"Acts of disclosing": An ethnographic investigation of HIV/AIDS disclosure grounded in the experiences of those living with HIV/AIDS accessing Paarl Hospice House seeking treatment.

by

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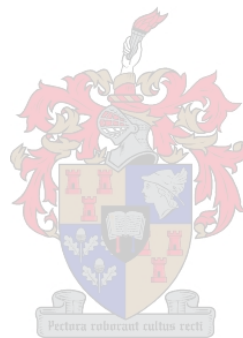
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Stellenbosch, APRIL 2005

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

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Signature: Rhonddie le Roux

Date: _____

ABSTRACT

Paarl, in the Western Cape, has been identified as one of the 15 national sites where antiretroviral treatment (ARVs) would be made available to people living with HIV/AIDS. Paarl Hospice initiated a support group for people to deal with this disease in 2003.

Since February 2004 Paarl Hospice has been recruiting people from the surrounding informal settlements for ARVs. By means of participant observation I explored how HIV/AIDS-related disclosure experiences unfolded in places, spaces and events associated with the support group in the context of factors enabling and preventing people from accessing Hospice House. I did this by considering the insights drawn from an anthropological approach. I found the meanings of disclosure in the majority of studies to be limited and restricted. Available studies approached disclosure in a top-down fashion by regarding the definition of disclosure as the announcement of HIV-positivity at the time of diagnosis only. These studies have not considered social differences relating to disclosure neither did they focus on the actual process of disclosure.

By means of a constructivist approach to grounded theory I seek to broaden the definition of disclosure to account for the range of ways in which disclosure practices take place. I found that disclosure could not be separated from the situational context in which it occurs and that it can only be understood in relation to the circumstances and relationships in which it takes place. In this study, disclosure was an ongoing process, situated somewhere between active, public announcement of an HIV-status and complete secrecy and somewhere between voluntary and involuntary revealing of the disease.

OPSOMMING

Paarl in die Wes-Kaap is geïdentifiseer as een van die 15 nasionale areas waar antiretrovirale medikasie beskikbaar gestel sou word aan mense wat leef met MIV/VIGS. Paarl Hospice het gedurende 2003 'n ondersteuningsgroep geïnisieer om aan MIV/VIGS aandag te gee.

 Sedert Februarie 2004 is Paarl Hospice in die proses om mense te werf uit die omliggende informele behuisingsgebiede vir antiretrovirale behandeling. Met behulp van antropologiese insigte en deelnemende waarneming kon ek nagaan hoe verskillende maniere van MIV/VIGS-verwante bekendmaking ontvou in plekke, ruimtes en gebeurtenisse wat verband hou met die ondersteuningsgroep. MIV/VIGS-verwante bekendmaking is ondersoek te midde van inhiberende en fasiliterende faktore wat mense verhoed of aanhelp om Paarl Hospice te besoek. Ek het bevind dat die definisie van bekendmaking in die meeste navorsing gebrekkig is. Beskikbare navorsing het bekendmaking volgens 'n bo-na-onder-wyse benader as die openbare bekendmaking van 'n MIV-status na afloop van diagnose alleenlik. Met behulp van 'n konstruktiewe benadering van die begronde teorie het ek gepoog om die definisie van bekendmaking uit te bou om sodoende die verskeidenheid maniere waarop bekendmaking plaasvind te akkommodeer. Ek het vasgestel dat bekendmaking onlosmaakbaar deel is van die situasionele konteks waarin dit plaasvind en dat dit slegs begryp kan word in verband tot die verhoudings en omstandighede waarin dit plaasvind. In hierdie studie was bekendmaking 'n voortdurende proses, gesitueer tussen aktiewe openbare bekendmaking en volledige geheimhouding van 'n MIV-status, asook tussen volkome vrywillige en onvrywillige bekendmaking van 'n MIV-status.

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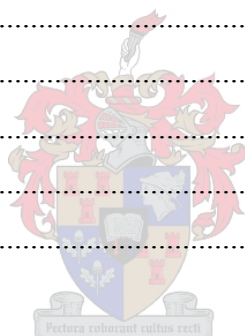
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CHAPTER ONE

BACKGROUND

1.1   Introduction

In what follows, I will map out the motivating reasons for choosing to conduct the study on HIV/AIDS illness experiences as well as how ideas for the present study originated and evolved. The problem statement will be introduced near the end of the chapter after having sketched the context of the study. I will also show the relevance and aims of this study and hint at the methodology, which will be employed to conduct the research as well as the way in which data will be analysed.

The number of people living with HIV/AIDS continues to grow. In 2003, the number of people living with HIV/AIDS globally escalated to an estimate of 38 million (UNAIDS 2004:5). Almost two thirds (25 million) of all people living with HIV/AIDS are living in sub-Saharan Africa (UNAIDS 2004:6). The statistics represent a vast number of people living with the reality of the disease. These figures reflect the devastating effects of the disease, but what lies beneath these devastating numbers of HIV/AIDS cases in sub-Saharan Africa? What is the personal meaning and impact of HIV/AIDS for particular people?

With advances in pharmacology, the status of AIDS in Northern countries is changing from an acute, fatal illness to a manageable chronic disease (Morris 2000:191), and the availability of highly active antiretroviral therapy (HAART) symbolises hope to many living with HIV/AIDS. Antiretroviral treatment (ARVs) is regarded as a heroic scientific discovery, which provides a possible way out of the biophysical entrapment caused by the disease. The availability of ARVs to treat HIV infection amongst adults and children in southern Africa means that the disease no longer needs to be equated with a physical death but that it can be treated. The shattering impact of the disease on the body of the person living with HIV/AIDS can now be dealt with. The roll-out of ARVs at fifteen sites nationally means that living a longer life is becoming increasingly a reality for people living with HIV/AIDS in South Africa. Towards May 2004 approximately 4000 South Africans infected with HIV/AIDS have

benefited from receiving ARV treatment from the public health sector, since the actual roll-out of ARVs earlier in 2004 (Kapp 2004:1710).

The public debate concerning HIV/AIDS in South Africa has focused mainly on the pro- and anti- sides of providing antiretroviral treatment for people living with HIV/AIDS (Kenyon, Skordis, Boulle & Pillay 2003:56). In November 2003, the South African government announced its support of highly active antiretroviral therapy (HAART) in the public health sector. HAART has the potential of providing people living with HIV/AIDS with longer lives, and lessening the impact of AIDS substantially. The debate focusing on issues such as barriers to treatment, for instance affordability, lack of resources and infrastructure has deflected attention away from the dilemmas confronting particular communities where HIV/AIDS is a threatening, lingering reality. The roll-out is a time-consuming process, but now that treatment is available it is necessary to cast a view on places where treatment is an actuality and to consider how those seeking health care are responding to treatment.

According to Treichler (1999:11), because of the physical reality of AIDS, the perspective of science and medicine of HIV/AIDS is often regarded as more significant than social meanings of the disease. Rogers (1991:21) states that the positivist ethos of biomedicine centres on a world of "real things" and of "scientific truth". The vast amount of HIV/AIDS cases growing by the day, hints at the biophysical reality of the disease, and science rightly is in the position to respond to this "real" disease by developing "real" medication. But the fact that science is in a position to offer a view of the biological dimension of HIV/AIDS closer to its so-called "reality" obscures the social dimensions of the disease, which means that the knowledge provided by approaches focusing on the biology of HIV/AIDS is believed to be more convincing and of more importance than that focusing on the social experience of the disease. "*The story of illness that trumps all others in the modern period is the medical narrative. The story told by the physician becomes the one against which others are ultimately judged as true or false, useful or not*" (Frank 1995:5).

In order to gain a full picture of HIV/AIDS, the view should be directed not only at the biological dimension of HIV/AIDS as provided by science and medicine, but also

on the social dimension of the person living with HIV/AIDS. The person diagnosed with HIV/AIDS unavoidably falls into a vast net cast of diverse meanings (Morris 2000:192). "*AIDS is a nexus where multiple meanings, stories, and discourses intersect and overlap, reinforce and subvert each other*" (Treichler 1999:19). Just as much as HIV/AIDS is a real disease, which affects real people (Treichler 1999:11), the reality of the social meanings of HIV/AIDS should not be discarded. These social meanings and constructs should be explored and investigated in dealing with the epidemic (Lwanda 2004:42). HIV/AIDS is at the same time "*an epidemic of transmissible lethal disease and an epidemic of meanings*" and just as much as the infectious disease is spreading, meanings of the disease will continue to multiply (Treichler 1999:11). HIV/AIDS is therefore both a biophysical reality and an epidemic which has social implications and both of these realities need to be explored in order to get a deeper understanding of HIV/AIDS.

1.2   Social implications of an HIV/AIDS diagnosis

The biomedical perspective focuses on the diseased body of an "AIDS patient" (Bond & Vincent 1997:112) and accordingly ARVs are regarded as a suitable medical solution to HIV/AIDS. This approach reduces the person living with HIV/AIDS to a position of patienthood and the problem is therefore located in the body of the "patient". But an HIV/AIDS diagnosis creeps into all spheres of the person's life (Adam 1992:14). Even though the test is accurate and reliable, the consequences of the knowledge it symbolises may be regarded as too threatening to reveal to others, and the individual may fear potential negative responses from his/her social network (Alonzo & Reynolds 1995:307). HIV/AIDS is frequently kept a secret from others in the social network because it stirs up feelings of shame (Sontag 1999:147). As a result of differing social identities and attitudes confronted in their particular social networks, individuals living with HIV/AIDS will face various difficulties associated with HIV/AIDS (Alonzo & Reynolds 1995:305). Upon testing positive, the individual has to become accustomed to being diagnosed with HIV/AIDS and might consider ways of disclosing the status in a particular social network (Alonzo & Reynolds 1995:308).

First of all the individual would have to get accustomed to the revelation of the diagnosis which signals testing positive for antibodies to the disease in his or her body. Testing positive for HIV consequently presents the diagnosed with various practical challenges. As a result of shame associated with the disease, the individual may decide to hide the diagnosis. In addition to the social factors which could influence the way in which the person diagnosed with HIV/AIDS manages physical, emotional and social contact (s)he might have to cope with physical challenges posed by HIV/AIDS, such as HIV infections and opportunistic diseases which would manifest during the latter stages of the disease. At the time of the diagnosis this could be relatively unthreatening as one could test positive for the presence of antibodies to the virus and be asymptomatic. It is therefore possible to be infected but not ill. With time and as the disease progresses, HIV/AIDS-related symptoms would begin to manifest. As a result the disease brings forth many different ways of being ill. The person living with HIV/AIDS therefore has to manage the disease both physically and socially, adapting to its progressing and changing nature. As HIV/AIDS is potentially a fatal physical and social experience, the individual living with HIV/AIDS has to meet both the physical challenges of the disease and deal with the social implications thereof (Alonzo & Reynolds 1995:313).

These social implications posed by the physical challenges of the disease could be investigated by using an anthropological perspective in order to provide another view on HIV/AIDS in addition to the dominating biomedically framed story. The focus of an anthropological perspective on HIV/AIDS is on the social individual who is living with HIV/AIDS (Bond & Vincent 1997:112). This perspective takes into account the social experiences of the person living with HIV/AIDS, and the focus is thus not exclusively on the biological side of the disease. This perspective will accommodate the fact that an HIV/AIDS diagnosis is not merely the straightforward acceptance of the results. The diagnosis has to be integrated into the social networks of which the person living with HIV/AIDS is a member. It is also clear that there is no predetermined HIV/AIDS illness route and individuals living with HIV/AIDS have to manoeuvre their way through varying physical and social demands posed by the disease. Although some participants might be constrained by the disease, the aim of investigating the social experiences of the person living with HIV/AIDS is to endow

the participants of the study with a degree of agency instead of merely assigning the participant to a position of passive patienthood.

1.3   Variety of social experiences

In the section above, I have shown that both the biological and social understandings of HIV/AIDS need to be considered. As the disease moves towards chronicity because of the availability of treatment, the changing social meanings of HIV/AIDS also need to be reconsidered (Huber & Scheider 1992: xxi, Sosnowitz & Kovacs 1992:140). People are born into societies which shape their perceptions of the world and influence the way in which they behave in the world. People born to a certain society are likely to have different views from those born into another society, and are socialised to perceive and respond to sickness in particular ways (Hahn 1995:76). Apart from the biological events, which will shape a person's perception and response to sickness, socio-cultural effects play just as prominent a role and should not to be discarded as secondary and marginal. In order to get a closer look at the various understandings of AIDS, variations by region, social class, cultural area, gender and generation will have to be considered. AIDS can therefore not be treated as a "monolith". These differences will have to be taken into account in order to treat the illness by establishing suitable treatment programmes (Adam 1992:9) and to gain an understanding of the variety of and changing meanings of the disease. Because the disease continuously takes on new forms and meanings it creates ever changing social challenges for people living with HIV/AIDS. Research has to keep track of these social confrontations facing people living with HIV/AIDS (Sosnowitz & Kovacs 1992:142). The diversity of "lay" explanations and responses to HIV/AIDS should not be discarded as incongruent to the biomedical framing of HIV/AIDS. These differing "lay" meanings of the disease are due to understandings of the aetiology and biology of the disease, advances in technology in providing treatment for the disease and the various contexts in which these responses and social meanings are shaped and embedded. The seemingly incongruent responses to HIV/AIDS from people living with the disease should not be regarded as secondary to a scientific definition of HIV/AIDS, as merely signalling an underlying cause. Instead a variety of social illness experiences signify the different physical and social challenges posed to people living with HIV/AIDS.

1.4 Development of the idea for research

1.4.1 *NRF project*

A qualitative research project investigating the responses to the implementation of a new medical treament (antiretrovirals), provided me with a space in which I could initiate my research. My study is situated in the context of a National Research Foundation project entitled *AIDS, Activism and Social Capital,* which focuses on the provision of antiretroviral treatment to people living with HIV/AIDS in the public health sector. The project aims to investigate the antiretroviral treatment roll-out in a number of public health sites in the Eastern Cape and Western Cape. I decided to conduct my project in Paarl, where community initiatives are taking the lead in treating HIV/AIDS.

After having familiarised myself with the new antiretroviral treatment programmes, I identified Paarl as a site for investigating "lay" perceptions and understandings of HIV/AIDS as chronic disease. I then conducted some informal interviews with relevant medical officers in charge of the ARV programmes at Paarl TC Newman Hospital and Tygerberg Hospital.

One of the prerequisites identified by Dr Nellis Grobbelaar (medical officer in charge of the ARV programme at Paarl TC Newman Hospital) in qualifying for ARV treatment in Paarl is the issue of disclosure. In order to qualify for ARVs the patient has to disclose his/her status to those providing treatment. In the past, revealing one's positive status predestined one to a fatal physical and social death as biomedicine was in no position to treat HIV/AIDS. Only opportunistic infections associated with HIV/AIDS could be treated as the disease progressed. The meaning of disclosure shifted with the advancement in pharmacology. At present, disclosure of one's status in a biomedical environment no longer necessarily implies a devastating physical death awaiting the person living with HIV/AIDS. Instead it offers the person in search of health care the possibility of a longer life as a result of the introduction of antiretroviral treatment. At this stage, a potential barrier posed to health officials providing ARV treatment, is to ensure that ARV tablets are taken at fixed times daily.

Therefore, upon follow-up visits to the ARV clinic held at TC Newman Hospital, antiretroviral tablets are counted to check on adherence.

A cue given by Dr Grobbelaar made me realise that the treatment process is not straightforward for health seekers. He told me that one of the HIV/AIDS patients had neglected to take her medication for three days. She explained to him that she had been home visiting her mother. This example pointed the way in which I would steer my research in looking at the various ways in which people living with HIV/AIDS deal with the various physical and social dilemmas associated with the disease and which could have momentous implications. *"If a patient is on treatment, we know that it is effective if you take 90-95% of your medication. So patients may not neglect to take their medication"* (Dr N. Grobbelaar, personal communication, March 4, 2004). This percentage signifies one side of the story. But what is the other side of the story? The medication might be effective in dealing with the biology of the disease, but strategically refusing/neglecting to take the medication might be "life-saving" in other ways. The question remains as to how the person living with HIV/AIDS manages to integrate treatment into their everyday lives. Why, if the treatment is effective, did the particular woman referred to above not take her medication? Is there perhaps another "death" awaiting the person living with HIV/AIDS in revealing his/her status to others?

Apart from getting used to the new diagnosis and physical challenges posed during later stages of the disease, the person living with HIV/AIDS concurrently faces the challenge of revealing or hiding his/her disease to others upon accessing treatment sites. If disclosure in a biomedical context signifies the act of making an HIV/AIDS status known verbally, how is HIV/AIDS disclosed in other spheres of life? How do people living with HIV/AIDS manage to integrate and disclose an HIV/AIDS status and treatment into their social circles? Where does disclosure lead to?

1.4.2   *Conversations with medical officers*

Upon mentioning my interest in exploring "lay" explanations of the disease, I was subsequently referred to Paarl Hospice as a possible site for conducting the research.

Paarl Hospice was deemed a suitable space for investigating different understandings and responses to HIV/AIDS as it had been actively involved in dealing with HIV/AIDS since 2003, before the actual roll-out of antiretroviral treatment. Because of the time constraint of the research and the sensitive nature of the disease, it seemed to be more sensible to conduct research within the already established environment of a support group at Paarl Hospice, which assists people living with the disease.

A conversation with Dr Helmuth Reuter (medical officer in charge of the ARV programme at Tygerberg Hospital) clarified the significance of such a study for future research exploring social experiences of people living with HIV/AIDS, especially those on the newly initiated antiretroviral treatment programmes. Dr Reuter hinted that there was a need to delve behind the HIV/AIDS statistics and to reveal the experiences and "lay" understandings of the illness by listening to people's explanations of the disease. He also suggested the appropriateness of investigating this particular treatment site. Paarl Hospice therefore proved to be a suitable site as a point of entry for the research in order to explore "lay" experiences of HIV/AIDS in relation to the specifics of the site. It would therefore make sense to investigate the uniqueness of the space, which Paarl Hospice provides to people in dealing with their illness as well as the role of Hospice House in the recruitment of people living with HIV/AIDS for ARV treatment. I will contextualise my study in terms of the national and provincial antiretroviral programmes in Chapter 3.

1.5   Paarl Hospice

1.5.1   *Introduction to the support group*

Having been directed to the presence of an integrative palliative care approach responding to the HIV/AIDS epidemic, I realised the possibility of other avenues of dealing with HIV/AIDS and which offer a space for people to manage the disease. Weekly, on Thursdays, a support group is held for people living with HIV/AIDS at Hospice House, and group members are transported to and from Paarl Hospice to their homes in the informal settlements on the outskirts of Paarl (see Chapter 3). Apart from infectious disease management and the recruitment of people for antiretroviral

treatment, Hospice House also takes care of the emotional, spiritual and psychological needs of people living with HIV/AIDS. Day care (the support group), and associated activities, which are an extension of patient care, were deemed a suitable point of entry for conducting the research and contextualising the experiences of those accessing the treatment sites within the context of the specific treatment approach employed by Hospice House. Because of the language problem (a vast number of people living with HIV/AIDS in the Paarl area is Xhosa-speaking), and the fact that Hospice House employs a translator, I was able to address the problem of not speaking or understanding Xhosa. As a result of the time constraints of the fieldwork phase (approximately three months), I had to make use of the translator. It was not deemed practical to gain an adequate familiarity with Xhosa within this timeframe. It also made more sense to establish rapport with participants in the environment of the support group where participants " ... *already feel safe*" (Chief nurse of Paarl Hospice, personal communication, February 2, 2004) by taking part in the support group activities. I will continue the discussion of the particularities of Paarl Hospice and the Hospice support group in Chapter 3.

1.5.2   *Problems pointed out by Paarl Hospice staff*

Initial conversation with the chief nurse at Paarl Hospice pointed to issues, which patients seemingly come to face in accessing treatment, including stigma, shame and ideas about promiscuity associated with HIV/AIDS. Hospice House had to think through a strategy to engage with people living with HIV/AIDS without overriding confidentiality issues. Subsequently it was decided to get a support group off the ground in order to maintain confidentiality. Whilst doing rounds in the community (the informal settlements on the outskirts of Paarl) Hospice House staff came across two women with young children who were not in a position to do something about their illness as a result of the advanced stage of the disease, shame and poverty. This encounter made it clear to Paarl Hospice that dealing with HIV/AIDS creates many problems. It will be necessary to ascertain whether people living with the disease experience the same problems as indicated by Hospice House. Do these people experience the same challenges, such as shame and poverty, and confidentiality issues

as framed by Hospice, which might prevent them from seeking treatment? What does the support group offer them in managing their illness?

In Chapter 5 I will continue to explore the problems identified by those in search of health care and the role of Hospice House in dealing with the disease.

