was easy to insist that medical anthropology was first and foremost anthropology; not necessarily to declare an alliance to either biological or cultural anthropology. This argument is nearly impossible to map out in the European context. Apparently medical anthropology never locked horns with biomedicine in Europe either.

European anthropology did not experience so much the disadvantages of being a servant of biomedicine as in the US. That trend in Europe is very recent, and I wonder if it is only in the heads of anthropologists (Van Dongen, email communiqué).

European anthropology in general had not experienced an ‘anthro-boom’ and had not ‘as yet’ (by 1997) gone through a phase of jumping on the medical anthropology bandwagon. Greek academia, for the most part, had no particular vested interest in the field; it had no reference point as was the case for universities in other areas of Europe in the mid-1990s. Teaching medical anthropology in Greece needed to be more than a recycling of the US experience. In a student-centred approach, relevant currents from European and Greek philosophy and social history need to be included. In the arena of critical medical anthropology, the inspiration of German and French scientists needs to be explored.

Isn't it possible to discuss with your students their own scientists (philosophers, social scientists, etc.) and compare them to your background, and talk about the pros and contras of cross-fertilization? After all, the situation in Greece is very different from the US and both different from The Netherlands (Van Dongen, email communiqué).

It was no longer important to become a professor among peers; infinitely more essential to be a better teacher of students. The easy road was to write a safe version of a medical anthropology textbook in Greek and teach a safe course. In contrast, the challenge:

Okay, I got your points on the safe version. Maybe the most important thing to do in a book for anthropologists-to-be is to immerse them into the wonderful and amazing discipline and to lift them out the common-sense world (Van Dongen, email communiqué).

Should anthropology have the last word on human behaviour? Or should it *suggest* and leave some stones unturned? Perhaps it is presumptuous – even colonial – to assume that we can make every social-cultural-behavioural phenomenon comprehensible to Others.

I have an image of anthropology that goes like this: Did you ever knit and had the experience of 'the knot' which you could not unravel? I did when I was in primary school (with the nuns, bah!). Anthropology is unravelling the knot (not a web – too orderly). When you have one thread you can pull it and see what kind of thread it is. You see to where it will lead. To the knot. You can't find the end and you definitely have the wrong thread, so you will take another. In the end the knot is very tight, firm, with lots of threads hanging down, all leading to the knot at the centre. Then you will have to give up. You cut the knot and all the threads are falling on the floor. Now you will see all the different parts, their colours, their 'meaning', but now you also have to make the whole again. That's impossible! Since all those loose threads are not very interesting (although very clear to see). I would prefer to leave the knot as it is with all the threads hanging out, so that others will have to unravel something themselves, which they cannot, or have something to hold on. That's what anthropology is: leaving a little knot at the end. You see? (Van Dongen, email communiqué)

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Van oude mensen

Wat blijft in wat verandert

RINEKE VAN DAALEN

Mijn moeder was het grootste deel van haar leven een sportieve vrouw. In haar jeugd, toen weinig mensen aan sport deden, gingen ze bij haar thuis al zeilen, roeien en kamperen. Als we aan zee waren, dook ze de branding in en zwom ze naar de verte. Ze raakte steeds verder weg en toen we klein waren, zagen we het met angst en beven aan. Zou ze niet verzwolgen worden, zou ze ooit nog terug komen? Ze had altijd haast, ze had zich aangewend om te rennen. Ze sprong de auto in, racete ergens heen, stormde de auto weer uit, en holde naar haar volgende bestemming. Ze was sociaal: zij was degene die de contacten tussen gezin en buitenwereld onderhield. Ze was actief: ze zette zich al vroeg in voor 'het milieu', en ze was al een eind in de vijftig toen ze met een jongensachtig plezier illegale afgravingen probeerde op te sporen.

Ze is nu 88 jaar en rennen is er niet meer bij. Als je haar tien jaar geleden had verteld hoe ze nu zou leven, zou ze het met afgrijzen hebben aangehoord. Ze kan niet meer alleen naar buiten, eigenlijk kan ze binnen ook bijna niets meer alleen doen. Ze heeft een leger verzorgers die haar dagelijks een paar uur komen helpen met de meest primaire handelingen. Er gebeurt niet veel in haar leven, maar toch heeft ze hoe gek het ook klinkt wel plezier in haar bestaan. Iedere vrijdag komt ze logeren en dat vindt ze heerlijk. Ze is niet dement, maar wat dokters 'mentaal verouderd' noemen. Het is een verlegenheidsterm, want haar situatie is moeilijk te omschrijven. Het laat zien hoe onvolkomen een begrip als dementie is. De mensen van wie ze houdt blijven de spil waar haar leven om draait. Ze zal ons altijd herkennen, ze onthoudt het als er iets ergs aan de hand is en ze zal daarnaar informeren. Maar ze heeft geen tijdsbesef en haar begripsvermogen is afgenomen. Ze kan heel veel niet, maar ze kan ook heel veel wel.

Ze is iemand anders geworden, maar toch niet helemaal. Ze is ook zichzelf gebleven. Ze kan met kracht een zin beginnen, en dan halverwege blijven steken. Ze weet dan niet meer hoe ze verder moet gaan. Dat zijn voor haar en voor ons pijnlijke momenten. Maar ze kan ook een grapje maken,

dat ze vroeger gemaakt zou kunnen hebben. Kijkend in de krant kan ze verbijsterd vragen: “Wat betekent ‘inloggen’ nu weer?” maar ze kan ook foutloos een stukje Homerus opzeggen. De basis van haar persoonlijkheid is hetzelfde gebleven. Ze heeft een opgewekte en positieve instelling. Als je maar even kan langskomen en snel weer vertrekt, zegt ze: “Ach het geeft niet, gezellig om je even gezien te hebben.” Ze heeft vertrouwen in de mensheid. De aannemer met zijn zoon kunnen ’s ochtends om zeven uur bij haar binnen komen vallen en geen seconde zal ze denken: ‘Wat komen die nu weer doen?’ ‘Ontzettend aardige mensen,’ zegt ze. Het geeft leven in de brouwerij en ik denk: “we zouden steeds iets moeten gaan verbouwen in haar huis.” Ze vindt het gezellig om met ons te eten, zeker de dingen waar ze speciaal van houdt.

Ze is een voorbeeld van iemand die een goede jeugd heeft gehad. Een vrolijke en beschermde jeugd, waaraan ze een reservoir gelukkige herinneringen heeft overgehouden. Een vrije en open jeugd, waarin veel mogelijk was, en waarop ze haar hele leven heeft kunnen teren. Toch heeft het leven haar niet alleen maar goed behandeld. In de oorlog is ze ternauwernood aan de vernietiging ontkomen, en ze moest bijna twee jaar lang onderduiken zonder buiten te komen. Maar dat heeft haar basale vertrouwen in het leven niet ondermijnd. Wat ze met die oorlogservaringen heeft gedaan, is niet zo duidelijk. Voor ons, haar kinderen, zijn die ervaringen altijd onzichtbaar gebleven. En daarin verschilt ze van veel andere ouders van haar generatie. Door dat vastberaden wegmoffelen heeft ze ons waarschijnlijk een zware last bespaard. Voor haarzelf zijn die ervaringen denk ik ook buiten bereik geraakt. Wat dat voor haar betekent, weet ik niet.

Mensen slaan hun leven lang ervaringen op, met anderen die hun meer en minder na staan. Die ervaringen schuiven over elkaar heen, sommige zinken weg, sommige zijn zo belangrijk dat ze altijd blijven doorklinken. Mensen kunnen nog zo sterk veranderen als ze ouder worden, maar tegelijkertijd blijven ze wie ze waren.

Een project voor en door psychotische patiënten en hun families in Nicaragua

RIMKE VAN DER GEEST

In Matagalpa, een stad in het centrale hoogland van Nicaragua (pop. 200.000), voert de zoektocht naar genezing voor een gezinslid met een psychotische stoornis dikwijls langs een lange rij 'hulpverleners'. Families geven hun spaarzame geld uit aan natuurgenezers, tovenaars en gebedsgenezers om iets aan de mysterieuze aandoening van hun naaste te doen.

Psychiaters

Sommigen vinden vroeg of laat de weg naar de psychiater. Deze werkt gemiddeld een half uur per dag bij een openbare polikliniek om consulten te geven aan mensen die zijn privé-kliniek niet kunnen betalen. Aan dossiervoering doet hij niet, hij noteert slechts het geslacht en de leeftijd van de patiënt, vraagt wat deze likt en schrijft een recept uit, waarbij op- en afbouwschema's een ongebruikelijk fenomeen zijn. Met dit recept kunnen de patiënten hun medicatie afhalen. De patiënten krijgen klassieke anti-psychotica, meestal in ouderwets hoge doseringen, voorgeschreven welke door het Ministerie van Gezondheid gratis verstrekt worden. Soms zijn de medicijnen op, dan dienen mensen ze in een plaatselijke apotheek te kopen. Zeer psychotische patiënten worden door de psychiater voor een tijdelijke opname verwezen naar het enige psychiatrische ziekenhuis in het land, in de hoofdstad Managua. Het vervoer ernaartoe moet door de familieleden zelf geregeld en bekostigd worden.

Als antropologisch onderzoeker woonde ik op een dag de consulten in de polikliniek bij. Het volgende dagboekfragment geeft een indruk hoe dat er aan toe gaat:

Als ik om half twee bij de polikliniek aankom is Lopez [pseudoniem] de psychiater, nog niet gearriveerd. Wel staat er een rij van zo'n der-

tig mensen voor een deur waarop psiquiatría geschreven staat. Ik praat met een vrouw die patiënte is. Tijdens ons gesprek staat ze plotseling op. “Ahí viene” (daar komt hij) zegt ze als Lopez in zijn pick-up komt aanrijden. Een verpleegster sommeert de wachtenden plaats te maken en niet te dringen. Het is kwart voor twee, de eerste bezoeker mag binnenkomen, de deur van de ruimte blijft vanaf dat moment open staan. Een jonge vrouw met een kind op haar arm meldt zich. Ze wordt vergezeld door een buurvrouw. Ze zegt ’s nachts niet te kunnen slapen, en haar buurvrouw vult aan dat ze stemmen hoort en dingen ziet. Lopez vraagt of ze haar medicatie goed heeft ingenomen. Ze zegt dat ze die al een poos niet meer neemt omdat ze in de polikliniek op waren, en in de apotheek te duur zijn. Het is een probleem dat tijdens de daarop volgende consulten regelmatig opnieuw ter sprake komt. Na de vrouw is een man aan de beurt. Hij komt van kilometers ver om een recept te bemachtigen voor zijn zieke broer. Ook voor hem zijn de medicijnen in de apotheek te duur. Met Lopez’ recept kan hij nu gratis medicijnen in de polikliniek afhalen. De derde patiënt, de vrouw met wie ik eerder sprak, steekt een heel verhaal af tegen Lopez. Daar is gezien de lange rij wachtende mensen geen tijd voor. Ze krijgt een recept in haar hand geduwd en laat zich gewillig uitwuiwen. Na haar komt de moeder binnen van een vrouw die een maand geleden naakt door de straten van Matagalpa liep. Het gaat inmiddels beter met haar dochter; ze is sinds kort terug uit het psychiatrisch ziekenhuis in Managua. Lopez schrijft een nieuw recept uit, en de volgende patiënt mag binnenkomen, en de volgende en de volgende... Het is half drie als de laatste bezoeker de ruimte verlaat. Vijftien consulten in drie kwartier, dat is gemiddeld drie minuten per consult.

Sinds juli 2007 werkt er een tweede psychiater in Matagalpa. Deze is drie ochtenden per week gestationeerd in het ziekenhuis van de stad en werkt in tegenstelling tot Lopez wel met dossiers. Voor een consult bij deze psychiater moet vooraf een afspraak gemaakt worden. Er wordt niet gewerkt met ‘afspraktijden’, maar met ‘afsprakdagen’. Op de afgesproken dag worden de patiënten op volgorde van binnenkomst gezien door de psychiater. Een wachttijd van vier uur is dan ook geen uitzondering. Van samenwerking tussen de twee psychiaters in Matagalpa is geen sprake.

