Chronic illness and wives as care givers

Narratives from the Western Cape, South Africa

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Narratives are currently much sought after in South Africa as part of the evidence of trauma and suffering presented to the Truth and Reconciliation Commission, for therapeutic purposes, the production of a 'new' history and to involve the 'community' in the process of transformation. In the process certain kinds of stories are privileged while others find little legitimation. This paper argues that the largely unheard stories of people who had amputations as a result of diabetes, as well as those of women who give care at home, yet do not receive assistance from formalised home care services, are equally important to understand cumulative trauma in South Africa. Such stories show that individual suffering is often loosely linked to and indicative of a wider 'social sickness'.

[narratives, chronic, amputation, body, space, South Africa]

In the aftermath of apartheid and the activities of the Truth and Reconciliation Commission, narrating or telling stories of personal and communal persecution, torture, upheaval and forced resettlement have become important ways for previously disadvantaged members of the South African community to promote reconciliation, private and public healing (see Goodman 1999; Halliday 1998; Krog 1998; Ndebele 1998: 19-20). Many of the stories were and are told in public forums and are or have been re-told and edited in publications, seminars and conference papers, newspaper and magazine articles, in radio and television broadcasts and in the hearings and proceedings of portfolio committees in parliament.[1] At the same time there are also a great number of stories that are told and heard in private.[2] Researchers nevertheless actively seek narratives and particularly three kinds of stories are privileged. First there are stories, which form the loci of the production of historical memory (see Nuttal & Coetzee 1998). Secondly, there are the stories of trauma, suffering and loss, which inform and become tools for therapeutic interventions, such as in the case of post-traumatic stress syndrome (Colvin & Harper 2000). Thirdly, there are the institutional narratives which first emerged in evidence delivered to the Truth and Reconciliation Commission and which exposed the co-optation of, for example, the health care system and of health care givers into the practices and ideologies of apartheid. More recently there are the narratives of transformation and change. These narratives are usually shaped in highly ritualized ways in meetings between people who write health care policy and manage services and those who represent ‘the community’. While the somewhat unfocused stories of members of the community are initially heard, they are constantly told and re-told and transformed into medicalized and technical varieties, which fit in more easily with medical discourse.

In this paper I look at the largely unheard stories of giving care at home, hardship, pain, loss and its cumulative trauma as narrated by wives and their husbands who, as the result of advanced diabetes, had both their legs amputated or who were going blind. My paper is based on longitudinal fieldwork I did over a period of time in Cape Town, South Africa amongst previously disadvantaged people. I first met the participants in the medical wards of a teaching hospital between 1993 and 1994 and followed them up again between 1997 and 1998.

I will give attention to the latest developments concerning health care in the home in the Western Cape. I try to show that certain categories of people largely fall outside the new developing systems of home based care, which is currently being instituted. The experience of the main care givers, the wives, as well as the trauma and anger involved for sufferers in the escalating loss of mobility, of a sense of wholeness, of independent functioning and of its cumulative stress is narrated.

I try to show that the institutional and medical narratives in operation in a time of transition do not adequately describe the everyday reality and experience of some sufferers. Medical narratives, by foregrounding certain aspects of, for example chronic disease marginalize other facets of people’s experience of illness and care giving. Despite potentially severe physical repercussions, some chronically ill sometimes resist health care providers and their medical regimens because medical narratives can only exert a certain level of authority over them and over their reality and experience of their illness.

Narrating illness and the body

Since affliction is encountered as existing in the body ill people often narrate the experience of their condition through the theme of the body. In sickness and suffering the body is many things:

> the object of cognition and knowledge, of representation in mental states and the works of medical science. It is at the same time the disordered agent of experience (Good 1994: 116).

When we as ethnographers try to make sense of suffering, illness or pain, our own representation is mediated through language and is socially and culturally informed. In South Africa the narration of illness is often not only the story of the sufferer, it also encompasses family and health care providers. The narrative and how it is interpreted therefore depends in part on who has the authority to ‘speak about’ or ‘voice’ it. In the formal interaction with the health services the story is that of the health care practitioners. When related to me it is never solely an individual narrative but that of patient and family. It is always also interspersed with, and informed by, institutional narratives.

I first discuss the latter, that is the historical background of the health care system in South Africa, and in particular in Cape Town. Then I will give attention to new emerging narratives of health care in the home. Finally I turn to the stories, which struggle to gain authority, yet which never really disappear, but form part of the ongoing experience of trauma and care giving.