The study is thus mainly site-driven in nature and will explore the social meanings of the HIV/AIDS illness experiences of people living with HIV/AIDS. More specifically, I will look at the ways in which people seek treatment and identify the particularities enabling or preventing people living with HIV/AIDS from accessing a particular treatment site. The uniqueness of the site in providing a space for people to come to terms with their disease will be investigated from the perspective of those living with HIV/AIDS. Accessing the treatment site, and the subjective accounts of those who have managed this process, are taken to be central in orienting the investigation. Before elaborating on the approach employed to conduct the study, I will briefly introduce the research question which guided the investigation.

1.6   Problem statement

As I employed grounded theory in exploring the problematic nature of the particular treatment site, I began to refine the research. I came to realise that the unifying problematic connecting the various ways in which people access and take part in activities associated with daycare at Hospice House is the issue of disclosure. The central problem, which I will investigate, is that of disclosure. Disclosure is an important feature of HIV/AIDS because of prevailing notions of secrecy, privacy and shame associated with the disease (Deacon, Stephney & Prosalendis 2004, Welch Cline & McKenzie 2000:71). In order to access treatment sites, individuals necessarily have to disclose their illness in some ways. But individuals are also embedded in other worlds beyond health care and have to disclose in these spheres as well. The revelation of the illness in an actor's social networks could be just as devastating as the biophysical threat posed by the disease. The question remains as to how people living with HIV/AIDS integrate the disease in their social networks. Furthermore it can be asked how the support group members living with HIV/AIDS, despite their embeddedness in so-called disadvantaged contexts, disclose their disease

on their way to Hospice House. It is also necessary to investigate the implications of disclosure of an HIV/AIDS status in the social networks of those living with HIV/AIDS. In Chapter 5 I will describe disclosure as encountered amongst a particular group of people living with HIV/AIDS on their way to seeking health care. The ways by which people disclose the disease will provide an indication of the opportunities or constraints encountered by those living with HIV/AIDS in accessing Hospice House. The focus of the study will not be on the victims of HIV/AIDS, but on those living with the disease in the process of negotiating his/her way to Paarl Hospice daycare through various obstacles.

In Chapter 6 I will seek to find a single process unifying the ways in which people living with HIV/AIDS navigate access to Hospice House. In what follows I will briefly introduce how the literature on HIV/AIDS and illness experiences in general guided me in narrowing down the research question.

1.7   Literature

1.7.1   *Unmapped terrain*

For some living with HIV/AIDS, personal and social support networks could provide possible assistance and support for dealing with the disease. Others may be rejected in the revelation of an HIV/AIDS status. Little has been done up to present to explore the social networks available to people living with HIV/AIDS and the function thereof in the lives of those living with HIV/AIDS. By exploring the available support networks for people living with the disease, possible routes could be mapped through the obstacles which the disease generates, and this could help guide the newly diagnosed through unknown territory (Adam 1992:13). It would therefore be valuable to map the route which people living with HIV/AIDS follow in accessing Paarl Hospice.

1.7.2   *Social experiences of medicine*

Whyte, Meinert and Kyaddondo (2004) propose a way of looking at the social experiences associated with medicines by arguing that medicines have "social lives"

and should not merely be regarded in terms of prescribed substances intended for treating biological symptoms. A different angle to exploring medicines could be taken by looking beyond the effects of the treatment on the body and instead investigate the meanings that people create in using particular medicines, and focus on the social efficacy thereof. One should therefore distinguish between the meanings which the providers of medicines attach to "giving" medicines, and the meanings which those at the receiving end create by "taking" medicines. Anthropologists are well equipped to describe the *"... lives that medicines have with people and between people "* (Whyte, Meinert & Kyaddondo 2004:14). This approach would be suitable to investigate the meanings which the daycare support group and associated activities offered by Hospice House takes on with people and between people. Such an approach would render the relations between the providers of medicines and the users of medicine visible and it would also contextualise illness experiences in relation to the treatment site and social spheres in which individuals are embedded. It therefore provides a different angle to the one offered by the providers of medicine. This angle of exploring medicine would enable an exploration of a range of possible meanings which people living with HIV/AIDS would attach to accessing Paarl Hospice.

1.8   An ethnographic approach
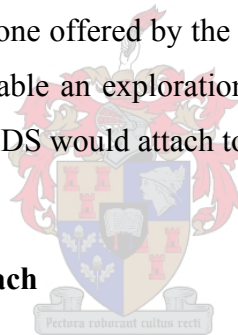
An ethnographic approach was used to conduct this study as the challenge was to obtain an understanding of the inner worlds of people living with HIV/AIDS as members of particular societies, and to analyse the patterns of interaction that accompany their particular points of view (see Hahn 1995:102). Central to this approach is the attempt to locate the situated concerns of social actors and to render social practices to a level of awareness (Whyte, Van der Geest & Hardon 2002:170). I therefore conducted the study by taking into account that the individual is always acting from a particular social context (Sobo 1999:10). In this sense, an anthropological approach enables the researcher to investigate the social relationships involved in providing and accessing a treatment site. It also facilitates an investigation of the social implications of accessing Paarl Hospice in search of health care for the people living with HIV/AIDS from an insider's perspective.

The examination of health-seeking behaviour is an important topic in medical social sciences. This approach explores the individual's complex health repertoires and strategies for getting help. Ethnography is a useful method, which enables the researcher to tap into the "experience-near" dimensions of people's lives (Brown 1998:8). Ethnography will enable the researcher to look at a whole range of meanings beyond the biomedical meaning of the disease, which provides a scientifically driven solution to HIV/AIDS as the only way of dealing with the disease. I will consequently seek to locate the patients' actions and the meanings ascribed to these actions within the context of opportunities and constraints they encounter in managing their illness.

I am aiming to obtain an insider's account of those living with HIV/AIDS as members of the support group, and of particular communities on their road to accessing Paarl Hospice. In this way I seek to contextualise an account of HIV/AIDS health-seeking behaviour by taking into account the particularities of the specific site being accessed and the circumstances that influence the ways in which people living with HIV/AIDS are responding to their illness. I am therefore aiming to get a deeper understanding of the perspective of support group members, and to see how this perspective fits a particular social environment (see Hahn 1995:280).

Many people think of AIDS as a disease and as a scientific challenge, and forget the human torment and social suffering of the illness experience (Farmer & Kleinman 1998:333). But HIV/AIDS is a sphere in which social dilemmas and the biophysical disease interact in complex ways (Alonzo & Reynolds 1995: 310). A conceptual distinction in medical anthropology between disease and illness will be of use in guiding the current study (see Chapter 2). Both concepts (i.e. *disease* and *illness*) provide a useful way of investigating different angles to sickness. I will make use of the conceptual category of *illness*, which can be defined as the perception of the person living with HIV/AIDS as having an illness. The focus of the study will therefore not be on providing disease accounts, which are objectively defined and based on clinical symptoms (Brown 1998:7). I will take the biophysical reality of HIV/AIDS as point of entry for the study, and will from there explore opportunities and constraints facing people living with HIV/AIDS, by means of illness accounts that emerge from the site of study. The intention of the study is to investigate the

experiences which medicine cannot describe (Frank 1995). The focus of the study will be to explore the everyday illness experiences of people living with HIV/AIDS in search of health care.

1.9 Qualitative methodology

In order to gain an insider's view of the process of accessing health care, I will have to immerse myself in the lived experiences of health care seekers. Ethnography is a suitable method of taking part, to a certain extent, in the everyday lives of those individuals taking part in this study. It can subsequently enable the ethnographer to describe the problems which participants encounter by looking at the ways in which they cope with these problems (see Whyte et al. 2002:166). As the research draws on qualitative methods, it will enable me to stay close to the experiences of the support group members. I sought to gain familiarity with the site and at the same time I needed to remain receptive towards a diverse range of field experiences whose meanings were not always clear. Participating in various activities enabled me to describe meanings that individuals attached to objects and events. This allowed me to investigate the relationship between what people said and what they actually did (Joralemon 1999:13) thereby enabling me to contextualise these insights (Joralemon 1999:30).
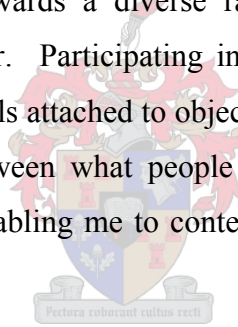
As I am interested in problems that might hinder health seekers in their search for treatment, I employed a systematic yet flexible approach of following the lived experiences of support group members living with HIV/AIDS. The study explored various events associated with the Hospice House support group and related activities offered to people living with HIV/AIDS. I employed multi-sited ethnography in order to follow the participants as they were being collected for the support group by the Paal Hospice minibus weekly. I did this by immersing myself in the group activities held at Paarl Hospice, and accompanying participants to events associated with the HIV/AIDS support group (Marcus 1995). Participant observation also enabled me to investigate the inarticulate explanations which participants did not verbalise explicitly. If explanations consisted of unstated understandings then participants often do not verbalise these even amongst themselves (Charmaz & Mitchell 2001:163). By taking part in the daycare activities and engaging in informal

conversations, I avoided being a mere observer of events but rather became someone who negotiated meanings together with the participants. Informal interviews were conducted in the context of daycare, where I did not enter the field with a set of predetermined questions in order to gain the same classifiable categories of information from each participant.

I will analyse the data by seeking to locate a centralising process, which cuts across the situated differences of people living with HIV/AIDS on their road to health care. I will do this without discarding these differences. Instead of merely providing an access story in the form of ethnography, the aim of the study is to move toward theory that is grounded in the context of the opportunities and barriers facing those accessing a particular treatment site. I will employ a constructivist grounded theory approach advocated by Charmaz and Mitchell (2001). This method merges the potential of ethnography for providing rich description of the support group activities and at the same time makes connections between various other events associated with the support group. As the study progresses, I will continuously compare emerging data with data obtained at the beginning of the research, as data collection and analysis occur simultaneously. This method advocated by Charmaz and Mitchell (2001) allows for an open-ended approach to grounded theory. I am hoping to construct a meaningful account of health seeking access by examining how HIV/AIDS is interpreted through social activity across various events. I will continue to map out the research process in Chapter 4.

1.10   Relevance of this study

As a result of the diverse range of biophysical and social challenges facing people living with HIV/AIDS, there is no clear road mapped out for those in search of health care. Accessing health care may therefore not be straightforward and problem-free and outlining the road to health care might be useful to those who come to encounter similar problems in seeking health care.

This study will investigate the responses to a particular innovative model of AIDS treatment and ground these responses in the context in which they are enacted. I will seek to investigate what lies behind the notion of "AIDS patient" by allowing the

person living with HIV/AIDS to chart his/her way through barriers to health care. A contextualised account of HIV/AIDS access guided by grounded theory unfolded by means of the method of participant observation.

1.11 Conclusion and brief overview

In this introductory chapter I familiarised the reader with the idea of how the study evolved, briefly introduced the site and participants involved in the study, acquainted the reader with the context, and hinted at the methodology I employed in conducting the study. I have concluded the chapter with a statement of the research problem - which only evolved during the process of fieldwork - in order to introduce the reader to the central theme of disclosure. In Chapter 2 I will investigate the relevant literature dealing with the research problem, in particular the concept of disclosure. Chapter 3 will contextualise the study in terms of the national and provincial antiretroviral treatment roll-out programmes, and will subsequently situate the study in the context of Paarl Hospice, as the site where the research was conducted. In Chapter 4 I will provide an account of the way in which I conducted the study and refined the research problem. Chapter 5 will illustrate various "acts of disclosing", and finally I will conclude in Chapter 6 with a discussion of findings generated in the study, providing a practical theory of disclosure in order to account for the ways in which people disclose their illness upon accessing Paarl Hospice House.

CHAPTER TWO

LITERATURE REVIEW

2.1   Introduction

Studies on disclosure seem to be widespread in the broader HIV/AIDS literature
(Long 2002:81). From the beginning, scientific papers on AIDS cast their focus on
high-risk groups and these risk group categories served as monolithic filters for
obtaining data (Treichler 1999:20). Dominant approaches to the HIV/AIDS epidemic
follow a biomedical and individualistic, psychological approach as anthropology has
been slow in responding to the initial impact of the HIV/AIDS epidemic during the
early 1980s when the disease first presented itself (Parker 2001:172). The concern of
biomedical and individualistic approaches to HIV/AIDS is to gather information
about sexuality associated with risk of HIV infections from populations that meet the
demands of predetermined risk-related categories as regards sexual behaviour. Since
its discovery, AIDS has been identified as a disease of "others" such as gay men and
Haitians (Siminoff, Erlen & Lidz 1991:265). Research on the behavioural and social
aspects of the disease are accordingly conducted with the aim of investigating *"How
is HIV transmitted? What is the pattern of sexual relationships? How can people be
influenced to change their behavior?"* (Akeroyd 1997:26). This type of research
agenda informs prevention and education programmes aimed at change in behaviour
(Parker 2001:164). The aim of these programmes is to prevent transmission of the
disease by claiming that the only means of lowering infection rates would be to
introduce changes in lifestyle and behaviour (Rogers 1991:38). These programmes
therefore focus on the individual and it is anticipated that by exploring the link
between sexuality and theories of individual psychology, programmes would be in a
position to explain and produce changes in sexual conduct and thereby reduce
HIV/AIDS-related risk behaviour. According to Holt, Court, Vedhara, Nott, et al.
(1998:50), existing research on HIV/AIDS disclosure is largely conducted deductively
in a quantitative framework in order to provide information on HIV/AIDS high-risk
related categories. Dominant research on HIV/AIDS disclosure concentrates on
patterns and frequency of disclosure of high-risk groups. Some qualitative studies
have been conducted, but these follow the same path by investigating disclosure of the

so-called high-risk groups, predominantly focusing on homosexual and bisexual men living with the disease (Holt, Court, Vedhara, Nott, et al. 1998:50).

Given that South Africa is in the midst of a growing HIV/AIDS epidemic which has a disproportionate effect on the poor and disenfranchised groups (Karim 2004:1394), anthropological research is in the position to examine from the bottom up the different ways in which inequality leads to ill health and how it is acted upon (Nguyen & Peschard 2003:452). By allowing for insiders' perspectives and taking wider social forces into account, anthropological research offers an alternative model for responding to the HIV/AIDS epidemic both cross-culturally and locally (Parker 2001:172-173).

Macro political and economic factors play a key role in determining the spread of HIV/AIDS among the disenfranchised (Sobo 1999:7) and can account for the barriers to programmes for the prevention and treatment of AIDS (Schoepf 2001, Farmer 1992). Packard (1989)[2] and Farmer (1992)[3] identified the unequal spread of disease epidemics amongst the disenfranchised by means of political economy approaches. Packard (1989) showed that tuberculosis claimed "victims" (in this instance mine workers) from the poorest segments of society (Packard 1989:xvii). Farmer (1992) situated AIDS in Haiti into a broader political and economic crisis thereby illuminating the current suffering experienced by rural Haitians (Farmer, 1992:253). At this point it is sufficient to mention that these approaches provided a useful way of revealing the unequal spread of disease epidemics. But it did not account for the ways in which the so-called victims attempted to manage their illnesses. Anthropology was therefore in a position to show that social, political, cultural and economic conditions position entire groups in a more vulnerable position as regards disease and account for transmittance of the disease (Nguyen & Peschard 2003, Fassin 2002, Parker 2001, Farmer 1996 & Farmer 1992). These studies would be useful in locating and mapping an understanding of the social position of those living with HIV/AIDS. But

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[2] In an investigation of tuberculosis in South Africa during the first half of the twentieth century, Packard (1989) revealed that the transmission of tuberculosis was linked to changing social and economic conditions within society (Packard, 1989:xix).

[3] Farmer (1992) explored Haiti's structural position within the larger HIV/AIDS pandemic in order to understand the spread of the Haitian HIV/AIDS epidemic from 1983-1990.

macro-theorists embracing the political economy approach emphasised structure over agency (Lupton 1994:161) thus relegating those living with the disease to a position of "victimhood", and their social experiences become overly determined by social conditions. Even though it is generally agreed that HIV/AIDS is spreading unevenly in South Africa due to the connection between unemployment, poverty and HIV-infection (Nattrass 2004:13) the political economy does not reveal how people living with the "invisible" chronic disease disclose their illness and access treatment sites. Therefore it can be asked how people living with HIV/AIDS from the informal settlements of Paarl manage disclosure in accessing a treatment site despite their so-called disenfranchised position.

In what follows I will therefore explore the concept of *disclosure* as employed in the broader HIV/AIDS literature relating to disclosure. I will seek to extract the meaning or definition of disclosure as implemented in the studies presented below. In the latter part of the chapter I will show how the anthropological concept *illness* could be employed to explore the process of disclosure in order to broaden the existing use of the concept of disclosure in the studies that will be presented. Thereafter I will conclude by introducing grounded theory as a possible approach to contextualise illness experiences of disclosure. The aim of the review is to look at different angles on disclosure as presented in the broader literature on HIV/AIDS-related disclosure. Instead of fixing an unchanging definition to disclosure I will therefore focus on possible meanings of the concept as revealed in the literature in order to gain an understanding of the possible ways in which disclosure is carried out.

2.2   Disclosure in the literature

2.2.1   *Traditional disclosure and HIV/AIDS-related disclosure*

Disclosure in the context of HIV/AIDS differs from the traditionally studied self-disclosure processes. The emphasis of research on the latter focused on personal relations in therapeutic contexts and personal relations in general. The two additional issues which accompanied HIV/AIDS disclosure lies in the stigma and secrecy associated with HIV/AIDS. Upon disclosure, the individual could be confronted by the danger of the undermining of relationships. HIV/AIDS-related disclosure seemed

to be of significance mainly in a public health and health care setting. It was also framed as a " ... *single piece of information, disclosed unilaterally, and largely governed by external policies ...*" (Welch Cline & McKenzie 2000:71). Disclosure also provided the person living with HIV/AIDS with the opportunity to access programmes for the prevention and treatment of the disease (Medley, Garcia-Moreno, McGill & Maman 2004:300). HIV/AIDS-related disclosure would therefore need to be approached differently in order to account for the possible additional dimensions of secrecy and stigma impacting on relationships, as well as to take into account the context of health care in which disclosure is centred.

2.2.2   *An "invisible" chronic illness*

HIV/AIDS could be considered to be an "invisible" chronic illness (Vickers 1997). An "invisible" chronic illness could be regarded as a continuing illness unseen by others, which might or might not be treatable or curable (Vickers 1997:241). The element, which rendered HIV/AIDS "invisible" seems to be the derogatory and stereotypical attitudes attributed to the illness. It will be necessary to ascertain ways in which the literature approached the ways in which people living with HIV/AIDS disclosed the "invisible" illness. Furthermore the different ways in which disclosure of this "invisible" illness was managed when the disease became visible, should be investigated. In the section below I will explore a wide range of studies relating to the disclosure of this "invisible" disease. I will investigate how HIV/AIDS disclosure took shape in these studies, aiming not to provide a detailed discussion of the findings of the various studies. Instead I will explore the meanings of the concept of disclosure in the context of HIV/AIDS.

2.2.3   *Unmapped sexual relationships*

Descriptions of HIV/AIDS had previously been dominated by notions of AIDS as a "gay disease" (Siminoff et al. 1991:265). This legacy still lingers and traces of it can be found in the studies focusing exclusively on sexual relationships of male homosexuals dominating the HIV/AIDS literature. A study conducted by Serovich and Mosack (2003) investigated differences between homosexual men who reported

their seropositive status to "all", "some" or "none" of their sexual partners. Understanding disclosure of a seropositive status is an important step towards reducing the transmission of HIV (Serovich & Mosack 2003:76). Obtaining such information was aimed at informing prevention programmes as well as providing an intimate partner with the choice of allowing or not allowing unsafe sexual behaviour to occur (Serovich & Mosack 2003:70). Disclosure in this study could therefore be understood to be the rational, verbal act of telling those implicated in the so-called high-risk sexual relationships of a seropositive status. Some participants indicated that they did not completely refrain from informing sexual partners of their HIV-positive status, but selectively disclosed it to some. The study investigated gay male disclosure patterns without taking into account the context in which disclosure occurred. As a result, a recommendation was made to investigate the situational context in which disclosure took place, and how this was likely to affect the actual disclosure (Serovich & Mosack 2003:79).

In the same way, Holt et al. (1998) approached unmapped sexual relationships by exploring the role of disclosure amongst British gay and bisexual men. The findings suggested that disclosure served simultaneously as a stressor and as a mechanism for coping with the disease (Holt et al. 1998:50). At the time of diagnosis and in the context of coming to terms with their diagnosis, non-disclosure seemed to be the norm (Holt et al. 1998:49). Non-disclosure was therefore based on a rational choice deciding not to inform others of HIV-positivity. The study assumed disclosure to be a one-way process in which the diagnosed informed others about an HIV-positive status via a verbal statement. Whether to disclose or not to disclose was considered situated on the extreme ends of the disclosure continuum. The diagnosed thus actively considered whether to tell or not to tell others about living with the disease (Holt et al 1998:59). Although the study mentioned that disclosure was not a once-off event, but it persisted over time (Holt et al. 1998:59), further discussion of this chronic event was not discussed in further detail. The actual context in which disclosure occurred, was not accounted for in this study.