Na een bezoek aan één van de twee psychiaters verandert er uiteindelijk nog niet veel voor de families met een psychotisch gezinslid. Zij hebben nog steeds geen idee wat er met hun naaste aan de hand is en wringen zich in

allerlei moeilijke bochten om de vreemde ziekte van hun gezinslid voor de buitenwereld verborgen te houden. In veel gevallen weigert het gezinslid bovendien de voorgeschreven medicijnen in te nemen of wordt medicatie-inname na het optreden van bijwerkingen gestaakt. Ook wordt vaak niet begrepen dat de behandeling moet worden voortgezet nadat de psychotische verschijnselen verdwenen zijn en komt het voor dat de familie van behandeling afziet of deze afbreekt, omdat zij de voorgeschreven medicatie niet kan betalen. Tot slot gebeurt het regelmatig dat mensen zich omwille van hun geloof onttrekken aan behandeling. Ze geloven dat God degene is die kan genezen en in navolging van deze geloofsgedachte is het innemen van medicatie zondig omdat daarmee tegen Gods wil wordt ingegaan.

Een project voor psychotische patiënten en hun families

In 2005 sloot ik mijn studie culturele antropologie af. Voor mij was de culturele, en in het bijzonder de medische antropologie vooral een periode geweest van reflectie op de zin van mijn werk als psychiatrisch verpleegkundige en een poging om via de 'theorie' van de antropologie de 'praktijk' van het 'zorgen voor' beter af te stemmen op de beleving van de betrokken patiënten en hun naasten. Mijn psychiatrisch-antropologisch onderzoek naar families met een psychotisch gezinslid in Matagalpa, leidde kort daarop tot een zelfhulpgroep voor familieleden in diezelfde stad: Cuenta Conmigo ['Je kunt op me rekenen']. Door middel van het afleggen van huisbezoeken werden familieleden benaderd en uitgenodigd om hun ervaringen met elkaar te delen. De herkenning en opluchting waren indrukwekkend, de behoefte aan informatie groot. De bijeenkomsten werden daarom uitgebreid met informatieve workshops. Familieleden kregen voorlichting over de ziekte van hun gezinslid en tips hoe zij met hem of haar konden omgaan. In veel gezinnen ontstond hierdoor na een tijd niet alleen een aangename sfeer in huis, maar ook vond er verbetering plaats in het welbevinden van het zieke gezinslid. Het activiteitenprogramma werd tenslotte uitgebreid met feestelijke en creatieve bijeenkomsten waar ook patiënten welkom waren. Stigma's en vooroordelen verdwenen tijdens deze bijeenkomsten naar de achtergrond; familieleden konden met eigen ogen zien wat iemand met een psychotische stoornis nog allemaal wél kan; patiënten deden mee aan spelletjes, maakten tekeningen, dansten en sloten vriendschap met elkaar. In korte tijd bleek het in Matagalpa mogelijk om met een minimum aan middelen de levens van zowel familieleden als patiënten een stukje draagbaarder te maken. Een verhaal ter illustratie:

Wanneer een vrijwilliger van het project bij de psychotische Denis (27) op bezoek gaat, is deze door zijn ouders met een touw, dat om zijn voet zit, aan de muur vastgebonden. Moeder Adilia zag geen andere mogelijkheid meer omdat haar zoon een paar dagen tevoren door een auto was aangereden: "Hij steekt zonder te kijken de straat over, het is te gevaarlijk", vertelt ze terwijl de tranen over haar wangen stromen. Denis praat, slaapt en eet nauwelijks. In zijn ogen is angst te lezen, hij heeft duidelijk last van stemmen. De vrijwilliger biedt Adilia aan haar te vergezellen naar de psychiater, en deze schrijft hem een antipsychoticum voor. Na het bezoek van de vrijwilliger beginnen de ouders van Denis ook de bijeenkomsten van Cuenta Conmigo te bezoeken. De informatie over psychose die ze te horen krijgen, horen ze voor het eerst. Denis knapt snel op; na twee weken slaapt en eet hij weer goed, en bij de eerstvolgende feestdag voor familieleden en patiënten kan iedereen zien hoe hij vol overgave meedoet aan de spelletjes.

Cuenta Conmigo heeft zich inmiddels tot een organisatie ontwikkeld. Sinds januari 2008 is er een bestuur en het aantal personen dat de activiteiten bijwoont groeit gestaag. Inspelend op de behoeften van de doelgroep wordt het programma voortdurend aangepast en geleidelijk uitgebreid. Zo wordt er geëxperimenteerd met bijeenkomsten voor adolescenten (broertjes, zusjes en kinderen van patiënten), maar ook met bijeenkomsten voor alleen patiënten, en voor familieleden en patiënten samen. Cuenta Conmigo probeert daarnaast samen te werken met andere disciplines met als doel de marginale hulpverlening aan psychotische personen en hun familieleden te verbeteren. Van belang is onder andere het contact met de twee psychiaters van Matagalpa. Er wordt gestreefd naar een systeem waarbij men elkaar aanvult. Medewerkers van Cuenta Conmigo leggen, ondersteund door psychiatrische verpleegkundigen, huisbezoeken af om de taken uit te voeren waar de psychiaters geen tijd voor hebben. Ze observeren de patiënt in zijn eigen omgeving; zien de doos met medicijnen waar de familie geen wijs uit wordt en zien ook hoe in huis met de patiënt wordt omgegaan. Psychische bijstand, adviezen en voorlichting worden tijdens de huisbezoeken direct in de sociale context geïmplementeerd, waardoor de kans op stabilisering van de patiënt en zijn familie vergroot wordt. De psychiaters op hun beurt verwijzen familieleden naar Cuenta Conmigo, maar ook psychologen en traditioneel genezers nemen contact op met de organisatie.

Het betrekken van de familie in de behandeling van psychotische patiënten

De mensen die bij de opzet van Cuenta Conmigo betrokken waren, hebben indertijd niet beseft dat zij met dit project een methode aan het ontwikkelen waren die op hetzelfde moment op andere plekken in de wereld door wetenschappers werd aangeprezen. Het integreren van familie-educatie en lotgenotencontact in de behandeling van een psychotische persoon is tot dusver een zeldzame praktijk. Familieleden moeten meestal zelf op zoek naar informatie over psychose, en lotgenotencontact vindt plaats binnen familieverenigingen, als die er tenminste zijn. Onderzoeken van de laatste jaren tonen echter aan dat het betrekken van de familie in de behandeling van een psychotische persoon in vele opzichten efficiënt en aantrekkelijk is: Pitschel-Walz et al. (2001) analyseerden 25 onderzoeken naar dit onderwerp, vrijwel allemaal gedaan in de Verenigde Staten, en ontdekten dat een nieuwe crisis in een patiënt, ofwel een terugval, met 20% verminderd wordt als familieleden erbij betrokken worden. Dixon et al. (2001) concludeerden na eigen onderzoek, eveneens in de Verenigde Staten, dat dit percentage na twee jaar behandeling zelfs tot 50% kan oplopen. Door aandacht aan de familie te schenken neemt volgens hen de medicatietrouw van patiënten toe en wordt het welzijn van zowel de patiënt als de familie vergroot.

Gezinsgerichte behandeling in Nicaragua

Maar wat heeft Nicaragua aan deze informatie, de omstandigheden in dit land zijn immers niet te vergelijken met die van de Verenigde Staten. Om te beginnen bestaat er in Nicaragua nauwelijks een publieke geestelijke gezondheidszorg waarin ideeën over het betrekken van de familie zouden kunnen worden geïmplementeerd. Van het toch al magere gezondheidszorgbudget in Nicaragua gaat slechts 1% naar geestelijke gezondheidszorg, waarvan 91% ook nog eens uitsluitend besteed wordt aan het psychiatrisch ziekenhuis in de hoofdstad (Informe de País Republica de Nicaragua 2005). Psychiatrische thuiszorg bestaat niet en psychiatrisch verpleegkundigen die dit werk zouden kunnen doen evenmin. Zoals het eerdere dagboekfragment liet zien, houdt de behandeling van psychose in de publieke sector in Nicaragua niet veel meer in dan het overhandigen van een recept voor medicatie of het tijdelijk onderbrengen van de patiënt in het ziekenhuis.

Ondanks deze weerbarstige context, denk ik echter dat Nicaraguaanse beleidsmakers kunnen profiteren van de uitkomsten van de bovengenoemde

onderzoeken en de ervaringen van Cuenta Conmigo. Bij eventueel nog op te zetten geestelijke gezondheidszorg kunnen zij direct kiezen voor een gezinsgerichte aanpak. Zeker in Nicaragua waar de familie de belangrijkste zorgverlener is voor de patiënt, kan dit een goedkope en efficiënte oplossing zijn voor de behandeling van psychotische mensen. Een voordeel dat landen als Nicaragua hebben, is dat ze een reeks stappen kunnen overslaan in de ontwikkeling van nieuwe systemen. Als landen met veel ervaring op het gebied van geestelijke gezondheidszorg tot de conclusie komen dat gezinsgerichte behandeling het meest efficiënt is, waarom dan geld verspillen aan het bouwen van grote ziekenhuizen en eindeloze eenzijdige behandelingen? Het is een belangrijk punt om over na te denken; de geldverspilling, maar nog schrijnender is uiteraard het onnodige leed dat families moeten doorstaan, simpelweg omdat niemand hun vertelt wat er met hun gezinslid aan de hand is.

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Listening

Friendship according to Kwame Opoku

SJAAK VAN DER GEEST

This essay is about two different things: listening and friendship. Strictly speaking they are not directly related, but it was through listening that I learned Kwame Opoku's views on and experiences with friendship. My essay can be read as a plea for listening and a reflection on friendship.

On listening

Spradley (1979: 4) begins his book on the ethnographic interview with a passionate plea for listening: "Ethnography starts with a conscious attitude of almost complete ignorance." Being conscious of one's ignorance makes listening a natural thing to do. Teaching ethnographic methods to students, as many of us have been doing, should, therefore, focus not so much on the art or craft of listening, but simply convince the students that there are things they do not know, which are crucial to know and which other people may know. The 'other people' are of course those we usually call 'informants', 'respondents', or 'interviewees.' Once we have 'discovered' that people we meet in the field have knowledge that we lack, that they have experienced things we never experienced and that we can *learn* from them, that they are *interesting*; once we have made that discovery, listening will come by itself.

It is probably here that anthropology differs most from all other academic disciplines: the conviction that our research 'subjects' should not be subjected to our superior knowledge and scrutiny, but rather that they are our teachers. Once students have acquired that insight, they have crossed the boundary into anthropology.

Spradley provides a beautiful example of such a teacher-pupil relationship between an informant and an anthropologist respectively. He quotes what the anthropologist Elizabeth Marshall wrote about her meeting with a !Kung woman, Tsetchwe, in Namibia:

“Tsetchwe began to teach me ...” In order to discover the hidden principles of another way of life, the researcher must become a *student*. Tsetchwe, and those like her in every society, become *teachers*. Instead of studying the ‘climate’, the ‘flora’ and the ‘fauna’ which make up the Bushmens’ environment, Elizabeth Marshall tried to discover how the Bushmen define and evaluate drought and rainstorm, *gemsbok* and giraffe, *torabe* root and *tsama* melon.... The naive realist assumes that love, rain, marriage, worship, trees, death, food, and hundreds of other things have essentially the same meaning to all human beings. Although there are few of us who would admit to such ethnocentrism, the assumption may unconsciously influence our research. Ethnography starts with a conscious attitude of almost complete ignorance (Spradley 1979: 4; emphasis in original).

In my case, the ignorance was overwhelming. In 1969 I spent almost six months in Kwahu-Tafo, a rural town in Ghana, doing nothing else other than learning the language. Some of my teachers were small children. They taught me the words for the things most physically present: table and chair, nose and eye, yam and rice. “The stranger is a child,” was one of the first and most useful proverbs I learnt. Slowly I moved from children to adults... Many years later my interest turned to older people.

Older people

Among all those who could become teachers to the anthropologist, older people stand out. They have lived longest and have the most stories to tell. For many years I was indeed an attentive listener to their stories. Getting older myself, I wanted to know if and how they managed to keep their spirits high in spite of (or thanks to) their advanced age with all its limitations; and if/how they were able to stay interesting and relevant to the younger generations.

Ironically, I was usually the only listener. I remember one instance when I was conversing with an older man who explained to me the meaning of certain proverbs. A woman in the house drew nearer, apparently to listen to our conversation. I asked her if she had learned any proverbs from the old man. She had not, she admitted. The old man cut in: “She will not learn proverbs, because the proverbs will not earn her money.” I realised that the woman had been more interested in what I came to do than in the words of the elder who was with her everyday. Many times older people complained

to me that there were no listeners for their stories. One man told me that his head was full of things but no one came to collect them, so he would take them with him (when he died). Another one said that there was no greater pleasure for him than a young person coming to him to ask his advice. The implication was obvious: such a young person never came. The fact that young people do not come to listen constitutes the greatest reason for loneliness among older people in Kwahu-Tafo (cf. Van der Geest 2004).