Historical narratives

Like all the narratives so avidly sought by researchers in South Africa today, those of the chronically ill in my study has to be contextualised against the backdrop of the former segregation of 'Black', 'Coloured', 'Indian' and 'Whites'[3] populations through State-sponsored racial legislation. In terms of health service provision, apartheid resulted in the legalisation of racial discrimination, segregation and oppression. This affected both the organisation of health services and the health of the people.[4] As a result distinct patterns of disease and health status could be discerned in the country from 1960 to 1994. Differences existed between 'Blacks' and 'Whites' respectively and between 'Black' rural and urban areas. Only rudimentary health services were available in Cape Town's townships[5] and in informal settlements[6] no State-sponsored health services were provided until at least 1985.[7] Major discrepancies existed in the quality and quantity of health services formerly provided for the different racial groups. Hospitals were separated along racial lines to the point where admission forms had to indicate a patient's race.[8]

The most comprehensive and efficient medical care facilities were and still are concentrated in the 'White' metropolitan areas and the life expectancy of the 'White' population is on a par with that of developed countries, while that of 'Blacks', 'Coloureds' and 'Indians' more closely resemble that of the so-called 'underdeveloped world'.[9] The legacy of former legalised segregation is still evident in the unequal distribution of health care services and facilities in what have become traditionally 'White' and 'Black' areas. In the post-apartheid South Africa the formerly racially segregated boundaries between population groups are supposed not to exist anymore. At the same time public spaces are supposed to have become accessible to all. Yet in reality this is not the case. The lives of older people who had limbs amputated as a result of diabetes become increasingly constrained to the inner and invisible spaces of their homes, which largely become the boundaries of their lives. Thus for many disabled the historical legacy of apartheid is exacerbated by lack of attention to the problems encountered by sufferers like those described between 1997 and 1998 in this paper.[10]

Each of the four couples I will discuss live in sub-economic housing in the 'Coloured' townships on the Cape Flats. In the years before the first free elections townships were marginalised areas where state inflicted and other forms of political violence were rife (see Lewis 1987).[11] After 1994 gang related violence became the bane of Cape Flats communities (Jensen 1999).

Most of the houses in these areas consist of 2 to four rooms; have electricity and outside toilet facilities. Some of the streets are paved, but most are not. If sidewalks exist they are usually unpaved. The quality and scope of health care facilities and services offered in the townships vary from the most basic kind of preventive services in some areas to relatively sophisticated 24-hour curative services in others.

The new narratives of home based care

Until recently chronic illness and caring for the chronically ill fell largely outside of the parameters of the State health care services and has consequently been the responsibility of family, and in particular of women. Women (kin) also took and still take care of convalescents at home.[12] Under the new dispensation community and preventative health services have become a priority. One of the aims of the Strategic and Service Delivery Improvement Plan (Department of Health and Social Services 2000: 142) is:

> To facilitate the provision of home-based care for the Elderly, the Disabled and Frail and develop strategies to educate the community on Home Based Care through improved collaboration between Programme Managers, Regional Managers and NGOs (non-governmental organizations) between 2000 and 2003.

A number of non-governmental organisations (NGOs) have trained community health workers to provide community based care for people with AIDS in urban setting (Soal 1997). Some other efforts have extended such training to include follow-ups at home for people suffering from chronic illness. Accordingly community health workers in, e.g. Masiphumelele (a 'black' township), are also supposed to assist the disabled and to do rehabilitation (Drummond-Hay 2000). In such protocols it is not spelled out what home-based care will actually entail. Where it is available it usually consists of home visits by health care workers or volunteers to the homes of especially the terminally sick to provide services such as counselling, social assistance, practical support, nutritional and care education and assistance with DOTs.[13] Eventually it will also include services such as basic nursing (pain control, bed baths, symptom monitoring, referral to necessary services, re-assessment of needs, etcetera). Currently most home based care focuses on AIDS sufferers.

Institutional narratives on home based care are shot through with issues such as the lack of information about the appropriate kinds of home care needed, inadequate financial support and the reluctance of health care givers to accept the services of volunteers and community health care workers trained by non-governmental organisations as being professional. Other concerns include the concern that, while home based care will be cheaper and more community based, it might ultimately provide second-rate services and shift the burden of care from the formal health services to under-resourced communities (Soal 1997; Berman et al. 1987).