Knight (2004) similarly explored disclosure relating to HIV/AIDS risk-related relationships, and was one of the few studies that accounted for the actual context in which disclosure occurred. This study examined the barriers experienced by gay men

in the health care setting where disclosure of sexual practices in the context of screening and counselling interventions was taking place. Barriers identified by participants were to be found in the health care setting itself that was likely to result in a lack of disclosure because of the orientation of the physician. Disclosure in this study was therefore presented as revealing risk-related sexual behaviour in the health care setting. The function of disclosure in this case was to reveal a risk-related sexual orientation to improve the conditions in which disclosure was taking place, and to explore risks of HIV infection in gay men in order to improve screening and counselling interventions (Knight 2004:2149). Disclosure in this case was considered to be the revelation of sexual orientation and information of so-called high-risk practices, which required gay men to reveal their HIV-positive status. The context in which disclosure took place was found to influence the act of disclosure.

2.2.4 *Relational complexity of keeping or disclosure of secrets*

Similarly to the conclusion reached by Holt et al. (1998), that disclosure was not a once-off event, a study conducted by Landau and York (2004) investigated the disclosing or concealing of an HIV-positive status amongst people living with HIV in Israel. The study showed that disclosure was not ended upon revealing an HIV-positive status to significant others. The study was conducted retrospectively (in hindsight using questionnaires) in a context removed from where the actual revealing or hiding of an HIV-positive status to significant others occurred, namely in a hospital that people visit for treatment of their disease. The study aimed to investigate the link between the intention to disclose medical information about oneself and the actual disclosure thereof. The findings showed that the disclosure process was tremendously complex and could not be accounted for by reasoned and volitional intent (Landau & York 2004:122). Revealing medical information regarding an HIV-positive status was situated at two polarising extremes of hiding one's secret from others, or telling them about it. The complexity of the actual disclosure process was hinted at, but the study did not focus on the actual process of disclosure and was conducted with hindsight using questionnaires.

Another level of complexity was added to disclosure in a study by Greene and Faulkner (2002). This was one of the few studies conducted amongst women. Disclosure and non-disclosure decisions were investigated among a group of African-American women. The study investigated ways in which women disclosed an HIV-positivity in their relationships. Two ways of disclosure were identified. Daughters would directly tell their mothers and boyfriends about an HIV-positivity, whilst other men (like fathers) were told via a third party (Greene and Faulkner 2002). The intention behind employing a third party in making an HIV-positive status known in some instances was not investigated. It was not clear from the study whether the negation of direct self-disclosure was decided upon strategically by the participant or was due to a lack of social skills (Greene and Faulkner 2002:312). The study showed that disclosure was considered in terms of relationships. Despite the fact that the results were restricted to a sample of minority women, the complexity of social relational issues entailed in the disclosure process was hinted at. Disclosure was considered to be direct, or via a third party, verbal stating of HIV-positivity. This study reveals information regarding how HIV-positivity is mapped on the two extremes of either disclosure or non-disclosure.

The complexity of social relational issues implicated in the disclosure process was also pointed out in a study by Derlega, Winstead and Folk-Barron (2000). The emphasis on disclosure, according to the functionalist perspective employed in this study, stressed the importance of managing personal relationships, and indicated that the latter could be sustained or damaged by disclosure or non-disclosure. In order therefore to establish how people living with HIV/AIDS considered the making of stigmatising information known to others and intimate partners, self-disclosure questionnaires were used to explore the costs and benefits of disclosure versus non disclosure (Derlega, Winstead & Folk-Barron 2000). The findings suggested that decisions to disclose, or to withhold information from others, were consistent with the functionalist approach (Derlega et al. 2000:54). The diagnosed could thus rationally decide whether to inform or not to inform others of HIV-positivity upon weighing the anticipated risks and benefits of revealing a stigmatised seropositivity in social and personal relationships. Considerations included for non-disclosure entailed risks for the person disclosing the information, such as anticipation of rejection, gossiping and protecting others by not revealing information. The participants in the study also

preferred non-disclosure in relationships which they considered to be artificial. The functionality of disclosure was regarded as a rational strategy and mechanism to manage relationships and to maintain the self by either telling or not telling those implicated in social relationships of living with a stigmatised HIV-positivity.

In their study of a Chinese community, Ow and Katz (1999) identified the functional role of secret-keeping and the alternative option of disclosure of information about life-threatening diseases in a collectivist tradition among fifteen families in Singapore. Disclosure occurred to parties which provided support to the family. Taking into account the collectivist orientation of the Chinese culture such information might be disruptive to the group and it was also found that this life- threatening information was often kept a secret in order to protect the family. Disclosure and secret-keeping might be a way of coping with the life-threatening information, or it might be informed by traditional values of self-disclosure, which subsequently might hinder an individual to engage freely in search of health care (Ow & Katz 1999:622). Although this study did not focus on HIV/AIDS-related disclosure, it added to the understanding of the role of disclosing information about life-threatening diseases and secret-keeping in a collectivist orientation. It showed that underlying group norms might influence choices regarding disclosure. The actual process of disclosure and the variety of possible ways in which to reveal and to hide information was not considered. Disclosure and secret-keeping were understood to be opposites. According to these studies, disclosure was presented as a decision to reveal or not to reveal HIV-positivity in order to maintain social relationships.

2.2.5   *The changing nature of HIV/AIDS*

The complexity of the changing nature of HIV/AIDS was not accounted for in the studies presented above. Even though the focus of a study by Alonzo and Reynolds (1995) was mainly on the potential functional role of revealing or concealing an HIV-positive status in social relationships, and not on linking these two processes explicitly to disclosure, it was useful in that it was one of the few studies which took into account the shifting nature of HIV/AIDS. In the study by Alonzo and Reynolds disclosure seemed to be of concern at the time of testing only. Upon diagnosis, and

given that the person diagnosed with HIV/AIDS showed no HIV/AIDS-related symptoms, the individual was in the position of either informing or not informing others about the diagnosis. But as the disease progressed, the changing nature of the disease increasingly prevented the diagnosed from hiding the diagnosis, as was the case during the asymptomatic phase of the disease (Alonzo & Reynolds 1995:308-309). Disclosure, as illustrated in this study, was merely problematic at the time of testing as an event of informing others about an HIV-positivity at the time of testing. As long as the diagnosed was asymptomatic, (s)he might decide to hide the disease. As the disease progressed into the symptomatic phase, hiding the disease was rendered more complex. Even though the complexity of hiding the disease was influenced by the progression of the disease, the actual process of concealing the disease was not equated with non-disclosure. As the person living with HIV/AIDS might begin to show symptoms during the symptomatic phase, these symptoms were not equated with a form of disclosure. The delayed onset of symptoms was therefore not necessarily equated with non-disclosure, but the latter could be considered to be the rational choice of not making an HIV-positive status known.

2.2.6 *Rational non-disclosure during the latency phase*

Similar to the findings of Alonzo and Reynolds (1995), the study of Greene and Faulkner (2002) showed that non-disclosure was a "rational choice". But disclosure and non-disclosure extended beyond the event of making an HIV-positive status known upon testing. The absence of disclosure during the latency phase was therefore not equated with non-disclosure (see Greene and Faulkner 2002). The person diagnosed with HIV/AIDS could be asymptomatic for up to ten years. The absence of HIV/AIDS-related symptoms during the latency phase of the disease provides the person being diagnosed with HIV/AIDS with an opportunity for non-disclosure. The availability of treatment could also extend the time during which the person living with HIV/AIDS may possibly employ non-disclosure by controlling HIV/AIDS-related symptoms with suitable treatment (Greene & Faulkner 2002:314). In this study, treatment was not equated with a form of disclosure, but merely facilitating the person living with HIV/AIDS with extended time in which to consider disclosure or non-disclosure.

In a sample of 138 gay men living with HIV/AIDS, recruited from a Midwestern University, Serovich tested the "consequence theory" by investigating how disclosure could be predicted by the disclosure rewards and benefits (Serovich 2001). Similar to the study of Greene and Faulkner (2002), Serovich refuted the disease progress theory according to which disclosure was predetermined to accompany the progress of the disease. Serovich argued for the rational motivation of disclosure and proposed that an HIV status would be revealed upon consideration of the costs and benefits of revealing the diagnosis. The reason given for this theory, was that HIV/AIDS no longer followed a clear-cut linear path of HIV to AIDS, and that therapies disrupted the unambiguous progression of HIV to AIDS (Serovich 2001:361). It was not clear whether disclosure was a consideration only at the time of being tested. The study offered an account of the ways in which individuals living with HIV/AIDS considered the actual event of disclosure in terms of potential benefits or negative consequences. Even though the complexity of the actual process of considering costs and benefits of disclosure was stressed, the study did not focus on the actual process of disclosure (Serovich 2001:363).

In addition to the changing nature of HIV/AIDS complicating considerations of whether to disclose or not to disclose HIV-positivity, Nemoto, Operario, Soma and Bao (2003) investigated an added problematic concerning disclosure. Apart from the difficulty of "coming out", the person living with HIV/AIDS, once having disclosed an HIV status, had to deal with "staying out" which seemed even more complex (Nemoto, Operario, Soma and Bao 2003:17). This particular study also focused on a risk-related category, exploring the double problematic confronting gay men, who at the same time as the disclosure of their HIV-positivity had to reveal their sexual identity. These individuals had an additional task of dealing with prohibitions posed by cultural stereotypes regarding sexuality. The study by Nemoto et al. (2003) stressed the importance of suitable treatment programmes, which could combat stereotyping and enable gay men to "stay out" upon disclosure of an HIV-positivity. Disclosure in this sense was simply the once-off revelation of an HIV-positivity, which was complicated by a revelation of a so-called prohibited sexual orientation. Revealing a sexual identity was not equated with disclosure. Although not explicitly equating disclosure with "being out", managing the latter was considered just as

problematic as the once-off disclosure of HIV-positivity. In the same way Vickers (1997) did not equate the progression of the disease with disclosure. During the latent phase, people living with the "invisible" chronic illness might employ "passing" or "covering" as a means of managing to live with the disease in order to keep it submerged (Vickers 1997:243). Despite the progression of the disease and health care-seeking behaviour which might be noticed in his or her social and personal relationships, these changes in the world of the person living with HIV/AIDS were not equated with disclosure. The absence of HIV/AIDS-related symptoms merely facilitated the option of disclosure, but as the disease progressed and health deteriorated, disclosure might no longer be an option (Vickers 1997:243). According to Vickers (1997) disclosure was only an option in the absence of HIV/AIDS-related symptoms when the disease was still invisible, and disclosure did not seem to be problematic during the manifest stage as HIV/AIDS-related symptoms began to appear. Disclosure could therefore be regarded as a rational statement of living with the disease. Even though the disease might manifest in visible symptoms, this visibility was not equated with disclosure. The physical presence of stigmatised HIV/AIDS-related symptoms merely prevented the person living with HIV/AIDS from disclosing an HIV-positive diagnosis.
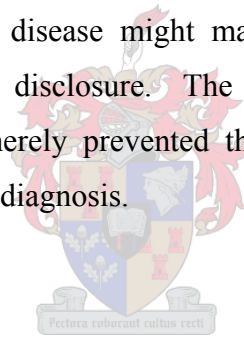
2.2.7   *Public disclosure*

Another study equating disclosure with the verbal statement of HIV-positivity was one conducted by Paxton (2002). In-depth interviews were held with 75 HIV-positive speakers from Africa and Asia Pacific to assess the impact of publicly disclosing their status. The findings provided evidence of a difference between disclosure to family members and disclosure to peers. The former was considered to be far more complex than disclosure to peers facing the same dilemma (Paxton 2002:563). Complexity was associated with considering the costs and benefits of telling family or peers about an HIV-positivity. Disclosure in this sense was an instance of breaking the "barrier of silence" and "coming out openly" as an HIV-positive person in the capacity of speaking as an AIDS educator. This was the only study which I came across that connected speaking out publicly about an HIV-positivity with disclosure.

2.2.8 *(Dis-)close(-ure)*

In the discussion above, I presented a range of studies on disclosure in the context of HIV/AIDS. The aim was to investigate the meaning of the concept *disclosure* and how it has been presented and studied by several researchers. I also wanted to obtain an overview of the ways in which disclosure occurred instead of merely seeking to provide an overview of the functions of disclosure. As presented above, HIV/AIDS-related disclosure linked with notions such as "secrecy" and "privacy" regarding the disease (Petronio 2000). Disclosure seemed to be an event of verbally announcing an HIV-positive status and thereby rendering to the invisible HIV-status a level of visibility. In the studies presented above, these notions of "secrecy" and "privacy" applied to an HIV-positive status. In most of these studies disclosure was presented as a once-off process that was only problematic at the time of the diagnosis. Disclosure was presented as a rational choice of either informing others verbally or not disclosing an HIV-positive status. This choice was only available during the latent phase of the disease in the absence of visible HIV/AIDS-related symptoms. Because the goal of these disclosure studies was to inform prevention and education strategies aimed at high-risk groups, samples used in most of the studies on HIV/AIDS-related disclosure excluded all those living with HIV/AIDS and who did not belong to these designated categories. In these studies, disclosure was also investigated retrospectively without considering the actual context or process of disclosure. Few studies accounted for social and cultural differences in the disclosure process, and it was recommended that further work needed to be done as regards exploration of these underlying differences (Yep 2000:95). As treatment for HIV/AIDS was not available up to fairly recently and was in the process of being rolled-out in South-Africa at the time when the field work for the current study commenced (February 2004), I could not come across any studies on HIV/AIDS-disclosure relating to the availability of antiretroviral treatment.

2.3   Contextualised understanding of disease

In what follows I will discuss how exploring HIV/AIDS anthropologically could provide a contextualised understanding of HIV/AIDS by looking beyond the links

between empirical data on sexual behaviour and theories of individual behaviour in relation to the study of disclosure.

2.3.1 *Health-seeking studies*

According to Siminoff et al. (1991:262) the limited number of studies available on the usage and delivery of health care focus on the health care providers' attitudes towards care of their patients. In the current study I will focus on the process of health care seeking in order to account for several underlying factors influencing various illness responses. These factors might be situated in the social context from which the person seeking health care acts or accessing a treatment site could be enabled or prevented by the particular treatment model (Tipping & Segall 1995:2). Exploring health-seeking behaviour in the context of HIV/AIDS, in the current study, would therefore situate the health seeker in the social context in which the individual made decisions and acted from.

An anthropological study conducted by Guro Huby (1997) in Scotland, looked at the complexity of accessing a heath care service site from the perspective of the participants. The experiences of participants as formed and articulated in everyday action were taken as the point of entry for investigating the type of support offered to people with a terminal illness. Even though the study of Huby (1997) did not focus explicitly on disclosure, I gained some useful insights in the process as entailed for participants in accessing health care. Huby pointed out that the failure of service users to turn up for appointments would often be interpreted by researchers and service providers as a failure to organise or to cope (Huby 1997:1153). One should recognise that in seeking health care the person living with the illness is vulnerable to the intrusion of many different people (Huby 1997:1158). Huby (1997) showed that avoidance surrounding access to health care services should rather be interpreted as a way of controlling one's experiences and of deliberately avoiding the scrutiny of others in the health care setting. This perspective avoids a reductionist explanation ascribing absence to the participants' failure to cope. The findings in this study by Huby (1997) showed that the lack of language articulating a particular experience, and the act of avoidance of attending health care, should rather be investigated by

looking at the way in which participants expressed the relationship between their personal experience and the wider social forces which influenced this experience (Huby 1997:1157). This important study by Huby took into account the context in which experiences of accessing health care were made explicit. By taking into account the context from which the participants acted, and the context in which they acted, the unsaid, the silences and the acts of avoidance were considered to be as important as the articulated experiences. It was shown that the interplay between experience and context should therefore be rendered visible.

2.3.2 *Different ways of being regarded ill*

As pointed out in Chapter 1, there are other ways in which one could be considered to be ill despite the biophysical reality of the particular disease. In what follows, I will distinguish briefly between two of the vantage points offered by Hahn (1995). The anthropological concept *illness* would be employed to investigate the ways in which people disclose their condition of living with HIV/AIDS on the way to health care and in a particular health care setting.

2.3.2.1 *Disease*

A conceptual distinction is made between *disease* and *illness* (Hahn 1995). In biomedicine disease is the biological malfunctioning of the physical body which can be revealed by medical investigation and diagnosis (Jones 1991:47). The character of medical care is becoming more scientific and rational and subsequently the explanation which science offers reduces illness to an objective validation provided by clinical medicine (Lupton 1994:87-88). As the disease is identified in the body of the patient, the routine means of treating disease is by inducing bodily interventions (Hahn 1995:28). Patients' subjective accounts are therefore regarded as secondary. What is stressed in the biomedical approach is the underlying physiological pathology (Hahn 1995:267). Biomedicine therefore provides scientifically valid evidence of the physical reality of HIV/AIDS by focusing on the patient's body.

2.3.2.2 *Illness*

According to Gilbert, Selikow and Walker (2002:8), illness signifies the experience of disease in terms of subjective explanations of not feeling well. In addition to focusing on the body as a source of disease, illness situates the experiences of disease in the social environment. An illness experience might therefore include social as well as physiological processes (Brown, Barret & Padilla 1998:11). An anthropological perspective would focus on illness and embrace subjective illness accounts. The latter would be relegated by the biomedical model, which centres on the presence of biophysical evidence of the disease (Hahn 1995:267). In Chapter 5 I will take the physical reality of HIV/AIDS as starting point for exploring social experiences of being ill and investigate subjective accounts of disclosure.

The aim of the discussion above was to illustrate the different ways in which people living with HIV/AIDS could experience illness. Because the focus of the current study will be to examine the understandings of those living with HIV/AIDS in a particular social setting, attention will be focused on illness accounts. Focusing on illness accounts does not question the validity of the biomedically-proven evidence, but merely situates the body in a physical and social environment. These conceptual distinctions provided a useful way of exploring how people can be considered to be ill (Brown, Barret & Padilla 1998:11).

2.4   Grounded theory

Health and illness are embedded in particular socio-political, cultural and interactive contexts (Jones 1991:47). The World Health Organisation defines *health* as " ... *a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity* ..." (ibid). Several questions now arise –

- How could illness experiences be situated in the various contexts in which they are embedded without relegating those living with HIV/AIDS to a level of mere passive "patienthood"?
- How could one stay close to participants' experiences in order to investigate a variety of meanings ascribed to accessing a treatment site?

- How could the process of accessing a treatment site be explored, thereby unifying diverse illness experiences, without refuting the variety of illness experiences?

A grounded theory approach focuses on the lived experiences of individuals. This approach would deem it appropriate to take into account the contextual information in which human action is embedded (Crabtree & Miller 1992:111). In contrast to the political economy approach mentioned earlier in the chapter, employing grounded theory could therefore account for contextual information at the same time as human action. The individual is accordingly not relegated to a position determined by the context, but the grounded theory approach focuses on the ways in which the individual acts in responding to the wider contexts.

Exploring the field with no predetermined research question in mind (see Strauss & Corbin 1998:12), but rather with an interest in a specific area of study, the grounded theory approach enables the researcher to look for patterns emerging from the field in order to derive theory from data (Rogers 1991:172). This study likewise explores illness experiences of people from a particular community living with HIV/AIDS in the context of accessing a specific treatment site that manages their disease. A grounded theory approach enabled me to look for a unifying social structural process in explaining the variety of ways in which a treatment site could be accessed and the ways in which illness could be disclosed (see Crabtree & Miller 1992:27). However, in contrast to the majority of disclosure studies discussed in the first part of this chapter, the grounded theory is a suitable way of overcoming the top-down nature of these studies. It allows the researcher to create new categories and concepts emerging from the data (Charmaz & Mitchell 2001:162). The researcher is therefore able to identify the particularities of the social event, in this case centring on accessing Paarl Hospice House and related activities, and to explore the different ways of disclosure from the ground up. The aim of the study is to obtain a variety of situated meanings of HIV/AIDS disclosure as the study evolves.