Els van Dongen has written some horrifying accounts about the loneliness of older people in South Africa, and the cruelty done to them by the younger generation. One of her most recent articles starts with a quote from an older woman:

The children are no good at all.... If we tell them, "Don't do this", they will tell you, "That was your time. Don't come and tell us. This time is ours!"

She then continues to paint a disconcerting picture of generations in conflict and the rejection of old people's memories by the young (Van Dongen 2008).

I am giving these examples of disinterest and not listening to reiterate the point Spradley was making and to which I referred a while ago. Being a 'stranger' holds tremendous advantages in an ethnographic situation. Familiarity, as we know, breeds contempt, or at least it produces boredom, though none of the younger people in Kwahu-Tafo ever used these terms. They kept saying that they respected their elders and often went to them for advice, but my observations told me this was just wishful – or rather respectful/polite – thinking. After some time most elders confided to me that the young never came. But that problem of boredom with the old stories and even possible contempt did not apply to the anthropologist. I loved to sit with them and listen. One of them fascinated me in particular, Kwame Opoku.

Kwame Opoku

*Okyeame** Kwame Opoku was born in Kwahu-Tafo in 1919. When he was a boy he was sent to another town to learn tailoring, and a few years later he

* *Okyeame* (often translated as 'linguist') is an official at the chief's court, whose function is to speak for the chief and enhance the rhetoric of the words the chief has spoken.

settled there as a tailor. He then stopped his tailor work and opened a store in the nearby town of Nkawkaw. His business flourished. After that he moved to a farming village and started a cocoa farm. During that period he was also buying and selling cocoa. He married three times and when I met him he was living with his third wife, with whom he had six children. In total, he had sixteen children and he was able to send all of them to school, although he himself had hardly attended school. Kwame Opoku had been an *ɔkyeame* at the chief's palace for about thirty years. His work as an *ɔkyeame*, he used to say, had opened his mind and broadened his knowledge on a lot of customary and legal matters. He died in March in 2002. His death came too early; for him and for me. He was one of the most impressive teachers I met during my life as an anthropologist. He had a philosophical mind and a gift for expressing that mind. Whatever topic I broached, he was able to reflect on it, using his experiences as didactic data. The conversations resulted in transcripts that could compete with some of Montaigne's celebrated essays. I had wanted to make a long series of recordings of more conversations but the news of his death disrupted that plan. One of my favourite conversations with him was on friendship and love. I quote a few paragraphs from it.

On friendship*

One day I asked Kwame Opoku what friendship was. He answered:

The inscription on my house reads: *Onipa nua ne nea ɔne no ka* (A person's brother is the one who loves him). If a brother does not love you there is nothing you can do. A person who loves you should be everything to you. No matter how a brother may be, you can't do away with him (*Wɔye oo, wɔnye oo, worentumi mpoa*). Whether a brother is good or bad, he will succeed you in the future, but a friend never will. At the same time, the love between friends can be deeper than the love between brothers. I have a friend and the love between us is more special than the one between my brother and me. I am able to disclose all my

* This text by Opoku has been taken from a compilation of conversations with six elders about issues of 'life, love and death' (Atuobi et al. 2005). Originally, the conversations were recorded as they had been held, as dialogues. I have edited those texts in such a way that the questions asked by me and others have been left out so that the reader only 'hears' the elder speak. The meaning of his statements has not been affected by this.

secrets to him (*Mitumi ne no ka atrimu sem*), something I don't do with my brother. I scarcely converse with my brother and at times our conversation ends in a quarrel. My friend and I are able to share one bed, eat together and even bathe with one bucket of water, something I don't do with my brother. All this is done out of love (*Ne nyinaa ye ɔdɔ*).

Love in friendship is the purest (*Adamfoɔ mu dɔ no na eye ɔdɔ ankasa*). Because friends always pray that the other won't die or fall into trouble so that their friendship will last a long time. But it is the wish of some people that their brothers die so that they can take their belongings. Indeed, there is no pure love among brothers. Love in friendship is very deep and there is happiness in it.

Friendship usually starts casually. It starts first with greetings which will later on develop into a conversation. This goes on for some time. Then it develops into full friendship. Friendship may end when one leaves the other and travels to a distant place. But even when such a thing happens friends are able to maintain their friendship by sending messages to one another. Friendship can last till death. I have seen such a friendship. I had one. We used to buy the same cloth. I informed him about my love affairs with women and he did the same. None of us travelled without telling the other. I became extremely sad when he died.

There are two major causes, which break a friendship: women and money. These two things mostly bring friendship to an abrupt end. When such a deep friendship breaks there is little chance for reconciliation.

Friendship can spoil someone's marriage, especially among women. Women friends like discussing the 'chop money' that their husbands give and other things. The woman who thinks she is receiving less money and fewer cloths from her husband may develop ill feelings towards him and this always leads to divorce.

Friendship between men can also spoil a marriage. It all depends on the friend's character. If one leads a good life and the friend is also good, a woman will never object to such a friendship. If a woman hears you are discussing problems with a friend, for example, how to look after the children and how to set up a profitable venture, she won't complain because it shows how good the friend is. But when your discussion is about drinking and other useless things it will worry the woman and this can lead to divorce.

Let me tell you about my own friendship. I saw that my friend did not like gossiping and that he respected himself (*Obu ne ho*). I also saw that he was hard working. These qualities attracted me. Ever since we

started our friendship we have been going on well. We plan how we can look after our wives. My wife is aware of all these qualities in him so she receives him warmly whenever he is here and she feels happy when he is around. When we were young we used to help each other in clearing our farms (*Yedi nnɔboa*). But now that I am old I can't go to farm, but we visit one another frequently for conversation. When we meet we share our meals together. Even when I am not around and there is a problem with the children my wife contacts him for help.

A friend is someone with whom you share secrets.

Michel de Montaigne

Every time I read his words I am struck by their depth and eloquence, so similar in style to what De Montaigne wrote in his *Essays* more than four centuries ago. I cannot resist quoting also some of *his* words on friendship.

“... you cannot judge a relationship until the partners have attained strength and stability in mind and in years” [quote from Cicero]. For the rest, what we commonly call friends and friendships are no more than acquaintanceships and familiarities, contracted either by chance or for advantage, which have brought our minds together. In the friendship I speak of they mix and blend one into the other in so perfect a union that the seam which has joined them is effaced and disappears. If I were pressed to say why I love him, I feel that my only reply could be: “Because it was he, because it was I.” (De Montaigne 1958: 97)

Kwame Opoku's words in particular give me an immense sense of happiness, because I was able to salvage them from oblivion by sitting near him and listening. But the words also fill me with regret that I was unable to capture and save more of his gentle wisdom for future generations.*

* I thank Patrick Atuobi who introduced me to Kwame Opoku and joined all our conversations. I thank Els van Dongen for being a colleague and a friend for almost twenty years, although the 'seams' of our friendship never disappeared.

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Anthropological theory and therapeutic action

ROB VAN DIJK

In *Repetition and repertoires: The creation of cultural differences in Dutch health care*, Els van Dongen (2005) states that performative and strategic use of cultural differences plays an important role in mental health for immigrants. Basing her paper mainly on secondary data she points out that migrants are exoticised and stereotyped. Reference to cultural differences helps to conceal inadequate mental health care. According to Van Dongen, “culture and cultural differences are created and used in mental health care for migrants by repertoires and concepts which are in fact repetitions” (2002: 179). Summarizing her argument, the power of the often-heard cultural explanations for the problematic behaviour of migrants, and of the collision course the therapeutic process takes in mental health care for migrants, has its roots neither in empirical data, nor in ethnographical research, but in its endless repetition and in the practical use therapists make of this category of explanations. The point of view of Van Dongen is certainly inspiring, but after reading her paper we still do not know what happens in the consulting room. How do therapists in their work with migrant patients apply the cultural information anthropologists have for so many years disseminated in Dutch mental health care? How does the repetition take place? These questions are the subject of my contribution to this book of friends.

Reflections in Dutch professional literature about the use of the culture concept in health care (cf. Van Dijk 1989; Bartels 2002; Van Asperen 2003; Gailly 2008) are rare, in contrary, for instance, with the United States where the significance of cultural competence in health care is highly debated (cf. Gregg 2006; Lakes et al. 2006). Moreover, what is known is rarely based on observations in the consulting rooms of Dutch mental health care workers, i.e. on the ethnographic study of therapeutic practice. Geiger (2006: 281), however, underscores the necessity of intense observational studies of clinical encounters as they are the very nexus of disparities in medical care. As anthropological research did not reach the consulting room in the case of migrants, it remains a black box. So what we know about this black box is ultimately derived from interviews with care providers talking about their therapies, from migrant-patients, or from articles written by intercultural experts and

advocates of interculturalisation. Sometimes, however, outsiders accidentally catch the therapists in the act and get a glimpse of the use of culture in mental health care. Below I will describe such an occasion and illustrate how therapists create an interpretative framework that meets their ends.

Being a medical anthropologist working as a consultant on intercultural affairs in an institution delivering mental health care in a highly culturally and ethnically diverse catchment area, I am interested in the construction of culture and cultural differences. In order to explore the possibilities of doing research into this subject I organised several focus group discussions with professionals. I asked them to present a case that illustrates in their opinion the role of culture in building a therapeutic relation and offering therapy. In most cases, the professionals discussed the subject with some distance and in more or less general terms. But in the scope of this contribution, in one of the focus groups a revealing discussion about a migrant patient took place. Although nothing can be said about whether or not the exposed mechanism is representative for team processes in a clinical environment, it offers an interesting insight into the minds of therapists. Furthermore, it illustrates how anthropological concepts are transformed to be of use in the medical context, or as the Dutch say, how these concepts adopt 'the colour of the wallpaper.'

The transformation of Rachida

A psychiatrist, a social worker, a psychologist, and an art therapist, all working in the same clinical unit, agreed to participate in a focus group discussion. Unlike other occasions, they were all familiar with the case which one of them presented. Moreover, the patient had already been discussed in a team meeting, so what they raised about this patient seemed to me to be more or less a repetition of earlier team discussions. To me the case was not unfamiliar either; the psychiatrist had consulted me some months before. He had asked me about the availability of group therapy for migrants in the region, as he intended to refer on his patient. Like other cases, the focus group discussion was recorded on audiotape and transcribed verbatim. What follows is the essence of a twenty-five minute centripetal exchange of views. To protect the privacy of the patient I have changed some of the personal data.

The psychiatrist introduced one of his patients. He illustrated the case with quotes, registered facts and figures from the voluminous patient dossier he had at hand. Within minutes an interesting discussion unfolded, in

which the four therapists reconstructed the case, each from their own experience with the woman. They gave me the impression that there was nothing left they did not try to make the therapy a success, but despite all their efforts the treatment had failed and they were faced with their inability to establish an effective therapeutic relationship. It made me sense an atmosphere of helplessness.

The patient was a young woman in her early thirties of Moroccan descent, who I will call Rachida. She was referred to the clinic two years before because of enduring depressive complaints. At that moment she already had a clinical history, though the patient dossier offered hardly any information about. After admission as an outpatient she took part in the group therapy program. Having completed the program, she was referred to the psychiatrist for medication and individual counselling.

The psychiatrist began with telling us that Rachida was living in Fez, Morocco, when she became acquainted with a Dutch man. She fell in love and followed him to the Netherlands. According to Rachida, her family did not agree with this turn in her life. After her migration they lived together, but never married. Several pregnancies ended prematurely. Finally this relationship ran ashore. After the two broke up, Rachida was living on her own in an apartment in a large block of flats, and led a lonely and secluded life. She would often sit all day on her couch staring at the wall. She had hardly any contact with the Moroccan women in the neighbourhood. Now and then she visited her sister, a university student living in Belgium. Those visits made her feel good and afterwards she would appear to be less depressive.