Ultimately the long duration of chronic illness affects individuals and households in specific ways and requires long-term solutions and adaptations for all involved. At the same time problems are often aggravated through the cumulative tendencies specific for chronic illness conditions.

This was the case for the four men I will discuss, Mr. Abrahams, Mr. Akkers, Mr. Salie and Mr. Adonis, as well as for their wives.

Becoming ill and naming the sickness

When narrating their illness all the sufferers and their wives described an initial sense of inchoateness. The four men all said that they became increasingly aware that their bodies had become unpredictable and "I could not trust me anymore" (Mrs. Abrahams). The wife and daughters of Mr. Abrahams traced the onset of his illness and its symptoms to the time when his mother, who lived with them, had a severe stroke. Mrs. Abrahams and her eldest daughter shouldered most of the responsibilities of caring for the invalid, Mrs. Abrahams Senior. At the time both they and Mr. Abrahams worked a full day and the two daughters who were still at school looked after their grandmother in the afternoon. It was a time of stress, anxiety and exhaustion for the whole family. Mrs. Abrahams first noticed that her husband, who did not want to go for a medical examination, was changing.

> He would lose his train of thought [*verloor sy draad*], telling me the same thing, in a long mixed-up way and then he would start all over again. Sometimes he was almost like a drunk, people would roll their eyes when he went on like that. And then he would just get angry, or sad, and he seemed unwell, but he was stubborn, saying he was not really sick.

According to Mr. Salie he had been unwell for a long time, becoming incoherent and disorientated. It was during a time of great political upheaval, boycotts and street violence in the early and mid 1980's that:

> He became very violent and abusive at times, and constantly complained of pain in his legs. He also had trouble with his eyes. We did not go to a doctor because there was nobody at the local clinic. It was in the time of school and bus boycotts, fighting, tyres burning, shooting. I was so afraid for the children, you never knew if they will come back tonight. When he collapsed I ran to … he had a car. We took him to … hospital. They said he had sugar and high blood. He stayed there for a few days, then they gave him pills and sent him home (Mrs. Salie).

Afterwards Mr. Salie attended the diabetes clinic when he could get off from work, but although he was given pills, the pain of his legs became worse. Finally he went to the hospital again, where a doctor told him that he needed an operation in his right leg to try and restore the blood flow. The operation was unsuccessful and it was decided that his leg should be amputated. The second leg was amputated in 1994.

Whereas Misters Abrahams, Adonis and their families had previously described an initial feeling of disintegration and inchoateness, institutionalisation and diagnosis, providing a name for the malaise, gave it 'official' status and recognition and brought a kind of order to their own understanding. According to Mrs. Adonis:

> Then it at least got a name. We knew what we had to deal with, or we thought we knew. Other people also have diabetes and we knew you could have quite a good life. It was suddenly just easier, even while it was relatively serious.[14]

The naming process, the diagnosis, was one of the sources of the illness narrative. The formation of illness into a narrative occurred as much at the level of the institution as it occurred at the experiential level. All through the subsequent narratives of the four men and their wives, the institutional, the personal experience and social elements of illness and narrative intersect and are in dialogue with each other. I touch on this issue in the following sections.

Sickness and the impact on the sufferer's family

Current analysis of the experience of acute illness often stresses the way in which it disrupts the sufferers' sense of self and necessitates a reintegration of personal and social identity (Kelly & Field 1996; Rajaram 1997). Yet, unlike people who are severely ill and then recover, the very chronicity of an illness like diabetes, the recurrence of incidents like hypoglycemia, the cycles of being hospitalized and of interacting with the health care system, result in a continuous renegotiation of the sense of self, social and personal identity. The men involved in the study ultimately had to stop working. All four men suffered from insulin-dependent diabetes mellitus and related complications. They were dependent on their disability pensions, and as their wives could not work anymore, their financial position deteriorated. Both legs of Mr. Abrahams, Mr. Akkers and Mr. Salie were amputated as a result of their diabetes. Mr. Adonis and Mr. Akkers were going blind. All four men became impotent. All of these factors seemed to compromise their public identities and personal perception of their own masculinity. According to Kleinman:

> there are threats to daily activities, special occasions, career, relationships, and, perhaps most distressingly, self-esteem (1988: 46).