2.5   Conclusion

The concept of disclosure needs to be broadened in order to account for the range of ways in which disclosure practices take place (Petronio 2000:xiv). In this chapter I have looked at how the concept was approached in the broader HIV/AIDS literature and concluded that the meaning of disclosure in the majority of studies discussed in the first part of this chapter was restricted and limited. Available studies mainly approached disclosure in a top-down fashion by regarding the definition of disclosure as the announcement of an HIV-positivity at the time of diagnosis. These studies have not taken into account social differences relating to disclosure neither did they focus on the actual process of disclosure. I briefly hinted at political economy approaches to studying disease and illness, but found that, although these approaches seemed useful in explaining the unequal spread of disease, it did not account for the ways in which people managed their illness. Finally, I have considered the anthropological concept of *illness* in exploring HIV/AIDS experiences, and concluded that illness experiences could be suitably investigated by means of grounded theory in order to broaden the definition of disclosure. The following chapter provides an overview of the context in which the study was conducted.
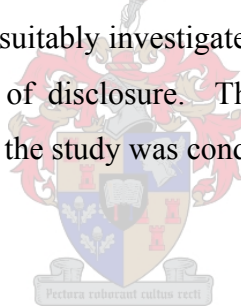
CHAPTER THREE

NATIONAL AND PROVINCIAL ARV PROGRAMMES AND PAARL HOSPICE

3.1   Introduction

As discussed in Chapter 2, the aim of this study is to provide a contextualised account of disclosure in a particular health care setting. In this chapter I will provide the context in which the study will be situated. Firstly I will provide some information on the national and provincial antiretroviral roll-out programmes and will subsequently locate the domain in which I conducted the study of these programmes. As I conducted my study within the activities of Hospice House, I will provide the reader with a general introduction to the Paarl Hospice philosophy and describe the particular daycare Hospice House programmes offered to people living with HIV/AIDS. The aim of this chapter is not to provide a comprehensive description of the national and provincial ARV programme, neither will it provide extensive detail on the workings of Paarl Hospice. Instead it will outline the context in which the study took place in order to examine the interactive processes between the different role-players.
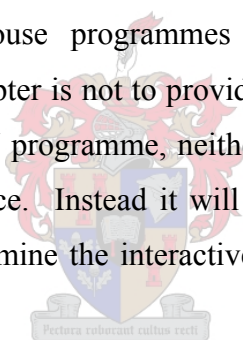
3.2   Announcement of a national antiretroviral treatment plan

In August 2003, the South African government agreed to a national treatment programme (Nattrass 2004:13). The aim of the treatment plan is the provision of highly active antiretroviral treatment (HAART) free of charge in selected government hospitals (Karim 2004:1394).

3.2.1   *Locating the provincial ARV programme: Conversations with health officials*

A five-year national programme for antiretroviral treatment had been announced, upon which each province now has to establish their own treatment plan for managing

HIV/AIDS. The Minister of Health approved the ARV programme in October 2003. By the end of 2004, the Western Cape have started to make ARVs available to patients at 15 identified sites. Paarl has been one of those 15 sites since February 2004. The provincial programme consists of five priority areas (Dr H. Reuter, personal communication, March 1, 2004). This study concentrates exclusively on the general area of ARV roll-outs for adults.

3.2.2 *Provincial programme in Paarl*

Together with Malmesbury, Stellenbosch, Vredenburg and Vredendal, Paarl is encompassed in the West Coast/Winelands Region (Dr N. Grobbelaar, personal communication, February 27, 2004). Many people in the vicinity of Paarl need treatment but the programme can only accommodate a very small number of people living with HIV/AIDS. The ARV clinic in Paarl is situated at the TC Newman Hospital where the first patient received ARVs on 2 February 2004. People living with HIV/AIDS need to meet certain criteria in order to become possible candidates for ARV treatment. Both clinical and socio-psychological criteria apply equally rigorously in qualifying for ARVs. The general criteria to qualify for the programme at the TC Newman Hospital include patients with HIV/AIDS-related diseases or those with a CD4 cell count[4] of lower than 200. In addition to a clinically screened CD4 count, patients' social circumstances also have an influence on whether they will be assessed as suitable candidates to undergo ARV treatment for life. Patients' circumstances at home are investigated to establish if there is any evidence of alcohol or drug abuse, and candidates should have a record of keeping appointments at clinics. Then community workers (in this case from Paarl Hospice), a social worker and the whole team decide whether this patient will be suitable to start ARVs (Dr H. Reuter, personal communication, March 1, 2004). In addition, candidates need to have a basic knowledge of HIV/AIDS, they should abstain from alcohol, acute depression has to be treated, they need to disclose to someone, and they should have some kind of a support network. They should also be willing to live with the possibility of side-effects and should also be willing to seek the help of a health

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[4] An individual has to undergo clinical screening in order to qualify for ARVs. The CD4 lymphocyte count is carried out to assess the individual's immune status (Van Dyk 2001:65)

worker and disclose an HIV/AIDS status if the condition deteriorates (Dr N. Grobbelaar, personal communication, March 4, 2004).

3.2.3 *Provincial programme: Two avenues*

The provincial programme can be divided into prevention and treatment. As my study will be located within the latter, I will continue the discussion by looking at treatment options for those living in Paarl and who are already infected.

The second part of the programme is aimed at people already living with HIV/AIDS. During the first phase of the disease, the person living with HIV/AIDS is asymptomatic and thus showing no clinical symptoms. Delaying treatment to the advanced stages of the disease lessens the chances of the person living with HIV/AIDS of building up resistance against treatment. The large number of people who are infected but do not yet qualify for treatment (asymptomatic phase) are referred to support groups. This asymptomatic group will need treatment later, but in the meantime they are referred to support groups in the community.

During the next stage of the disease HIV/AIDS-related symptoms begin to manifest and the person living with HIV/AIDS becomes sick with, for instance, colds or TB. This group is treated in clinics for opportunistic diseases like TB, chronic diarrhoea, cancer and AIDS-related diseases.

The next group of people is those to receive ARV treatment. In the past disclosure predestined the person towards stigmatisation, but at present disclosure means that the patient will be able to get medication. "*I tell them to disclose. It's all about medication. I won't give them medication. If they don't disclose I won't give them medication*" (Dr N. Grobbelaar, personal communication, March 4, 2004). In Paarl these patients are referred to Paarl Hospice where they receive HIV/AIDS-related support and education. Palliative care is also available for patients in the developed stage of the illness, which includes pain management, symptomatic control and supporting the family (Dr N. Grobbelaar, personal communication, March 4, 2004).

3.2.4 *The role of Paarl Hospice in providing treatment*

The role of Hospice House seems ambiguous in managing the HIV/AIDS crisis. Previously Paarl Hospice would provide community-based support for terminally ill patients diagnosed with HIV/AIDS. Because Paarl Hospice had been active in the community, they were recruiting patients to go onto ARVs since 2004. Usually ARV recruitment would be a medical component in the treatment of the disease (Dr H. Reuter, personal communication, March 1, 2004).

3.3 Hospice

3.3.1 *Paarl Hospice*

The hospice concept originated in the United States in 1979 and Paarl Hospice opened its doors twelve years later in 1991. Palliative care entails the management of symptoms in order to provide symptomatic relief, as well as taking care of psychological, social and spiritual needs. "*Hospice is not a place. It is a philosophy. It is an attitude*" (Hospice chief nurse, volunteer course field notes, March 15, 2004). The late Rev Geoff Normanton started Paarl Hospice with the Paarl Rotary Club in May 1991. In 2001 it was formed into a Section 21 Company. Hospice is an NGO, which means that funds are generated by means of public fundraising and donations. Paarl Hospice is affiliated with the Hospice Association of Western Cape (HAWC) and the Hospice Palliative Care Association (HPCA). Services cover the Drakenstein Health District 2, including Paarl, Wellington, Klapmuts, Simondium, Mbekweni, the informal settlements of Fairyland, Milky Town, Smarty Town, Ghost Town; Hermon, Saron, Gouda and surrounding farming communities. Services are free to all patients and the staff is approachable 24 hours per day (Hospice chief nurse, volunteer course field notes, March 15, 2004).

3.3.2 *Palliative care*

The WHO definition of palliative care states that,

> "*Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*" (WHO 2004:1).

Palliative care is aimed at quality of life and entails pain relief (physical, spiritual and social). With the advent of HIV/AIDS, palliative care has to be balanced between acute treatment and the symptomatic control (UNAIDS 2004:3). Instead of aiming to provide a cure for HIV/AIDS, palliative care is in a position of providing integrative treatment of illness-related symptoms of disease.

HIV/AIDS-related daycare centres based on different models may be available for patients to receive integrative palliative care, counselling, emotional support, cooked meals, and services for children. Although the underlying palliative care principles as discussed above are present in most models, there are differences (UNAIDS 2000:12).

In the next section I will provide information on the particular model of palliative care that Paarl Hospice subscribes to and which they offer people living with HIV/AIDS.
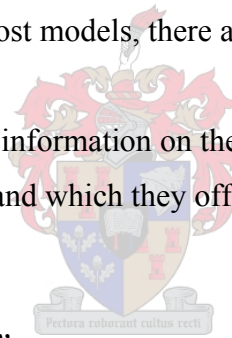
3.3.3 *Paarl Hospice philosophy*

Before I provide more detail on the support group at Hospice House, I will present a general overview of the Paarl Hospice philosophy underlying its various activities. Besides providing care for terminal patients, Paarl Hospice extended its perception of palliative care to encompass care for those living with HIV/AIDS. It evolved into a community-oriented organisation. Now that ARVs are available, adults as well as parents with children are recruited for ARVs and prepared for a long-term positive attitude towards life and treatment.

Hospice embodies a non-judgmental stance towards caring for the terminally ill. This can be seen to be its driving philosophy. Regarding HIV/AIDS, Paarl Hospice " ... *is not interested in how people contracted the virus. What is more important is to look at the present. People are sick now, and what can we do about it now? We take it from*

here, from who is sick, what we can do now to help these people and to make it better" (Hospice chief nurse, volunteer course field notes, March 31, 2004).

As every illness situation is unique, an approach of pastoral narrative is employed in order to reach a closer understanding of each patient's illness. My study will mostly centre on support group activities, therefore I will provide some information on pastoral narrative.

The goal of narrative therapy entails listening from a "not-knowing" stance to patients' stories about their illness, to make no assumptions, to see each person as the expert of his or her own life, to show respect for the person's knowledge and to be curious about the person's story. Through various volunteer courses the underlying narrative approach is made available to hospice staff in order to equip them with the necessary skills (Hospice chief nurse, volunteer course field notes, March 17, 2004).

In the following section I will present the obstacles experienced by Paarl Hospice in managing HIV/AIDS in the local communities.

3.3.4 *Barriers identified by Paarl Hospice*
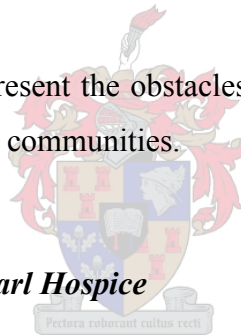
While doing rounds in the informal settlements, Paarl Hospice came across people in sickness and isolation caused by HIV/AIDS, many of whom were too ill to move and not in the position to afford a taxi to seek help for their illness. The major obstacle for Paarl Hospice was the need to manage the illness, but at the same time not to overstep the "confidentiality barrier" produced by the disease. This required sensitivity to stigma issues accompanying the illness. For instance, Hospice House staff could not visit too often as frequent visits might arouse the curiosity of neighbours, friends and family members. Subsequently Hospice House staff decided to establish a support group for out-patients with HIV/AIDS from the informal settlements around Paarl. Since April 2003, Paarl Hospice had been doing rounds in the informal settlements of Paarl, recruiting people for the daycare support group held weekly at Hospice House near the Paarl town centre.

### 3.3.5 *Recruitment of people living with HIV/AIDS for the support group*

On Thursdays, a support group is held at Hospice House for those living with HIV/AIDS. Criteria outlining membership include a low CD4 cell count, as well as willingness and "responsibility towards life". New patients are referred to Paarl Hospice by clinics (at present Hospice House and TC Newman Hospital are working in close contact in dealing with the HIV/AIDS pandemic), by the translator or by word of mouth. Hospice House employs a home-based carer who serves as an extension agent and translator to Hospice House. She "walks" the community in Fairyland weekly. During house-to-house visits, dressed in her uniform consisting of a black skirt and white blouse, she visits patients and recruits prospective candidates for the Hospice House HIV/AIDS support group. Many people living with HIV/AIDS in the surrounding Paarl area are Xhosa-speaking and, as a Xhosa speaker and living in the local neighbourhood, she is easily approachable. In this way she gets introduced to new patients.

3.3.6 *Daycare support group*

A support group is held weekly at Hospice House. The group started in 2003 with eight adults and five children and is growing by the day. A list of names is compiled of those who attend the support group. Patients are transported to and from the informal settlements by the translator and volunteer driver, who drop them off at Hospice House. The idea behind the support group is to provide people with a space to interact socially and to share a spectrum of concerns around HIV, including stigma and symptoms. Daycare is an extension of patient care (Hospice Social worker, personal communication, May 13, 2004).

Throughout the morning, patients have the opportunity to see the volunteer doctor and nurses in a nursing station adjacent to the area where the daycare activities are held. Nutritious meals are provided and patients take part in craft activities, which mainly centre on sewing and embroidery work. Daycare activities are quite flexible as they are run by in-house volunteers. The idea behind the crafts is to have fun. It is about creativity and colour, and for people to explore and keep on making new things by

keeping in mind their fluctuating health. It is for people to socialise and to get together (Crafts volunteer, personal communication, May 15, 2004). Support group members are offered the possibility to obtain ARVs. Paarl Hospice patients were of the first to receive ARV therapy in February 2004. In addition to qualifying as support group members, Hospice set out criteria which possible candidates for ARV treatment have to meet. The criteria will be dealt with briefly. Qualifying criteria for ARVs include a low CD4 cell count, the patient should show responsibility by abstaining from alcohol and signing a treatment contract. The requirements laid out in the treatment contract include: the participant's promise to him or herself, to the family, and to the Paarl Hospice team. Some of the criteria are the following: the promise to take medication regularly and on time, to have a support network of either friends or the support group at Hospice, an awareness of the possibility of side-effects of treatment which would cease within the first months after starting treatment, a commitment to use the medication for life, the responsibility to obtain treatment from the clinic and to keep appointments promptly, a promise not to fall pregnant while using this particular medication and always to use birth control. Pregnancy might be an option once the viral load had been successfully lowered and the participant had gained some strength. Treatment would then have to be substituted with a suitable form of treatment.
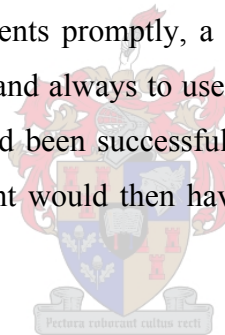
Although support group members obtain ARVs from the TC Newman Hospital, they have to subscribe to criteria laid down by Hospice House. In the long run, Paarl Hospice is aiming to wean current support group members off from the support group to become patient activists (a support base for those living with HIV/AIDS) in the local communities, to provide patients with insight into their illness and to empower them to look after themselves (Hospice chief nurse, personal communication, February 26, 2004).

3.3.7 *Hospice volunteers*

Apart from services offered by professional staff (which includes nurses, a social worker, and a part-time doctor), Paarl Hospice relies on volunteers who provide their services free of charge. Volunteers are seen as co-workers to be given suitable

assignments and to be presented with opportunities to undergo suitable training in order to integrate the Paarl Hospice philosophy into their working with the patients. As I will mainly focus on issues of accessing Hospice House centring on daycare from the support group members' perspective, I will briefly provide some information on the volunteers involved in the daycare programme. The volunteer team exists of members from diverse social environments providing specific services to daycare. Volunteer drivers collect support group members from the informal settlements each week. Reasons given for volunteering include being brought up in a community-centred environment and a responsibility to set time aside for involvement in community activities. Volunteer drivers sometimes engage in informal conversation with support group members in the minibus on general issues such as housing, appearance and illness. The crafts volunteers engage in supporting group members in Hospice House. Crafts volunteers put together projects from bits and pieces of haberdashery. Some of the reasons given for volunteering include satisfaction in seeing an end product evolving from fragments of cloth being put together, to see people having fun, and to put new ideas together. Another motivation for volunteering arises from a non-materialistic orientation towards life. During the daycare session, patients would be given different projects to work on, volunteers would continuously acknowledge progressing craftwork or provide the necessary assistance. These sessions are very informal in nature and the volunteers and patients interact continuously.

Kitchen volunteers would be mainly involved with providing daycare members with meals prepared by a volunteer chef. Kitchen staff would have the opportunity to interact informally with support group members inquiring about their health, circumstances at home or commenting on the craft products. Kitchen staff does not necessarily opt for working with those living with HIV/AIDS. Some volunteers are also involved in helping with the kitchen activities with the cancer support held on a different day at Paarl Hospice.

Apart from spending time with different volunteers during daycare, group members also have the option for seeing a volunteer doctor or nurses at Hospice House during the morning session. As I did not gain access to counselling sessions, and will merely

focus on the support group side of daycare, I do not provide any further information regarding this topic.

3.4   Conclusion

In this chapter I have provided the backdrop against which the study has been conducted. To begin with I have located Paarl Hospice in terms of the national and provincial antiretroviral programmes. Subsequently I have contextualised Hospice House in terms of the general palliative care model by looking at the particularities of Paarl Hospice integrative palliative care. The following chapter will provide a discussion of the methodology employed to explore disclosure by the ways in which people living with HIV/AIDS accessed Hospice House and took part in support group and related activities.
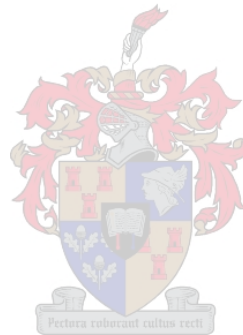
CHAPTER FOUR

DESIGN, METHODOLOGY AND ETHICS

4.1 Introduction

In the sections below, I will provide a description of the process of conducting fieldwork and look at the ways in which I generated ethnographic material relating to HIV/AIDS illness experiences through participant observation. I will conclude with an overview of the way in which data analysis was approached.

4.2 Access

4.2.1 *Negotiating access*

Negotiating access to people living with HIV/AIDS in and around Paarl entailed at the same time narrowing down the research question. In order to identify the involvement of Paarl Hospice in the context of the provincial and national ARV roll-out programmes I arranged for informal interviews with relevant medical officers. Through these conversations I narrowed the research question down upon deciding to centre my study to that segment of the ARV programme focusing on the provision of antiretroviral treatment for adults. A medical officer in charge of the ARV programme at Paarl TC Newman clinic, advised me to negotiate a research relationship with Paarl Hospice, which is running a daycare group for adults living with HIV/AIDS. He suggested that it might be worthwhile to investigate the uniqueness of Paarl Hospice in addressing the HIV/AIDS crisis.

Having contextualised the involvement of Hospice in addressing the HIV/AIDS crisis within the provincial and national programmes, I turned to Hospice where I had no difficulty establishing a research relationship. The chief nurse, who was as excited as myself about the idea of investigating from the participants' point of view why they choose to access Paarl Hospice in search of health care, immediately welcomed me. Because of the sensitive nature of HIV/AIDS, we decided that it would be more convenient for participants if I conducted research at Hospice House where they

already felt secure. Taking into account that Paarl Hospice is an NGO, the channels for negotiating access were relatively open compared to securing access to a primary health care setting. I did not have to channel my proposal through official routes (except that my proposed protocol had to be submitted to the Ethics Subcommittee of the University of Stellenbosch). It saved me a tremendous amount of time and allowed me to start with the research.

4.2.2 *Volunteer researcher*

The biggest concern settling on a workable agreement to conduct the proposed research seemed to be to not to interfere with the work that Paarl Hospice had been doing since 2003, namely working with people living with HIV/AIDS. The chief nurse, who initiated the day care programme, and I resolved this concern by deciding that I would conduct research as a representative volunteer of Paarl Hospice. This arrangement seemed equally profitable to the researcher, participants and Hospice House. When working with the daycare members, volunteers utilise certain "tools" and as a student volunteer I had to equip myself with these tools in order not to transgress the research agreement. While familiarising myself with the Hospice House model of care, it allowed me at the same time to contextualise participants' experiences against the backdrop of the Paarl Hospice approach. The underlying values guiding the Paarl Hospice approach include an attitude of being non-judgemental, allowing each person to be the expert of his/her illness, listening respectfully and occupying oneself with what Scrimgeour (2002) calls "doing hope". These values were also explicated in the volunteer course, which it was agreed I should undertake in order to equip myself with the appropriate tools. Whilst undergoing the training course, the values explicated in the course material, especially those of respectfulness and allowing all participants to be the experts of their own lives, confirmed the position I wanted to take in conducting the research. These principles subscribe to what Hahn calls the hallmark of an anthropological perspective by " *... listening to others of all traditions ...*" in order " *... to understand how things look from the other's point of view*" (see Hahn 1995:274). Listening, in this sense, indicates a way of getting closer to the participants' experiences by guarding against interjecting oneself into the inquiring process. The values of listening and respecting

also conform to the way in which ethnographic interviewing and observation are conducted.