Having depicted his patient, the psychiatrist explained his concerns about Rachida. She did not manage her medication at all well and consumed several times more of the medication than prescribed. He also noticed suicidal thoughts. Making contact with Rachida proved to be difficult, although she spoke Dutch reasonably well. "If she visits me, she doesn't talk. (...) She just says: 'I'm doing well', 'I'm not doing well', or 'Things go bad'. That's all she tells me." He did not succeed in getting more information about her background and her relations with her family. Her reluctance to talk about her personal history and the life she was living was, according to him, not solely due to her depressive complaints, but had everything to do with Moroccan culture. She probably blamed herself for cutting off the bonds with her family by leaving against their will.

The other therapists joined in, elaborating on the theme, tuning in on the same wavelength. The exchange of views had one focus and was mutually reinforcing: step by step Rachida was portrayed as a traditional Moroccan woman. The therapists recall Rachida's somatising attitude. "She is com-

plaining about pains in her belly, about headache and so on.” They all agreed that going into the many losses in her life proved to be impossible. The social worker illustrated the patient’s behaviour in the clinic that she found typical for her, depicting it as theatrical without explicitly putting it that way. “She sits in such a way in the corridor, that you start thinking, what is the matter with you? She sits as if broken in a chair nobody ever uses.” The art therapist concluded through her contacts with Rachida that “She has done something in the textile industry”. The social worker summarized the conclusions of an earlier team discussion; Rachida is certainly of Berber descent and raised in the countryside, the Rif area in the north of Morocco. “Of course there is hardly any school [in the Rif, RvD]. She cannot read or write her mother language. Children start working at the age of eight in carpet workshops. (...) Girls are always considered less important than boys.” For a moment they discuss the possibility that Rachida might be slightly mentally retarded, but this suggestion remains without solid ground.

At the end of the day an image of Rachida was established as an illiterate Moroccan-Berber woman, as a girl-child neglected and with a theatrical way of expressing herself, who transgressed the standards of her family and is now sad because of losses not worked through. This combination of factors equally explained, according to the therapists, her depressive complaints as well as the laborious therapeutic contact. In light of this patient portrait, the referral to a unit specialised in treating migrants appeared to be an obvious choice. Case closed.

The forging of an interpretative framework

The case of Rachida illustrates in general, in my opinion, the beliefs of care providers in Dutch mental health care about culture, and the way they deal with cultural differences. Firstly, general information about the cultural background of ethnic groups as it is presented in professional literature is not questioned and is considered self evident and applicable to individuals, in this case Rachida. Secondly, explanations for behaviour and health beliefs that are in the eyes of therapists problematic in the therapeutic relationship are primarily looked for in the ‘there and then’, in the Moroccan culture and conditions of life in Morocco. Rachida’s behaviour is hardly related to the ‘here and now’, to what is at stake in her social world in the Netherlands. Thirdly, and most remarkable in the context of the argument, is the modelling of Rachida step by step to the stereotypical image of the traditional Moroccan woman living in the Rif, distilled out of anthropological field

research and repeated by expert-therapists over and over again in medical literature. Information that does not mesh with this image, even if it is part of the patient's dossier, stays unnoticed, is ignored or not included in the image under construction. In Rachida's case, the patient dossier tells us that Fez, one of the largest cities in Morocco, and not the Rif is her place of birth. Furthermore, it tells of two sisters that one appears to be illiterate while the other is studying at a Belgian university. Apparently, the latter did not experience the assumed preference for boys in the Moroccan countryside, and went to school. These discrepancies could prove to be plausible, but should at least have provoked some thought; but in no way did the therapists confront their constructed image of Rachida with these self-registered facts.

In the same way, more or less obvious questions hidden in the patient's story, that in one way or another could have disturbed the image under construction, did not surface. If she had been illiterate and spoke only a Berber dialect, in which language did Rachida and her new male Dutch friend communicate in Morocco? Was he Moroccan too and of Berber descent? What has the fact that Rachida mastered the Dutch language rather rapidly got to say about her intellectual and coping capacities? The same goes for questions exploring Rachida's social worlds. How do people in Morocco and the Netherlands think about Moroccan women having a relationship with a – probably – non-Muslim man? What did she hope to achieve by starting the relationship? Was she trying to follow the footsteps of her sister? How did she get a residence permit if she was not married? The focus on the construction of Rachida as a 'traditional' Moroccan woman silenced these and many other relevant questions before they could emerge and ignored the individualized experience of culture. The four therapists agreed to a large extent on the interpretative framework which they had forged, and finally confined Rachida in. The constructed image seemingly met a shared need to reduce uncertainty and frustration. Facing a dead end in therapy, this image offered them a way out, a possibility to close the case. Their intentions were undoubtedly good, but the process came close to a conspiracy in stereotyping.

The deformation of the anthropologists' echo

What does the case of Rachida tell us about stereotyping as a form of repetition without a reality check? Looking back to this patient discussion, what strikes me most is how she was moulded more and more on the cultural archetype of a traditional Moroccan woman as the conversation went on. Instead of exploring how Rachida and the choices she made relate to her cul-

tural background and what is at stake in her social world (Kleinman 1995), the therapists identified her completely with her culture, at least their representation of Moroccan culture. They repeated or rather echoed anthropologists' input, and echoes become deformed and decontextualised in their repetition. In other words; "a careless use of the term culture to describe social and psychological phenomena" (Gregg 2006: 546). So this discussion also unveiled to some extent how anthropological information is transformed in a medical context and becomes instrumental to the therapists' job.

Rachida disappeared as an individual and reappeared on the stage as an anonymous representative of what was supposed to be her culture. This process of on the one hand de-individualising and on the other culturalising the patient offers therapists an explanation of their inability to understand the patient and to build a therapeutic alliance, and of the stagnation in the therapeutic process it provoked. The case makes clear that stereotyping is not so much the input of the therapeutic process, but most of all the consequence of its failure. It is the failsafe of therapists, helping them to contain a deranging therapeutic process. In the work of therapists with migrant patients, a dynamic interpersonal process – as culture is considered in contemporary anthropology – is transformed in medical settings into a static feature of the patient. The way therapists implement the anthropological concept of culture increases their agency, their ability to make sense of their experiences, and stay in control in their therapeutic contacts with patients whom they define as culturally different. The tenacity of a static interpretation of culture in mental health care finds its roots in the non-threatening explanation it offers therapists for a failing assistance (Van Dijk 1989). Starting from the premise that health care is a production of culture (Bartels 2002), self reflection and critical evaluation of familiar methods and insights cannot be excluded.

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Trust as condition for communication

SELMA VAN LONDEN & ARIE DE RUIJTER

An underlying pattern in the work of Els van Dongen (e.g. 1994, 2000, 2004, 2005) is communication. We not only detect this in her choice of topics and themes, but also in her experimentation with all kind of styles: written texts, documentaries, and paintings. In particular, she focuses on people who are marginalized, exploited, and excluded by the dominant discourse. In her research she indirectly or directly criticizes the definition of reality of the ruling economic, social, and cultural elite. In taking this position she underlines the limitations of these forms of cultural dialogue by pointing to the repressive character of such classifications and practises. After all, true communication is *herrschaftsfreie Dialog*, implying not just the technical ability to understand the other, but also the existential intention to listen to the other, and to take the position of the other. In a sense, a prerequisite for communication is partnership, and this requires trust.

Trust

Trust, as a form of bonding and bridging social capital (Putnam 2000)', promotes predictability, the harmonization of behaviour, and involvement of actors. Trust strengthens the functioning of the world economy, smoothes organizations' operations, and allows for the successful co-operation of actors. As a matter of fact, trust is never given just like that; people know that trust can be violated, and therefore must be built up in concrete interactions. Trust presupposes the psychological condition of emotional and affective binding. By reflecting on their interactions, participants can construe and learn to understand the underlying structures, mechanisms, and basic processes of the world they live in. This promotes transparency and legitimacy in social arrangements. However, knowledge and understanding are not sufficient; participants must also be willing to approve these arrange-

* See for example the special issue of the journal *Revue internationale de politique comparée*, 2003, dedicated to trust and social capital.

ments. The existing 'order' must be morally acceptable, must be accepted as fair and just.

Because trust is not given just like that in a modern society with flexible connections between people and parties and anonymous client-system relationships, it is very important that society is structured in such a way that trust and solidarity is promoted by the setting up of institutions and schemes, whereby rationally acting egoists are stimulated to co-operate in stable and calculable connections. Here we touch on the impact of strategic alliances. After all, it must be possible to harmonize activities with one another. The nature and degree of co-ordination are related to the structural characteristics of the society concerned – that is, scale, complexity, openness, dynamics, stratification, and such like – but also with cultural characteristics – the often implicit rules, opinions, values, norms, and the repertoires of action related to them. Continuity and routines are required here. In short, trust and (efficient) co-ordination are mutually constitutive. These, in turn, raise the question of the conditions under which, and mechanisms whereby, they can be brought about in the light of the differences in interests and positions of those involved, implying that each of those involved – from individuals to organizations and nations – can act in a co-operative or competitive and even antagonistic manner. In a nutshell, this poses the question of social order or social cohesion, to be defined as the efficient and effective connection between different units or actors in a system. As has been stated above, this connection includes functional co-ordination, trust or solidarity, transparency, stability, and experienced fairness. In the current world especially, these conditions are under pressure because of deep, radical transformations due to globalisation.

Globalisation and localisation: A tandem process

We see the growth of mutual dependencies as well as a condensation of relationships and interactions between a steadily increasing number of actors. We see a massive acceleration of the global exchange of people, goods, services, and images. Apart from this acceleration, we also see greater distribution: increasingly, more and more countries and regions are becoming involved in networks that span the globe (Appadurai 1990). A worldwide web of interdependencies has been spun. Bound up with this, we see a transformation of the nation-state with the shifting of accents to above or below-state arrangements. The nation-state is losing its 'naturalness'. In a period of 'open borders', migration, an ongoing division of labour, and advanced

technology, society is becoming more pulled apart than ever before (Salet 1996: 7). This implies that networks (both formal and informal) are becoming increasingly important for the economic and social functioning of individuals and groups (Castells 2000). The influence of these networks can be interpreted both positively and negatively. For example, social networks can remove a feeling of insecurity and alienation, but at the same time they can have a coercive and restrictive effect by promoting conformism and smothering individual initiative. Further, the structural exclusion of particular groups from networks, or the failure to intervene promptly to deal with the negative influence of networks, can result in tensions and social inequalities in society, and in extreme cases leads to instability and violence. The 'risk society' (Beck 1992) is something that many people have to come to terms with individually.

However, globalisation breeds its own counterforce: localisation. The rise of a global system is accompanied by a rebirth of nationalism, regionalism, and ethnicity (Anderson 1992; Roosens 1989). Apparently globalisation and localisation constitute and feed each other (e.g. Van Binsbergen 1999; Featherstone 1990; Friedman 1995; Giddens 1990; Hannerz 1992, 1996; Hall 1991; Robertson 1995). In this era of time-space compression, distant localities are linked in such a way that local happenings are shaped by events occurring many miles away and vice versa. Social relations become dis-embedded, that is, they are increasingly 'lifted out' of the context of local interaction to become re-embedded again in different forms and conditions (Giddens 1990). This interplay between globalisation and localisation, or 'glocalisation' (Robertson 1995), results in complex mixtures, new social hierarchies, changing cultural boundaries, and multiple identities'. In other words, the culturally homogenizing tendencies of globalisation imply continued or even reinforced cultural heterogeneity. "The paradox of the current world conjuncture is the increased production of cultural and political boundaries at the very same time when the world has become tightly bound together in a single economic system with instantaneous communication between different sectors of the globe" (Basch, Schiller & Blanc 1994: 29). Individuals are increasingly confronted with the task of selecting from a number of different elements and combining them to create a unity that is meaningful in their eyes. The outcome is a permanent patchwork of cultural material that happens to be available. This 'hybridization' matches a world of grow-

* Instead of 'glocalization' one could use the term 'hybridization' or 'creolization', if one wanted to emphasize processes which take place on the periphery of the world system. It is not a one-way traffic from the centre to the periphery, because the periphery talks back.

ing migration and cultural diversity'. We witness a reinforcement of the production of 'localisms'. This bucks the trend of the past two centuries in which newly formed national states tried through nationalistic programmes to homogenize their entire territory culturally and linguistically, as well as economically and socially (Brubaker 1992).

As a consequence, we see a transformation of the nation state involving the evaporation of the triad of territory, people, and culture. The world, divided into separate national states, is yielding to a multicultural global society, sometimes slowly but more often with abrupt jolts. This type of society is ambiguous, chaotic, and confusing since various social and cultural systems exist side by side. Consequently, we are faced with an indefinite future, an uncertain environment, and a fragmented identity.