Unlike the victims of torture or other forms of political violence, the kind of violence to which the four men were subjected was more insidious and ongoing. It included increasing poverty, frustration, loneliness and humiliating experiences. On more than one occasion one of the incontinent, wheel-chair bound men had to deal with the revulsion of other patients when he had to wait in line for a long time for health services. Other harrowing experiences included having flashbacks concerning the amputations. This was when they had been done under local anaesthetic which, while painless, included the shocking experience of hearing the sound:

> like a butchery, my leg being sawn off, you know that horrible sound of a saw going through bone … the smell of bone and meat (flesh) (Mr. Salie).

All four of the men frequently expressed increasing indicators of trauma, anger and bitterness. The passing of years increased rather than diminished this. Insulin-dependent diabetes and its concomitant health-problems ultimately led to social relations being ruptured and, like the disease, the breach could never be fully healed. In their own, as well as their wives' stories the theme of the lowering of the sufferer's agency as a result of the disease process as well as their increasing 'irrational' behaviour and growing anger emerged repeatedly.

According to Mr. Abrahams, he had become perpetually angry (*beneuk*) with himself, his body, and the world. Mr. Adonis, in turn, seemed to view his losses of consciousness and resultant confusion afterwards as a form of weakness, almost as an insult with which he could not come to terms. Mr. Salie felt that his "life had come to an end, there is nothing left for me. It makes me so bitter, so bitter. I scream at my wife, my anger, I scream and hit".

Anthropological studies of chronic conditions stress not only the disintegration of the sufferers' world through illness, but also how they manage to put it together again, to triumph over trials and tribulations. Yet the very chronicity of their diabetes, the recurring bouts of hypoglycemia, despair, "little accidents" (of incontinence) and finally the amputations meant that these men could never again achieve complete 'wholeness' as understood by a healthy person. Many of their social interactions and relations were altered, to the point of being permanently compromised.

The four men found nothing heroic in the everyday experience of being chronically ill or of being amputees. Mr. Adonis lost his sense of humour, he did not want to do many of the things he used to do before. There were no challenges for him (Mr. Adonis). He would "carry" his sickness, "bear" (*verdra*) it, but never with a sense of acceptance. It became an 'object' which could hardly be tolerated. He viewed his condition not as an ordeal to be overcome, but as an imposition, and as such he was always at odds with it. Similarly Mr. Abrahams frequently raged against the loss of his legs and everything else that this violent deprivation implied. He could never "make peace" with it. Mr. Akkers said that he:

> hates what I am. Nothing can take away my anger or change my life, only to get my legs back.

All four of the men became increasingly resistant to following their dietary and treatment regimens. Taking them to the health care services became an ordeal for their wives. The four men had, over a period of time, inexorably suffered irreparable loss of their health and were:

> going down, you cannot stop it. It is a slow line into (the ground). It goes down relentlessly (without mercy), slow, but it does not stop (Mr. Salie).

The men were also expressing continuous anger or fury (*woede*), emotions with which their families, friends and health care providers found very difficult to deal. Rosaldo (1993) alerted us to the importance of attending to the "rage devastating losses can bring" (1993: 10). Yet, unlike death, their loss was not swift and immediately overwhelming. As Mr. Adonis once said:

> As I look back I feel the fury creeping up slowly. Every year my loss gets bigger.[15]

Mr. Abrahams, Mr. Salie and Mr. Akkers also repeatedly expressed their anger, sorrow and feeling of helplessness. Their wives were at times overwhelmed by fury at the loss of their own lives, which the deaths (in 1998) of Misters Abrahams and Adonis seemed to bring into sharp focus, and the sorrow of progressively 'losing' their spouses as "complete husband(s)" (Mrs. Abrahams).

What I am trying to argue is that the continuously expressed anger of these two men cannot simply be pathologised as part of their depression, as health-care givers often implied. Much of their subsequent miscommunication with doctors and health care staff lay in the unwillingness of the latter to acknowledge the underlying and increasing anger experienced by these men, when they were supposed to have come to terms with their condition a long time ago. As one doctor said:

> Yeah, we know the stages, loss, denial, anger, grief, acceptance, whatever, but he has been stuck in anger forever. It's not as if he's going to die tomorrow.

Unlike death, their bereavement and social death was insidious and ongoing. They were perpetually moving "one step forward, two steps back" (Mr. Adonis), gaining a bit but losing even more. The continuous anger experienced by these men tells us something about the experience of being chronically ill, yet suffering from an invisible disease. Just as Rosaldo (1989) finally realised that the anger of the bereaved Ilongot should be seen for what it was, a deep emotional state of rage as a result of loss, so should the growing fury of these men perhaps be accepted as a part of the experience of insidiously advancing bereavement, manifest by recurring, disempowering encounters with the health care system.