4.2.3   *Level of involvement*

Another issue, which we had to resolve, was the researcher's level of involvement. I was informed " *... these people have little ... they demand a lot ...*" (Hospice chief nurse, personal communication, February 26, 2004). As a volunteer representative, I would not have to deliver on demands, which could interfere with the work Paarl Hospice had been doing. We decided that my position would be that of participant observer, listening to patients' stories in the context of the support group, but also taking part in the daycare group activities as well as following relevant events associated with the HIV/AIDS daycare group. Another issue, which we discussed, was that of conducting supplementary prescheduled interviews with selected participants during the later stages of the research. We agreed that I would make use of consent forms, let the participants choose a place of convenience where the interviews could be held, respecting each participant as being the expert of his/her own illness, using pseudonyms, and providing each participant with a copy of the interview (either a transcribed or a recorded copy). I guaranteed that patients' anonymity would be ensured (by using pseudonyms) and that information would be kept confidential (only revealing information within the context of the research project). I was cautioned not to question how the illness was contracted because " *... we take it from here, we don't look at the past, we take it from who is ill and what we can do to help him or her ...* " (Field notes, February 26, 2004). If any information regarding this taboo topic would be revealed in the course of the project, I would respect participants' confidentiality by making it known only in the context of the research project.

Having cleared the concerns on the participants' side, another issue which had to be settled was the question raised by Hospice, "What's in it for us?" My assurance of spending approximately four months as a volunteer (middle February 2004 until end June 2004) among the support group members, and taking part in the daycare activities seemed to settle this issue. Immediately after we had discussed these

concerns, I was given the go-ahead to interact with the group members on condition that I let them be in charge of how and what they wanted to share with me. The chief nurse introduced me to the staff and group members, informing the group who I was and telling them that I would be taking part in the weekly Hospice House activities for approximately four months. She presented me to the group as someone wanting to " *... see how we are doing things at Hospice House ...* " As the group members were multilingual, and the majority of the participants were Xhosa-speaking, the Hospice translator explained to the participants in their home language that I was a researcher and that I was going to spend time with them " *... wanting to know how things work for them ...* "

4.2.4 *Thinking about ethics throughout the research process*

Wilson (1993) provides valuable views as regards ethical fieldwork. According to Wilson (1993:198), doing ethical fieldwork is more about thinking over the research process than about mechanically applying a predetermined protocol. Before I started conducting research, I had to reassure Hospice House that I would not override any ethical boundaries. At the start of the project, the chief nurse and I decided that I would keep close contact with her as regards my involvement in the activities of Hospice House. She introduced me to the group, gaining their consent before I could go ahead with the project. It would not have been useful to have obtained informed consent only at the start of the project, as new members were being introduced to the group throughout the research process. I would therefore have to consider and reconsider the ethical aspects of the research continuously depending on the ever-changing nature of the field. I introduced myself to each participant, making sure that they knew about my position as researcher, and allowing them the freedom to refrain from or to take part in the research. Getting consent continuously at several stages during the research, would open up a " *... two-way channel of communication ...*" (Fluehr-Lobban 1998:185) which would avoid the mechanistic act of signing of a consent form (Joralemon, 1999:20). My continuous scribbling in a notebook also reminded participants that I was not a usual volunteer, but a researcher. Recording observations visibly signalled to participants that what I was doing was research, but it also reminded them that they were participating in the research (Dewalt, Dewalt &

Wayland 1998:273). Throughout the research process I was guided by Bernard's statement on the ethical imperative of social science research of doing no harm to participants (Bernard 2002:216). Following the principles of respectful listening and letting the participants be in charge of their illness experiences (as discussed previously), I sought to ensure that I was doing no harm. Aside from the ethical conduct in collaborating with participants to generate data, an ethical approach is also required in how one uses data. I informed the participants that I was interested in their experiences and that I wished to convey the information in a written project. What they revealed to me would therefore be made apparent. But I assured them that I would not make their names available and decided to use pseudonyms instead (see Wilson, 1993:187). I therefore assured them that I would treat the information participants provided me with, confidentially.

By thinking about ethics, the researcher continuously had to be vigilant about unexpected situations which might have ethical implications on the research participants. As the nature of the research project was open-ended, the need to be continuously thinking about ethics was deemed appropriate within the context of this study.
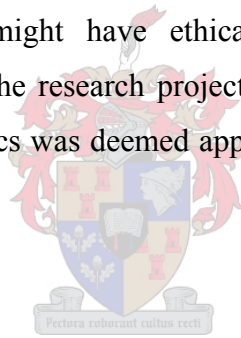
4.2.5   *Participant observation*

Although applied research could be done within a matter of a few weeks (Bernard 2002:331), I needed to establish rapport with participants because of the sensitive nature of HIV/AIDS, and therefore decided to participate as a representative volunteer instead of entering the field with a predetermined list of questions as a data collection tool. The strength of participant observation is that I would become the primary instrument for collecting and analysing data through my own experience (Bernard 2002:338). Conducting research as a representative volunteer allowed me to get closer to participants' experiences, which would otherwise not have been possible. I embarked on the research using participant observation as a means to explore the setting and to familiarise myself with the daycare activities. I took part in various activities in order to obtain a rich, detailed description from various participants' point

of view as regards HIV/AIDS-related activities in the support group context (Segar 1990:219).

Participant observation was a useful way of learning about the overt and tacit ways of a particular group (Dewalt et al. 1998:261-262) as well as for discerning between what was said and actual behaviour (Crabtree & Miller 1992:47). I needed to look beyond verbal ways of stating experiences as the main activity of the support group was the making of crafts. A useful way to do this, was to take part in the craft activities.

4.2.6 *Literature*

An important study that guided me in exploring alternative ways of sharing experiences of living with HIV/AIDS was a participatory qualitative project conducted in Khayelitsha. The *Long Life* project invited people living with HIV/AIDS to tell their stories via drawings using their own bodies as points of departure (Morgan & The Bambanani Women's Group 2003). Participants were also given cameras to document their experiences. These sketches and photos were then used to put the participants' experiences into words. Artworks were therefore not merely sketches of stories, but were subsequently employed to inform stories (Morgan et al. 2003:15). I found the project significant in that it pointed to the fact that engagement in the process of craftwork was an experience in and of itself. This could be explored as a means to discover experiences relating to the production of the crafts. Tangible craftwork as a means of examining past experiences, current dilemmas and fears and future expectations about living with HIV/AIDS could be just as practical in examining experiences regarding HIV/AIDS and allowed participants abundant freedom and control in which to articulate experiences and to share these experiences publicly with others.

The site in which I planned to conduct the research, employed crafts like embroidery and sewing as the main support group activity for members living with HIV/AIDS. As the goal of the craft activities in Hospice House was not regarded as a way to express experiences of HIV/AIDS, the activity of engaging with craftwork via

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participant observation enabled me to explore the meanings which participants attached to this activity in the context of the support.

4.2.7 *Grounded theory and generation of data*

Grounded theory guided me in exploring the field without any prior hypothesis (Rogers 1991:72). As a result of the fluid nature of the field, I employed Charmaz and Mitchell's (2001) open-ended approach to grounded theory. It allowed me to collect rich ethnographic data of entire scenes in an open-ended way where illness experiences unfolded. It also helped to structure my observations without losing focus amid the ethnographic detail. At the same time it guided me in making connections between these various places by looking for a single process cutting through a range of illness experiences connected to the one event (the support group and related events made available by Hospice House). Grounded theory therefore guided me to explore across various sites the ways in which participants' illness experiences unfolded and to look for a process which would unify this range of experiences. Before providing more information on the way data analysis was approached, I will describe the various places and events of my fieldwork research.
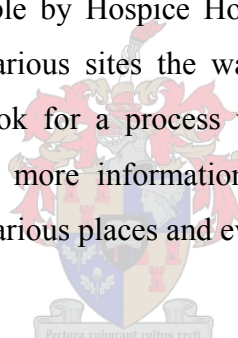
4.3   Places, spaces and events of fieldwork

4.3.1 *The support group*

Upon my entry to the field, I started to record observations of participants' verbal and non-verbal experiences visibly. I had to make quick scribbles of what I observed because of the very dynamic nature of the field. For the largest part I jotted down only a few key words. These jottings would then aid me in recalling whole events and scenes, which I reworked into a flowing text as soon as I got home. Although these notes reflected the observed realities to a certain extent, the process of fixing the events and behaviour in the form of field notes reduced the very dynamic nature of participants' behaviour (Emerson, Fretz & Shaw 2001:365). A group of approximately 15 to 20 adults from the informal settlements around Paarl living with

HIV/AIDS would be collected and brought to Hospice House weekly where they would spend the morning taking part in a range of activities in the context of a support group. The group members were all adults living with HIV/AIDS in varying stages of the disease. They had little insight into their illness, little support and were in the process of being recruited for ARV treatment. I decided to immerse myself in the activities of the whole group, to be able to grapple with a diverse range of experiences. These activities included the opportunity to take part in making various craftworks, to see the nurses or volunteer doctor for treating HIV/AIDS-related symptoms, socialising amongst group members, getting nutritious meals and interacting with volunteers.

Toddlers would also accompany the parents, but I wanted to focus exclusively on the adult group. Every Thursday, after the participants have been collected, they arrived at Hospice House. The morning was spent in an open area, reserved for support group activities. Despite the presence of various volunteers at daycare, I decided not to focus on the volunteers as such but to contextualise the participants' behaviour within the context of these relationships between the various volunteers and participants. Focusing on the participants' behaviour prevented me from getting distracted by the dynamic relationships and events happening at daycare. I took part in a range of activities such as handing out meals at tea time and again at lunchtime. Sometimes I just sat with participants, ate a sandwich with them, enjoyed a cup of coffee, or at other times I just to sat and talked about what they wanted to share with me at that particular moment. At other times I could only stand in awe of the various pieces of craftworks, which participants wanted to show, assembled from bits of haberdashery, and I also had the opportunity to acknowledge these creative projects accordingly. On days when the volunteer in charge of the crafts was absent, I participated by helping participants with crafts: sometimes helping with embroidery work, winding brightly coloured embroidery cotton onto pieces of cardboard for them to take home, searching the haberdashery cupboard for pieces of cloth for reworking into a creative piece of sewing, sometimes threading a needle when the participant struggled with bad eyesight, sometimes acknowledging completed aprons or table mats, sometimes just sitting and talking casually and very informally. By immersing myself in a world of sewing tiny stitches, I could get closer to a feeling of the context which volunteers provided the participants. It also allowed me to engage with the

participants in talking about their illness experiences in the context of the support group being immersed in this space in which various illness experiences came into view.

4.3.2 *The nursing station*

Because of the time constraints of the research, I decided not to negotiate access to the counselling sessions between the visiting doctor, nurses, translator and participants, which would take place in the nursing station (a separate room but adjacent to the daycare area). During these sessions the participants had the opportunity to voice any complaints regarding their illness to the medical staff. But, as I was more interested in the social illness experiences, I decided to focus my research on the support group and relating activities. I was invited once to sit in during a session in which the chief nurse assessed a participant's readiness for antiretroviral treatment. Only the chief nurse, translator, participant and I were present. Informed consent was gained verbally before the assessment took place. We moved to a separate room. I had not planned to sit in on any of these sessions, but as the opportunity crossed my way, I decided to observe the session. This revealed illuminating issues relating to the research question. In this case, I was more of an observer than participant, but observing was very useful. I found Hahn's emphasis on "listening" useful in this context. By merely "listening" I could get a glimpse of a particular participant's experiences of the process of recruitment for antiretroviral treatment (Hahn1995:274).

4.3.3 *The minibus*

Initially I decided to limit my study in order to focus on the support group activities held at Hospice House. I nevertheless took part in as many as possible activities associated with the support group events evolving in the field. As the research progressed and I gained more familiarity with the support group events and realised that following participants' experiences from their homes, and again on their way back to the informal settlements, would be a vital part of the study. Multi-sited ethnography provided me with the opportunity to look beyond a single site of study and to follow the support group not only in Hospice House, but also in other related

spaces and activities (Marcus 1995:106).   During these minibus excursions[5] I had ample time to observe the way in which participants approached the vehicle, and interacted with neighbours, friends or family members on embarking the vehicle. I could also observe the way in which participants interacted with one another on the way to Hospice House, as well as the interaction between the staff and participants, and I could also participate as a volunteer probing information, which participants presented to me.   Instead of regarding the minibus excursions as irrelevant to the research question, I realised the importance of these initial observations surrounding the minibus. I began to realise that the participants were involved in a social situation unfolding beyond the physical place where the support group was held, and that I would have to look beyond my initial narrow focus on the support group activities at Hospice House.

4.3.4   *Other events: Ekwezi and Paarl Hospice volunteer course*

During the later stages of the research, I was able to follow the participants to several events relating to the support group. Early in March 2004 an event was held at Ekwezi (a community centre near the informal settlements of Paarl) where the first month of antiretroviral roll-outs was celebrated by medical staff, patients, funding agencies, and the media. The first people living with HIV/AIDS to receive ARV treatment were recruited from the Hospice House support group, therefore Hospice House arranged for them to attend the event. I had the opportunity to follow participants to this event which provided me with a context in which I could observe and probe participants' experiences of the event. Three members of the Hospice House group were present and I sat with them in the designated area. These support group members voluntarily decided to attend the celebrations.

On 31 March 2004, four members of the Hospice House support group took part in the volunteer course held by Paarl Hospice. The course was held for volunteers to provide them with the necessary training relating to the Paarl Hospice philosophy. At

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[5] Volunteer drivers collected participants for attending the support group at Hospice House from the informal settlements around Paarl. Participants would later be returned to their homes after attending daycare held at Hospice House.

the time, the four participants were all using ARVs and were given the opportunity by the chief nurse at Hospice House (who was also presenter of the particular session) to share their experience of HIV/AIDS with the audience (volunteers). The participants were in control of telling their stories regarding their experiences of HIV/AIDS and ARVs. They were then prompted through respectful questioning by the presenter. I was merely present as a volunteer researcher taking part in the course and who was being introduced to the Hospice House philosophy. Again multi-sited ethnography seemed to be useful in exploring the unfolding of illness experiences relating to a social situation.

4.3.5 *Unstructured interviews*

I decided to conduct some unstructured interviews to supplement and clarify observations and information collected during participant observation. The translator (home-based carer) doing rounds in the informal settlements informed group members about the possibility of taking part in individual interviews. I decided to choose only two participants, as a few in-depth interviews would be more useful than large numbers of general ones. The participants were chosen according to their willingness to take part in the interviews. One of the interviews was conducted at the participants' home and the translator was also present. She had to translate one interview, as the participant was a young Xhosa-speaking male and I was not equipped to speak or understand his language. The second participant was a female Hospice House daycare member who was also part of the local support group in Fairyland, which was in the process of getting off the ground when I conducted the interview. These interviews, conducted at the later stage of the research were helpful in clarifying some unstated issues which unfolded whilst I was conducting participant observation. Open-ended interviews and letting the participants be the experts of their stories was a non-threatening way of getting close to the sensitive nature of the lived experiences relating to HIV/AIDS. In this instance I used consent forms (see Appendix A), and gained permission of the participants to record the interviews mechanically. Again anonymity and confidentiality were guaranteed. These tape-recorded interviews were subsequently transcribed as field notes. Upon request, I provided both participants with a tape-recorded copy of the interviews.

4.4   Grounded theory and data analysis

I continuously moved back and forth between events, scenarios, informal conversations, observation, and participation in activities guided by grounded theory in order to get a closer understanding of the way in which invisible illness experiences unfolded. I coded these ethnographic scenes rather than doing micro line-by-line coding (Charmaz & Mitchell 2001:166).

An assumption of grounded research is that research participants " ... *are meaning-giving beings* ... " (see Crabtree & Miller 1992:111). Right from the start of the project, participants and the researcher were mutually implicated in the process of gathering and analysing data, which could not be separated as two watertight processes. In the coding process, which was already underway at the time of data collection, participants provided me with in vivo concepts which I used to guide further observations and analysis (Charmaz & Mitchell 2001:165, Strauss & Corbin 1998:65). At times, in vivo concepts guided me in getting a deeper understanding of participants' experiences relating to daycare. Participants provided me with words or phrases which reflected their experiences. By immersing myself in the data, I could stay close to the participants' experiences without fixing the data ahead of time (Chase 2003:95). The most crucial in-vivo concept, which stimulated further informal conversation, observation, and participation in support group activities, was disclosure. This concept enabled me to make connections across sites and to gain a range of experiences connecting various participants in time and space. The pre-scheduled open-ended interviews were guided and analysed with the in-vivo concept of disclosure in mind. These interviews confirmed that disclosure seemed to be the central activity connecting observed and verbal behaviour. Constantly, throughout the informal conversations, participants were talking openly about disclosing, telling, and not telling various people about their illness. My next observations were guided by closely paying attention to specific events, places or strategies that appeared to be linked by disclosure. By moving continuously between generating data and analysing data, I could compare newly generated data with data from the beginning of the research process.

I found looking for process useful in seeking a suitable manner to explore and analyse disclosure relating to HIV/AIDS illness experiences across the various sites (see Strauss & Corbin 1998). With the process in mind, I looked for ways in which disclosure took place across the various sites either routinely or tactically as a response to problematic situations. I also investigated how disclosure evolved and changed as well as verbal statements and silences regarding disclosure amongst and between various actors (Strauss & Corbin 1998:165). I found that by focusing on process, I was able to condense a considerable amount of data and to give theory a sense of life (Strauss & Corbin 1998:177).

4.5   Conclusion

In this chapter I have provided a description of the places and events where I conducted participant observation and explained the fieldwork process. I have also provided an account of my position as volunteer researcher, which I found to be indispensable in getting a deeper understanding of illness experiences centring on several places, spaces and activities related to the Hospice House support group held for people living with HIV/AIDS. I concluded that data collection and analysis guided by grounded theory could not be separated and turned out to be a useful way of exploring the field as well as structuring and analysing field data. Grounded theory enabled me to broaden my focus by looking beyond the confines of the physical place where group activities occur, and to include various other events relating to the space that Hospice House offers to people living with HIV/AIDS. At the same time as exploring the field I could get closer to explaining the process of how various illness experiences unfolded across various sites. In the following chapter I will present various ways of disclosure that unfolded during the fieldwork process.

CHAPTER FIVE

DISCLOSURE: HIV/AIDS ILLNESS EXPERIENCES

5.1   Introduction

In the following section I will present a variety of HIV/AIDS illness experiences that are common among the support group members and will then explore how disclosure figures as the centralising process connecting these experiences in the process of accessing Paarl Hospice and seeking to deal with the illness. I will situate these experiences in relation to the infrastructure offered by Hospice House for people living with HIV/AIDS to treat the disease.

5.2   Disclosure at the time of testing before getting in

At some stage before qualifying to join the support group, those in search of health care had to confront their illness via HIV/AIDS-test results because HIV/AIDS was the entrance point for people to become support group members of Hospice House. An HIV-positivity and a CD4 count of less than 200 would enable one to join the group (as discussed in Chapter 3). But what was behind the biomedical criteria? How did the people being tested make sense of this devastating disease suddenly rendered visible through the results? How did they make sense of the test results? How did their understanding of the results influence the choices they made to manage their illness? Did they merely accept the results and search for health care in response to their illness?

Jeannie, a single mother of two teenage boys had been living with HIV/AIDS for a long time. While living in Umtata, she went to a clinic to inquire about a small wound on her forehead. At the time she had been warned that the wound could be related to HIV, but no HIV/AIDS test was done. In 2001 she took an HIV/AIDS test. Even though the results turned out to be positive, she did not respond to it and told me, "*I didn't take it seriously. I couldn't see anything*". When she arrived in the Western Cape many people dying of AIDS suddenly surrounded her. In 2003 she was

tested again and accepted the results. Being surrounded by HIV/AIDS deaths, and upon confirming test results, she took an overdose of tablets in order to subvert the shame of living with a "death sentence", and perhaps to overcome the uncertainties of the long process of dying with which the disease confronted her. Being a member of the Hospice House support group, she could see that some people were getting better and were not afraid of death anymore.

In this case being confronted with seropositive results did not initially lead to disclosure. Because the person diagnosed with HIV/AIDS could be in the asymptomatic phase of the disease for several years, it might be difficult for some to accept the test results and disclose their illness in the absence of HIV/AIDS-related symptoms. Non-disclosure had to be situated in the circumstances in which Jeannie found herself at the time. Upon being tested again, and being surrounded by HIV/AIDS deaths, acceptance of the test results did not necessarily lead to a public statement of her seropositive status. In this case, inflicting her own death could be seen as a form of disclosure of the reality of the disease in Jeannie's world. Perhaps she did not want to be seen by those in her community as "dying" whereupon she decided to end her own life. This account which Jeannie shared with me is another example of disclosure, a retrospective verbal account of her process of coming to terms with the disease shared with me at the time of the interview. I would not have been able to understand her reactions to the test results at various times and places if she had not provided me with the context in which she was involved at the time. Being a member of the support group and being informed that antiretroviral treatment could surmount the "death sentence" associated with HIV/AIDS, Jeanie seemed to be quite comfortable in disclosing her illness to me during a support group session.

