

**TALKING ABOUT MEDICAL TALK:
EXPLORING EXPERIENCES REGARDING COMMUNICATION IN
HIV/AIDS HEALTH CARE IN A TERTIARY HEALTH CARE
SETTING**

A Dissertation submitted to the Division of Communication Sciences and Disorders,

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Pathology

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ABSTRACT

The challenges of communication in the multilingual and multicultural South African health care context are exacerbated by the complexities and demands introduced by HIV/AIDS. Despite the wealth of information on aspects related to the doctor-patient relationship, communication in HIV/AIDS care settings has received very little attention in the literature. South Africa leads the HIV/AIDS pandemic in numbers, yet almost no locally relevant information is available on the nature of communication in HIV/AIDS care settings. The study has aimed to address this need. A qualitative research design within an interpretive paradigm was followed. The primary aim of the study was to describe and explain communication in a paediatric outpatient HIV/AIDS clinic from the multiple perspectives of caregivers, counsellors and doctors. Semi-structured interviews with 11 caregivers of HIV positive children, four NGO trained HIV/AIDS counsellors and four doctors were conducted. A phenomenological data analysis procedure was followed. Rich descriptions of the communication experiences of the three groups of participants were constructed and five central themes were identified. Communication in the clinic meant sharing meaning across differences. The language and cultural divide between caregivers and doctors could be successfully bridged by a doctor facilitative conversational style and the participation of counsellors in communication. Effective communication was dependant on systemic support and infrastructure. Communication in the clinic involved more than words, was shaped by context, required the collective effort of all role players, and was transactional in nature and powerful to affect the lives of caregivers, counsellors and doctors. Recommendations regarding practice and education were made.

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Deo Gloria.

Vir Paul

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1. INTRODUCTION

“...in order to accomplish any public or private goals, people have to talk to each other, and in more and more cases, the people come from more or less different cultural backgrounds” (Tannen, 1985, p. 203).

Intercultural¹ communication is a reality of everyday practice in public health care institutions in South Africa. Yet very little local research has been published on this subject (Levin, 2004). The current study aimed to describe the experiences of caregivers, counselors and doctors regarding communication in paediatric HIV/AIDS care in South Africa. The study formed part of a larger funded² research project namely the Health Communication Project that has been running since 2000 and is based at the University of the Witwatersrand (Wits) under directorship of Professor Claire Penn of the Department of Speech-Language Pathology and Audiology. The goal of the Health Communication Project is to examine the challenges of communication in the South African multicultural and multilingual public health care context across different disease processes and health care settings. The project has included studies of interpreted and direct doctor-patient interactions in various contexts including community based Audiology (Evans, 2000; Fisch, 2001) and tertiary level medical paediatric wards (Levin, 2004; Prince 2004). The project has also included studies on communication in HIV/AIDS health care (Garcia, 2004; Steenkamp, 2004; Rust 2005). However, the current study is the first to describe communication in HIV/AIDS care from the multiple

¹ The terms intercultural and cross cultural are used interchangeably throughout this dissertation.

² The Health Communication Project has been funded by the Medical Research Council (MRC), the South Africa Netherlands Research Programme on Alternatives in Development (SANPAD), the Carnegie HIV/AIDS Grant Wits and the National Research Foundation (NRF).

perspectives of caregivers, counsellors and doctors through analysis of in-depth semi-structured interviews.

The first part of the introduction provides a broad context for the current study by paying attention to issues central to communication-in-health theory. Various factors that influence communication between health care personnel and patients will then be discussed with specific relevance to the current study namely, the broader South African public health care context, HIV/AIDS specific issues as well as patient- and doctor characteristics. Finally, research strategies in the field of communication-in-health as well as the state of research on communication in HIV/AIDS care in other parts of the world and in South Africa will be discussed.

1.1 Communication in medical practice: central, important and complex

Communication is central to the practice of medicine. Diagnosis is dependent on high-level interviewing skills that enable the doctor to draw correlations between clinical and laboratory data (Engel, 1977). However, medicine's irrevocable turn in the scientific direction during the modernist time period (Aita, McIlvain, Backer, McVea and Crabtree, 2005; Moodley, 2000) has led to "bypassing the patient's verbal account by placing greater reliance on technical procedures and laboratory measurements" (Engel, 1977, p.132). Subsequent changes in patterns of medical care have led to the replacement of longstanding personal doctor-patient relationships to "short-term encounters with numerous disparate specialists and other health workers" (Korsch, Gozzi and Francis, 1968, p.855). Despite advances in sophisticated technologies and scientific medical knowledge regarding diagnosis and treatment, interpersonal communication remains the primary tool for the exchange of information between doctor and patient (Street, 1991, in Ong, de Haes, Hoos and Lammes, 1995).

In addition to playing an important part in arriving at a diagnosis, doctor-patient communication serves various other functions. Firstly, communication creates the relationship between doctors and patients (Coyle and Sculco, 2003; Ong et al., 1995). Secondly, communication enables doctors and patients to exchange information. The

informational needs of both doctors and patients are met when both parties alternate between giving and seeking information. Thirdly, medical communication allows doctors and patients to reach the ideal of 'shared decision making' where both parties are involved in treatment related decisions (Ong et al., 1995).

Literature on doctor-patient communication specifies various doctor communication behaviours, such as instrumental versus affective behaviours, verbal versus non verbal behaviours and medical versus everyday language registers (Ong et al., 1995). Instrumental (task focussed and cure orientated) and affective (social-emotionally focussed and care orientated) behaviours both form part of the doctor's role functions (Ong et al., 1995). Instrumental behaviour refers to the doctor's technical skills that are used to solve problems and which award the doctor his/her expert status (Hall, Roter and Katz, 1987, in Ong et al., 1995). Affective behaviour is used to establish and maintain positive doctor-patient relationships (Buller and Buller, 1987, in Ong et al., 1995) and to distinguish the patient as a person as opposed to a case (Ben-Sira, 1980, in Ong et al., 1995).

Doctors' use of medical terminology frequently causes problems for patients (Bourhis, Roth and MacQueen, 1989; Helman, 1994) and is described as an "outstanding barrier to communication" (Korsch et al, 1968, p. 862). Doctors are considered as functionally bilingual since "they speak at least their native everyday language (EL), and they also are fluent when in a highly specialised register, namely medical language (ML)". Patients however are unfamiliar with most of the medical terminology and thus have a better understanding of the doctor's message when EL is used as opposed to the specialised ML register (Bourhis et al., 1989, p. 339). An interesting finding of Bourhis et al.'s (1989, p. 345) survey of communication in a Canadian hospital setting was that doctors had a higher estimation of the frequency with which they converted to EL during interaction with patients, compared to the patients' and nurses' estimation of the doctors' convergence within consultations. One explanation offered in response to this finding is that of implicit knowledge, namely that "after years of medical practice, it may be difficult for doctors to clearly differentiate between medical and everyday language when

discussing medical issues with patients". Doctors may thus perceive medical terminology commonly used in practice to belong in EL, rather than ML.

However, ML is not entirely unwelcome among patients. Billings-Gagliardi, Mazor and Belanger (2001) found that lay people appreciated essential and relevant terminology, such as the medical name of the diagnosis, but that irrelevant medical terms lead to confusion. Korsch et al. (1968, p. 863) interestingly found that not all mothers were dissatisfied when medical language lead to misunderstandings in paediatric consultations. Some mothers were impressed with "the quantity and fancy nature thereof, and possibly felt flattered".

In addition to identifying and examining different communication behaviours, communication-in-health research also often assesses the influence of doctors' behaviour on the behaviour and well-being of patients. The four most commonly used patient outcomes measuring the extent of this influence include patients' satisfaction, adherence to treatment, recall and understanding of information and health and psychological outcomes (Ong et al., 1995). The extent to which the doctor meets the patient's expectations influences the patient's satisfaction and/or adherence to treatment. Patients expect doctors to provide them with information and explanations regarding the nature and the cause of the disease. They also expect doctors to display affective communication behaviours (Korsch et al., 1968).

Patients often find it difficult to recall information that was shared during interactions with health care professionals (Ong et al., 1995). There is an association between the patient's recall and understanding of information and the amount of information given, the health care professional's information giving behaviour and the time spent on information giving (Ong et al., 1995). The limits of human memory, aggravated by the stress often experienced during medically related interactions, further strain patient understanding and recall (Glascoe, Oberklaid, Dworkin and Trimm, 1998). Certain doctor communication behaviours are associated with a better health status in patients, such as little controlling behaviours, sufficient affective communication and information giving

(Kaplan, Greenfield and Ware, 1989, in Ong et al., 1995). The effect of doctors' communication behaviour on patients' psychological well-being is frequently illustrated in psychosocial oncology studies. When cancer patients receive insufficient amounts of information psychological difficulties such as uncertainty, anxiety, depression and problems with coping may occur (Ong et al., 1995). Coyle and Sculco (2003) recently found that missteps in communication with cancer patients lead to loss of hope, a sense of abandonment and reduced feelings of self-worth and dignity.

One of the reasons for the increasing interest in communication between doctors and patients is the complex nature of this form of discourse (Ong, de Haes, Hoos and Lammes, 1995). The doctor-patient relationship involves "interaction between individuals in non-equal positions, is often non-voluntary, concerns issues of vital importance, is therefore emotionally laden and requires close cooperation" (Chaitchik, Kreitler, Shaked, Schwartz and Rosin, 1992, in Ong et al., 1995, p. 903). All interactions in health care can be seen as intercultural "as patients, at the very least, do not share the terminology, assumptions and norms of the health profession culture" (Wohl, 1989, in Ulrey and Amason, 2001, p. 450). Doctors and their patients view ill health in different ways. The doctor views disease through the medical model that bases diagnosis and treatment on observable and quantifiable facts. [The patient's perspective of his/her disease is often very different from that of the doctor, and is influenced by personality and background as well as the cultural, social and economic characteristics of the context in which the illness occurs.] Clinical interaction between doctors and patients are thus communication between different perspectives which ultimately challenges the doctor-patient encounter, as well as management decisions (Freeman, 2004; Helman, 1994). The interaction between the medical and lay perspectives of disease is further influenced by the physical context in which it occurs, and also the social class, gender- and age groups of the respective parties. Doctor-patient interaction occurs between "two parties separated by differences in power" which "may be based on social class, ethnicity, age or gender, and is a crucial influence on any consultation" (Helman, 1994, p. 136).

Literature on doctor-patient communication also emphasizes the reciprocal nature of communication between these parties. Various interdependent expectations and communication roles have been identified for patients and doctors. Patients expect doctors to pay attention to their complaints and doctors correspondingly expect patients to provide them with information (Shadid, 1993). Patients also have the communicative task of obtaining adequate explanations whereas doctors have the task of providing adequate explanations and advice (Erzinger, 1991). Other interdependent communication tasks include the patient's task to describe his/her concerns and the doctor's task to explore the patient's symptoms. Erzinger (1991) also found that patients have the task of developing a personal relationship with the doctor, whereas the doctor had the task of understanding the patient's personal situation. The overall success and atmosphere of the clinical interaction is dependent on the extent to which patients and doctors meet each other's expectations and assist each other in performing these and other communication tasks (Shadid, 1993; Erzinger, 1991).