It is also indicative of the processes whereby a normative system, such as medicine and health care, dominate how anger and cumulative trauma are defined as a psychological problem and as a kind of deviance. The men's own stories about pain, humiliation, disempowerment, suffering and anger of chronicity were medicalised and thereby marginalised and subjugated. These stories became indicators for the lack of ability or willingness to deal with their amputations or failing eyesight and was invariably diagnosed as depression or maladjustment.

The experience of caregivers

The stories of serious and debilitating chronic illness, like diabetes or stroke, are not only about the subjective experiences of the sufferers, but are equally socially and clinically encountered. Advanced chronic illness plunges the family of the sufferer, into "a world of vulnerability and dependence" on the medical system and on others (Kaufman 1988: 341, 347). During both the 1993/94 and the 1997/98 research periods, the family members who took care of the sufferers of chronic illness were mostly women. This trend is congruent with gender expectations in South African society. Even in the hospital the registrar usually wanted to know whether there was a wife, daughter or other woman related to, for example, the stroke victim who would take care of him/her. The husbands of stroke victims usually relied on female relatives to take care of their wives, even though the impact of this kind of responsibility could be quite extensive for the caretaker.

In the case of Mrs. Salie, it was assumed by medical and nursing staff from the beginning that she would take charge for her husband's care, especially when it became apparent that he refused to do so himself.

> When I visited him in the hospital, the doctor said I need to look after him, he said the sister and the dietician will tell me about his diet. They told me what he could eat, what he must not eat. They showed him how to give the injections, but he never got it right – he hated to do it and always ended up with a big bruise. Then they showed me how to do it. He said he cannot do it; it makes him feel sick to see his own blood. One can say his sickness became mine, I had to look after everything almost like, I can say he was dependent. But he also hates that you know. The loss, losing his independence. It was worse after they amputated his legs. He did not even want to touch the stump(s), he said it nauseated him, so I cleaned and bandaged it.

Mr. Akkers eventually became incontinent, and like Mr. Salie and Mr. Adonis his own bodily fluids oozing out of him and of penetrating his skin when injecting himself nauseated him. Both men experienced the injections and finally the amputations as invasions of the intactness of their bodies. Contrastingly, their wives increasingly experienced their own bodies as "open" to that of their husbands as they became unusually aware of and responsive to its smallest changes. All their wives and main caretakers expressed a kind of permeation between the bodies of their husbands and themselves. Thus they had to "read" it, or to develop a "feeling" or "sense" (*aanvoeling*) that their husband's blood sugar might be too high or too low.

> You have to always be alert (*wakker wees*)… they (staff at the clinic) never said how you will get to be so aware of the tiniest thing. I saw him becoming all quiet and confused and then he started to be so pale and sweaty. He sort of snored and did not respond. He was in a coma, but they never told me how to see that coming, but I did see, and afterwards I remembered. I learned to see the tiniest change. I have become very watchful, looking for the tiniest signs. I think, or I don't think about it, but I am always watchful in a way I cannot explain (Mrs. Akkers).

It was as if the boundaries between Mrs. Akkers' body and that of her husband became blurred at the times when she became acutely aware of the almost imperceptible changes in his moods. Mrs. Adonis became intensely vigilant as to whether her husband was becoming sleepy when he should not be so, or "sagging a bit", holding things "awkwardly", and being very quiet. If she walked into a room where he was she immediately became aware if something was wrong, or while she was busy she suddenly found herself going to look at him, sensing a problem. She touched her husband surreptitiously to:

> check if he was getting cold, sweaty. When his sugar becomes too high, I can start to smell it, a sort of fruit smell. It is very light and becomes stronger.

Mrs. Abrahams and her daughters said that they also got a premonition (*'n gevoel*) then she would "know" that Mr. Abrahams was about to become comatose, but sometimes it still happened quite unexpectedly:

> He will often be quiet, but sometimes I will just get this cold contraction in my heart, then I will know it is this kind of time (*sulke tyd*) (Mrs. Abrahams).