In this context of social relations under pressure and diverging attitudes, cohesion and co-ordination no longer seem to be provided for by the simple continuity of existing institutions. The issue, however, is that it is not only social relations that are 'under pressure' or in transition. Cohesion addresses a more fundamental question. Cohesion brings home to us the fact that humans as social beings are dependent on each other. The 'other' is both a means and a hindrance to self-realization. Reciprocal dependence – with all its concomitant risks – requires sustained co-operation and sustainable structures, which in their turn raise questions concerning the conditions of their genesis, and the differing interests, views, and positions of those involved.

The interplay between globalisation and localisation points to the blurring of boundaries between state, civil society, and economy, between governments and private organisations, and between formerly circumscribed societies and markets. Nowadays, the contexts in which processes of governance, management, and policy developments take place are increasingly marked by networks, shifting power configurations, and differentiated multicultural arenas. These multicultural arenas give rise to attempts to live peacefully together, to co-ordinate activities, and to balance interests, but also to conflicts, controversies, and variations. The current society is nothing but 'a never ending story' of antagonistic co-operation, in which unequal access to and control of scarce resources play a major part.

* "The process of hybridization may create such multiple identities as Mexican schoolgirls dressed in Greek togas dancing in the style of Isadora Duncan, a London boy of Asian origin playing for a local Bengali cricket team and at the same time supporting the Arsenal football club, Thai boxing by Moroccan girls in Amsterdam and Native Americans celebrating Mardi Gras in the United States" (Hermans & Kempen 1998: 1113).

Although multiculturalism as an ideology holds that cultural diversity is tolerated, valued, and accommodated in society, within a set of overarching principles based on the values normally associated with a liberal democracy – e.g. the civic unity and equality of all people within the nation state, and individual rights – we know that the practice of multiculturalism effectively reinforces domination by one specific ethnic group. Diversity is domesticated, shaped and harnessed to the yoke of the dominant socio-cultural order and economy. The domestication is, however, hardly ever a complete success. In particular, glocalization emphasizes the idea that the global powers are – and will always be – quite vulnerable to very small scale local ‘resistances’ (Nederveen Pieterse 1996). In short, while these new processes of transnationalization hold out new opportunities for some groups of the population, the same processes are mainly disadvantageous to other groups. New inequalities arise. Some groups manage to obtain strong positions in certain fields, others are excluded from important facilities, opportunities, and resources, such as democratic and legal rights, markets, particularly the labour market, welfare state provision, family, and community. In practice of course, exclusion from different resources will overlap. This exclusion affects both intra- and intergenerational mobility. It is very hard for members of these excluded groups to escape from this ‘societal trap’. It is highly likely that specific groups will fall further behind economically, socio-culturally, or technologically. Drop out symptoms will increase. Large groups are in danger of ending up on the sidelines of social life. We have to remember that opportunities for mobility and the availability of resources are highly differentiated. We have to acknowledge that social practices and identities are construed in a context of inequality of power and unequal access to scarce resources. We also have to acknowledge that the global restructuring of production that is taking place favours a number of countries and ethnic groups but bypasses or even harms a considerably larger number. Poorer segments of the world population are increasingly pushed towards degraded areas and are forced to overexploit natural resources, straining the adaptability of local cultures. The commercialisation of agricultural production and the processes of migration accompanying industrialization have had all kinds of ‘gender-effects’ and have deepened the interactive patterns between rural and urban areas. Labour markets are characterized by numerous forms of fragmentation. Attempts at macro-economic stabilization are accompanied by institutional reforms which emphasize liberalization, deregulation, and privatisation, all implying a withdrawal of the state in favour of the private sector. In a number of countries, the ‘separation’ of state institutions from the internal dynamics of society has resulted in a complete collapse of the

state and absorption of the state-functions by an intricate network of legal and illegal transactions between patrons and clients. Sometimes this leads to the complete marginalisation of a growing number of groups who increasingly resort to the informal sector as a means of survival. The related risk of social isolation is a fertile breeding-ground for racism and ethnocentrism entailing many possible disastrous consequences, as ethnic violence in so many parts of the world clearly demonstrates.

This appropriation of scarce resources will partly follow old classical boundaries of region, socio-economic class, age, gender, and religion, but will also run along new lines of ethnicity and lifestyle. Because the disadvantages of this social variety – lack of consensus, increasing strife over scarce provisions – can often rely more on public interest than the advantages, increasing demands for integration and decreasing tolerance for variety will become significant social powers. This creates a new problem: growing variety stirs up powers which hinder the pursuit of integration and the blossoming of trust.

A challenge

How to handle this problem of developing the ability of persons to deal with ever changing surroundings? Because we live in a world characterized by multiplicity, uncertainty, ambiguity, and ambivalence, it is becoming more and more important to learn how to cope with the uncertainties which people create in and through their own actions. However, in the current post-traditional society, the views held in the past and the related guidelines for action no longer form the basis for a 'natural' social order. The challenge posed to politicians, administrators, managers, and citizens at the present time is the development of skills, which can be labelled the 'management of diversity'. Otherwise, trust will never emerge.

It is a difficult task to lay down the basis for competence in dealing with socio-cultural diversity in formal rules. It has to do with the ability to deal with uncertainty, with unknown situations, with limited means, with one's own shortcomings. After all, in a global world and a plural society, a person will inevitably have to associate with people who have different ways of thinking and acting. This person does not find his freedom in blindly observing rules, nor in a self-evident orientation towards the general interest, nor in the possibility to do everything he wants to do, but in the ability to act judiciously under different specific conditions (Van Gunsteren 1998). Authorities – and of course, this also holds true for other relevant and sig-

nificant actors – should promote the development of competencies that enable all parties to deal adequately with difference*, with the result that the ‘other’ is not denied, excluded, or banned, but is treated and respected precisely as the ‘other’.

So, we do not need a common culture or identity. People only need recognition to develop trust. What is vital here is that all actors are identified in terms of recognition instead of rejection, whatever their culture. Els van Dongen has shown that such recognition is of the utmost importance for the emergence of trust and legitimacy that, in turn, could provide the groundwork for institutional sustainability**.

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* This implies, for example, promoting not only learning to know, learning to do, and learning to be, but especially ‘learning to live together’ as described by Jacques Delors in “Education – un trésor est caché dedans” (1996).

** As has been stated before, sustainability not only requires trust and recognition; the social fabric must also be conceived as legitimate, equitable, and fair. Such a conception will only be made possible when the existing distribution of rights, obligations, and positions are morally acceptable and provide for participation and inclusion.

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Primary Health Care

Terugblik en vooruitzicht

CORLIEN M. VARKEVISSER*

In de jaren vijftig en zestig werden in verschillende Derdewereldlanden pogingen ondernomen om gezondheidszorg van de grond te tillen die de circa 70% van de bevolking zou kunnen bereiken. Deze bevolking was tot dusver verstoken van biomedische gezondheidszorg. Actieve medewerking van de dorpelingen zelf werd *de* sleutel tot succes geacht in deze projecten. Middels een korte training van hooguit zes weken werden gezondheidswerkers opgeleid: mannen en vrouwen, traditionele vroedvrouwen en traditionele medicijnmannen, geschoolden en ongeschoolden. Deze werden geacht in de primaire behoeften aan preventieve en curatieve gezondheidszorg van hun dorp of wijk te voorzien, inclusief moeder- en kindzorg. Vooral de experimenten in China (blote-voetendokters), Guatemala, Costa Rica, Mexico en India inspireerden tot navolging.” Vanuit de hoek van ‘community development’ en de kleinschalige landbouw was men eveneens aan het experimenteren met participatieve benaderingen.”” In een door de WHO, UNICEF en CMC (Christian Medical Council) goed voorbereide vergadering van de lidstaten van de VN in Alma Ata, in 1978, onderschreef het merendeel van

* Dit artikel is deels gebaseerd op eigen evaluaties van PHC uit de tachtiger jaren zoals vervat in mijn oratie (Varkevisser 1996). De laatste vier alinea's berusten op informatie van twee oude PHC kompanen, Jarl Chabot en Leon Bijlmakers, die nog werkzaam zijn op het gebied van Public Health.

** Zie bijvoorbeeld het boek van Horn over China (1969), David Werners baanbrekende *Where there is no doctor* (1977) dat stoelde op zijn PHC ervaringen in Mexico, of Behrhorsts beschrijving van een PHC project in Guatemala (1974). Djukanovic en Mach (1974) en Kenn Newell (1975) bundelden deze en andere PHC ervaringen en legden de basis voor een coherente PHC benadering.

*** In Farming Systems Research experimenteerde men in de jaren zeventig en tachtig met Rapid Appraisals die de lokale situatie en de aanwezige kennis en behoeften van boeren als uitgangspunt namen voor landbouwprojecten (zie Chambers (1983), Grandstaff et al. (1987) en Varkevisser et al. (1993).

de lidstaten de resolutie 'Health for All', waarin de principes van "Primary Health Care" (PHC) waren vervat.

De meer technische principes achter het te volgen beleid deden nog het minst stof opwaaien. Men werd geacht, voor *simpele* maar *goede* en *zo goedkoop mogelijke* zorg te kiezen, die *acceptabel* zou zijn voor de bevolking. Toch stuitte een van de voorstellen die dit beleid moesten ondersteunen, de beperking van het aantal door de overheid verstrekte geneesmiddelen tot 200-300 bij voorkeur generieke middelen, al op soms forse tegenwerking van de farmaceutische industrie.

Anders stond het met drie politiek geladen meer ethische dan technische principes van PHC die begin jaren zeventig ook in onze eigen maatschappij sterk de discussie bepaalden: *equity*, het best te vertalen met gelijke kansen voor iedereen, *participatie* van de doelgroep, en armoedebestrijding door middel van *intersectorale samenwerking*.

In de gezondheidszorg betekent *equity* dat er extra aandacht en middelen zouden moeten gaan naar degenen die deze zorg het hardst nodig hebben: vrouwen en kinderen, sociaal-economisch zwakkeren, bejaarden en gehandicapten. Dit impliceerde in de meeste ontwikkelingslanden een zekere herverdeling van fondsen: van de stad naar het platteland, van ziekenhuis naar eerstelijnszorg, van curatieve zorg naar preventie. Hervreiding bleek een uiterst moeizaam proces toen de overheidsmiddelen schaars bleven. Zonder dwang, en dat begrip komt in de Alma Ata Verklaring niet voor, kwam herverdeling vrijwel nergens tot stand. De belangstelling voor PHC was echter groot onder bi- en multilaterale donoren alsmede onder vooral kerkelijke NGOs. De fondsen stroomden aan het eind van de zeventiger jaren dan ook toe.

Het begrip *participatie* kent vele definities en interpretaties.^{*} Het is een van de meest rekbare begrippen in het ontwikkelingscircuit. In Alma Ata werd participatie veelzijdig gedefinieerd: de gemeenschap werd niet alleen geacht gebruik te maken van geboden diensten – passieve participatie – maar ook zelf verantwoordelijkheid te dragen voor het eigen welzijn. PHC zou tot individuele en collectieve zelfredzaamheid moeten leiden. Daartoe moest de gemeenschap betrokken worden in het bepalen van prioriteiten in de gezondheidszorg en een directe bijdrage leveren aan die zorg in de vorm van

* Sommigen verstonden er uitsluitend dorpsgezondheidszorg onder; voor anderen (bijvoorbeeld de PHC groep die in 1981 op het Koninklijk Instituut voor de Tropen, Amsterdam werd opgericht) was PHC de combinatie van 'community based' activiteiten en eerste-lijns gezondheidszorg. Deze combinatie lijkt voort te leven in de huidige 'Integrated District Health Approach'. De PHC benadering van de Antwerpse School bestond uit eerstelijns gezondheidszorg met mobiele activiteiten in de dorpen.

menskracht (comité leden en dorpsgezondheidswerkers) en middelen. De menskracht en middelen die de gemeenschap investeerde, moesten in goed overleg met alle dorpelingen worden vastgesteld. De dorpelingen beslisten uiteindelijk.