Kalli, an Afrikaans-speaking HIV-positive male showed no HIV/AIDS-related symptoms. During a support group session, I sat with Kalli. Without any probing of his illness on my part, he told me that his wife found out during her pregnancy that she tested HIV positive. He subsequently went for a test voluntarily. The doctor told him he was also seropositive. "*It doesn't show. I am not ill. There is nothing wrong with me. I don't regard myself as HIV- positive. But to the doctor I am positive*". He told me that he attended daycare to support his wife. Later on he told me, " *... we can't blame each other for bringing on this illness*". Although the test results

provided evidence of the disease, Kalli would not disclose the reality of the illness upfront. In the absence of physical symptoms, the reality of the disease was too far removed, which could be a reason for not publicly disclosing living with the illness. Being a member of the Hospice House support group on the other hand could be a form of implicit disclosure because criteria for membership imply an HIV-positivity as point of entry. But to himself, he was merely attending the support group to support his wife. Telling me that they could not blame each other for bringing on the illness, he disclosed the presence of the disease in his life world in a different way.

In both these cases disclosure took place on more than one occasion and seemed to be more complex than the mere upfront statement of an HIV-positivity at the time of testing. If disclosure was going to be the prerequisite for becoming a member of a support group or approaching a treatment site, one would need to look at several ways in which disclosure could take place, as hinted at by the examples discussed above. Many factors would have to be taken into account in order to understand the meanings each individual ascribed to the illness upon undergoing an HIV/AIDS test, and the way in which each participant would respond to the test results and subsequently start looking for ways to manage their illness. One would need to look beyond biomedical meanings of HIV-positive status to a range of other situational meanings which people living with HIV/AIDS reveal when confronted with the test results. In the examples provided above these meanings unfolded in relation to the circumstances in which individuals found themselves at the time. Disclosure seemed to be embedded in these circumstances.

5.3 The visible-invisible minibus

The complexity of HIV/AIDS disclosure only set in upon being tested seropositive. Being collected by the minibus from their homes in the informal settlements might be experienced as a barrier to those seeking to manage their illness. Jeannie, a daycare member once told me that an obstacle to becoming a member of an HIV/AIDS support group might be that some were ashamed of their illness. She said, "*I would say people are not scared ... they are ashamed ... they are not going to get hit if they join the support group ... that's why I would say they are ashamed*". In the face of

shame surrounding the disease, the question remains as to how participants managed to approach Hospice House without the threat of causing suspicion amongst family members and neighbours. Furthermore it can be asked how people living with HIV/AIDS, now part of the Hospice House daycare group, approached the seemingly invisible minibus.

We drove with a white minibus from Paarl through the industrial area to the informal settlements to collect daycare members for the support group activities to be held at Paarl Hospice. As we drove on, people took note of us, some staring at the bold green lettering on the side and rear of the minibus reading *Paarl Hospice*. We had a list providing us with the names of those who were to attend the support group, and the translator (home-based carer) navigated us effortlessly to the various homes. She was wearing the same uniform, a black skirt and white blouse, which she usually wore whilst doing her weekly rounds in the informal settlements recruiting people for the Hospice House support group. The driver made his way through the congregations of people loitering in the streets by hooting persistently. Women spreading clothes on fences kept on staring while we drove past. We moved from house to house collecting various daycare members. Were the locals staying behind aware of the whereabouts of their neighbours who, due to their illness, embarked the vehicle to attend the support group at Hospice House?

Support group members embarked the vehicle explicitly, most of them lugging similar crafted bags. By following these members weekly on their visits to Hospice House, I noticed that even though it might seem that they embarked the vehicle transparently as people living with HIV/AIDS, it did not necessarily have the same connotation for their neighbours in the various places where they lived. Often pedestrians would indicate that they wanted a lift from the Hospice House "taxi", and the translator would have to remind them that the vehicle was not an operating taxi service. This also took place in the informal settlements. Some residents thought the vehicle belonged to a food aid service, commenting that they had "*No food, no clothes!*" These incidents made me realise that embarking the vehicle did not unambiguously mean one was living with HIV/AIDS and that one was being collected by Paarl Hospice to attend an HIV/AIDS support group. The volunteer driver told me that in some areas the locals still associated the Hospice House vehicle with cancer. These

observations provided me with indications about how locals devised strategies to access Hospice House in order to manage their illness, without conveying the real purpose behind their visit. It seemed that some participants rendered their illness invisible by embarking the invisible minibus. The space provided for dealing with the "invisibility" of the illness might be an opportunity for some to overcome shame and stigma associated with the disease. But at the same time it might be a barrier for some in terms of accessing it, as the HIV/AIDS minibus entering and exiting the local neighbourhoods was not visible. How did Hospice House and the minibus become visible to people living with HIV/AIDS? How did people living with HIV/AIDS find their way in? In what follows I will look at the ways in which participants managed disclosure of their illness by embarking the vehicle.

5.3.1 *Disclosure by approaching Hospice House*

Jeannie mistook the Hospice House minibus visiting her neighbour for a food agency. She misread "Hot Spice" written on the vehicle. At the time her neighbour had cancer and she could not understand why a company working with food would employ a sick person. In the mean time her neighbour passed away, but the "Hot Spice" vehicle continued to visit at her neighbour's place. Jeannie started to get ill and upon her inquiry about this vehicle she was told about the comings and goings of Hospice House and she was referred to the Hospice House translator who was doing weekly rounds in order to recruit possible candidates for the support group. By confronting her illness using "Hot Spice" as a way in to seek health care, Jeannie bypassed the shame associated with HIV/AIDS, and she managed to disclose her illness in such a way as to guard against having her relationships severed. Disclosure was considered safe within the available invisible infrastructure offered by Hospice House, and she decided that she could disclose her illness in this context. This way she could also create a set of new relationships in dealing with her illness. But in her own neighbourhood she risked the danger of having her relationships severed. Therefore she decided not to reveal the real intention of her inquiry about the "Hot Spice" company because she showed no HIV/AIDS symptoms yet. This way she could maintain her relationships with her neighbours. Disclosure and non-disclosure

seemed to involve an assessment to enabling and disabling factors relating to everyday relationships in her neighbourhood.

But in some instances people living with HIV/AIDS might not have the choice of negotiating access to health care, which might prevent them from rationally choosing to reveal or not to reveal the illness. At the end of 2003, Sophie was very weak and she could not walk or touch anything. She was being told at the clinic that she " *… was not going to make it*". The clinic staff advised her to call her family and to tell them she was dying. Sophie started making plans for someone to look after her son. She phoned her brother and together they went to social services to arrange for him to adopt her child. Her sister-in-law wanted to know if there were people who could give her medication. Together they went to social services and then Paarl Hospice came. She cancelled the adoption. Disclosure in this case centred on more than revealing an HIV-positivity. Disclosure manifested involuntarily on Sophie's body upon which she verbally announced her "death sentence" to close relatives. In this case, verbal disclosure seemed to be a consequence of deteriorating health. Illness prompted Sophie to share her HIV status with close relatives. Disclosure also seemed to be relational. Although she risked disclosing her illness in the face of a social death awaiting her, in this case it led to strengthening her ties with her family and led to accessing health care. Disclosure was thus not always a verbal account only.

Besides HIV/AIDS-related disclosure at the time of testing, disclosure was a prerequisite in approaching health care. But the problem was not merely to inform Hospice House about one's illness. The personal and social relationships in which people living with HIV/AIDS were involved, had to be considered in disclosure of the illness.

5.3.2   *Disclosure and clothing the virus*

Once participants established a way into Hospice House, they still had to bypass the suspicion, which might be stirred up in the local community given their new routine of embarking the Hospice House minibus weekly. Even though some of the locals might regard the vehicle as a taxi, the bold green lettering on the side and rear of the

minibus reading *Paarl Hospice*, might cause suspicion amongst some of the more attentive community members. Participants did not necessarily embark the vehicle as people living with HIV/AIDS to spend the day at Hospice House. I noticed that Hospice House daycare members went to great effort in their visits to Paarl Hospice. The volunteer driver and translator would always comment teasingly about the members' tidy appearance. Among themselves members would also comment on each other's appearances. When embarking the vehicle fellow patients would be greeted with, *"She looks so smart!"* It seemed that commenting on anything from dress to hairstyles was a way to subvert the visibility of the illness. These people do not look ill. They could exploit the situation of showing no physical HIV/AIDS-related symptoms and instead displayed an image of being healthy and well dressed. This image could then be sustained by comments about dress. Even though participants did not publicly disclose their illness when embarking the vehicle, the lingering reality of a devastating virus lay beneath these layers of clothing and remarks about appearances. This talk about smart dressing hid the virus. But as HIV/AIDS was the point of entry to become support group members, embarking the vehicle could be regarded as a form of indirect disclosure to fellow group members and to Hospice House. It seems that the illness could be camouflaged strategically by wearing tidy garments. The question remains as to how people living with HIV/AIDS camouflaged their journey in the vehicle to Hospice House.

5.3.3   *Embarking the vehicle: Disclosure to Hospice House, non-disclosure to the community*

Sina, a middle-aged Afrikaans-speaking lady living with HIV/AIDS embarked the vehicle. By embarking the vehicle, she implicitly disclosed to Hospice House and fellow support group members her illness. As we drove past her brother who was talking to some friends in the vicinity, she shouted from the minibus telling him to hang the wet blanket which she had washed that morning on the fence to dry. She then told us that she was not strong and complained that she would be sick for a whole week if she had to do it by herself. She decided not to inform her neighbours of the actual purpose of her visit to Hospice House, because " ... *stories will do the rounds and people will gossip ...*" She told us her neighbours could read on the

minibus that Paarl Hospice was collecting her, but she hid her illness telling them that she was an employee of Hospice House. Sina exploited the invisibility of Hospice House to deal with her illness and in this way managed to overcome gossiping and being shamed further. In this case, disclosure is not merely the public announcement of an HIV-positivity. The act of embarking the vehicle could be considered a form of disclosure to those who were aware of Sina's illness. But for those she told that she visited Hospice House for work, embarking the vehicle did not seem to be related to her illness. By doing so, she could distract attention away from her illness. By simultaneously managing disclosure and non-disclosure, Sina could maintain social relationships with Hospice House as well as with the community where she resided.

Helen, an Afrikaans-speaking mother and grandmother had to squeeze through a narrow alleyway from where she was living in someone's backyard to make her way to the street where the Hospice House minibus, staff and fellow daycare members waited on her. In this area, there were not many people living with HIV/AIDS. Even though she willingly embarked the vehicle, she camouflaged her illness by telling neighbours " ... *these people come to visit me because I have cancer*". Embarking the vehicle could be regarded at the same time as a form of disclosure and non-disclosure. To Hospice House and her fellow support group members Helen's condition was taken for granted. It was not necessary for her to announce her illness publicly and the mere act of embarking disclosed her illness. But in the community where she was living, and where she had to face the threat of being rejected, she decided not to disclose her real illness. Embarking the vehicle in the local neighbourhood could be a form of non-disclosure because she embarked the minibus under the pretence of having cancer. Helen attributed her illness to a condition that would provoke less scrutiny from her neighbours. At the same time as maintaining her ties to her local community she could reach out in seeking health care. The ways in which disclosure occurred, could be understood by taking into account the social situations in which it unfolded as well as considering the implicated personal and social relationships.

In Fairyland, Patrick and his wife were waiting outside their "hok"[6] at his fruit stall. He told me that he opened up this stall since being told by Hospice House about

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[6] Tin shanty home.

healthy eating habits. He was also selling crafts, which he assembled during the support group sessions. Patrick was one of the first members from the Hospice House support group to start antiretroviral treatment. As we approached, I noticed his wife wearing the colourful apron, which she made during one of the daycare sessions. His neighbours did not know that he was seropositive and were only assuming this when he was picked up. Patrick told me that he only told one of his friends about living with the disease, and, because his friend spoke out, people began to assume that he was ill. It seemed that disclosure concerned a rational, public stating of an HIV-positivity. Even though Patrick was selling crafts and vegetables in the neighbourhood where he was living, this evidence was not equated with living with HIV/AIDS and could therefore be regarded as a form of non-disclosure. Although people might assume that he was ill, it seemed that in the absence of physical evidence of the disease, embarking the vehicle could be regarded as a form of non-disclosure to the people staying behind. ARVs in this instance could be regarded as a form of disclosure to Hospice House, but simultaneously as a form of non-disclosure to the community where Patrick was staying.

Selling produce and craftwork could then also be regarded as a way of non-disclosure as attention was being deflected away from Patrick's illness. His neighbours, assuming that he was seropositive, held no danger. Patrick would have to tell them publicly about his illness before it could be considered disclosure. ARVs also seemed to add another level of invisibility. By taking ARVs, Patrick told me he was feeling " ... *full of energy and feeling fresh ...*" and that he used to be " ... *down and feel weak* ". Patrick could thus promptly embark the vehicle. His illness was only being disclosed to Hospice House upon embarking the minibus because Paarl Hospice was aware of his condition. Disclosure occurred at many levels and in different ways depending on one's personal and social relationships.

As we drove on, I probed to find out from the volunteer driver why he decided to invest time in working with this particular group of people living with HIV/AIDS. He told me, " ... *the reason why it is so special to work with these people, is because they are true ... they are not wearing masks ... they don't cover up ... you see them for who they are*". I realised that Paarl Hospice might not be aware of the ways in which people living with HIV/AIDS had to find strategic solutions to plan ways in which to

overcome the shame associated with HIV/AIDS in order to embark the Hospice House vehicle. The space which Hospice House offered to these people might buffer them against the humility of living with the disease in some ways, but coming from particular neighbourhoods, these people had to "wear masks" and "cover up". This prevented them from publicly disclosing their illness.

5.3.4 *Involuntary disclosure*

It seemed that participants could devise ways in which not to disclose their illness while at the same time embarking the Paarl Hospice minibus. The question remains then as to why some participants decided to stay at home and did not embark the vehicle. Furthermore it can be asked whether participants always had an option of hiding their illness upon entering the vehicle and how those staying behind managed to deal with their illness in the neighbourhoods.

We stopped at Eve's house in Mbekweni. The translator, wearing her uniform (a black skirt and a white blouse) disappeared inside the house to inquire about Eve's health. Eve had until recently been attending daycare, but her health had rapidly deteriorated. She was not in a condition to move around freely anymore. She was also ill with tuberculosis which was not responsive to treatment, and she could no longer attend daycare. The physical demands of the illness presented itself involuntarily as a barrier for Eve to attend daycare. In this case Eve did not disclose her status. She was not able to hide her illness any longer. If she were to enter the vehicle, the physical manifestation of the disease's progression would have been a form of disclosure of her illness to the community and her fellow group members. In this case her choices were restricted. Perhaps she did not want to be seen in this condition by either her neighbours or Hospice House support group members. Even though she did not want to be seen, group members inquired about her health, and the progression of the disease was made known to them by Hospice House staff. In this case disclosure was not a choice of the participant. Instead, because of her sudden absence in the support group, due to the physical manifestation of the disease, disclosure of her condition was revealed to group members by Hospice House. The fact that she was not approaching the vehicle, as she would usually do on Thursday

mornings, and the new arrangement of the translator visiting her instead, could be regarded as a form of non-voluntary disclosure due to the progression of the illness.

These physical challenges related to HIV/AIDS could be a barrier which others living with HIV/AIDS might have to overcome, in order to access health care and disclose their illness. Because the symptomatic phase of the illness had set in, it was more difficult for Eve to hide her illness. Disclosure is not always a motivated individual choice.

Embarking the Hospice House vehicle was a way for participants to receive ARVs. ARVs could prolong the asymptomatic phase and enabled participants to subvert shame associated with the disease. Why did some participants then decide not to embark the vehicle in order to qualify for ARVs? What were the other barriers preventing health seekers from embarking the vehicle? It is necessary to investigate how participants managed non-disclosure in the presence of physical evidence of the disease setting in and to look at the reasons why some participants still decided not to embark the vehicle even if it could save them from a physical death.

Even though Paula refused to attend daycare, Hospice House continued visiting her. Despite having a low CD4 count she did not qualify for ARVs because she was not responsible. She refused to stick to her appointments at the clinic. She also had difficulty moving around after her wheelchair was damaged. As we drove past her house, the translator told us that she was one of " ... *the very sick patients* ..." and "... *she fell pregnant again because her husband wanted to have another child although she is HIV-positive*". The rest of the crowd in the minibus overhearing the conversation replied, "*How could she have done this!*" The example of Paula staying behind at home could be a form of non-disclosure, signalling that she did not want to reveal her illness by embarking the vehicle. But to Hospice House this act was a form of disclosure because she informed the staff at Hospice House of the reasons why she did not attend daycare. She could reveal her pregnancy to the community and Hospice House support group members and thus deflect attention away from her illness. Perhaps she disclosed aspects of her illness by not attending daycare, which was not dealt with by the Paarl Hospice model. Perhaps Paula was caught up in circumstances at home which made it impossible for her to cope with her illness.

Paula did not want to sever her relationship with her husband, which prevented her from qualifying as a suitable candidate for treatment by her husband's demand of wanting another child. But falling pregnant might be a form of non-disclosure, deflecting attention away from her illness and shifting attention away from her ill body to a body which could take part in a life-giving activity. By refraining from embarking the vehicle, and informing the translator of the reason for her pregnancy, Paula disclosed more than the physical reality of the HIV/AIDS. The neglect to untangle and respond to the clues relating to her illness, which Paula hinted at, meant that she would be likely to remain captured in the grasp of the illness. Perhaps not joining the support group, and thereby thwarting the opportunity to obtain ARVs, was not her own desire. In order to understand why she decided not to join the support group, it is necessary to understand the circumstances in which she was embedded.

This example showed the complexity of disclosure and diverse responses to situational factors. Disclosure has to be managed carefully in order to maintain personal and social relationships. But by not being able to disclose her illness in the way expected of her, Paula had been excluded from becoming a support group member. In some instances it might be difficult to hide the private world of the illness from the public eye.
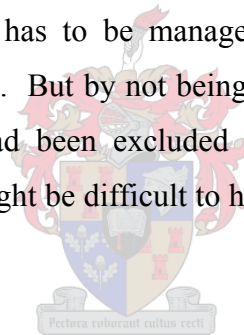
Nearing Myriam's house, a nineteen-year-old teenager hiding underneath a cap approached the minibus. He mumbled something hurriedly telling us his mother was not feeling well and would not be attending daycare. Perhaps she did not want to be seen in public in this condition. Perhaps she did not want her fellow group members to see her being ill. Perhaps she did not want others to gossip about her being ill or death setting in. Physical presence in this instance could be a form of disclosure whereby Hospice House and fellow participants would have been able to read the physical symptoms on her body. Therefore she sent her child to excuse her from attending daycare. Before he made his way towards the house, he looked around him to make sure he remained invisible and unseen and disappeared inside the house. Even though this boy was living with his mother in the same house, and was not ill, the way in which he approached the vehicle signified the pejorative connotations relating to the disease which he tried to overcome by hiding underneath his cap. It was not simply a matter of deciding not to embark the vehicle. If Myriam did not

send her son, Hospice House might have come looking for her and it was possible that she was trying to overcome this type of disclosure. She preferred to send her healthy son and in that way did not have to disclose her illness.

Each individual was tied up in certain social contexts, which made it easier for some to access health care and disclose their illness, whilst at the same time preventing others from disclosure and visiting Hospice House. These obstacles were present in the participants' close personal relationships, local community or in the model Paarl Hospice offered them in disclosing their illness. Declining to access Hospice House could not merely be equated with non-disclosure. Looking at several situations in which participants declined to access Hospice House, provided a glimpse into the social circumstances in which individuals are embedded as well as available opportunities offered to them. It also revealed the shame associated with HIV/AIDS.