'*Sulke tyd*' referred to a specific, repetitive experience that started off with a realisation that Mr. Abrahams had not been sticking to prescribed foods and times. It intensified and corrective action had to happen "quickly" before it was "too late." Mrs. Abrahams (or her daughters) usually tried to get her husband to drink some tea, or to eat something before he became comatose. This was not always possible if he did not cooperate, as explained by Mrs. Akkers:

> I have to go out to do the shopping. It is very difficult to take him (Mr. Akkers) along. You struggle to get him to the taxi rank on the sand, the road. And the chair cannot go in the taxi, especially when it (taxi) is full. My daughter usually stays with him. The problem is he does not listen to her. He can be very very stubborn and angry. If she tries to get him to eat something he, he once just slapped the coffee out of her hand. He says he is not a child; don't take him for a child. So I come back and … he was almost unconscious. My daughter was so scared. I watch him and see the signs, the paleness, the sweatiness, the loss of interest, his breathing, but not always, sometimes it takes a long time, say when his sugar is too high. That can take longer.

Mrs. Adonis, in turn, described this awareness as follows.

> As I got to know the sickness, I can read it better all the time I can always see what is happening, but I cannot always stop it, he is stubborn. Sometimes it is a big struggle, then I will have to wait until he goes into a coma. It sometimes made me feel sick [with worry and fear].

This intense vigilance referred to by the women was culturally constituted inasmuch as these care-takers had to 'learn' how and what to perceive with their own bodies, while also giving attention to the bodies of others, that is those of the sufferer and of each other. All the women said that they not only became extremely alert to their husbands and their own 'alarm', but also immediately perceived it in the 'signs' that something was wrong with their husbands in their children as well. Mrs. Abrahams only needed to enter the room where one of her daughters was, and she would know at once that something was '*wrong*' with her husband again. Kleinman stressed that:

> For the chronically ill, details are all. To cope with chronic illness means to routinely scan minute bodily processes. Attention is vigilantly focused, sometimes hour-by-hour, to the specifics of circumstances and events that could be potential sources of worsening. There is the daily quest for control of the known provoking agents. Enervating decisions must be made about when to initiate or terminate an activity, when to move from baseline medication to secondary drugs, and when to seek professional help. And all this occurs in the context of active lives that are filled with the same pressures, vagaries, and exultations [of] ... normal living (1988: 47).

For the caretakers of their chronically ill spouses spatial and temporal arrangements and experiences became largely circumscribed and controlled by the needs and illness of the husbands. The women could never be late with meals, almost never leave their husbands unattended, and they carefully scrutinised them for any signs of a change in their blood sugar levels. The vigil was as intense as caring for an infant, if not more so.

The lives of the four women consisted of times of apparent normality interspersed with crises. Eventually all of them resigned from work. This in turn had major financial implications for the families. Like their husbands, the life trajectories they had anticipated for themselves were transformed. Mrs. Adonis said her husband's sickness "impacted" on her life in multiple ways, and her "real" time and experiential time became unsynchronised, interrupted or it simply "fled by". The rhythms of her life and even her body had to yield to that of her husband. She had to "move with him all the time." Space closed in on her as her husband's illness "hemmed" her in, made her so tired she could "not go any further". "His life, his sickness" had become "the boundaries of my life."

After Mr. Abrahams' left leg was amputated he was hospitalised for two months as a result of various complications. He was abusive to hospital staff and they had informed his wife that she had to stay with him or take him home. Frightened and unsure, she, her daughters and other family members decided to let him remain in hospital.

Mrs. Abrahams took leave from her work and tried to spend "every moment" with her husband. She woke up in the morning, dressed, made breakfast, saw her younger daughters off to school and tended to her invalid mother. Then she went to the hospital at visiting time and sat in a chair next to his bed "forever". According to her:

> That chair became my world. Outside things were happening, things went on. On that chair my life stopped for a while. People came to visit but [Mr. Abrahams] was always so depressed or unpleasant that even the family did not come so much anymore. When I went home, it was winter, it was sometimes already dark. I spent days inside those curtains [of his hospital bed].