Dit uitgangspunt was ongetwijfeld het meest paradoxale principe van PHC. De politici in Alma Ata bepaalden dat dorpelingen zouden moeten beslissen over hun eigen welzijn en zorg, maar volgens een van tevoren vastgesteld stramien. Dorpscomités zouden dorpsgezondheidswerkers kiezen die, getraind en uitgerust door het Ministerie van Gezondheid en geïnteresseerde NGO's, simpele curatieve zorg en moeder- en kindzorg zouden moeten leveren en de dorpshygiëne bevorderen. Beloning van de dorpsgezondheidswerkers, in natura of geld, zou komen van de dorpelingen. De verantwoordelijkheid voor ondersteuning van de gezondheidswerkers zou liggen bij het dorpscomité en de gezondheidsstaf in de districten.

Het derde ethische principe tenslotte, armoedebestrijding door *intersectorale samenwerking*, vloeide regelrecht voort uit de twee voorgaande. Het was te voorzien dat veel behoeften van de gemeenschap – aan water, brandhout, zaaigoed, krediet, grond of onderwijs – bijvoorbeeld slechts indirect aan gezondheid gerelateerd zouden kunnen worden. De relatie armoede/gezondheid vormde in Alma Ata een belangrijk maar explosief discussiethema. De meest voorkomende gezondheidsproblemen in ontwikkelingslanden zoals infectieziekten en ondervoeding, waren immers direct aan armoede gerelateerd. Onderzoek in onze eigen samenleving had aangetoond dat verhoging van de levensstandaard vooral sinds het midden van de 20e eeuw een grote bijdrage had geleverd aan de afname van infectieziekten. Intersectorale samenwerking stond daarom in Alma Ata hoog in het vaandel, enerzijds vanuit praktische overwegingen omdat de gezondheidszorg alleen nooit zou kunnen voorzien in de ruimere aan gezondheid gerelateerde behoeften van de bevolking, anderzijds vanuit ethische overwegingen die de bestrijding van armoede en – impliciet – van de politieke systemen die deze armoede in stand hielden, als doel op zich voor ogen hadden.

Niet ieder land was even gelukkig met de ethische grondslagen van PHC. De (voormalige) Sovjet-Unie bijvoorbeeld, het gastland van de VN vergadering in Alma Ata, stemde tegen. Veel Latijns-Amerikaanse en ook Aziatische landen zoals Bangladesh en de Filippijnen betuigden althans in het begin niet meer dan lippendienst aan PHC en werkten particuliere initiatieven passief of zelfs actief tegen. Dat neemt niet weg dat er vele PHC-projecten op gang kwamen in Afrika, Latijns Amerikaan en Azië, gesteund door lokale en overkoepelende (veelal kerkelijke) NGOs, de internationale donorgemeenschap en de Ministeries van Gezondheid in de ontwikkelingslanden zelf.

Het is niet verwonderlijk dat de jonge artsen, verpleegkundigen, sociale wetenschappers en aanverwanten die zich met enthousiasme op de praktijk van PHC wierpen veelal met twee linkerhanden in het veld stonden. Gemeenschappen bleken complex, met tegenstrijdige belangen. Wensen van dorpingen gingen soms lijnrecht in tegen wat projectverantwoordelijken mogelijk of zelfs maar wenselijk achtten (een bioscoop, bijvoorbeeld). Betaling van dorpsgezondheidsactiviteiten en -werkers bleek moeilijk te organiseren en leek te botsen met het principe van *equity*. Het op gang brengen van daadwerkelijke participatie was enorm tijdrovend en daardoor duur. Dat verdroeg zich niet met de centrale doelstelling 'Health for All' waarvoor de WHO het jaar 2000 als streefdatum had gesteld, maar waarvoor de grote donoren met hun projectgebonden donaties aanmerkelijk minder tijd uittrokken. Kortom, er waren vele onopgeloste kwesties, er moesten compromissen gesloten worden en er was weinig informatie die daarbij behulpzaam kon zijn. De successen en mislukkingen zouden goed moeten worden geanalyseerd.* De WHO riep daartoe aan het eind van de jaren zeventig een speciale tak van onderzoek in het leven: Health Systems Research (HSR). HSR diende, evenals PHC, door goed getrainde lokale gezondheidstaf te worden ontwikkeld en uitgevoerd, met participatie van de lokale bevolking en onder goede begeleiding.** Inmiddels zijn er dertig jaar verstreken sinds de Alma Ata declaratie. Wat is er terecht gekomen van PHC?

Gedurende de jaren tachtig nam de belangstelling voor PHC geleidelijk af, vooral onder bilaterale donoren als DGIS (Nederlandse overheidsinstelling voor Internationale Samenwerking). Parallel aan deze ontwikkeling propageerden de Wereld bank (WB) en het Internationaal Monetair Fonds (IMF) een nieuwe economische benadering met 'Structural Adjustment Programs' (SAPS) die beoogden een gezond economisch systeem te bevor-

* Voor terugblikken op verworvenheden en problemen in de toepassing van PHC, zie onder andere, het aan PHC gewijde themanummer van Social Science & Medicine (Rifkin & Walt 1989), de beschouwing over PHC vanuit een 'multi-level' perspectief (Van der Geest et al. 1990), de verzamelbundel van Streefland en Chabot (1990) en de artikelen van Muller (1995) en van Van der Velden en De Wildt (1995).

** De WHO gaf speciaal voor de training van gezondheidswerkers in het doen van onderzoek 32 modules uit (*Designing and conducting Health Systems Research projects*) die over de hele wereld worden gebruikt, niet alleen door gezondheidswerkers maar ook aan universiteiten in ontwikkelingslanden (Varkevisser et al. 2003). Op zijn minst 200 kleine onderzoeken vloeiden voort uit workshops voor District Health Teams in Afrikaanse landen bezuiden de Sahara op door de teams zelf gekozen problemen. (Varkevisser et al. 2001)

deren met marktwerking hoog in het vaandel.' Het is moeilijk, geen verband te zien tussen de afnemende belangstelling voor PHC en de toenemende aandacht voor SAPS. De WB en het IMF stelden structurele aanpassing als voorwaarde bij het verstrekken van leningen. Een van de standaardrecepten van structurele aanpassing betrof bezuinigingen op de overheidsuitgaven, met name in de sociale sectoren zoals gezondheidszorg en onderwijs. De beoogde marktwerking bleek echter moeilijk verenigbaar met *equity*, en dus ook met PHC.

Gelukkig blijkt dat in de praktijk NGOs en Ministeries van Gezondheidszorg zich niet altijd veel gelegen lieten liggen aan marktwerking in hun gezondheidsactiviteiten op de laagste bestuurlijke niveaus. Bestaande NGO projecten liepen vaak gewoon door, of speciale geïntegreerde gezondheidsprogramma's in zuidelijk Afrika bliezen PHC nieuw leven in omdat ze op dorpsniveau de dorpsgezondheidswerkers heel goed konden gebruiken bij het geven van voorlichting en het ondersteunen van 'home-based care groups' van en voor AIDS patiënten (Zambia, Zimbabwe, Zuid Afrika). In Rwanda en Ethiopië is 'Community Health' zelfs een prioriteit van de overheid, waar veel overheidsgeld voor uitgetrokken wordt omdat men beseft dat de Millennium Ontwikkelingsdoelstellingen (naar beneden brengen van zuigelingen-, kinder- en moedersterfte, bijvoorbeeld) niet gehaald zullen worden zonder actieve medewerking van de bevolking zelf. De overheid in Ghana heeft het 'Community Health Planning and Services' initiatief omarmd, met speciale 'CHPS compounds' in de meest afgelegen gebieden, teneinde de preventie en bestrijding van malaria, longontsteking en andere kinderziekten ter hand te nemen met inschakeling van lokale vrijwilligers. Het Ministerie van Gezondheid in Kenia heeft een 'Community-based Health Strategy' geformuleerd ter ondersteuning van de diverse 'Communities' Own Resource Persons' (CORPS) die door de diverse gezondheidsprogramma's in het leven zijn geroepen om preventie, essentiële gezondheidszorg en intersectorale samenwerking op het niveau van dorpen en wijken te bevorderen.

In Rwanda lijkt men een probleem te hebben opgelost dat vanaf het begin de effectuering van PHC heeft bemoeilijkt: het niet betalen van dorpsgezondheidswerkers. Het aantal Community Health Workers (CHWs) is tussen 2004 en 2007 gegroeid van 12.000 naar 45.000. Ook hun taken zijn uitgebreid, maar de werklust van iedere CHW is toch afgenomen door de bijna viervoudige toename in aantal. Daardoor is het voor een CHW moge-

* Zie Bijlmakers (2003) PhD studie over de invloed van SAPS op gezondheid en gezondheidszorg in Zimbabwe.

lijk als part-time vrijwilliger te werken. Zelfs als deze opzet maar gedeeltelijk werkt is de kennis onder de bevolking over bijvoorbeeld hygiëne en voeding toegenomen door de grootschalige training van CHWs. In Ethiopië probeert men een andere oplossing: in het kader van het 'Health Services Extension Programme' (HSEP) ontvangt de CHWs een minimum loon. Dit geeft aan dat de regering vertrouwen heeft in het werk van de CHWs.

Ook in het werk van de 'traditionele vroedvrouw' valt een accentverschil op sinds de jaren zeventig en tachtig van de vorige eeuw. In de meeste landen wordt, op advies van de WHO en UNICEF, traditionele vroedvrouwen ontraden bevallingen buiten het ziekenhuis te verrichten. Daarentegen worden zij getraind in het tijdig onderkennen van risicofactoren voor mogelijke complicaties bij de bevalling, opdat zij een vrouw 'at risk' zullen doorverwijzen naar het dichtstbijzijnde ziekenhuis. De traditionele vroedvrouw krijgt dan ook geen doos meer met materialen om bevallingen te doen. De moedersterfte in veel landen blijft echter onaanvaardbaar hoog. Dit is voor een deel toe te schrijven aan de soms gebrekkige zorg in de ziekenhuizen bij complicaties rondom bevallingen en het onvoldoende doorverwijzen.

We zien dus een golfbeweging in PHC. De benamingen zijn misschien anders, de taken zijn wat verschoven, de technische middelen uitgebreid, de beloning van dorpsgezondheidswerkers is hier en daar ter hand genomen, maar het principe van *participatie* van de dorpingen lijkt nog springlevend.

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Forgetting

Part of the cycle of life

MARIANNE VYSMA

Els van Dongen was the first (medical) anthropologist I met who was an intrepid explorer in the territory that interests me: the borderland or liminal space between identity and culture. Her book (which I read before I met her) *Worlds of Psychotic People* gave me a glimpse of possibilities on how to traverse that seemingly impenetrable terrain. Although I went in a different direction, guided by other inner imperatives, her independence of spirit and insistence on authenticity continue to inspire me. For instance, much of the literature on trauma has focused on remembering with its emphasis on learning, growth and creativity. I am interested in the darker more implicit, less examined part of the whole: forgetting.

People who have undergone severe collective trauma very often report that they suffer from repetitive anxiety dreams and nightmares in which they re-live, in part or in full, the traumatic situation. The quality of the dreams is so vivid that they have the sense of re-experiencing the trauma. Such dreams, and the intensely painful recollections they bring again to the forefront of consciousness as a result during the waking hours, are so intrusive that often people are afraid to go to sleep. What such people seem to experience is a sort of pathological remembering. Pathological in the sense of the compulsive character because people report being in the 'grip' of such memories, much as they were caught in the vise of the events themselves.

Trauma and forgetting

What such patients seek, explicitly, is help in forgetting. Their immediate request is concrete and specific: a 'normal' period of sleep, with *un*consciousness. It is the kind of sleep that in health we take for granted, precisely because the 'I' – waking consciousness – is gone, and it is therefore as if nothing happens. Nonetheless, as every doctor or psychotherapist knows, sleep also has a function. It is 'a natural, periodic suspension of conscious-

ness during which the powers of the body are restored'. Or, as Shakespeare wrote:

innocent sleep,
sleep that knits up the ravell'd sleeve of care,
the death of each day's life, sore labor's bath,
balm of hurt minds ...

Macbeth, II, ii, 36-40

But often, and more implicitly, the patients seem to ask for a more diffuse and general sort of forgetting, which has to do with finding the energy to pick up the tread of their lives again. This is the kind of forgetting that, in the normal existential course of a person's life, has to do with mourning. Except that collective trauma is precisely an interruption in the 'normal existential course of life'. The state of dissociation, when it is deep enough and lasts a long enough time, introduces a feeling of disconnectedness, of being essentially alone, even when there are others, of being endlessly stuck in a dark place of pain, that is like being in hell, in the underworld, a kind of death-in-life.