5.3.5 *Disclosure and craftwork in the minibus*

Initially I thought that daycare members would openly discuss their illness amongst fellow group members. The social worker told me, "*The idea behind daycare is to give patients a space to interact socially and to share a spectrum of concerns around HIV, stigma and symptoms*". But my view was refuted when I began following participants to and from Hospice House. Daycare members would also hide their illness to a certain degree, amongst themselves. I noticed that they were cautious to discuss their illness frankly with other participants. When embarking the vehicle participants would take out their craftwork and carry on working on bits of embroidery. Myriam once showed her work to Sina who was also an Afrikaans-speaking lady. They discussed each other's work. One of the new members excitedly wanted to know from Sina, "*Did you know how to do that or did someone show you?*" She seemed eager to learn. "*I made it myself! Someone showed me at Hospice and had given me the fabric but I made it myself!*" she replied, proudly spreading the meticulously hand sewn apron on her lap. Myriam took out her apron and continued working on it. Not speaking about the illness and focusing on craftwork instead relegated the illness invisibile amongst participants. When daycare was presented to new members as a place where one would be taught new craft skills the focus was

suddenly drawn away from illness. Even among themselves, there were some secrets, which participants did not openly disclose. Not talking about the illness might perhaps be a way of avoiding the shame associated with illness. Perhaps participants talked about the disease, but deliberately excluded me from their conversation being aware of my incapability of speaking or understanding Xhosa. Perhaps participants disclosed aspects of their illness among themselves, but wanted to withhold it from me. It seemed to be more acceptable to display one's product to fellow group members than to display one's illness to others. It seemed that participants acknowledged each other as sharing the same secret without having to say it openly. Physical presence in this case was also a way of disclosing living with HIV/AIDS. Craftwork could be regarded as an indirect form of disclosure which linked participants together in dealing with their illness. It could also be used to buffer them against shame. Disclosure took on different forms and revealed different aspects of the illness depending on the context in which disclosure unfolded.

5.4   Disclosure in the support group held at Hospice House

After collecting participants for daycare they were being dropped off at Hospice House. The recently renovated building is situated near Paarl town centre. The only visible evidence revealing the identity of the building and distinguishing it from the local residences was an unobtrusive white sign posting near the back entrance reading *Paarl Hospice* in bold black lettering, and which also provided the relevant contact number. Participants entered through the back door where they were appropriately welcomed and embraced by the volunteers. Arriving at Hospice House thus implicitly meant that participants complied with the minimal criteria set out by Paarl Hospice to attend the support group: having a CD4 count of less than 200 and being possible candidates for ARV treatment. Illness was the common denominator for participants' attendance and thus there was no need for them to disclose their status openly every time they attended daycare. Besides this implicit disclosure, the question remains as to how participants experienced daycare and what did they reveal in daycare.

5.4.1 *Implicit disclosure and public disclosure*

Ina, a lady living in Fairyland, once told me that she would come back to the support group because where she was staying " …*there is nothing* … " and she " … *has nothing to do there*". She dealt with her illness by attending to boredom and she thus spent less time being concerned about her illness. When I probed Ina to find out what she liked about visiting Hospice House she told me,

> "*I learned a lot just because I can't do needlework … but Hospice helped me. I feel better to be with a lot of people with the same problem as I, and I think that when I speak to someone who will understand me and know my situation and feel the pain that I feel. I like the people that work here and I love to be with them. And the love they give to us and the care they give to us*".

Jack, again, liked the interaction between those who were ill and those who were not ill. Hospice House was a place where he could just relax amongst others with the same illness. Another participant told me, "*All we want is hugs because it makes us feel better*". Disclosure centres on more than a public statement that one is living with HIV/AIDS. Depending on the circumstances, which participants associated with their disease, these aspects are also disclosed in the context of the support group. Another form of disclosure could be taking part in the craft activities scheduled for people living with HIV/AIDS.

Jeannie used this space provided by Hospice House to show her participation in the local community. She sometimes showed up wearing a yellow reflector coat. An identification number in bold red was written on the shoulder. She wore this coat throughout the session. By wearing her reflector coat she did not arrive at Hospice House as an HIV-positive patient, but as an employee of the local neighbourhood watch. She might also be revealing to fellow patients that one could still be working despite being ill. The conversation between the staff and fellow group members would then immediately shift from discussing the illness to her duties of as a member of the neighbourhood watch. Her active participation in the community was usually proudly acknowledged by Hospice House staff. In this case, strategically deflecting attention away from her illness in the community and in the Paarl Hospice support

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group amongst fellow group members and Hospice House staff, could be a form of non-disclosure in order to subvert anticipated hostility which could be evoked by the disease. There was no need for Jeannie to refrain from being a healthy member of the community. She once told me that she used to be scared of death, but ever since becoming a member of the support group she could see that " *... people here look much better now. They look much healthier*". Even though her health might deteriorate, she would be in a position to avoid being exposed to the shame associated with the disease. She was a possible candidate for ARVs and could thus have the opportunity to combat the humiliation associated with the disease. Perhaps for this reason she did not want to attend Hospice House as an ill person but rather as an active healthy community member. Non-disclosure in this case was a considered option and could at the same time be regarded as "disclosure" to Hospice House staff and the support group members as the support group was held for people living with HIV/AIDS. This is another example of situational disclosure.

 Some participants used this space to disclose more private matters and voiced their interpretations of the illness. For instance, Irene one day approached the translator and they disappeared outside. Irene told the translator that her husband, who was also present at daycare, demanded from her to leave him. She had no place else to go to. She was told to leave home for two weeks while her husband stayed with another woman. The translator was concerned that he might infect other people because he was living with HIV/AIDS. Irene had no one to share this information with. Despite her husband's aunts also being present at daycare, she decided not to approach them, but to tell the translator. What was she saying about the illness by mentioning her husband's demands? And why did she approach Hospice House in this instance? Irene disclosed more than the physical reality of the illness in this case. Perhaps this issue, which she brought to the fore, was connected to her illness, and could not be addressed by the Hospice House model. The question remains as to how she will be able to confront her illness. Disclosure seemed to be a situationally considered choice, in this case revealing aspects of her illness to those who could be of assistance and provide possible support in dealing with the illness. She decided not to disclose to close family members as this entailed the risk of having her relationships severed in these personal spheres. It seemed that in the space of the support group, participants revealed other issues apart from the physical demands of the illness. They did not

necessarily reveal these issues in all circumstances. The illness was used as an entry point for accessing Hospice House in search of health care, and to construct their particular understandings of their illness and their lives. They also disclosed the social circumstances in which they were embedded and how this influenced their illness.

5.4.2 *Disclosure whilst taking part in support group activities at Hospice House*

I became aware that participants were hiding their illness to some extent from fellow group members upon embarking the vehicle. I subsequently used these observations to explore if participants would deal with their illness in the same way in the support group setting, or if they would reveal more by being removed from the local context in which gossiping prevailed.

Participants mostly engaged in craftwork. By taking part in craftwork, the participants legitimatised their membership of the support group and were at the same time acknowledged for their productivity and ingenuity. Craftwork could be regarded as a form of disclosure. It was the activity that unified a range of participants across various stages of the illness. The craft volunteers would show participants some basic sewing skills and put together a variety of ideas which participants could elaborate on. It seemed to be important see how daycare members progressed and considerable interest was given to the finished product. Taking part in the crafts was a way for members to gain acceptance from fellow participants and staff. In this way the illness was displaced although it was ever present. Volunteers would usually elaborately approve of participants' work as a means of encouragement. Even though patients might not feel physically well, they could still bypass this barrier by engaging in an activity that was physically not very demanding. Once during a support group session, despite not feeling well, Petunia nevertheless engaged in craftwork. During the morning she had been assembling a dress for her toddler daughter and did not interact with fellow members. When she called me she had already finished sewing together the sides of the toddler's dress. A kitchen volunteer overheard my fascination with her work and commented to the other participants, "*You guys, I have always told you that Petunia is ifactory ... she works like a factory ... Petunia, you*

are ifactory ... guys ... what is the Xhosa for factory?" In this way Petunia was being encouraged for her skill and gained recognition from other volunteers and fellow group members. Suddenly the attention moved away from her illness and became focused on a beautiful dress which she had completed.

Rebecca, a middle-aged Xhosa-speaking lady once called me to show me an apron that she had completed. I sat with her and excitedly she began to show me how she worked the stitching on the back of the garment in order to hide it from showing through on the right side of the fabric. I could hear in her tone of voice that she was very proud of her accomplishment and she wanted to show her ingenuity. Being absorbed by her work and the minute flow of detailed hand sewing, I could take pleasure in and recognise her inventiveness. I realised that her work was a means to gain acceptance not only from fellow group members but also from people who were not ill. Perhaps participants wanted to disclose something more than the devastating reality of the disease in their lives. Although participants did not disclose their illness publicly and directly in the context of the support group, taking part in the craft activities could therefore be regarded as another way of disclosure demanded by the context of the support group.
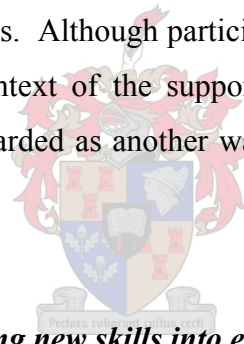
5.5   *Disclosure and integrating new skills into everyday life*

Some participants explicitly used these craft products to integrate themselves into the community. Patrick took out two felt crafted bags. With the few words of Afrikaans that we shared, and supplementing with vibrant gestures, he told me that he and his wife had sewn and decorated the bags. He pointed to the large blue embroidery capital letters which spelt his name. Then he took out another bag and proudly showed me the tassels, which he had sewn to the corners. I became absorbed in the embroidery, little buttons, and the fact that he was living with HIV/AIDS diffused into the background. He told me that he was selling some of his crafts as well as vegetables from his spaza shop adjacent to his home. In the Hospice House context it was known that he was living with HIV/AIDS and the selling of duvet covers and pillow cases from his spaza shop could be a way of disclosure of the disease to Hospice House. But at home, selling his craft works, did not necessarily have the

same connotation. Perhaps in this case it could be considered as a form of non-disclosure to the community in order to maintain his relationships with them and in this way overcome the shame associated with HIV/AIDS. He told us that people only assumed he was living with HIV/AIDS upon being collected by Hospice House.

Some participants were less explicit in showing their craftworks to others. Once, sitting with Lina admiring a pillowcase which she had just completed, I probed to find out if she had shown it to anyone in her community,

> "*No, I don't have any friends. It is only my husband and I. My husband is my friend. I have no other friends. Friends only gossip. I have shown my mother-in-law and my husband and my grandma. They think it is nice. I only show them. I don't want friends. I want to be alone. My husband promised to buy me a sewing machine for my birthday.*"

Lina did not want to disclose her illness to others, besides her close relatives and Hospice House, by showing them the crafts which she had assembled. She disclosed her illness via engaging in craftwork only to those whom she could trust and thereby avoiding gossip and the danger of social relationships being severed upon revelation of her HIV-positive status. In this case disclosure led to her new skill being acknowledged by her close relatives and she was also encouraged by the promise of a sewing machine. Non-disclosure, by not showing others her crafts, meant that Lina could maintain her position in the community. Disclosure and non-disclosure occurred simultaneously depending on the kind of relationships in which the participant was implicated.

Jeannie had been a member of Hospice House daycare for some time. She recently joined the local Peace Committee. She was using her newly acquired embroidery skills beyond the context of Hospice House daycare. Whilst winding some burgundy, green, yellow, and blue embroidery cotton for her on a piece of cardboard to take home, she told me that she had embroidered the cover page for the local Peace Committee file. She decided not to cover it as she would normally do. Instead she wanted to put her newly accomplished skills to practice. During daycare she once showed me the piece of embroidery work. In the Hospice House context, it signalled her membership of the support group and of an underlying disease. But it signalled more than a mere biological disease. Perhaps she wanted to show Hospice House that

she had been active in the community and that she was not too ill to be a productive member of society. At the same time, the embroidery work, which read *Rainbow End Peace Committee*, worked in bright colours of chain stitching, could be regarded as a form of non-disclosure to the committee members by distracting their attention away from her "invisible" illness to a beautifully crafted object that could be appreciated by the community. Jeannie told me she did not care if people told "stories" about her, although it seemed that she did not inform committee members of the link between the newly acquired decoration in the file, and the underlying lingering disease.

Disclosure and non-disclosure in these examples were ambiguous. Crafts in the Hospice House context could be equated with a way of disclosure. But outside the sphere of Paarl Hospice this same craft object could be regarded as non-disclosure because it was not equated with HIV/AIDS activities. In the Hospice House context disclosure was merely a routine activity, but in other contexts, non-disclosure seemed to be a selectively chosen strategy. Disclosure in both contexts served to maintain social relationships with those who participants disclosed to, as well as to those who they refrained from disclosing their illness.

5.6   Disclosure and the ARV contract
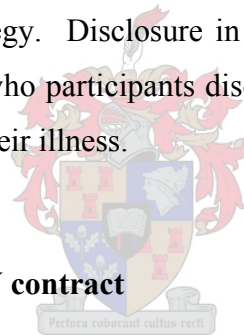
Another form of disclosure was implicated in starting ARV treatment. At first I thought any adult living with HIV/AIDS could approach a health care site in order to obtain antiretroviral treatment. But I soon discovered that this was not the case. Those in want of ARVs had to go through a process of disclosure in order to obtain ARVs. In the Hospice House sphere, participants had to sign a treatment contract. By signing the Hospice House treatment contract, the participant disclosed many things in various ways.

Felicity had been referred to Paarl Hospice before going on ARVs upon her return from the Transkei where she had been visiting her family. Although ARVs would be dispensed by the clinic, support group members who wanted to go on ARVs had to comply with Hospice House criteria as well as general ARV criteria (see Chapter 3). At Hospice House the translator would explain the content of doctor's reports in the

participants' own language. Nothing was kept from the participants. Felicity was dressed in casual shorts and a colorful T-shirt. She was coughing continuously. She handed an envelope to the nurse. Before she left for a brief visit to the Transkei she joined the Hospice House support group. Together with fellow patients she was told about HIV/AIDS and antiretrovirals. Before she could start ARV treatment, Hospice House had to assess her understanding of HIV/AIDS and readiness for ARVs. The nurse, translator, Felicity and I moved to a separate room, which would ensure more privacy. The chief nurse explained to her that I was a student researcher and asked permission that I could sit in on the session and record some observations. She agreed with a smile. Then the nurse wanted to know from Felicity if she knew what HIV/AIDS was. Hesitantly Felicity denied any knowledge of the illness and laughed. The nurse wanted to know in a cheery manner, "*Were you then not part of our many discussions?*" Felicity replied that HIV was a virus, which could cause AIDS. A contract was presented to her. The translator translated the content as the nurse read through it. Before Felicity could start using ARVs she had to sign the contract and thus subscribe to certain criteria. Felicity then mentioned that she was very weak, had diarrhoea, a chesty cough and a runny nose. She signed the contract and would be able to go on ARVs the next day. Embracing each other the session came to an end. Felicity disappeared amongst the support group engaging in embroidery work.

Firstly, the HIV/AIDS test results which Felicity presented to the chief nurse, was a form of disclosure which revealed the biophysical reality of the disease as well as its progression. But disclosure in this sense was not enough to go onto treatment. The participant had to sign a contract, which could also be regarded as an act of disclosure. But before signing the contract, the participant had to disclose verbally to the chief nurse aspects of the disease in order to assess the participant's readiness to start treatment. Signing the contract, the participant implicitly disclosed ascribing to criteria set out by Hospice House and the provincial programme to qualify for ARVs (see Chapter 3). Felicity's weakness and persistent coughing could be considered as another level of disclosure. Disclosure in this context seemed to be multi-dimensional. During this session, disclosure was prompted by the chief nurse, but at the same time it manifested as involuntary physical symptoms in the participant's body.

There might be others living with HIV/AIDS in need of ARV treatment who would not be able to disclose on all these levels due to the difficulty of complying with the criteria set out by Hospice House. Disclosure could be a barrier for these people in accessing health care. The Hospice House model of recruiting patients for ARVs might enable some to disclose their illness and in this way obtain ARVS, but on the other hand it might prevent others from managing and disclosing their illness. Disclosure, in order to obtain ARVs, occurred in many ways and these different ways need to be taken into account in order to understand the obstacles which people might face in seeking treatment.

5.7   Disclosure, ARVs and the support group

Apart from disclosure as a prerequisite for obtaining ARVs, participants had been prompted by the chief nurse in the context of the support group to disclose their experiences of treatment to fellow group members. Participants would not initiate talk about their health or illness spontaneously. But upon being prompted by Hospice House staff they seemed to disclose their experiences willingly. Soon after the first participants started ARVs the chief nurse provided them with the opportunity to inform fellow group members about their experiences of it. In the environment of the support group they could disclose certain information which they could perhaps not share in other contexts. In this way fellow group members were being initiated into the next step awaiting them.

Helen told us that she was sleeping well, had gained weight and was not experiencing any side-effects. She devised a way to overcome the new daily task of having to take her medication. In order to remind herself to take all the tablets, she put all the morning's tablets in one container and tablets to be taken at nighttime in a separate container. Jan was fortunate that his sister reminded him to take his medication. He had not at that stage forgotten to take his medication even once. Patrick continued winding embroidery cotton on pieces of cardboard whilst telling us that he used to feel very weak, but he was feeling fresh and full of energy and was not experiencing any side-effects.

In these examples, disclosure of ARV experiences occurred upon being prompted by Hospice House staff. In this context the mere physical presence of participants could be a form of disclosure to supplement verbal disclosure. The physical improvement of a participant's health could also be another level of disclosure as other participants could substantiate the verbal statements concerning the efficacy of ARVs with physical proof.

5.8 Disclosure and integrating ARVs into the everyday life

Because ARVs could relegate the illness to a level of invisibility once symptoms began to manifest, it seemed that ARVs aided participants in manoeuvering their way beyond the shame associated with the disease. Why did some participants then neglect to ensure that they had proper medication?

In order to be effective, patients had to use ARVs twice daily at set times. Once on our way to the informal settlements after daycare, Helen told us that she was running short of ARV tablets to take that night. The previous week she had arrived at the clinic too early for an appointment and was told to reschedule an appointment in three days' time. In the mean time she had run out of ARVs. She wanted to borrow three tablets from Sophie. Sophie, who was sitting in front of Helen overheard her complaint, and replied that she would not lend her ARVs because, " ... *it's expensive"*. Helen gave up trying. *"You don't care, but you are going to die ... but you don't care?"* Returning Sophie to her house, the translator accompanied her and upon returning handed three tablets wrapped in tissue paper to Helen saying that she must return it. Helen could overcome the obstacle of disrupting treatment efficacy by disclosing strategically in the context of the support group her difficulty in obtaining ARVs. This example could be regarded as a form of disclosure by borrowing ARV tablets from a fellow group member. If Helen would have disclosed her problem in other contexts she might have been ostracised further for exposing her illness in this way. Despite being shown on her "carelessness", this type of strategic, open disclosure seemed to be effective.

5.9 Disclosure and re-turning stories on the way home

Upon returning to their local communities participants seemed to face the same obstacles which caused them to mobilise various strategies in order to manoeuvre their way to health care. How did participants navigate around these obstacles in order to continue their everyday lives? If obstacles in the communities where participants live ostracised them further, it can be asked how participants guarded against being rejected and having relationships severed.

Helen enthusiastically seized the opportunity to take part in the research because she wanted to inform the university that her illness had been caused by poverty. Not far from Hospice House we drove past a prostitution house and Helen pointed to the building on the corner saying that it was a good idea the to close the place down. She told me,

> *"It spreads the illness. For R500 an hour you get a death sentence. It's a disgrace! Your whole body goes to waste. A man approached me the other day offering me R500. He recognised me from my past. I screamed. I didn't want it. I told him to back off. I don't need his R500 even if I was starving!"*

On our way back to the community Helen once told me that she did not care about "stories". She would not let "stories" kill her. She was looking after herself. She wanted to attain dignity. She was living in her little "hok" in someone's backyard and she was keeping to her appointments regularly as well as using ARVs. She told me openly that she did not have a choice back then. She had to sell her body to make a living. She was not ashamed to disclose these circumstances which she equated with leading to her illness openly.

Taking into account that I was conducting research as a volunteer representative, disclosure in this way strengthened Helen's ties with Hospice House by showing her responsibility in managing her illness. Verbal disclosure pointed to several things besides the biophysical reality of the disease. By disclosing the cause of her illness to me, Helen safeguarded herself against being blamed for living with HIV/AIDS. She thus strategically decided how she would disclose her illness and to whom she would reveal which aspects thereof. By doing this she also informed her fellow support

group members that she was not to blame for her illness because they were also present. This way she strengthened her ties with Hospice House and fellow group members. ARVs provided her with the opportunity to manage her illness. Taking ARVs could be a form of disclosure in the Hospice House environment because staff were aware of Helen's illness condition. She had no need to disclose her illness experiences to the neighbourhood, where she was living as ARVs relegated the disease "invisible". In this way she could overcome gossip. ARVs in this case could thus be regarded as a form of non-disclosure in her neighbourhood. Disclosure seemed to bring many aspects of the illness to the fore. Again disclosure and non-disclosure occurred simultaneously and could only be understood in relation to the social context in which these acts unfolded. Driving back home one day after spending the day at Hospice House, I caught a sight of the white minibus driving through the streets of Paarl. I had to look twice to make sure it was the same minibus that had taken the participants to and from the informal settlements. Had I not gained an insider's perspective, the minibus would probably be just another local taxi transporting people from one place to another. But by having had the opportunity to spend some time with the participants, tagging along with them on their various routes to Hospice House, I could renegotiate my unexamined idea of the local taxi which everyone and anyone could access. Observing and taking part with the participants in various acts in and around the minibus, we constructed a diverging kaleidoscope view from the inside by looking at various ways in which disclosure could be managed around the "invisibilities" of HIV/AIDS.