She kept the curtains drawn if possible, because new nursing staff were not always aware that she was spending so much time in the hospital while the head nurse "looked the other way" (*kyk deur die vingers*). When staff came to make her husband's bed, to give him medication and so on, she would "quietly disappear" (*stilletjies wegraak*). Not wanting to draw unnecessary attention to herself, she brought very little with her each day and tried to "make myself so tiny, invisible." When a different registrar rotated to the ward, he initially insisted that she should not spend so much time outside visiting hours with her husband. Mr. Abrahams had to be restrained after a few days and the head nurse told his wife that she could stay with him again. After that she "really made myself thin" (*het myself eers dun gehou*), especially when the curtains were open. Thus her very bodiliness, and the space within which she moved, was condensed. She would physically "pull" herself "in", sitting up straight, elbows tucked in, legs folded sideways and feet bent in under the chair. Sometimes she felt so out of place that she remained in the chair, not daring to move, even if she was thirsty, tired, hungry, or wanted to go to the toilet. Even time lost its structure. Her lack of mobility and confinement, her sense of being 'out of place' in the hospital as well as her decreasing contact with the 'outside' made her feel apprehensive and vulnerable, as if the external had become more threatening. The shrinkage in spatiality diminished her as well. A similar compression of space happened for Mrs. Salie:

> I hardly go anywhere nowadays, it is too difficult with the wheelchair and when I do go out I always hurry back. This little house has become my life.

Mrs. Adonis, in turn, had to resign from her work. She was:

> very angry and it took me a long time to accept that I had to give up my life like that. I felt a part of my life had been lost.

The four women's lives had been delimited and compromised by the illness and disability of their husbands. Whereas before they had constructed themselves as independent individuals, they had had these margins eroded, their bodies increasingly fused with the rhythms of those of their husbands (see Kaufman 1988). He had taken "over my whole life", making her feel as if there was "no corner of my life any more completely mine" (Mrs. Adonis).

Conclusions

The narratives of trauma and distress of the chronically ill are often delegitimated and negated by current struggles around the ability to give voice and to be heard. Like the sufferers from chronic pain described by Kleinman (1995), the stories of the four men involved the experience of being:

> violated by practitioners, betrayed by biomedicine. And that enervating and deeply angering sensibility carries over into their family .. settings (Kleinman 1995: 123).

Ultimately chronically ill amputees and their wives had to cope with a sickness on a day-to-day basis interspersed with many episodes of decline and concomitant dread. Sometimes they improved, at other times their condition worsened. Some of the complications they experienced could have been avoided, others not. Their illness had brought many difficulties such as reduced income, substantial expenses, struggling with transport to and from clinics and having to wait for long periods for health care services.

In a country where health care services were supposed to become more accessible, where previously unheard stories were being sought and where previously existing spatial segregation and restrictions had disappeared, these people were largely invisible and unheard. The boundaries of their lives had contracted in a very real, as well as a metaphorical sense.

Notes

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1 The hearings of the Truth and Reconciliation Commission (TRC) and of the portfolio committees of parliament were open to the public. Almost all the evidence (the format was often in the form of story-telling) delivered to the TRC was made available in transcriptions and on the internet. Such narratives were also edited and presented in radio and television programmes and in the printed media. A number of 'struggle' tour operators currently make extensive use of the telling and re-telling of such stories of suffering in the course of township tours.

2 See van Dongen in this issue.

3 In South Africa previous apartheid legislation provided for classification according to four main 'racial' categories, i.e. 'White', 'Coloured', 'Indian' and 'Black'. Although these categories were not officially in use anymore Apartheid legislation had previously controlled and separated every aspect of life according to racial classification: separate residential areas, health, education, welfare, local government, employment opportunities, the right to collective bargaining, the franchise, access to land, business licenses, credit, graveyards, public amenities, the right to marriage and sexual liaison. (Brewer et al 1988: 157). Apartheid laws also created a wide variety of offences and crimes based on racial classification.

4 Evidence given to the Truth and Reconciliation Commission. 18th June, 1997. Cape Town, Department of Health Submission: 209-210.

5 Langa, Nyanga, Guguletu and later Khayelitsha.

6 Such as Crossroads.

7 Evidence given to the Truth and Reconciliation Commission. 18th June, 1997. Cape Town, Department of Health Submission: 209-210.

8 Experience of a Township Doctor: 76. In the case of academic hospitals, the majority of the staff and trainees were White. When non-White medical students were eventually admitted to the University of Cape Town Medical School, they were not allowed to stay in campus accommodation and could not join academic or social clubs. Black students had to use a smaller, separate laboratory for anatomy training and were not allowed to handle the corpses of White people. These were eviscerated in an anteroom and the organs were then studied in class.

9 17th June 1997, Cape Town, Academic Hospitals: UCT: 106-107. Department of Health Submission to the TRC.

10 All health services are in an on-going process of transformation and restructuring. At the time of the research the process was still very haphazard and ineffectual.