Despite the complexity and importance of communication in medical care, it is only recently that under- and postgraduate training started paying attention to medical students' communication skills (Maguire and Pitceathly, 2002). Training in communication skills has gained increasing importance in medical education around the world (Simpson, 1991, in Dacre, Richardson, Noble, Stephens and Parker, 2004) and in South Africa. For instance the Universities of Cape Town (UCT) and the Stellenbosch (US) have recently included specific focus on communication skills in their undergraduate curricula (Penn, Evans, Fisch and Ogilvy, submitted; Levin, 2004; Faculty of Health Sciences, Stellenbosch University, 2003). Effective communication skills are included in definitions of the doctor's professional competence (Epstein and Hundert, 2002) and are seen as a requirement for ethical health care delivery (Moodley, 2000). Doctors benefit in various ways from effective communication skills. Firstly, good communication skills are important predictors of patient trust (Thom and The Stanford Trust Study Physicians, 2001). Good communication skills also enable doctors to identify their patients' problems with greater accuracy. Finally effective communication skills

lead to greater work satisfaction and less work stress among doctors (Maguire and Pitceathly, 2002).

Recent studies of communication in health care contexts have begun to acknowledge that factors beyond doctor and patient characteristics influence medical interactions (Aita et al., 2005; Brown, Harris, Webster-Bogaert, Wetmore, Faulds, and Steward, 2002; Kelly and Brown, 2002; Crabtree, Miller and Stange, 2001). These factors include the broader health care context and practice/system characteristics. The nature of the disease that is discussed also impacts on the doctor-patient interaction. Patients' needs and expectations regarding communication and relationships with doctors are influenced by disease characteristics (Ong et al., 1995; Battegay, Weber, Willi, Eich, Siegenthaler and Lüthy, 1991). Communication is especially important in the case of life threatening and/or chronic diseases such as cancer, diabetes, rheumatoid arthritis and human immunodeficiency virus/ acquired immune deficiency syndrome (HIV/AIDS) (Lazcano-Ponce et al., 2004; Coyle and Sculco, 2003; Ajoulat, Libion, Bois, Martin and Deccache, 2002; Brown et al., 2002; Ong et al., 1995). The specific factors that might have an influence on communication in paediatric HIV/AIDS care in South Africa will now be discussed.

1.2 The broader South African public health care context

Communication between caregivers, counsellors and doctors in a South African paediatric HIV/AIDS clinic must be studied against the backdrop of the country's history and current practices. South Africa is one of the world's most unequal societies (Fallon & da Silva, 1994, in McIntyre and Gilson, 2002). Apartheid policies had the chief objective of maintaining economical and political power in the hands of white people. These policies have thus promoted racial disadvantage in terms of access to economic and social resources and have thereby created racial differences in socio-economical status (McIntyre and Gilson, 2002). Eleven years after the 1994 democratic elections still sees economic and social privilege concentrated in white groups (Nattrass and Seekings, 2001 in Schneider and Fassin, 2002). After coming into power in 1994 the African National Congress's (ANC) vision for the re-structuring of health services came into effect. The

ANC's National Health Plan had the vision of creating a "single, comprehensive, equitable and integrated National Health System (NHS)" (African National Congress, 1994, p. 19). The ANC's health plan and the new White Paper on Health (Department of Health, 1997) emphasize primary health care (PHC) similar to the Alma Ata declaration. PHC "embodies the concept of community development, and is based on full community participation in the planning, provision, control and monitoring of services. It aims to reduce inequalities in access to health services, especially in the rural areas and in deprived communities" (African National Congress, 1994, p. 19).

However, the South African public health care context is still characterised by a vast language divide between doctors and the majority of patients. South Africa has eleven official languages with isiZulu and isiXhosa having the highest number of first language speakers (Statistics South Africa, 2001). Yet the majority of South African health care professionals - with the exception of nurses - are proficient in only English and/or Afrikaans (Drennan and Swartz, 2002). The language divide is a legacy from the apartheid era as apartheid policies gave limited opportunity to black South Africans to train in health care professions other than nursing (Marks, 1994 in Jewkes, Abrahams and Mvo, 1998). Although recruitment practices of training institutions have since shifted, the language demographics of health care professionals are likely to change slowly (Drennan and Swartz, 2002). Interpreting between health care professionals and patients from African language groups was thus always and continues to be part of the South African public health care context (Drennan and Swartz, 2002; Wood, 1993).

1.2.1 Interpreting in South African health care

No formal language policy has been developed or formulated for the South African health care context (Schwartz, 2004). There is also no provision for official interpreter posts in the public health sector (Beukes, 1996 in Drennan and Schwartz, 2002). A wide variety of training expertise and functions exist among medical interpreters (Penn et al., submitted). Improvements have been made to the limited training opportunities that existed for interpreters in the African languages (Du Plessis, 1999). The University of the

Orange Free State (UOFS) (Du Plessis, 1999) as well as non-governmental organisations elsewhere in the country (Ntshona, 1999) offer training programmes in interpreting. Some of the historically black South African universities have also started to implement changes to address the unique needs of interpreting training in South Africa (Du Plessis, 1999). Although trained interpreters might thus be employed by health care institutions, most institutions continue to rely on *ad hoc* interpreting arrangements where anyone who speaks the patient's language may be called upon to interpret (Roberts, 1997, in Drennan, 1998; Wood, 1993). Other medical, allied health care- or nursing personnel, or even non-medical staff members, family members or fellow patients may act as *ad hoc* interpreters (Wood, 1993). When *ad hoc* interpreters, other than nurses, participate in consultations, confidentiality and the accuracy of interpreting becomes problematic (Schwartz, 2004; Fish, 2001). Levin (2004) reported that only 60% of caregivers were satisfied with the performance of interpreters in a South African paediatric hospital where *ad hoc* interpreting practices were followed frequently.

Various views of the interpreter role are held by health care professionals. Interpreters may be perceived as invisible interpreters who are expected to provide exact translations of the doctors' and patients' messages respectively (Swartz, 1998). This view of the interpreter's role seems the most obvious and is often unconsciously assumed as correct, especially by clinicians who have not considered the interpreting role carefully (Swartz, 1998). Interpreters may also be viewed as cultural brokers for health care personnel. Cultural brokerage implies that the interpreter explains the context and the meaning of the patient's life to the interviewer. Interpreters as cultural brokers also guide the interviewer in determining whether the patient's beliefs and behaviour is in keeping with the cultural group he/she belongs to (Swartz, 1998). An interpreting model of partnership has also been described. According to the interpreting partnership view the health care professional and the interpreter function as a team in order for the patient to benefit from the specialised knowledge of each party (Westermeyer, 1990 in Wood, 1993). Familiarity and shared working experience between interpreter and health care professional has been found to facilitate effective interpreted communication (Friedland and Penn, 2003).

The South African health care context thus poses various challenges to communication between health professionals and patients. Although very limited research exist on communication in HIV/AIDS care, the characteristics of the local pandemic are likely to challenge communication in this context even further. Characteristics of HIV/AIDS which might have an adverse effect on communication in medical settings will be discussed next.

1.3 Characteristics of HIV/AIDS

HIV/AIDS is a chronic and fatal disease (Siegel and Lekas, 2002). HIV/AIDS is also complex as is evident from labels found in the literature such as “a collection of diverse epidemics” (Voelker, 2005, p.281) or “an epidemic of stigma” (Herek and Glunt, 1988, in Saunders, 1994, p. 334). The estimated number of people infected globally with HIV is currently at 39.4 million. Sub-Saharan Africa has the highest number of HIV/AIDS cases worldwide, with 25.4 million infected individuals whereas 1.6 million individuals are infected in North America and Western and Central Europe. Of the HIV/AIDS cases in Sub-Saharan Africa 57% of infected adults are women. Among Sub-Saharan HIV infected individuals between the ages of 15 and 24 years, 76% are female. South Africa has the highest HIV infection rate in the world, with an estimated 5.3 million individuals infected, 2.9 million of whom are women (UNAIDS and The World Health Organisation, 2004).

HIV/AIDS in Africa is situated in specific social and economical circumstances and is not primarily rooted in the behaviour of individuals (Schneider and Fassin, 2002). Doctor-patient interactions partly take place in the context of history and political events (Kelly and Brown, 2002). HIV/AIDS in South Africa is an unequal epidemic reflecting the racial disadvantage of the past (Johnson and Budlender, 2002 in Schneider and Fassin, 2002). The unbalanced doctor-patient power distribution is thus exacerbated in cases of cross cultural medical encounters, especially when patients are from disadvantaged groups. HIV/AIDS in Africa is furthermore unequal with regards to gender. Sub-Saharan Africa is the only world region with an HIV infection rate higher for women than men. Women in this region are more vulnerable to HIV infection and their

status, roles and rights in society cause them to be more severely impacted by AIDS (Duffy, 2005; Voelker, 2005; Tlou, 2002).

“Pervasive stigma” has accompanied the disease since its outbreak (Meel, 2005, p. 149). Unlike other stigmatised conditions HIV/AIDS carries a double stigma – as a terminal illness and as a sexually transmitted disease. Disclosure of a positive HIV/AIDS diagnosis in South Africa is associated with “job loss, partner abandonment, social ostracism, personal injury, refusal of medical treatment, refusal of insurance and death” (Ross and Deverell, 2004, p. 206). HIV/AIDS patients who are also members of marginalised groups are often more severely stigmatised (Saunders, 1994). Vulnerability to contract the HI virus and to develop AIDS is linked to poverty, illiteracy, stigma and discrimination (Muthuswamy, 2005). Stigma can thus play into and strengthen existing inequalities that are related to power and domination in a specific community (UNICEF, 2001). Stigmatised individuals are regarded as “culturally unacceptable” or inferior (Williams, 1987, p.140, in Gillespie and Gerhardt, 1995) and do often not receive the same respect and regard as non-stigmatised persons (Saunders, 1994). Stigma and discrimination are closely related (Maluwa, Aggleton and Parker, 2001, in UNICEF, 2001) and health care professionals have been described as the “primary offenders” in this regard (Meel, 2005, p.151). Negative interactions with health care professionals can have significant effects on the health and quality of health care of people living with HIV/AIDS (Meel, 2005). HIV/AIDS-related stigma and consequent discrimination have a negative impact on all aspects of HIV/AIDS prevention, diagnosis, treatment and care (Brown et al., 2001, in UNICEF, 2001).