5.10   Disclosure and the Fairyland support group

Various HIV/AIDS support groups offer different spaces to contain, safeguard and assist members with certain difficulties associated with their illness. The setting, philosophy of each group and various related factors might be influencing who could make use of these facilities and the ways in which illness experiences would be disclosed. If participants would be safeguarded from shame associated with the disease at support groups, the question remains as to why participants living with HIV/AIDS decided not to attend the Fairyland group in managing their illness. If participants could devise ways to manage disclosure of their illness by embarking the Hospice House vehicle in such a way as to bypass the shame and humility associated

with the disease, it needs to be explored why participants could not devise strategies to manage disclosure of their illness in a similar way in order to join the community support group right on their doorstep.

Jeannie and Ina, two Hospice House support group members living with HIV/AIDS initiated the Fairyland local support group in March 2004. As we drove through the neighbourhoods, the community hall in which the support group was held towered majestically above the makeshift "hokke". It was situated within walking distance of most Hospice House daycare members. Despite the proximity Jeannie told me that Paarl Hospice daycare members refused to join the Fairyland support group. I thought they would choose to make use of the proximity of the facility as it would be less disruptive. If they attended the local Fairyland support group they would not have to wait on a minibus. Neither would the minibus have to drive up and down the streets to collect fellow members. I came to realise that participants preferred to bypass the local support group and chose to go to Paarl Hospice, an unfamiliar place removed from the community. Jeannie, a member of both support groups told me that the Fairyland group demanded people to introduce themselves at each weekly gathering. Members had to disclose upfront that they were living with HIV/AIDS. This turned out to be an unpleasant experience for most. Some started crying upon verbally revealing their status. Jeannie told me that some participants would not tell their families because "*... stories will do the rounds ...*" and for the same reason participants kept their status from their neighbours. She then went on telling me that the Fairyland support group failed once before because people attending it were not sick and exploited the situation by betraying those whom disclosed their status to the rest. She told me, "*That's how people knew and that's why the group didn't work. These people are dirty and rude. That's why they spread rumors*".

Accessing the Fairyland group could thus be regarded as an act of disclosure. This act would put participants at the risk of being exposed to "rudeness" and "gossiping" in the local neighbourhoods and even in the proximity of their own homes. A more direct form of disclosure encountered in the Fairyland support group would be the overt verbal disclosure of an HIV-positivity. It seemed that Hospice House support group members were not ready yet to reveal their illness in this way, and thus refrained from making use of this facility. They preferred to attend a support group

which would buffer them against these obstacles whilst dealing with their illness. Even though Paarl Hospice was driving through the streets weekly to collect members for daycare, the same degree of shame and exposure was not associated with being a Hospice House support group member because the real purpose behind the Hospice House vehicle driving through the streets was unknown and not associated with HIV/AIDS. Each support group accordingly provided a certain space in which members could be prevented or enabled to disclose their illness in certain ways.

Ina told me that apart from disclosing her status in the context of the Fairyland support group, she shared her status with her neighbours. She said,

> "*I told my neighbours but when I disclosed to them they told me that I am not HIV-positive. I am not looking as someone with HIV-positive because they said the people who are HIV-positive they didn't tell the people their status. They don't believe me. They still don't believe me. I tell them they don't believe me. They think I got money from someone that I must tell them that I am HIV-positive*".

Ina could simultaneously disclose her illness verbally and physically (by being present in the Fairyland support group) because, upon disclosing her illness to those living in close proximity of her she was not believed and therefore she was not ostracised. The combination of the absence of physical symptoms and verbal disclosure of the disease seemed to provide Ina with the opportunity to remain "invisible." Ina did not have to combat shame in this case. Instead she struggled to convince her neighbours that she was indeed living with HIV/AIDS.

It seemed that each individual would disclose his or her illness depending on the situational context and seek appropriate circumstances and ways in which to disclose. The obstacles facing people living with HIV/AIDS which relegated the illness to a state of "invisibility" differed situationally. Different possible forms of disclosure were therefore weighed up and subsequently "acted out" in relation to the circumstances.

**5.11   Disclosure at related HIV/AIDS events**

I was astounded to see that Hospice House support group members would disclose their status openly to strangers in places outside the boundaries of the support group. Participants strategically found ways to disclose only certain aspects of their illness in the neighbourhoods where they were living.   In the Hospice House context participants also guarded their illness experiences.   The question remains then as to why participants would disclose their HIV/AIDS illness experiences openly at the celebrations held at Ekwezi and again at the Hospice House volunteer course.   How did participants manage disclosure in these places?

5.11.1 *Disclosure at the celebration of the first month of ARV roll-outs*

Members of the Hospice House support group openly addressed unfamiliar audiences at two separate occasions.   Hospice House group members were amongst the first in Paarl to go on ARV treatment and for this reason had been invited to take part in the celebration of the first month of ARV roll-outs held in March 2004 at Ekwezi (a community facility near the informal settlements).   I followed three Hospice House daycare members to the celebrations to find out why they were being so candid about their illness in this context when the exact opposite was found in the neighbourhoods and at Hospice House.   Even though the focus of the celebration was on people living with HIV/AIDS to inform a wider audience about their lived experiences of ARVs, and that attendance would implicitly mean that a participant was living with HIV/AIDS, three members of the Hospice House support group nevertheless insisted on attending the celebration and therefore disclosed their illness by being present.

Upon our arrival, Helen asked me where the rest of the Hospice House participants were.   She then said that, if they knew the meeting was not going to be held in Mbekweni, they would have attended.   I found this statement supporting of what I had observed so far.   It seemed that participants did not want to be seen living with HIV/AIDS in their neighbourhoods.   Their presence at an HIV/AIDS event held in the vicinity of where they were staying would have been a form of disclosure to others who would have seen them.   Perhaps it would be easier for participants to disclose

their illness in a context removed from a place which they associated with providing obstacles to their path to health care. If they disclosed their illness by being present at an HIV/AIDS event held in Mbewkeni, for instance, their personal and social relationships could have been at risk. Helen was willing to disclose her status in front of international television, medical staff and others living with HIV/AIDS and facing similar barriers. She did however not want to disclose her illness in the neighbourhood where she was staying. By disclosing her illness at the event she was applauded for this act and gained recognition. She told me, "*I don't care ... people must tell if they must tell* ". Helen addressed unfamiliar audiences, but she told me she was not ready yet to disclose to her mother. She also told me that her mother was drinking. "*If I tell her she will drink more*". Even though her mother was living in the vicinity where she was staying, she only assumed her daughter was sick. Helen's mother wanted her to tell her that she was living with HIV/AIDS. She managed to make use of alternative routes to negotiate new relationships and to access places which would safeguard her from the stigma and obstacles in her local environment even though ties with her local neighbourhood and with close family members were severed by the illness. The situation in which disclosure took place and the circumstances in which the individual was embedded, influenced the way in which disclosure took place.
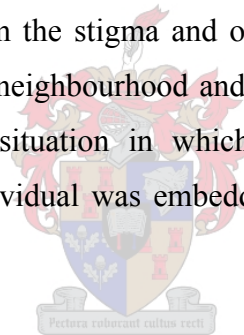
During the proceedings, participants were offered the opportunity to share their experiences of ARVs with the audience. Even though the morning's processions were conducted in a language unfamiliar to Felicity (she was a young Xhosa-speaking woman), and most other participants, which means they had been excluded from the official talk, Felicity immediately stood up addressing the audience in Xhosa. She wanted to disclose publicly and differentiated herself in this way from the rest of us who were not ill. She told us that she was very ill, but after starting treatment she felt better. In the context of "celebrating victories of the future, of individuals, of families and of communities " she disclosed her experience of treatment. Perhaps by refusing to visit the community support group in Fairyland, despite it being a few blocks from where she was staying, Felicity showed that the circumstances in which she was embedded, did not allow her to disclose her illness in the same way as she did at Ekwezi. It seemed that the places she decided to visit offered an opportunity for her to bypass the barriers which she might have to face in the informal settlements. She

would rather disclose to unfamiliar people in this context than she would in a place where her illness would count against her. Disclosure in this context could be regarded as an selective act which occurred in relation to the specific social situations in which participants were embedded in relation to a wider context.

5.11.2 *Disclosure at the volunteer course*

Having followed members of the Hospice House support group for some time I noticed that in making their way to health care they would disclose different aspects of their illness in different ways and places. In the context of the volunteer course I found that participants were quite comfortable in openly disclosing concerns about their illness to the volunteers upon being probed. Again the volunteer course was held in a place removed from the local community and, although the audience was mostly unfamiliar, there were some familiar faces that the daycare members had learnt to trust. The chief nurse invited a few people living with HIV/AIDS from the Hospice House support group to address the volunteers undergoing the volunteer training course and to share their experiences of living with HIV/AIDS with us.

At a later stage, during a follow-up interview, I wanted to know from Patrick why he decided to share his illness experiences with us if he was cautious not to disclose his status in the neighbourhood where he was staying openly. He told me,

> "... *what makes me talk there is because of the education that I got from Hospice. So it wasn't difficult for me to disclose myself to other people. Hospice teaches me about safe sex... I was ashamed at first listening to people talking about safe sex ... using condoms ... I was thinking that it was something that someone must talk to you in private, but ever since Hospice told me about safe sex, I decided no ... it's not a shame that there are a lot of people who are living with HIV ... so it's no shame to go out and talk about it ...* "

Openly talking about his illness might however not be tolerated in the neighbourhood where Patrick was staying. Talking about the illness would mean that one transgressed the taboo of talking about private matters in public. He could therefore not disclose his illness in this context. He seemed to be vigilant in seeking ways not

to be trapped by the shame caused by the illness. He did this by selling crafts and fruit from his spaza shop and not telling people where he gained the new knowledge and skills. But he found a way to overcome the shame associated with the illness. He was using ARVs and was " *… feeling fresh and full of energy*". He only disclosed his illness openly to audiences and at places where there was no risk of stigma and humilitation. The way in which he disclosed his illness experiences was directed by the specific situation of the volunteer.

Upon being probed regarding what happened when she found out about her diagnosis, Lizzie disclosed a diverse range of things associated with the discovery. She was employed at a bakery when she got tested the third time. Lizzie told herself,

"*I must be strong and I wasn't getting strong. Every time someone asked me for a slice cake and coffee I was scared. I was so scared to cut the cake. Then the manager wanted to know why I called someone to cut the cake every time and why I did not do it myself. I decided I was not going to tell anyone. I would rather die. I started using medications and still I did not tell anybody. I did not want to tell my mom, and told her I had low blood when I took my medicine. I was very skinny at the time. For seven years I kept it my secret. I was married when I was diagnosed. But things have changed. My husband got cross when he found out. He accused me of bringing the virus. He asked for a divorce. He died October 2003. I've been staying with another lady in Mbekweni. But there is life beyond HIV. I carry on, I visit the doctor regularly. It is not so bad living with HIV. It was bad at the time when I had to face it. I was confused. I was loosing my mind then*".

 She told me during a follow-up interview why she decided to speak out at the volunteer course.

"*I am not scared anymore … it is the pastors that gave me strength that you must believe and not be scared*".

Lina openly disclosed the barriers affecting her in seeking health care. The space offered at the volunteer course for participants to disclose their illness perhaps enabled them to disclose aspects of their illness in certain ways which might remain "invisible" and which were overlooked in other contexts. Lina could bring other aspects relating to her illness to the fore, thereby illuminating the way in which she

understood her illness. Disclosure in this context was relational and situational, and prompted by Hospice House staff, who encouraged participants to address a particular audience. It could therefore not be expected that this type of disclosure of illness experiences would occur in other places and in similar ways. This space safeguarded participants from rejection which might occur if they revealed these illness experiences in a similar fashion in other situations. The mere physical presence of five participants addressing the volunteers, accompanied by the chief nurse and translator, could also be regarded as disclosure. But in order to interpret it as an act of disclosure, the situation in which this act was embedded had to be taken into account.

5.12   (Dis-)close(-ure)

In this chapter I have presented the various ways disclosure unfolds by following participants living with HIV/AIDS as they navigate their way to Hospice House and related events in search of health care. Disclosure of the illness was not only problematic upon being tested and coming to terms with seropositive test results. Participants had to continuously manoeuvre their way through various obstacles on the road to health care. These obstacles had an impact on the way in which participants disclosed their illness. Barriers could be found in the neighbourhoods in which participants resided or in the Hospice House context. Participants moved within and between social and personal relationships in and beyond their neighbourhoods. But they also had to establish new relationships in seeking treatment. In each of these relationships shame and stigma associated with the disease seemed to be a possible barrier to seeking treatment. Participants nevertheless managed to find ways in which the illness and illness experiences could be disclosed whilst maintaining existing relationships and establish new ties with Hospice House staff and volunteers.

In order to understand the ways in which participants constantly disclosed their illness, their embeddedness in particular circumstances and relationships had to be taken into account. Disclosure seemed to be a multi-faceted process, which revealed many aspects of the biophysical reality, as well as social experiences of the disease, by taking into account the situational factors facilitating or inhibiting disclosure.

In the following chapter I will conclude the study by drawing together the findings generated by fieldwork by means of theory grounded in the data. I will then compare my results with the findings I came across in the literature (as discussed in Chapter 2).
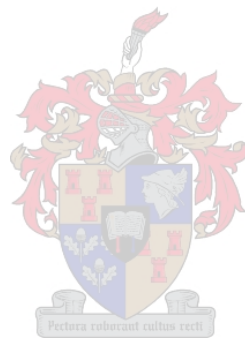
CHAPTER SIX

CONCLUSION

6.1   Introduction

In the paragraphs below I will conclude the current study with a discussion of disclosure generated whilst conducting fieldwork.   I will compare the empirical findings with how the concept of disclosure was framed in the literature. Finally, I will show how "acts of disclosing" unfolding in the field could account for the various ways in which participants accessed Hospice House and related events.

6.2   Disclosure

The literature (see discussion in Chapter 2) regarded disclosure as problematic only at the time of HIV/AIDS testing. Studies were conducted retrospectively and did not take the actual process or context of disclosure into account.   In the literature disclosure was equated with making an HIV-positivity known.   Disclosure was framed as a once-off event and seemed to be a one-way occurrence in which the person living with HIV/AIDS would rationally and publicly disclose a single fact, namely the participant's HIV status.   Disclosure and non-disclosure were presented as if they were polar opposites and individuals had the choice to engage in either full active disclosure or complete secrecy.   In a minority of the studies, a third party facilitated disclosure upon agreement by the person living with HIV/AIDS. In most cases, self-disclosure prevailed. These studies did not account for wider HIV/AIDS illness experiences and focused on disclosure of the biophysical reality of the disease. In some cases disclosure entailed the additional revealing of so-called "high-risk behaviour" because most of the studies were conducted to investigate unmapped high-risk sexual behaviour informing prevention and education programmes aiming at behaviour change.

6.3   "Acts of disclosing"

Political economy approaches suggested that HIV/AIDS is spreading unequally amongst the impoverished worldwide. These approaches revealed the structural facts underlying seroprevalence progression by exposing the social inequalities facilitating the development of the disease (Fassin 2002: 66). But I had to look elsewhere for an explanation of how participants accessed Hospice House despite their disenfranchised position. By means of grounded theory I could situate illness experiences in the context of the life of participants living in the informal settlements around Paarl, and could explore disclosure as enacted from within these circumstances. A grounded theory approach enabled me to explore the general antiretroviral treatment roll-out for adults whilst staying close to participants' experiences of this national event in the context of the Hospice House support group and related events for people living with HIV/AIDS.

By means of exploring participants' illness experiences, I could look at various ways in which the participants regarded themselves to be ill without discarding the biophysical reality of the disease. Grounded theory also allowed me to explore the different levels of activity in which participants engaged, and I could therefore look beyond the mere efficacy of particular treatment models. It also enabled me to establish how participants responded to the particular model and how they infused meaning to their behaviour. I found disclosure to be the central unifying theme explaining the various ways in which people from the informal settlements around Paarl living with HIV/AIDS accessed Hospice House and engaged in related activities. I found that disclosure in the context of the study seemed to be more complicated than the clear-cut, public verbal statement of a "single fact" as pointed out in the literature. In the current study disclosure seemed to implicate more than announcing the participant's HIV status.

Because HIV/AIDS could be regarded as an "invisible" chronic illness, participants had to manoeuvre their way past various obstacles, such as shame, gossiping and stigma associated with the disease, and they were faced with the possibility of having relationships severed upon making the illness known. In their own communities participants were moving around in networks of social and personal relationships. By

accessing a treatment site, participants had to establish new social ties. Disclosure seemed to be a vital aspect of each set of these relationships. Participants had to move past the "invisibilities" associated with HIV/AIDS, which seemed to prevail at many different levels within the arrangement of relationships. Disclosure was found to be problematic not only in establishing new social ties regarding Hospice House but also in the communities where participants were living. Although verbal disclosure of an HIV-positivity was initially a prerequisite of qualifying for the Hospice House support group, other ways of nuanced disclosure seemed to be central in maintaining membership.

Revealing HIV/AIDS in the context of the current study seemed to be more complex than the mere statement of an HIV-positivity or the decision not to inform others of an HIV status. Various acts of disclosure occurred across the spectrum between the extremes of disclosure and non-disclosure. Between that which is said and that which is not said, several modes of disclosure could be found and the context in which the process unfolded had to be taken into consideration.

Although HIV/AIDS was the point of entry for revealing illness experiences in accessing Hospice House, I never came across upfront disclosure by any participant who openly stated, "*I am HIV-positive*". I found that disclosure was not merely a single event but an ongoing event of disclosing. As I followed participants to the various related events and spaces associated with the support group, I realised that disclosure was not a once-off event, but that it was continuously changing. In this study, disclosure seemed to be situated somewhere between voluntary and involuntary revealing of the illness, and it would be practical to situate the process of revealing the illness across the spectrum between complete silences and explicit statements. By exploring silences from the participants' perspective, I found that silences in some instances seemed to be a vital form of disclosure, and it should therefore not merely be trivialised by more accessible and overt public disclosure utterances. But in order to understand these nuanced ways of disclosing, the various contexts in which disclosure unfolded had to be taken into account.

6.4   (Dis-)close(-ing)

In the context of the study, there seemed to be no charted way in which participants could disclose their illness, as each participant was caught up in complex worlds and were facing different challenges in confronting his/her illness. Disclosure seemed to be situational and seemed to fit the specific context in which it occurred. I found no absolute answer to provide a universal solution for participants to disclose their illness. Instead I found that each participant managed to navigate his/her way through a range of barriers, and they therefore revealed their illness as lying somewhere between full active disclosure and complete secrecy and somewhere between voluntary and involuntary disclosure. In this study, disclosure could therefore be regarded as a multi-faceted, situational process which unfolded in relation to specific contexts and which could be mapped by the various ways in which individuals embedded in complex worlds managed to manoeuvre their way past obstacles in order to access a treatment site. Grounded theory was appropriate for investigating the unfolding of the actual processes and complexities of disclosure on the way to the Paarl Hospice support group as well as in the support group environment.

A possible way to overcome the restricted meanings of the concept *disclosure* as found in the literature, is to take into account the infinite ways in which variously embedded actors revealed illness experiences by navigating their way through barriers to Hospice House. The forms that disclosure took seemed to be situationally contingent. I found that disclosure took place in the flux of everyday life and to understand these multiple "acts of disclosing" I had to explore the circumstances and contextual relationships in which these acts unfolded.

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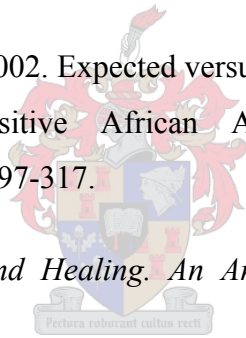
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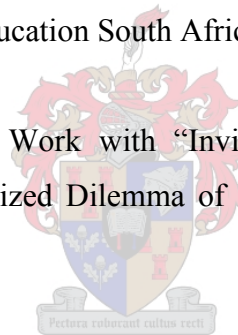
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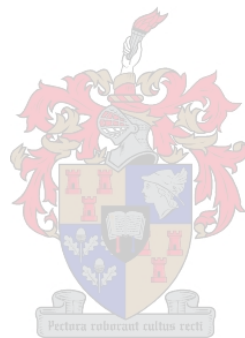
Appendix A

CONSENT FORM

The researcher has explained that she would like to use our conversation as part of her research for the completion of her Mphil degree in Social Anthropology. I am reassured that she will be considerate and ethical in the use of our conversation and will not use my name at any stage. I have agreed that she may tape and transcribe our conversation for the purposes of the research.

Signed: …………. Signed: …………..

Date: ……………. Researcher: Rhonddie le Roux