11 According to a report of the Truth and Reconciliation Commission violence peaked on 17-18th June 1980 in the 'Coloured' townships of Elsies River, Lavender Hill and Bishop Lavis when a two-day stay away was held to commemorate the uprising of 1976. "Coloured' leaders had been detained in advance and meetings and gatherings banned during this time. A fare increase had also precipitated a bus boycott. There were incidents of arson, looting and street protests, with some speculation about the involvement of gang elements.

12 By 1995 only a small proportion of disabled people across all 'race' groups (5%) received professional assistance at home to enable them to cope better. Compared to the other respondents, 'Coloureds' (11%) were more likely to receive this type of assistance. This was

probably the case because the best health care services still exist in the Western Cape, where the majority of the 'coloureds' live. Only 2% of those living in rural areas in the former homelands receive this type of assistance, compared to 11% in formal metropolitan areas.

13 Directly observed treatment for tuberculosis sufferers.

14 Toe het dit ten minste 'n naam gekry. Ons het geweet waarmee ons ten minste geweet waarmee on te make het. Of ons het gedink ons weet. Ander mense het ook diabetes, en ons het geweet mens kan 'n heel goeie lewe hê. Dit was skielik sommer makliker, al was dit nogal ernstig.

15 As ek so terugkyk voel ek die woede so stadig opkruip. Elke jaar word my verlies groter.

References

Berman, P.A., D.R. Gwatkin & S.E. Burger
1987 Community based health workers: Head start or false start towards health for all? *Social Science & Medicine* 25(5): 443-459.

Brewer, J.D., A. Guelke, I. Hume, E. Moxon-Browne & R. Wilford
1988 *The police, public order and the state-policing in Great Britain, Northern Ireland, the Irish Republic, the USA, Israel, South Africa and China*. Houndmills, Basingstoke, Hampshire: The Macmillan Press.

Colvin, C.J. & E. Harper
2000 *The torture project at Cape Town's trauma centre for survivors of violence and torture. Report and funding proposal*. April 1998 to 2000. Unpublished document. Cape Town: Trauma Centre.

Drummond-Hay, C.
2000 *Should community health workers be incorporated in South Africa's new national health system? A study investigating the roles of community health workers, and illustrating the attitudes of residents to local healthcare services in an informal settlement near Cape Town*. MA dissertation. Department of Anthropology. Cape Town: University of Cape Town.

Good, B.
1994 *Medicine, rationality and experience. An anthropological perspective.* Cambridge: Cambridge University Press.

Goodman, D.
1999 *Fault lines. Journeys into the new South Africa*. Berkeley: University of California Press.

Halliday, A.
1998 Forgiving and forgetting: the Truth and Reconciliation Commission. *In*: S. Nuttal & C. Coetzee (eds), *Negotiating the past. The making of memory in South Africa*. Cape Town: Oxford University Press South Africa, pp. 43-56.

Jensen, S.
1999 Discourses of violence: Coping with violence on the Cape Flats. *Social Dynamics* 25(2): 75-97.

Kaufman, S.R.
1988 Toward a phenomenology of boundaries in medicine: chronic illness experience in the case of stroke. *Medical Anthropology Quarterly* (NS) 2: 338-54.

Kelly, M.P. & D. Field
1996 Medical sociology, chronic illness and the body. *Sociology of Health & Illness* 18(2): 241-57.

Kleinman, A.
1988 *Illness narratives: Suffering, healing and the human condition*. New York: Basic Books.
1995 *Writing at the margin. Discourse between anthropology and medicine*. Berkeley: University of California Press.

Krog, A.
1998 *Country of my skull*. Johannesburg: Random House.

Lewis, G.
1987 *Between the wire and the wall: a history of South African coloured politics*. Cape Town: David Philip.

Ndebele, N.
1998 Memory, metaphor, and the triumph of narrative. *In*: S. Nuttal & C. Coetzee (eds), *Negotiating the past. The making of memory in South Africa* Cape Town: Oxford University Press, pp 19-28.

Rajaram, S.S.
1997 Experience of hypoglycaemia among insulin dependent diabetics and its impact on the family. *Sociology of Health & Illness* 19(3): 281-96.

Rosaldo, R.
1993 *Culture and truth. The remaking of social analysis*. London: Routledge.

Soal, J.
1997 An evaluation of a home-care project for people with HIV and AIDS. MA dissertation. Department of Psychology. Cape Town: University of Cape Town.