It thus comes as no surprise that an HIV positive diagnosis is associated with negative psychological consequences despite the known neuro-psychiatric effects of the disease, such as dementia and HIV related delirium (Freeman, 2004; Hughes, Jelsma, MacLean, Darder and Xolani, 2004; Olley et al., 2003; Siegel and Lekas, 2002; Schrooten et al., 2001). Significantly higher rates of depression have been found amongst HIV infected individuals compared to uninfected individuals (Freeman, 2004). Olley et al (2003) diagnosed 56% of a Cape Town sample of recently diagnosed HIV patients with

psychiatric disorder. Major depression (34.9%) was the most common diagnosis, while dysthymic disorder (21.5%), post traumatic stress disorder (14.8%) and alcohol dependence (10.1%) were also reported. The prevalence of depression in South African seropositive individuals is higher than the 10% rate that is reported in the developed nations (Clesla and Roberts, 2001 in Olley et al., 2003). The high levels of stress and stigmatisation faced by HIV/AIDS sufferers in South Africa might be responsible for the high local prevalence of psychiatric morbidity (Olley et al., 2003). Caregivers of HIV-infected individuals are also exposed to stress from various sources, such as knowledge of the imminent death of a loved one, community ostracism due to the HIV/AIDS stigma and the physical care of the sick person. When caregivers are HIV positive themselves the mental health consequences are furthermore compounded by deteriorating health and financial worry (Wight, 2000 in Freeman, 2004). It is thus expected that the psychological stress faced by HIV positive patients or caregivers will impact on their communication with health care personnel.

Health care workers in the HIV/AIDS field are also exposed to a “multitude of psychosocial stresses” and many care providers “begin to feel overwhelmed by what individuals and family members have to face emotionally, financially, socially and spiritually” (Ross and Deverell, 2004, p. 211). The stresses of working in the HIV/AIDS field make formal caregivers vulnerable to burnout and mental health difficulties (Ross and Deverell, 2004; Battegay et al., 1991). Burnout includes physical symptoms such as fatigue as well as psychological symptoms such as depression, negative attitudes and inflexibility. Burnout may lead to less and infrequent contact with patients (Battegay et al., 1991). It is thus vital that individuals working with HIV positive patients have access to support groups to facilitate the expression and discussion of work related experiences (Ross and Deverell, 2004). Treatment of formal caregivers’ emotional difficulties has shown to decrease the potential negative effects of their work environment (Hedge, 1999 in Freeman, 2004). Battegay et al., (1991) reported favourably on an AIDS case workgroup for doctors in Switzerland. The workgroup involved doctors presenting complex cases and exploring the emotional dimension of difficult doctor-patient relationships under the supervision of a liaison psychiatrist. Reflection upon the doctor-

patient relationship improved communication with, and empathy towards patients with HIV/AIDS. It thus seems vital that the psychosocial effects of HIV/AIDS on formal caregivers is recognised and that support structures are provided for the doctors and counsellors working in this field.

HIV/AIDS also has an impact on doctors' expectations regarding the practice of medicine in both the developing and the developed world (Ajoulat et al., 2002; Raviola, Machoki, Mwaikambo and Good, 2002; Bayer and Oppenheimer, 2000; Good, Machoki, Mwaikambo, and Amayo, 1998; Bategay et al., 1991). Doctors in public hospitals in Africa are faced with overwhelming numbers of patients dying from AIDS and very limited resources to respond. Physicians in these settings face moral and ethical dilemmas with "the very moral foundations of medicine as a scientific and caring profession called into question" especially since they are aware of the treatment possibilities and resources available in large parts of the developed world (Good et al., 1998, pg 167). The third world doctor's traditional and professional role as healer (Engel, 1977) is thus under threat from the HIV/AIDS pandemic.

The South African public health care sector has a long and difficult history regarding the provision of anti retroviral (ARV) therapy to the millions of South Africans living with HIV/AIDS. The South African Government's approval of a national HIV/AIDS treatment programme in November 2003 (Marshall, 2004) has significantly boosted the morale of public sector health care professionals (Kapp, 2004). Before antiretroviral drugs became available in the South African public health care sector the management of HIV infected individuals focussed on psychological and social support, prevention and treatment of infections, symptom relief and prevention of transmission (Schweitzer, 2000). The psychological stresses and consequences of working in limitedly resourced and overfull HIV/AIDS clinics are thus very likely to negatively influence doctors' communication with patients and colleagues.

1.3.1 HIV/AIDS counselling

HIV/AIDS is a disease that affects biological, psychological and social functioning in powerful ways (Siegel and Lekas, 2002). Effective HIV/AIDS care cannot ignore the emotional and social difficulties in the lives of HIV positive patients. The informational and emotional content of HIV/AIDS communication require the addition of supplementary members to the traditional doctor-nurse hospital clinic team, namely HIV/AIDS counsellors. HIV/AIDS counsellors generally perform pre- and post HIV test counselling as well as ongoing counselling and support (UNAIDS, 2000, in Ross and Deverell, 2004). The Health Professions Council of South Africa (HPCSA) and the South African Medical Association (SAMA) recommend that a person may only be tested for HIV infection after informed consent has been obtained and pre-test counselling has been performed (Bekker, 2002). HIV test counselling requires that patients “are fully informed of the consequences of a positive result before they are tested (pre-test counselling) and thereafter be given support if it is positive (post-test counselling)” (Bekker, 2002, p. 30).

More specifically pre-test counselling aims to “provide information on HIV, outline the possible consequences of a positive HIV test result, assess risk and discuss methods of risk reduction” (Schrooten et al., 2001, p. 250). Post-test counselling again involves explanation and discussion of the test result. Individuals who have tested negatively are counselled on how to remain seronegative. Individuals with positive test results receive the opportunity to discuss their coping strategies. Post-test counselling also provides patients with information, including referrals to appropriate services (UNAIDS, 2000, in Ross and Deverell, 2004) and agreed upon risk reduction plans (Schrooten et al., 2001). Delivering a positive HIV test result has high requirements in terms of the time and skill to ensure that ample and adequate information and emotional support is provided to the patient (Schrooten et al., 2001). HIV/AIDS counsellors thus play an important role in communication between the health care system and HIV positive individuals / caregivers.

1.4 Patient and doctor characteristics that influence communication

Besides contextual and disease specific factors, the individual characteristics of patients and doctors also have an impact on communication in medical settings. These factors are discussed next.

1.4.1 Patient characteristics that influence communication

The patient characteristics that influence communication in medical settings include “socioeconomic background, cultural background, psychosocial factors, education and knowledge” (Blum, 1960, in Korsch et al., 1968) as well as priorities, values and philosophy of health (Aita et al., 2005, p. 3). The psychosocial issues faced by patients with HIV/AIDS have been discussed. HIV/AIDS patients attending public health care facilities in South Africa are mostly from low and moderate income groups. The psychological consequences of poverty include low self-esteem, depression and a sense of powerlessness and alienation (Bezuidenhout, 1998). HIV/AIDS patients living in poverty are thus in a position of very limited power during interactions with experts within the health care system. Power differences may inhibit effective communication between doctors and patients.

Patients’ educational background is closely linked with their socio-economic status. Patients with lower educational status have been found to be less likely to express their expectations for the medical interview to the doctor. Doctors also frequently fail to respond to the expressed needs of patients with poor educational backgrounds (Korsch et al., 1968). However, patients from all socio economic and educational backgrounds have the same interest in information from the health care professional (Glascoe et al., 1998). The priorities of patients may also influence their help seeking behaviour. For instance, women often attend to the needs of their partners and children before considering their own health care needs (Goosen and Klugman, 1996, in Freeman, 2004). Many poor women may thus spend the limited money that they have available on essentials such as food for their dependants, rather than on health care or medication for their own health needs (Freeman, 2004).

1.4.2 Doctor characteristics that influence communication

Aita et al. (2005) list the doctor characteristics that affect doctor-patient communication as style, values and philosophy of medicine. These factors will now be discussed.

Erzinger (1991) emphasizes that communication involves much more than the words spoken and that language is only one analytical component of communication. A specific conversational style accompanies the speaker's words. Tannen (1984, p. 8, in Erzinger, 1991) describes conversational style as "not something extra added on like frosting on a cake. It is the stuff of which the linguistic cake is made". International style and cultural rules determine doctors' and patients' responses to one another and thus the course of communication in clinical interactions (Kelly and Brown, 2002; Erzinger, 1991). Aspects that patients desire regarding the conversational style of the doctor are culturally defined. Erzinger (1991) cites research that has shown Latino patients in mental health care to have a need for doctors to display personal warmth, concern, formal friendliness and respect in interactions. Respect, empathy and friendliness have also been described as important attributes of the doctor-patient relationship and interaction in more general literature (Gill and O'Brien, 2003; Silverman, Kurtz and Draper, 1998, in Blitz, 2000). It thus seems that certain aspects of a doctor's conversational style, such as the display of care and respect, might be universally desired by patients (Shadid, 1993).

"How physicians approach patients and the problems they present is much influenced by the conceptual models around which their knowledge is organised" (Engel, 1980, p. 535). Doctors' 'conceptual models' or 'philosophy of medicine' (Aita et al., 2005) refers to the adoption of either a bio-medical or a biopsychosocial or patient centred view of the medical profession. These philosophies influence the doctor's interaction with his/her patients.

The reductionistic, bio-medical model was born in the modern time period of major scientific advancement which encouraged medical doctors to be scientists. The focus of bio-medicine is on scientific examination, description and diagnosis of pathologies and the swift removal of symptoms, signs and pathogenic disease causing agents (Van

Velden, 2003). Disease prevention is a key objective of the medical ideology (Marks, 1999). Medical professionals in the bio-medical framework are thus “disease centred” and the emotional and spiritual dimensions of human existence are not considered (Van Velden, 2003, p.193).

The biopsychosocial model was proposed by George Engel in his 1977 paper in the journal *Science*. Engel (1977) recognised the need for a medical model that would account for the reality of diseases and human experiences as well as disease abstractions. According to the biopsychosocial model, an understanding of any disease should include the social and cultural environments in which the disease exists as well as the psychological impact of the environment on the individual. Similarly medical treatment should include the psychological, social and cultural factors of an individual’s life, and not only the biological aspects (Brody, 1999). Although it is acknowledged that bio-medicine and its purely scientific orientation will always be essential to the treatment of acute surgical and medical emergencies, the biopsychosocial model advocates a holistic systems-theory perspective of the patient (Van Velden, 2003).

The patient centred clinic method is closely related to the biopsychosocial model. Patient centred models also advocate a holistic view of the patient (De Villiers). However, whereas the biopsychosocial model represents an ethically neutral scientific paradigm, the patient-centred method includes both scientific and ethical elements. “The patient-centred models suggest that the physician ought to use this integrated knowledge of the patient as a whole person within a particular ethical framework that respects the patient’s basic rights and dignity, and takes very seriously the patient’s own life goals and projects” (Brody, 1999, p. 585). The South African government’s emphasis on PHC implies that medical culture in this country should change from traditional paternalism to a model of partnership (African National Congress, 1994) where health care professionals and the community (the patients) participate in mutual decision making. The South African health care sector is thus moving towards a patient-centered medical culture.