But what is forgetting? Our memories are what makes each of us unique. Memory provides continuity and an awareness of self as distinct from all others – as well as a sense of autonomy. Such a distinction lies at the heart of what it means to be human and the mystery of human consciousness. The process of memory consists of both remembering and forgetting.

Forgetting: To let go

The etymology of forgetting (and its Dutch and German relations, *vergeten* and *vergessen*) comes from the Old High German 'gietan' (from which the word 'get' derives and which is also associated with the Latin word *prehendere*), meaning: to receive or to grasp, which is then changed into its negative by the prefix 'for' (in Dutch and German: 'ver'). The imagery is then of letting go, a sort of 'un'-grasping or, more paradoxical: of 'un'-receiving. In French the word is *oublier* and in Spanish it is *olvidar*, both of which stem from the Latin *oblivisci* (of which the English word 'oblivious' is another descendant), translated as 'to forget', but also parsed into the components 'ob': in the way; and 'levis': to smooth, as if forgetting involves 'smoothing something that is in the way'. The way forward perhaps.

Forgetting seen in this way involves the curious mingling of active and passive, of something that is within the purview of the will and then again, just outside it, of something that is, psychologically-speaking, part of the ego and yet again not at all. This is clearest to me in the languages I speak the best, Dutch (my mother tongue) and English (in the symbolic sense, my father tongue). In this 'un-getting', 'un-grasping', a state of muscle-tension and a relaxation of that state, I see a hand opening up, slowly (sometimes perhaps reluctantly, in which case the hand will continue its cramped and grasping motion helplessly and fruitlessly), and letting go of what it was clutching. That something tumbles heedlessly in free-fall, perhaps to be caught, perhaps not. If the hand is a symbol of the ego, particularly the ego function of 'knowing' (which survives also in the words comprehend or apprehend), then 'letting go' signifies a yielding or a surrender to a state of un-knowing.

This comes close to the meaning of the Greek word for forgetting, *leitheia*, which original meaning was 'being hidden', so that the idea of forgetting is conveyed by the image of 'being hidden from knowledge'. Heidegger has interpreted the Greek word for 'truth', *aletheia*, as being formed in terms of the negative for *leitheia*, that is: *a-letheia*, thus understanding 'truth' as what is unconcealed, discovered, revealed or remembered (Kerényi 1981: 120).

Lethe: The last frontier before rebirth

In Western mythology (which was, of course, in the time it was written, considered to be knowledge or truth), forgetting is associated with Lethe, which is sometimes a parched plain leading to the river Ameles (Unmindfulness), sometimes a river itself: the river of Forgetfulness; and sometimes a spring called Lesmosyne, next to the spring that is the goddess of Memory, Mnemosyne. Plato, for instance, tells of a soldier named Er, who was slain on a battlefield, but instead of dying, journeyed to the Underworld and returned to tell of what happens to the soul after death but before rebirth. Upon entering the kingdom of Hades, souls enjoy a period of rest or suffer a period of punishments. Then they are given the choice of a new life and pass before the three goddess of Fate. After that they are:

marched on in a scorching heat to [Lethe] the plain of Forgetfulness, which was a barren waste destitute of trees and verdure; and then toward evening they encamped by the river [Ameles] of Unmindfulness, whose water no vessel can hold; of this they were all obliged to drink a

certain quantity, and those who were not saved by wisdom drank more than was necessary; and each one as he drank forgot all things. Now after they had gone to rest, about the middle of the night there were a thunderstorm and earthquake, and then in an instant they were driven upward in all manner of ways to their birth, like stars shooting. (Plato, *The Republic*, Book x: 620)

In Dante's second book of his Divine Comedy, *Purgatorio*, rebirth into life (and love) is also accomplished by crossing a river,

it issues from a pure and changeless fountain,
which by the will of God regains as much
as, on two sides, it pours and it divides.

On one side, it is Lethe; on the other,
Eunoe; neither stream is efficacious
unless the other's waters have been tasted:

their savour is above all other sweetness.

Dante, *Purgatorio*, Canto XXVIII: 126-134

Discussion

Forgetting and remembering are thus inextricably linked: one cannot be done without the other. You can only re-member if you have first forgotten it, let it go, vanish out of the heart or mind, put it behind you, and only then can things come back or come up (*sou-venire*), or can you find or discover them again, and make them a part of your life story, to re-member or (*h*)er-inner, or *re-cordare*. But the reverse is also true: forgetting (or letting go) can only occur if somewhere there is the certainty that there has been a witness, that someone or something has seen, grasped, recorded what was experienced.

* A similar account is to be found in Virgil's *Aeneid*, Book VI, who, additionally, suggests that rebirth is more of a punishment rather than a grace; see, for instance "they are compelled . . . by a driving god, to live again" (line 720).

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At home with Antiretroviral Therapy in Uganda

SUSAN REYNOLDS WHYTE

In the early years of this new millenium, Antiretroviral Therapy (ART) for people living with HIV/AIDS became far more widely available in many African countries. Prices of antiretrovirals (ARVs) fell, free drugs became available, and a multitude of programmes emerged to offer treatment and support. The radical expansion of ART happened dramatically in Uganda, especially around 2004 and 2005 as big donor resources flooded in. Within a few years, a new historical generation emerged, a pioneer generation of people who learned to live with ART as it was becoming common.

In 2006 and 2007 a team of four Ugandan and four Danish researchers* followed 23 members of this First Generation, who were receiving treatment from different sources in Kampala and rural eastern Uganda. This was anthropology at home in that Ugandans were studying in Uganda, but also because some of the informants were long-time acquaintances of the Danish ethnographers, who had made homes in Eastern Uganda over long periods of fieldwork. It was also anthropology at home because we repeatedly visited people in their homes, together with their families, rather than meeting them at the clinic. In this chapter, honouring Els van Dongen for her years of leadership in the Medical Anthropology at Home Network, I will sketch some of the methodological and analytical issues arising from this fieldwork at home in Uganda.

For this First Generation, HIV/AIDS has become a chronic condition thanks to the treatment provided, which is in many ways revolutionary. Although they vary widely, ART treatment programmes all have certain common characteristics that make this experience of biomedical care unique in the Uganda setting. People on ART have more regular and supportive rela-

* Godfrey Siu Etyang, Phoebe Kajubi, David Kyaddondo, Jenipher Twebaze, Lotte Meinert, Hanne Mogensen, Michael Whyte and Susan Whyte comprised the team. The study was part of the Tororo Community Health (TORCH) collaboration, funded by DANIDA with the aim of enhancing research capacity. This chapter is a revised version of a paper presented at the 5th conference on 'Medical Anthropology At Home' held in May 2008 at Sandbjerg in Denmark.

tions with their health workers; counselling plays an important role in testing and treatment. In smaller treatment programmes they repeatedly see the same treatment provider as they come regularly to pick up their medicine. They become clients of programmes, and they are systematically referred to as clients, rather than patients.

Programmes have expectations about their clients. They should take their medicines on time every day. They should 'live positively' in the felicitous phrase of The AIDS Support Organization TASO. That is, they should eat well, avoid alcohol, get plenty of rest, engage in safe sex only, and not have children (except with the consent of their doctor). They should not have 'too many thoughts' (worries) and plan for the future. All of these good habits are in the realm of what Lone Grøn and colleagues (2008) call 'chronic homework.' They may be assigned in the clinic, but they are undertaken at home. A range of analytical concepts might be used to understand what is happening for the First Generation. A Foucauldian approach to 'biopower' emphasizes the disciplining of individuals and the formation of subjectivity (Foucault 1991). Paul Rabinow (1996) points us toward 'biosociality,' the formation and practice of social identity on the basis of biomedical diagnoses or treatments. 'Biological (or therapeutic) citizenship' (Rose and Novas 2005; Nguyen 2005) raises our awareness of the relation between the individual and overarching political entities. But 'homework' orients us to homes, and in Uganda that means domains of interaction that are fundamental to aspects of life beyond the biomedical. The methodology of our study led us to see 'homework assignments' within the realm of everyday life.

That everyday life is embedded in relations with other people. The informants we met and followed over the time of this study were always *social persons*, whether we were talking to them alone or amongst family and neighbours. The demographic bottom line is that the total fertility rate is one of the highest in the world at nearly seven, so families are large. Polygyny, divorce, death, and remarriage add further twists to family configurations. Relatives come to stay for shorter or longer periods: sisters or daughters who have left their husbands, and children who have lost their parents.

The 23 men and women who agreed to let us visit were a varied group including soldiers, farmers, and small-time traders and craftsmen living in towns and rural areas. We contacted most of them through their treatment programmes, and made a first life story interview with each. Thereafter we visited them seven times more, so that we were able to follow their lives on ART for a total of 18 months. Two people preferred to receive us at their places of work and one visited us at our office, but we found all of the others where they stayed. Our method was that of Continuing Friendly Conversa-

tions. We tried to let our interlocutors talk about what concerned them, rather than using a question guide. Sometimes the topic of ART hardly came up because they were preoccupied with other problems: a daughter who had gotten pregnant while at school, a brother who was cheating in a joint business venture, or a family member who had fallen ill.

Going home to people, we very rarely found them alone. In fact none of the 23 people we followed lived by themselves, with the single exception of a man who was working in one town and spent weekends with his family in another. Whether or not they knew we were coming, our informants were almost always together with other household members or neighbours when we arrived. We often found Hassan sitting in front of the town building where he lived, talking with the men who washed and mended shoes. When we visited Ivan, we found his compound busy with activity: his wife sweeping the veranda, his mother threshing groundnuts, a little boy trying to keep the chickens from eating the sorghum spread to dry on the ground. In homes family members came to greet us and often joined the conversation.

This method of repeated visits had consequences both personal and analytical. To begin with the latter, it provided a time perspective that is often lacking in cross-sectional interview studies. When we met them the first time, our informants recounted their life stories retrospectively. At that point all had started on ART, and two thirds had been taking the drugs for more than six months. They told us their illness narratives, but their accounts were far more than tales of illness and treatment seeking. They described their childhoods, their families, their partners, and their occupations. By and large these first chronicles were rich. Yet all took on new perspectives over the course of the ensuing seven visits. Partly our interlocutors added more information about themselves, but even more importantly, they emerged as social actors in relation to the others with whom they stayed. Moreover, their lives continued unfolding during the time we knew them. Sometimes unfortunate twists occurred, as when we arrived to find Dominic in the police lock-up accused of stealing a sheep, or another time laid up in bed after a wall collapsed on him. Families were refigured, as conflicts intensified and defused, partners died, and women fell pregnant. So each person, each 'case,' gained nuances because we got to know them in more dimensions, both retrospectively and prospectively.

Our interlocutors knew that we were interested in how they lived with ART; they had accepted to tell us about their illness and treatment. Yet many of the conversations and interactions had little to do with their situations as patients and clients. It is as if our method had the effect of de-centring AIDS and ART. Partly this may be due to the therapeutic trajectory itself.

Most of those who were weak or suffering side effects from the drugs when we first met them improved over time (although all had some down periods over the course of our acquaintance). Medicine taking and regular visits to the clinic became routinized so they were less interesting as topics of consideration. But more important, meeting people at home meant seeing them as parents, spouses, siblings, neighbours, employees, traders, farmers, and householders — not as patients, clients, or ‘users’ relating to ‘providers’. Very few were involved in forms of ‘biosociality’ (though two sisters whom we nicknamed the ‘AIDS stars’ were active in programmes for people living with AIDS). It was sociality and not biosociality that demanded their energies and sustained them. They were preoccupied with all kinds of plans, worries, and tasks, only some of which were linked to their diagnosis and drug regimen.

Although openness about being HIV positive is extolled as a virtue in Uganda, it is almost always selective. You share information with those whose particular support you need, while discretion is often practiced in relation to others. Even within a household and among close family members, there were those who had been told, and those to whom details of testing and treatment were never mentioned. That meant that we too had to talk carefully. In a home some people knew that we had come to visit because Grace was on ART, while others thought we came simply as friends or for some other reason. The practical consequence was that we sometimes could not ask how the treatment was going. We adopted a tactic of discretion, taking cues from the informant (‘only one of my children knows’), waiting for a private moment (a quick question as the informant walked us out to the road at the end of a visit), or sometimes an abrupt change of topic (when a colleague came into Matayo’s room at work, or a customer entered Alice’s shop). This very discretion contributes to the de-centring of ART in everyday life, in that you do not talk about it with everyone all the time. It also made us aware of how the sharing of ‘restricted’ information about being HIV+ or being on ART infuses special qualities into social relationships. This awareness formed part of the reflections we made about our positions as researchers and our interactions with our interlocutors and their families.