1.5 Communication-in-health research

Subjects relevant to the doctor-patient relationship have been extensively discussed and reported in non-medical as well as the medical literature (Roter, Hall and Katz, 1988; Korsch et al., 1968). However, it is only in the past three and a half decades that the dynamics of doctor-patient interactions have been observed “in any consistent manner” (Ong et al., 1995; Roter et al., 1988, p. 99). Both quantitative and qualitative methods are reported in the study of communication between health care providers and their patients. Quantitative studies are mostly cross sectional, include large subject samples and are consistently concerned about the generalizability of their findings (Lascano-Ponce et al., 2004; Schrooten et al., 2001; Ulrey and Amason, 2001; Wilson and Kaplan, 2000; Roter et al., 1988). Qualitative researchers in the area have used much smaller samples and consider the strength of their approach as the potential to provide in-depth and rich descriptions of clinical interactions (Fish, 2001; Evans, 2000).

Qualitative researchers in the field have criticized analysis of health care provider-patient interactions according to pre-determined researcher defined checklists as failing to capture the complexities, ambiguities, contexts and true outcomes of this form of discourse (Friedland and Penn, 2003; Bartz, 1999; Epstein, Morse, Frankel, Freney, Anderson and Beckman, 1998). Moreover, qualitative methods appear to be especially suited when multiculturalism adds to the complexity of medical interactions (Friedland and Penn, 2003; Kelly and Brown, 2002; Erzinger, 1991). Ulrey and Amason (2001) stated that their attempted quantitative measure of cultural sensitivity in a self-administered survey of 319 doctors was not as reliable as desired. Furthermore, multimethod approaches to the study of the complex interactions in medical settings have proved to be especially useful, for instance combining interpretive in-depth interviewing of role players with discourse analysis of actual health care provider-patient interactions (Crabtree et al., 2001; Evans, 2000; Bartz, 1999).

1.5.1 Research on Communication in HIV/AIDS health care: USA and Europe

Very little has been published about HIV/AIDS communication in medical settings (Wilson and Kaplan, 2000). Only a few studies focusing directly or indirectly on

communication regarding HIV/AIDS in medical settings in the United States of America (USA) and Europe have been conducted. For instance, Ajoulat et al. (2002) studied communication between doctors and caregivers of adult HIV/AIDS patients in France and the French speaking community of Belgium. They found that both doctors and caregivers were faced with difficulties and had specific needs regarding communication in HIV/AIDS care. Communication related to the prospect of death and HIV transmission and prevention was especially troublesome. Lazcano-Ponce et al. (2004) surveyed 379 doctors in Mexico on their communication with HIV-infected patients. They found that doctors who placed a high value on communication, had an attitude of acceptance over death and perceived their patients to adhere to treatment were more likely to engage in explicit (honest and open) communication with patients. Wilson and Kaplan (2000, p. 419) have investigated the influence of patient, visit, doctor and practice characteristics on HIV/AIDS communication in Boston, (USA). They found that the duration of the doctor-patient relationship and visit length were associated with better general- (“communication about diagnostic testing and therapies”) and HIV specific communication (“discussions about alcohol use, other drug use, sexual behaviours and, and sensitivity to patients’ HIV-specific questions and needs”).

The limited research on communication in HIV/AIDS care thus indicates that sensitive topics, such as death, sexuality, alcohol abuse, complicate the interactions between doctors and patients. Practice characteristics such as length of consultations and continuity of care seem to be related to the effectiveness of HIV/AIDS communication. Schrooten et al., (2001) surveyed 1366 HIV positive individuals regarding their experiences of receiving an HIV positive test result. The participants represented 11 different European countries. The researchers found that a large proportion of the participants were dissatisfied with the manner of HIV testing and the delivery of an HIV positive diagnosis. 14% of the participants did not provide consent prior to testing and 15% received the positive test results via mail or telephonically. Furthermore 54 % of the participants felt that inadequate support was provided when they were diagnosed as HIV positive and 19% experienced feelings of rejection by the health care professional when the positive test result was communicated. Communication of an HIV positive test result

is a resource intensive task that requires training, experience, talent, HIV/AIDS specific knowledge and time (Schrooten et al., 2001). If any of these resources are lacking improper communication procedures may result.

1.5.2 Research on communication in HIV/AIDS health care: South Africa

The activities of the Health Communication Project mentioned at the start of this introduction are among the first endeavors to investigate communication in paediatric HIV/AIDS clinics in South Africa. Figure 1 provides a diagrammatic representation of the Health Communication Project's studies conducted at the HIV clinic that has formed the research site of the current study. Garcia (2004) and Steenkamp (2004) have studied medical consultations in the clinic by means of conversation analysis of recorded interactions. Garcia (2004) examined direct doctor-caregiver interactions and Steenkamp (2004) studied interpreted consultations. Both these studies have aimed to identify facilitators and inhibitors to effective communication. Rust has recently completed a conversation analysis to describe the nature of interactions between caregivers and counsellors at the clinic. However, no work has been done on the self-reported communication experiences of caregivers, counsellors and doctors in the South African HIV/AIDS health care setting. The current study aimed to fill that gap by examining the experiences of caregivers, counsellors and doctors at the clinic by means of semi-structured interviews.

The current study thus adds a qualitative method to the research already completed at the clinic, namely that of interpretive interviewing. Through semi-structured interviewing the caregivers, counsellors and doctors were given the opportunity to describe and interpret their communicative experiences and the meaning they have attached to it (Desai, Kolasa, Bisgard, Prevots and Dibling, 1998 in Bartz, 1999). This method also allowed the relationship between the context and the meaning of participants' experiences to be illuminated (Bartz, 1999). The current study thus has the potential to offer additional insights on communication in HIV/AIDS care in this particular setting, to the completed conversation analyses of Garcia, (2004), Steenkamp (2004) and Rust (2005).

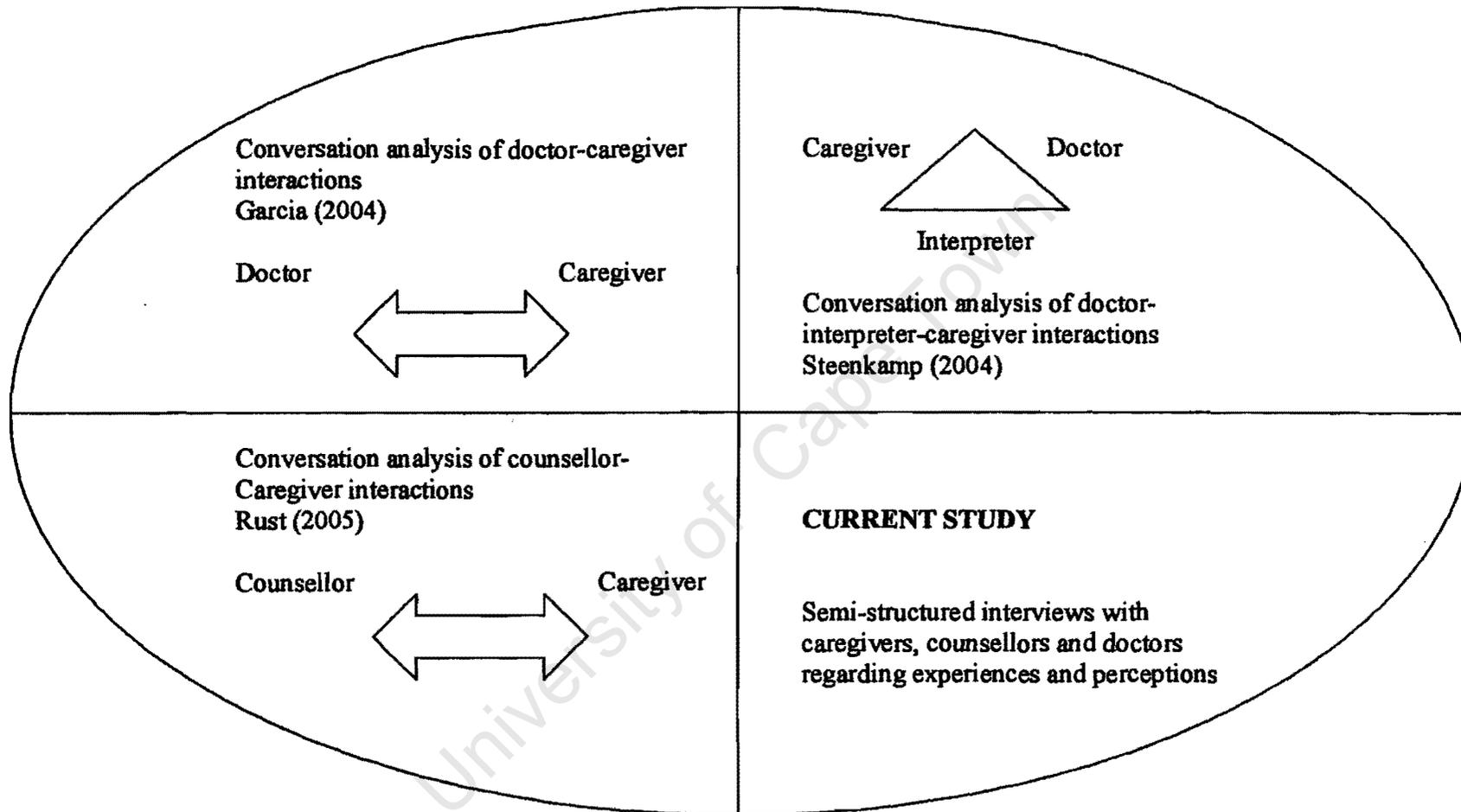


Figure 1: Diagrammatic representation of the larger research project on communication at the HIV clinic.

The multiple methods used within the Health Research Project within this setting has the potential to capture the richness of the content and the context needed to better understand communication practices in tertiary level paediatric HIV/AIDS care in South Africa (Crabtree et al., 2001).

The Health Communication Project has also conducted other studies at this research site. Figure 2 provides a diagrammatic representation of the communication research recently conducted at the site. Prince (2004) studied interpreted communication in the medical outpatients- and developmental clinics of the hospital by means of conversational analysis of interpreted interactions as well as semi structured interviews with all members of the triad. Levin (2004) investigated the role of language difficulties in creating access barriers to health care. He surveyed caregivers from the allergy and asthma- and short stay clinics, and doctors from across the hospital. Schwartz (2004) included the hospital as one of three settings in a study on current communication practices employed across the different levels of health care. Her results provide a rich description of the hospital, including the demographic characteristics of personnel and patients, policy regarding communication, current practices regarding interpreting and expertise and relationships within the larger hospital. The current study thus had a substantial source of recent and relevant research available to develop and support its analysis.

TERTIARY LEVEL PAEDIATRIC HOSPITAL IN WESTERN CAPE

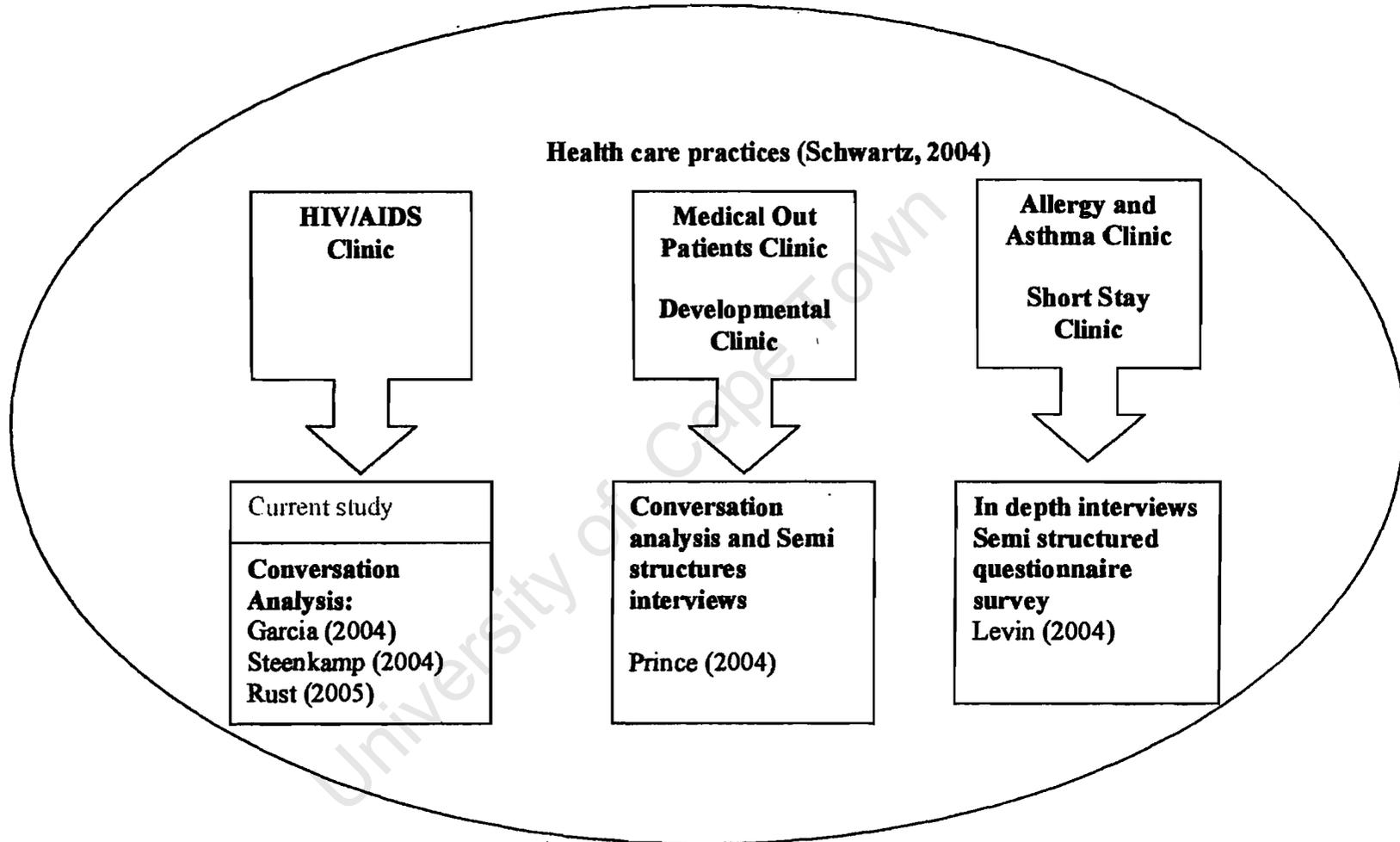


Figure 2: Diagrammatic representation of recent communication research conducted at the study site

2. METHODOLOGY

2.1 Aims

The primary aim of the study was to describe and explain the meaning and essence of the experiences of communication in a paediatric outpatient HIV/AIDS clinic for three categories of participants, namely:

- caregivers of paediatric HIV/AIDS patients,
- HIV/AIDS counsellors and
- medical doctors.

More specifically the study had the following objectives:

1. To describe and explain the participants' experiences regarding factors that facilitate or inhibit effective communication in a medical context; and
2. To describe and explain the participants' perceptions regarding linguistic and cultural factors that influence communication in a medical context.

2.2 Research design

Research design is structured by four issues namely the guiding paradigm followed, the participant of the study ("who or what"), the strategy of enquiry employed and finally the methods for the collection and analysis of the empirical material (Denzin & Lincoln, 1998a). The first three of these issues, as they hold reference to the current study, will be discussed in this section. Methods of data collection and data analysis are discussed in more detail under 2.5 and 2.6 respectively.

A qualitative research design within an interpretive paradigm was adopted in this study. Despite warning against attempts to provide a single definition for qualitative research, Denzin and Lincoln (1998b) provide a generic definition of qualitative enquiry as having a multimethod focus with studies that are conducted in natural contexts with the aim to interpret phenomena according to the meanings that people attach to them. A social scientific paradigm can be defined as a "basic orientation to theory and research" and "in

general ... a whole system of thinking" (Neuman, 1997, pg 62) with a specific ontology, epistemology and methodology (Patton, 2002; Terre Blanche & Kelly, 1999; Denzin and Lincoln, 1998; Neuman, 1997). Interpretive research methods are inductive and naturalistic (Terre Blanche & Kelly, 1999; Neuman, 1997). The interpretive paradigm in general can be described as "the systematic analysis of socially meaningful action through the direct detailed observation of people in natural settings to arrive at understandings and interpretations of how people create and maintain their social worlds" (Neuman, 1997, pg 68). The subject of interpretive research is meaningful social action, implying action to which social actors attach meaning and display in relation to the actions of others.

The ontological and epistemological position of the interpretive paradigm was specifically suited to answer the current research question. Interpretive social science's ontological position is that social reality constitutes of people's individual and subjective experiences of it and that this subjective sense of reality is central to an understanding of human social life. Social life is considered to be based on interaction between people and socially constructed systems of meaning (Neuman, 1997). The study of communication as social action by exploring the subjective experiences of the various participants involved in the process thus falls within the interpretive social paradigm. The viewpoint that social reality and meaning is subjective and that multiple interpretations are possible implies that no one meaning system is superior to any others (Neuman, 1997). Therefore the current study's aimed to learn about communication from the multiple perspectives of caregivers, counsellors and doctors.

The epistemology of the interpretive approach holds that the insight is gained into the experiences of others by interacting with them and listening to their stories (Terre Blanche & Kelly, 1999). The methodology of semi-structured interviewing was thus suitable to elicit the participants' communicative experiences. Interpretive social science and research methods are rooted in a method of understanding referred to as *verstehen* or 'emphatic reliving' or 'empathy' (Terre Blanche & Kelly, 1999, pg 123; Neuman, 1997). *Verstehen* suggests that the meaning of social action can only be fully understood by

taking the context in which it occurs into account (Terre Blanche & Kelly, 1999; Neuman, 1997). The contexts in which health-related interactions take place influence these interactions in a significant way. Interpretive research methods' sensitivity towards the role of context in social actions was specifically useful in the current study.

Decisions regarding the research design and specific methodological issues such as participant selection and data collection methods were made in conjunction with two experienced researchers, namely the leader of the larger research project and researcher contracted to the Health Communication Project. These researchers both have PhD degrees in Speech-Language Pathology and have extensive experience in qualitative research, including research on communication in health care. The expertise and experience of these two researchers added to the credibility and quality of this study (Patton, 2002).

2.3 Research Setting

An outpatient HIV/AIDS clinic (hereafter clinic) within an urban secondary/tertiary level paediatric hospital in Cape Town formed the research setting.

2.3.1 Description of the larger hospital

A complete description of the setting of this study is provided in order to contextualise the participants' experiences of communication in the clinic, and to accomplish the goal of a thick description (Denzin, 1989 in Patton, 2002).

The hospital employs 1100 staff members and treats 18500 in patients and 155000 outpatients per year (The Children's Hospital Trust, n.d.a). The hospital forms part of the medical training facilities of a Western Cape University. Undergraduate and postgraduate students are thus also working at the hospital. The hospital is the only exclusive paediatric hospital in southern Africa and possesses tremendous expertise in various areas of paediatric health care. Therefore children from over the country and the subcontinent are referred to the hospital. Approximately 40% of the hospital's patients are from outside the borders of the Western Cape or South Africa, including patients from Central

Africa. Significant differences exist between the languages spoken by the hospital's doctors and patients. Although patient language and race statistics are poorly kept at the hospital, the hospital staff estimated that the majority of the hospital's patients are isiXhosa first language speakers (Schwartz, 2004). Albeit incomplete, hospital statistics indicate that 25.8% of the hospital's patients are Afrikaans- and 23.6% are English first language speakers (Levin, 2004). At least 10% of patients were estimated to be speakers of the other South African black languages or languages spoken elsewhere in Africa, such as French and Swahili (Schwartz, 2004).

Schwartz (2004) quoted the following racial percentages among doctors at the hospital from the Provincial Administration of the Western Cape's statistics (November, 2003). 74.5% of the medical doctors were white, 11.8% were coloured, 8.1% were Indian and 5.5% were black. Not all of the black doctors could speak isiXhosa as they were from various indigenous language groups, including Sesotho and isiZulu (Schwartz, 2004). Schwartz (2004) noted that race statistics may act as a surrogate for language information given the South African socio-linguistic background. The White, Coloured and Indian doctors can thus be regarded as unable to speak isiXhosa. In fact, 3% of the doctors surveyed by Schwartz (2004) rated their isiXhosa ability as "very good" while 90.4% regarded their isiXhosa skills as "poor" or "very poor".

The hospital had no formal policy on communication between the health care personnel and patients, but two fulltime interpreters were employed in nursing posts (Schwartz, 2004). However, the high interpreter : doctor/patient ratio and the fact that the trained interpreters were only available from 8 am to 5 pm, resulted in doctors often having to rely on untrained *ad hoc* interpreters (Levin, 2004; Schwartz, 2004). Nursing staff were most often employed as *ad hoc* interpreters, although family/friends, general assistants and other health care professionals also participated in interpreted consultations (Schwartz, 2004). The additional task of interpreting to the nurses' already heavy workload often lead to stress and frustration among nurses, which might have impacted the nurse-patient relationship negatively (Schwartz, 2004). Furthermore, the doctors have

been reported to underutilise interpreters in interactions where caregivers were not English or Afrikaans language speakers (Levin, 2004; Schwartz, 2004).