Each Ugandan researcher developed a relationship with five or six informants, while the Danish researchers had sporadic interactions, but also pre-existing long-term relations with a few of the 23 respondents. The researchers and their interlocutors were individuals so the dynamics varied. But certain generalizations can be made about roles and positionality in anthropology at home in Uganda. The Ugandan researchers, and even more so those from Denmark, came trailing strings to the university,

to the national hospital, to treatment programmes, to the capital city and beyond it to Europe. They arrived within a landscape of 'Projects'; Ugandans are thoroughly familiar with the possibilities of interventions and the patterns of patronage and 'technical know-who' that might, or might not, mean a chance of getting some benefit. We tried to explain clearly that our study did not provide material support, but there may well have been latent expectations. Generally there was an ambiguity in our relationships to our informants, as if possibilities were being kept open. Our ambivalent roles as researchers, friends, counsellors, and patrons shifted, overlapped, and conflated. We came to see that this flexibility existed in other social relations as well. The kinds of exchanges and expectations we experienced drew our attention to the reciprocities of 'therapeutic clientship' in contrast to the rights and obligations of 'therapeutic citizenship.' It also made us analytically aware of the sociality within which ART was being domesticated.

We came as visitors to people's homes, and were usually received with hospitality: we were served tea and groundnuts, cold sodas, sometimes a meal. As visitors we brought 'escorts' – a kilo of sugar or rice, a bottle of cooking oil – as a small gift to the household. They thanked us for coming, in the Ugandan way, thanked us for remembering them, and for coming to check on them (*okutulambula*). We were introduced to whoever was present, we exchanged news of what had happened since our last visit. With many of the informants, this kind of reciprocity took on the contours of friendship. "Please spend the night." "Bring your wife next time – mine would like to meet her." Twice we went to visit an informant's relative admitted in hospital, as a friend of the family would do. In between our home visits, our informants sometimes rang, or 'beeped' so that we should ring them. A few stopped by our office at Mulago, the national hospital in Kampala, when they were coming to collect medicine.

While the researchers were treated as guests and friends, they were also often seen as counsellors or advisors. In principle, we can make a distinction. Counselling is a professional activity for which specialists are trained, and which forms an important part of the 'exceptional' response to HIV/AIDS (Whyte et al. n.d.). Advising is part of daily life, something friends and family do; a sensible person seeks advice from someone more knowledgeable. In practice, our informants conflated the two roles when they asked us for suggestions about how to deal with problems: how should I tell my fiancé that I'm positive, what should I do about the healer who is demanding money, what would be a good business strategy, how about the pain in my feet. We were educated cosmopolitan people, we were interested friends, we were somehow connected to their treatment – that was

the reason for our visits – and counselling formed part of all the treatment programmes in one way or another.

Another aspect of the conflation of roles concerned practical help. Even though people did seem to understand that we were not bringing a new AIDS project to help them, they still saw us as relatively resourceful people who might help as individuals. Several asked to borrow money, some wanted transport, one needed help to find free second line treatment. In making these requests, our informants were not necessarily treating us like researchers who should reciprocate for the data they were providing us. They were using us as they would use other friends and acquaintances in a position to provide help in a pinch. As one woman said to Jenipher, when she declined to lend (a fair amount of) money on the grounds that she did not have so much:

Yah, Jenipher, you look to be a good person. I think if you had [the money] you would have given it to me. Let me try somewhere else. You know you are now my friend. I will even come to visit you at home.

Lending and borrowing money is common between friends and relatives, as it is between patrons and clients. To be asked for money like this is to be acknowledged as a part of a social network.

Finally, we came to see that for our interlocutors the method of Continuing Friendly Conversations represented a way of extending sociality through links to people with resources, just as the treatment programmes themselves extended the social horizons of their clients. One of the best examples was a woman we call Suzan, whom we had actually decided to exclude from the study when we realized that although she received her treatment in Kampala, she stayed in northern Uganda, making it difficult for us to visit her at home. But she kept coming by our office whenever she made the long and expensive journey south to pick up her next supply of ARVs. One day she delivered the following letter to David, our research team member.

Hullo, How is the morning? Our side we are yet fine. I have been around and I was in need of talking to you, but I was on a sharp pain that day. Now sir, I am with a request to you to assist me to borrow me something like 20,000/= which I want to buy some clothes from Owino market. I take it to the village for sale. I have to make sure I pay that money back. Mostly in instalments, when I have to be coming for my drugs. I really feel ashamed for me to ask that from you, but I have think left and right – no other way. I am in need of doing something to help me for my transport, how to start has been a problem, that is why I

am to disturb you Sir. And Dr. apart from which I ask now, don't make it a must that if I came to you, you have to give something. No Dr. you have been helping me a lot. I just like how you handle me, how you talk to me. I feel very well. I feel that is a part of my treatment. I pass to you just to say hullo to you and your comfort only Dr. No more Dr. Thanks. May the Almighty God bless you and your family in whatever you are doing AMEN.

Yours faithfully, Suzan.

Suzan appreciated our colleague as a counsellor and she valued the recognition and regard he showed to her. She also treated him as a patron and friend of the family; one day her little daughter brought him a gift of a chicken. Asking for a loan to help cover the cost of coming to Kampala for her medicines was part of this multi-faceted relationship. But as in the case of Jenipher, the request for a loan was not a demand. They would still be friends whether or not he advanced the money (which he did).

Doing anthropology at home as we did here means getting drawn into people's lives and social networks. It means acknowledging that we live in the same world as our informants, or at least that our worlds overlap. As our study drew to a close all of the Ugandan team members said that they would be open to more contact with 'their' informants. They did not think it would be right to cut them off just because the research project was over. But more than that, doing anthropology at home raised analytical issues by making us appreciate the significance of everyday reciprocity between family, neighbours, friends and patrons. As important as the life-extending drugs were, it was the sociality of home life that sustained the First Generation of people on ART.

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Regarding Freud's *Jokes and their relation to the unconscious*

ALLAN YOUNG

Years ago, I read Sigmund Freud's *Jokes and their Relation to the Unconscious*. Like many anthropologists, I wanted to learn what Freud had to say about jokes and whether his observations might be extended to other kinds of stories, such as trickster myths. I have just finished re-reading this book, but my interest is no longer Freud but rather a German psychologist, Theodor Lipps, whom Freud mentions throughout the book. Today, Lipps is remembered mainly as the man who introduced the notion of *Einfühlung* or empathy into scholarly discourse. But Lipps was also the author of a book about jokes and humour, and this explains Freud's interest in him.

Jokes and their Relation to the Unconscious may seem an inappropriate subject at this time, and for a variety of reasons. I will mention just one: the book is an utter failure, even on Freud's own terms. It was published in 1905, just five years after *The Interpretation of Dreams*, arguably Freud's masterwork. The dream book is about jokes as well as dreams, in that Freud claims that they have a similar syntax. The joke book is not much of an advance in this regard, and where it does depart from the dream book, Freud's analysis is unoriginal and often banal. In addition, the book's title is rather misleading for, according to its author, jokes have very little to do with the unconscious and, in this respect, are the opposite of dreams. Dreams are private, dreams are organized around distressing sexual desires, their true meaning is denied to the conscious mind ... and so on. Jokes are entirely public, part of everyday discourse. It is true that their meanings are not immediately available to the listener; they are temporarily withheld rather than repressed. The so-called 'punch line' represents the moment when the withheld meaning (the 'lead-up' or preamble) is revealed. In Freud's words, at this point "laughter discharges a psychic expenditure" (the listener's effort to make sense of the lead-up). A joke is simply "a pleasurable way of expressing a thought ... and there is no need for bringing in the unconscious". Some jokes are equally effective (funny) when, on future occasions, they are repeated. That is to say, the punch line is repeated without the original preamble. This is a characteristic of certain Jewish jokes (told among Jews): the punch line is repeated on

an occasion that mirrors the joke's preamble. The repetition succeeds only if speaker and listener agree on the appropriateness of its extension to the present circumstances. So there are no secrets here; the meaning is on the surface. Freud is correct: there is no need for bringing in the unconscious.

Of course this does not mean that the same meaning is on the surface for all listeners. Most of the jokes in Freud's book are so-called 'Jewish jokes'. This phrase can mean two things: jokes about Jews and jokes told among Jews. The two things do not necessarily coincide of course. Many jokes about Jews are told among gentiles and, more to the point, among anti-Semites. One of the curious features of Jewish jokes however, is that the same joke or story may be pleasurable (to use Freud's term) to both Jews and anti-Semites. This is especially likely with jokes about 'matchmakers'. *Jokes and their Relation to the Unconscious* includes several matchmaker jokes. The typical setting involves a conversation between the matchmaker and the prospective groom in the presence of the girl's (the prospective bride) family. The family cannot hear the conversation:

Man whispers to matchmaker: "What kind of a match have you arranged? You told me she is a gem. By look at her! One leg is shorter than the other, and she must hobble around.

Matchmaker: ...Yes, it is so.

Man whispers: And her nose is no long it reaches her bottom lip.

Matchmaker: ... This is true.

Man whispers: And she has a humped back and cannot walk upright.

Matchmaker: My dear fellow, there is no need to whisper. She's also hard of hearing.

End of joke.

There is no denying that the joke is both cruel and crude – that is to say, grossly physical. And it is easy to see why a contemporary anti-Semite would have found it vastly amusing, since it confirms the physical unattractiveness of Jews, their diseased bodies, their duplicitous characters, etc. But what would Jews find the joke so funny? It is too simple and generally mistaken to dismiss the response as 'Jewish self-hatred'. Something else is going on and it relates not just how Jews looked at other Jews – how the assimilated Sigmund Freud looked at unassimilated *Ostjuden* – but likewise how Jews looked at gentiles looking at Jews. Freud had the time and space in his book to explore this theme – which he assuredly understood first-hand – but he chose to ignore it. Indeed he chose to ignore the particularities of culture and history altogether. Only at the end of his life, in *Moses and Monotheism*,

does he turn to culture and history, in a most provocative way, that justifies and rewards re-reading.

Freud's self-imposed limitations are most obvious when he turns to Lipps' perspective on jokes. Lipps has many things to say, and not all of them are interesting. But one comment on jokes and meanings is worth considering: "A joke says what it has to say", he writes, "not always in a few words, but in too few words. ... *It may even say what it has to say by not saying it*". Perfect! Of course, Lipps is speaking of only some jokes: the tired old formulaic jokes that Freud indiscriminately included in his book lack this quality. Here again, it is Freud's rejection of culture and history that prevents him from exploring this theme – one might call it the collective unconsciousness, i.e. what goes without saying.

But Lipps does not go far enough, especially as this observation applies to Jewish jokes, that is, jokes about Jews that Jews tell among themselves. I am thinking about Lipps' description of 'irony', an aspect of much humour. He defines irony as "the representation of one thing by the opposite". This is likewise Freud's definition. Much more is needed however. We need a taxonomy of irony, something that will distinguish the real thing (my judgement!) from the counterfeit varieties – the cheap cynicism and sarcasm that permeates popular culture in Anglophone society. And it seems to me that we need to be able to identify the sense of irony that goes beyond representations, and acknowledges the co-existence of contradictories ('A' and 'not-A') in the human condition and the human minds. This, it seems to me, is what one discovers in the most sublime Jewish jokes, but is entirely absent from *Jokes and their Relation to the Unconscious*.

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Rolbos*

Ek dwing hom om na my te kyk
my hande houdend om sy gesig
Verskroeie landskap
van verlore liefde

Ek is rolbos
Skop skoene uit
hand oor hand
kop beskerm in jou eie skoot
wagtend op die neerstorting
'N bal sal nie breek nie, het my broer gesê
toe hy my leer val

Lig Afrika op en
alles wat los sit rol Kaap se kant toe
Tafelberg, wereldnavel, windlokker
Son op son onder dieselfde see
rooi mis vloei van Seenheuvel af

My kind my dogter
Hou my vas

My lief my alles
Hou my vas

Ria Reis
Cape Town 18 July 2006

Translated into Afrikaans by Myfannwyn Gibson

* Rolbos, 'tumbleweed' in English; is a plant (size of a bush) that breaks away from its roots in the dry season. It is driven by the wind as a light, rolling mass, until it finds fertile land where it scatters its seed and sticks, as long as there is water.

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