2.3.2 Description of the HIV/AIDS clinic

The clinic, together with clinics at two other Cape Town hospitals, treated most HIV infected children living in and around Cape Town. Approximately 700-800 HIV positive children were treated by the clinic per annum. The clinic was operated by five attending doctors and functioned only one morning per week. The clinic has been receiving ARV drugs from the state after the national government's announcement of a national HIV/AIDS treatment programme in November 2003 (Marshall, 2004). However, the clinic has been providing donor funded anti-retroviral treatment for a small cohort since 2002 (Eley et al., 2004). In December 2004 (nine months after data collection for the current study was completed) 300 out of the hospitals 700-800 paediatric HIV/AIDS patients were receiving antiretroviral therapy (The Children's Hospital Trust, n.d.b).

At the time of the study treatment at the clinic was directed at and available only to children, despite the fact that HIV positive children most often have HIV positive parents with the same treatment requirements as their children. However, a Family Model of Care was being developed, in order to provide continuous HIV/AIDS treatment to entire families (The Children's Hospital Trust, n.d.b).

As in the larger hospital, a divide existed between the languages of the doctors and the patients in the clinic. None of the doctors working at the clinic were isiXhosa first language speakers, but spoke English and/or Afrikaans. The majority of the patients were isiXhosa speakers. However, different from the rest of the hospital, the clinic employed the services of a non-governmental organisation (NGO) that involved five lay counsellors providing HIV/AIDS counselling to caregivers. The counsellors were all isiXhosa first language speakers and most were HIV positive women themselves. The counsellors have completed a two week training course on HIV/AIDS counselling, that was presented by the director of the NGO who is a social worker by profession. The counsellors fulfilled a dual role in the clinic. In spite of their primary counselling function they acted as

interpreters in consultations where either the doctor or caregiver or both required a third party to bridge the language gap. However, the counsellors have not received training regarding interpreting or field specific medical issues, despite the HIV/AIDS related concepts that are routinely discussed during pre and post test counselling.

2.4 Participants

Three categories of participants took part in the study, namely

- i. The caregivers of children with HIV/AIDS attending the clinic;
- ii. HIV counsellors employed at the clinic, and
- iii. Medical doctors working at the clinic.

The sampling method used, as well as the ethical considerations, participant selection criteria, participant selection process and a description of the participants is provided next.

2.4.1 Sample size and sampling strategy

A purposeful sampling method has been followed where cases were selected with a specific purpose in mind. Purposive sampling is appropriate to select members of a difficult-to-reach population (Neuman, 1997). The clinic was vulnerable to becoming “over-surveyed” due to its cooperativeness (Ijsselmuiden, 1997) and the fact that HIV/AIDS is at the centre of various research efforts. In an attempt to protect the clinic from unwanted intrusion and to comply with the wishes of the clinic staff, it was aimed to spend as little time as possible in the setting for research purposes. Little time was thus spent on getting to know the setting before data collection commenced and the researcher therefore took advantage of whatever unfolded as it unfolded on the days of permitted access to the clinic.

Eleven caregivers, four counsellors and four doctors participated in the study. The study sample can be described as homogeneous, in the sense that participants shared similar backgrounds and experiences in the various categories of participants (Patton, 2002). The relatively small sample is suited to the purpose of the study, namely to produce in-depth

information that would lead to insight into, and a deep understanding of the nature of communication in a multi-lingual, multi-cultural HIV/AIDS care setting.

2.4.2 Ethical considerations

Permission to conduct the study was obtained from the University of Cape Town's Research Ethics Committee, the superintendent of the hospital concerned and the head of the HIV clinic. All participants gave their informed consent to participate in the study.

Separate consent forms were formulated for the respective groups of participants. Refer to Appendix A for examples of the various consent forms. Special care was taken to ensure that the consent forms would be easily understood by all participants. The consent forms were available in isiXhosa for all the isiXhosa first language participants. Furthermore the letters were phrased in a manner that made them easily comprehensible and free of academic jargon.

The counsellors working in the clinic obtained informed consent from the caregivers, and not members of the research team. The counsellors formed part of the health care team that the caregivers voluntarily consulted regarding treatment of the HIV positive children under their care. A good possibility existed that the caregivers attending the clinic were HIV positive and their right to confidentiality regarding a seropositive status had to be respected. Caregivers who were HIV positive were thus not at risk to disclose their status to anyone other than the health care team they have initially sought to consult, before informed consent was obtained. Furthermore, the fact that the counsellors spoke the same first language as the caregivers facilitated the caregivers' understanding of the information included in the consent form, as the counsellors verbally shared the information with the caregivers in addition to the written consent form. Consent was obtained from the counsellors before they were asked to assist in the process of obtaining consent from potential caregiver participants.

Researchers are under an obligation to give feedback and publish the findings of their research (Jesselmuider, 1997). Feedback has been given to the health care professionals

who participated in the study as the findings have implications on the way they deliver their services and interact with patients. Feedback was provided in the format of an informal presentation during the staff's morning meetings. The leader of the larger research project, the contracted researcher and the current researcher participated in this feedback session. The researcher has also shared the findings of this study at a multidisciplinary health care conference. Furthermore the researcher plans to publish the findings in a peer-reviewed journal(s) in order to share the results with the wider research community.

Feedback will also be provided to the counsellors who have participated in the study. The same format that was used to provide feedback to the doctors will be followed. The caregivers' names were not recorded during data collection in order to protect their confidentiality. The researcher has thus been unable to contact them for invitation to attend a feedback session.

2.4.3 Participant selection

Strict criteria were not applied in the selection of participants. The naturalistic character of the study aimed to capture the reality of every day in a particular context. The regular role players in the setting were thus invited to participate. The selection of participants will be discussed per participant category.

2.4.3.1 Selection of caregivers

To participate in the study the caregivers were required to meet the following criteria:

- To be the caregiver of the child accompanied to the clinic;
- To attend the clinic for treatment of their children;

No criterion regarding the length of time that children were patients at the clinic was set, as the researcher was not specifically interested in learning about the experiences and perceptions of caregivers who were new or ongoing clinic attendees. However, the length of time that the child was a patient at the clinic

was recorded so that these variables could be considered in the analysis of interviews.

- To have agreed to participate in the study.

2.4.3.2 Selection of counsellors and doctors

To participate in the study the counsellors and doctors were required to meet the following criteria:

- To be employed at the clinic or to volunteer their services at the clinic on a regular basis;
- To be available during the data collection period;
- To have agreed to participate in the study.

2.4.3.3 Participant selection procedure

After the hospital superintendent and the clinic head gave permission for data collection, participants were approached to participate in the study. The clinic head provided the doctors and counsellors with information on the study, and thereafter the research team obtained informed consent from the staff members who were interested in participating. Four of the clinic's six doctors and four of the five counsellors were available and willing to participate. The counsellors provided the caregivers with information on the study in the clinic waiting room, and obtained informed consent from the caregivers who have indicated a willingness to participate in the study.

2.4.4 Participant description

A brief description of the participants is provided in the following section.

2.4.4.1 Description of caregiver participants

Eleven caregivers of children with HIV/AIDS participated in the study. A summarised description of the caregiver participants is provided in Table 1.

Table 1 Biographical information of the caregiver (CG) participants

CG	Age	Relationship to child attending the clinic	Highest educational level achieved	First language	Area of residence	Original area of residence	Time period at clinic
1	49	Grandmother	Grade 8	SeSotho	Bonteheuwel	Not available ³	6-7 years
2	31	Mother		isiXhosa	Khayelitsha	Not available	4 years
3	33	Mother	Grade 9	isiXhosa	Khayelitsha	Transkei ⁴	5-6 years
4	24	Mother	Grade 12	isiXhosa	Nyanga	Transkei	2 months
5	28	Mother	Grade 12	isiXhosa	Langa	East London	5 years
6	22	Mother	Tertiary information technology qualification	isiXhosa	Crossroads	Ciskei	First visit
7	34	Mother	Grade 9	isiXhosa	Nyanga	Not available	First visit
8	34	Mother	Grade 11	isiXhosa	Phillipi	Ciskei	First visit
9	27	Mother	Grade 12	isiXhosa	Khayelitsha	Transkei	3-4 months
10	29	Mother	Grade 11	isiXhosa	Khayelitsha	Transkei	2 years
11	27	Mother	Grade 12	isiXhosa	Khayelitsha	Transkei	3-4 years

³ Unavailable biographical data refers to participant information that the interviewer failed to collect during data collection. As the interviews with caregivers were conducted in isiXhosa, the researcher only became aware of unavailable biographical data after the interviews were transcribed and translated. As mentioned previously, it was not possible to contact caregivers after data collection to obtain the missing information.

⁴ The Transkei and Ciskei are two of the former homelands that were created by the previous National Party government in the 1960's. The Transkei and Ciskei now form part of the Eastern Cape Province of South Africa (Wikipedia, 2005a, 2005b).

Apart from one caregiver who was the grandmother of the child she brought to the clinic, all caregivers were mothers accompanying their children. The grandmother was also the only caregiver who did not have isiXhosa as a first language, as she was a Sesotho speaker. The mothers all had an HIV positive diagnosis. All of the caregivers have attended secondary school. Only five have completed grade 12 and three caregivers did not proceed further than grade 9. The caregivers all moved to Cape Town from the Eastern Cape and now reside in peri-urban settlements surrounding the city, namely Khayelitsha, Nyanga, Langa, Phillipi, Crossroads and Bonteheuwel. Nine of the caregivers have been attending the clinic for a period of between two months and six years, while two caregivers were interviewed on the day of their first visit to the clinic. The caregivers were all referred to the clinic from another institution.

2.4.4.2 Description of counsellor participants

Four counsellors working in the clinic participated in the study. A summarised description of the counsellor participants is provided in Table 2 below.

Table 2: Biographical information of the counsellor (C) participants

C	Age	Highest educational level achieved	First language	Area of residence	Original area of residence	Working experience in clinic	Previous counselling experience
1	33	Grade 12	isiXhosa	Khayelitsha	Ciskei	3 years	None
2	25	Grade 12	isiXhosa	Khayelitsha	Ciskei	2 years	None
3	25	Grade 10	isiXhosa	Khayelitsha	Transkei	6 months	4 years
4	Not available	Not available	isiXhosa	Not available	Not available	8 years	Not available

The counsellors have not obtained formal training beyond their secondary school education and the two week NGO training course in HIV/AIDS counselling. They were all isiXhosa first language speakers who originated from the Eastern Cape and were now

living peri-urban settlements surrounding the Cape Town. Their experience in HIV/AIDS counselling ranged from 2 to 8 years. The counsellors thus shared various characteristics with the caregivers.

2.4.4.3 Description of doctor participants

Four doctors working in the clinic participated in the study. A summarised description of the doctor participants is provided in Table 3. Three of the doctors were paediatric specialists and 1 doctor was a general practitioner. They were all English first language speakers. Their experience of working in the clinic ranged from two weeks to 10 years.

Table 3: Biographical information of the doctor (D) participants

D	Medical specialisation	First language	Working experience in the clinic	Nature of appointment at clinic
1	General practitioner	English	2 weeks	Volunteer
2	Paediatrician	English	1-2 years	Volunteer
3	Paediatrician	English	2-3 years	Volunteer
4	Paediatrician	English	10 years	Permanent

2.5 Data collection

2.5.1 Method of data collection

Semi-structured, open-ended, face-to-face interviews were conducted with all the participants. The participants were interviewed by three different interviewers. A representation of the distribution of interviews between the interviewers is provided in Table 4. The leader of the larger research project as well as a contracted researcher each interviewed two doctors. The research project leader has also interviewed one counsellor. The current researcher attended the data collection sessions but did not participate in the interviews. The expertise and experience of these two interviewers in semi-structured interviewing added to the credibility, rigor and quality of the data collection procedure

(Patton, 2002). The current researcher, who was relatively inexperienced in semi-structure interviewing, was thus able to learn from these experienced interviewers without being removed from the interview setting where the participants' meaning making unfolded. An isiXhosa interviewer interviewed all the caregivers as well as three counsellors in isiXhosa. The motivation for the inclusion of the isiXhosa interviewer is further discussed under the next heading, 2.5.2.

Table 4: Distribution of interviews between the three interviewers

Interviewer	Caregivers	Counsellors	Doctors
isiXhosa interviewer	X	X	
Leader of the larger research project		X	X
Contracted researcher			X
Current researcher	Attends data collection without participating in interviews		

2.5.2 Construction of the interview guide

The semi-structured interviews were conducted by means of an interview guide or schedule. An interview guide lists issues or themes relevant to the research question. An interview guide was developed in conjunction with the leader of the larger research project and the contracted researcher. Separate interview guides were developed for the interviews with caregivers, counsellors and doctors, although similar themes were used in each of these. The interview guide was translated into isiXhosa for interviews with the isiXhosa participants. Examples of the interview guides appear in Appendix B. The guide was based on themes and guidelines that have emerged from past research findings on communication in South African health care (Evans, 2000; Penn, 2000; Fisch 2001; Friedland and Penn, 2003). Additional themes that were specific to HIV/AIDS health care were added to the guide, such as field specific terminology and counselling in HIV/AIDS.

The guide provided an explanation of the research problem and requested information regarding the participants' biographical information. The interview guide probed the participants' experiences regarding:

- communication in health generally;
- the facilitators and inhibitors to effective communication in the health care context;
- linguistic and cultural factors that influenced communication in the health care context; and
- communication related expectations and suggestions.

The semi-structured interview with an interview guide has various advantages that made it a specifically suited data collection method for the present study. First of all, the open-ended questions made it possible for participants to recount their experiences in their own words and terminology (Patton, 2002; Schurink, 2000; Neuman, 1997). Secondly, the interview guide provided direction for the variety of interviewers to all probe the relevant topics in interviews with the various participants (Patton, 2002). However, the interviewers were still afforded the flexibility, spontaneity and responsiveness to probe and question certain subject areas of interest as it unfolded in the various interviews (Patton, 2002). The systematic nature of data collection facilitated the later analysis of the raw data and added to the dependability of the research process to strengthen the quality of the data (Patton, 2002; Schurink, 2000). Finally, the interview guide allowed the researchers to decide beforehand how to make the best use of the limited time granted in the research setting and the single interview opportunity with each participant (Patton, 2002).

2.5.3 Interviewer of the Xhosa participants

An isiXhosa first language interviewer interviewed all of the caregivers and 3 of the counsellors in isiXhosa. This strategy aimed to avoid the limitations (Duffy, 2005) and possible miscommunication and misinterpretations of using English to communicate with all of the participants (Patton, 2002; Schurink, 2000). It seemed especially important not

to restrict the participants' stories with a language barrier similar to what they face in their interactions with the health care service. The isiXhosa interviewer was selected on the basis of her work experience as interpreter for the contracted researcher and her previous involvement in similar research. She had knowledge of semi-structured interviewing from previous experience and observation of interviewers in her role of interpreter (Neuman, 1997). However, the isiXhosa interviewer received some basic training for her participation in the current study according to the guidelines provided by Neuman (1997).

The purpose of the research and the content of the interview guide were discussed with the isiXhosa interviewer. However, she was not informed of the answers that might have been expected from participants (Neuman, 1997). The role of the interviewer in semi-structured interviewing was also discussed. The use of open ended questions, allowing the participants to tell their stories and the freedom to follow the participant's lead into relevant subject areas was emphasised.

2.5.4 Interview setting

All interviews were conducted at the clinic. The caregivers were interviewed individually in an office adjacent to the counsellors' offices. The counsellors and doctors were interviewed individually in their respective offices. Only the interviewer and interviewee were present during the interviews. In all interviews the interviewer sat directly opposite the interviewee, without a desk or other office furniture between them. The interview setting thus aimed to ensure the privacy and comfort of the participants (Neuman, 1997).

2.5.5 Recording of the data

The raw data of the semi-structured interviews were the actual quotations of the interviewees (Patton, 2002). As the spoken words of each participant formed the basic unit of data analysis (Skinner and Van der Walt, 1997) the interviewees' responses had to be recorded as accurately and objectively as possible. Therefore all interviews were recorded on audio- and videotape. The audio- and video recordings increased the accuracy of data collection and allowed the interviewer to be fully attentive to the

interviewee instead of attempting to produce verbatim transcripts during the interview (Patton, 2002). Furthermore, two sets of recordings reduced the possibility of data getting lost, and allowed the researcher the benefit of re-observing the interview during the analysis phase of the research. The combination of video- and audio recordings were thus beneficial to the use of audio recordings only.

2.5.6 Management of the data

After the interviews were recorded, the verbatim transcription process of the audio-visual material could commence. Two separate procedures were necessary for the transcription of the isiXhosa and English interviews. These procedures will now be discussed.

2.5.6.1 Management of the isiXhosa data

The researcher is not proficient in isiXhosa. A research assistant was thus required to transcribe and translate the isiXhosa interviews into English before analysis could begin. The assistant was selected on the basis of the following criteria:

- First language isiXhosa;
- English language proficiency at a Grade 12 higher grade level;
- Training and experience in verbatim transcription;
- Training and experience in translation of verbatim transcripts.

The selected assistant fulfilled all the above criteria. She was a first language isiXhosa Speech-Language Therapist who has been involved in transcription and translation of verbatim transcripts for a period of three years.

Verifying the isiXhosa transcripts and translations

A second translator verified the isiXhosa transcripts and English translations to ensure the reliability of these translations. She was selected against the same criteria as the research assistant. The second translator sampled 20% of the isiXhosa interviews and compared the recordings with the transcripts. She also verified the English translation of the

isiXhosa transcripts. Where the first and second transcribers/translators were in disagreement over the English translations, they have met to reach a consensus of opinion.

2.5.6.2 Management of the English data

The researcher transcribed all the interviews conducted in English. It was especially beneficial for the researcher to be involved in the transcription of some of the interviews, as she did not interview the participants herself. The transcription process allowed the researcher to become immersed in the data and lead to the development of initial analytic insights (Patton, 2002).

2.6 Data analysis

Phenomenology is one of several varieties of interpretive social science and has influenced the data analysis procedure in the current study (Terreblanche and Kelly, 1999; Holstein and Gubrium, 1998; Neuman, 1997). Phenomenology was selected as analytical influence due to the emphasis it places on the **experiences** of ordinary people of their life worlds or “world of everyday life” as opposed to the understanding of an outside observer and researcher (Schultz, 1962, in Barber, 2004; Patton, 2002, Creswell, 1998; Holstein and Gubrium, 1998). The focus of phenomenology is to explore how human beings make sense of and attach meaning to experience (Patton, 2002). Phenomenology aims to explain in detail how ordinary members of society produce and experience the world that they take for granted (the so called life world). Phenomenology was thus specifically relevant to the focus of the study, namely to learn about communication in South African HIV/AIDS care by interviewing the various participants on their communication-related experiences.

The process of qualitative data analysis refers to a procedure of transforming raw data into the findings of a research study. The current analysis was based the transcendental phenomenological model, as proposed by Clark Moustakas and Bruce Douglas (Patton, 2002; Creswell, 1998). The primary steps of the transcendental analytical approach that was followed in this study is depicted in Figure 3 below and discussed afterwards.

2.6.1 Epoche

Interpretive research acknowledges the role of the researcher in the process of meaning making of raw data. Every researcher carries certain viewpoints, belief systems and personal purposes (Harry, 1996) and values based on culture, socio-economic class and personality (Ahern, 1999). Although the researcher can never fully remove him/herself from the research process (Harry, 1996) or achieve total objectivity (Schutz, 1994, in Ahern, 1999), the aim is awareness of self. In order to provide accurate descriptions of participants' experiences the current researcher reflected on, examined and documented her personal experiences and researcher identities related to communication in health care and HIV/AIDS (Ahern, 1999; Neuman, 1997, Harry, 1996). Transcendental phenomenological analysis proposes this as the first step in the analysis process and refers to the process as *epoche*⁴.

The process of epoche has enabled the researcher to achieve personal awareness and clarity regarding her pre-existing prejudice, viewpoints and assumptions related to issues of communication in health care and HIV/AIDS. Moreover, the researcher's rigorous search for her identities as researcher before and during data analysis was especially important to avoid *othering* of the caregiver research participants who were doubly disadvantaged by poverty and disability and thus vulnerable to a power divide from the researcher (Harry, 1996). The researcher has identified four different research personas through introspection and reflection. A discussion of these personas can be found in Appendix C. The process of epoche has strengthened the quality of the findings of the current study. Reflection on and awareness of researcher subjectivity demonstrate validity (Ahern, 1999; Harry, 1996) and increase rigor (Patton, 2002).

⁴ Epoche is a Greek word that means "to refrain from judgement, to abstain from or stay away from the everyday, ordinary way of perceiving things... the phenomena are revisited, visually, naively, in a wide-open sense, from the vantage point of a pure or transcendental ego" (Moustakas, 1994, pg 33, in Patton, 2002).

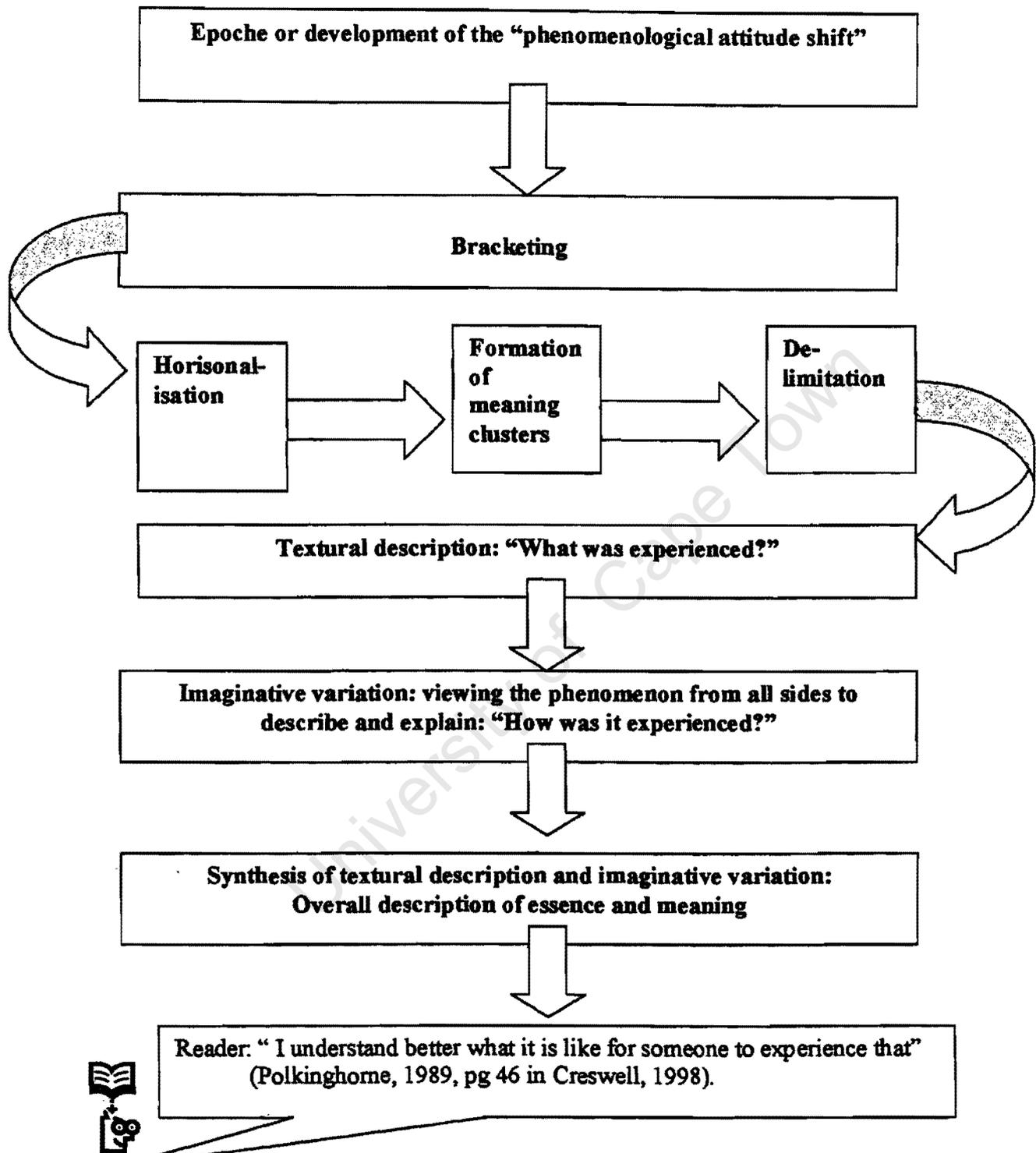


Figure 3: Graphic illustration the data analysis procedure (based on the transcendental phenomenological model, described in Patton (2002) and Creswell (1998).

2.6.2 Phenomenological reduction or bracketing

The second step of the data analysis process was known as **phenomenological reduction, or bracketing**. The following steps formed part of the bracketing process:

- Firstly, key phrases or statements related to the research question were identified in the interview transcripts. The identified phrases were removed from the text and evaluated, being treated as having equal value. The process is referred to as horisonalisation;
- Statements were next assigned with numerical codes and were grouped in clusters based on similarity in meaning;
- Lastly, the researcher undertook the process of delimitation to create an unrepitive and nonoverlapping list of statements by eliminating irrelevant and redundant data. The remainder of the data was developed into themes that were labelled with the participants' own words where possible.

2.6.3 Textural description and imaginative variation

Following the bracketing process the researcher constructed a **textural description** of the various themes developed regarding the participants' experiences (Creswell, 1998). The textural description illustrated "what happened" (Creswell, 1998, pg 150). Thereafter the technique of **imaginative variation** was performed to reflect on the textural description. Imaginative variation involved viewing the identified invariant themes from varying perspectives in order for all meanings to be explored. "Douglas has described this as 'moving around the statue' to see the same object from different views. Through imaginative variation a researcher develops enhanced or expanded versions of invariant themes" (Patton, 2002, pg 486). A description and explanation of "how the phenomenon was experienced" could now be constructed (Creswell, 1998, pg 150). Imaginative variation allowed the researcher to look further than the affect inherent in the experience to the deeper meaning for the entire group of people studied. The data analysis process from bracketing to imaginative variation was completed separately for the various groups of participants.

2.6.4. Synthesis of textural descriptions and imaginative variations

Finally, a synthesis of textural descriptions and imaginative variations of the experiences of the separate groups of participants was performed. The synthesis was achieved by comparing the themes of the three groups of participants' experience to identify similarities and contrasts. The resulting synthesis provided an overall description of the meaning and the essence of communication from the multiple perspectives of caregivers, counsellors and doctors. To ensure the trustworthiness of the analysis beyond the reflexive practice of the researcher, a second experienced analyst reviewed the transcripts and emerging themes and validated the findings.

2.7 Credibility and trustworthiness

Various procedures were followed to increase the quality of data collection and analysis. These measures have been discussed throughout this chapter and are now summarised.

The involvement of experienced qualitative researchers in the design of the study as well as in the interviewing of participants increased the credibility of the current researcher, who was relatively inexperienced and in the process of learning about qualitative research at the time of the study. Furthermore, this study has built on the findings of five recent studies on communication in health care conducted at the same hospital of current the research site (Garcia, 2004; Levin, 2004; Prince, 2004; Steenkamp, 2004 and Schwartz, 2004). The researcher's own field notes (Kelly and Brown, 2002) combined with the description of the setting found in the above listed studies have strengthened the validity of the researcher's description of the setting (Newman, 1997). The reliability and validity of the translated transcripts of the isiXhosa interviews were ensured by appointing a second translator to verify the original transcripts and translations (Johnstone, 2000). Two processes were adopted to ensure the trustworthiness or rigor of the analysis of the participants' words. Firstly, the researcher's ongoing reflection on and awareness of her own subjectivity guarded against premature interpretations of the data and reinforced the rigor of data analysis (Patton, 2002; Ahem, 1999; Harry, 1996). Finally, a second experienced analyst reviewed the transcripts and emerging themes and validated the findings to strengthen the trustworthiness of the analysis (Patton, 2002).

3. RESULTS AND DISCUSSION

In this section the themes that have emerged from the phenomenological data analysis procedure will be described and interpreted. To introduce the findings some background information regarding the participants' communication experiences as well as the organisation of this section is provided.

3.1 BACKGROUND TO THE PARTICIPANTS' EXPERIENCES OF COMMUNICATION IN THE CLINIC

3.1.1 Description of the setting

The researcher compiled field notes on the appearance and movement of the hospital and clinic throughout the data collection phase of the study. A short vignette was developed from the field notes and is presented next to provide the context of the participants' experiences and to accomplish a thick description (Denzin, 1989, in Patton, 2002).

The hospital building is spacious and recently built. The building appears child friendly, with a jungle gym on the outside grounds and another colourful play area next to the security entrance. The hospital is busy and filled with people. There are mothers and some fathers and grandparents accompanying children in the waiting rooms, corridors and on the stairs. One also sees hospital staff walking about. The doctors mostly appear hasty, holding on to documentation and armed with medical instruments e.g. stethoscopes around their necks. Although no music is playing, a continuous background noise of moderate intensity is present: ill children moaning or crying; healthy siblings chatting, laughing, playing; mothers comforting or talking to children or one another, colleagues greeting in the corridors.

A paradox exists in the pace of movement in the building. On the one hand the mothers or caregivers sit for long periods in waiting rooms. Appointment times are not given to patients. Instead they present themselves and their folder numbers to the administrations clerk upon arrival. The clerk gets the folder ready for the doctor and places it on a heap

with the folders of the other patients in the waiting room. Every now and then a doctor makes his appearance to take a folder from the heap and then calls out the name of the next patient. The doctors' pronunciations of isiXhosa patients' names are often incorrect and result in confusion amongst awaiting caregivers as to whom the doctor is calling (Levin, 2004). Most caregivers appear prepared to wait. Others seem agitated by the undefined wait. Two participants remarked during the interviews about this issue "*...you get bored from just sitting here on a chair in the waiting room doing nothing*" and "*sometimes here we wake up early in the morning and come here. They will not start with the people who come first but with other people*"⁵. Some waiting rooms have television sets mounted to the wall faced by the patients, mostly tuned in to children's programmes or day time soap opera's. There are walls decorated with posters, mostly carrying public health care messages.

On the other hand, the doctors and nurses seem to be working and moving at a high pace. Walking swiftly in the corridors to fetch patient folders or other documentation documentation, instrumentation, test results or to consult a colleague. When the doctor meets the next patient his/her pace slows down and caregivers are escorted at a polite pace to the examination room. A contrast is apparent in the expectant looks on the faces of some caregivers every time a white coat appears from the consulting rooms with the promise of redemption from waiting room boredom, and the doctors' often visible angst and haste when confronted with the waiting room full of patients with little time to attend to.

The overall impression of the hospital and the clinic is one of surprise by the quality and aesthetics of the building, and optimism about the standard of health care. It does not represent the chronic resource deficiencies and looming threats of subsidiary cuts that most South Africans associate with public health care services.

⁵ Direct quotations from the interviews with participants are presented in italics. Where the researcher has added to these quotations to make the references of deixis utterances clear, the text appears between brackets with no italics used.

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The overall impression of the hospital and the clinic is one of surprise by the quality and aesthetics of the building, and optimism about the standard of health care. It does not represent the chronic resource deficiencies and looming threats of subsidiary cuts that most South Africans associate with public health care services.

3.1.2 Communication processes discussed by the participants

⁵ Direct quotations from the interviews with participants are presented in italics. Where the researcher has added to these quotations to make the references of deixis utterances clear, the text appears between brackets with no italics used.

The results are mainly related to three separate communication processes in the clinic. These processes are now briefly discussed in order to provide a framework against which to understand the findings. Figure 4 provides a diagrammatic representation of the three communication processes that the participants discussed in the semi-structured interviews. Firstly, consultations between doctors and caregivers with and without the presence of interpreters were discussed. In consultations where no interpreter was present the interaction occurred in English. During interpreted consultations English was spoken between the doctor and interpreter and isiXhosa was spoken between the interpreter and the caregiver. Secondly, the interactions between counsellors and caregivers during HIV/AIDS counselling sessions were discussed. The counselling sessions were conducted in isiXhosa as this was the first language of both the counsellors and the caregivers. Thirdly, communication between doctors and counsellors were discussed. These interactions were only discussed by the doctor participants and were not a main focus of the study. The depth of description of doctor-counsellor interactions is thus limited. Interactions between doctors and counsellors occurred during hospital ward rounds as well as during and before and/or after interpreted consultations in which the counsellors fulfilled an interpreting function.

3.1.3 A note on the terminology used

The reader is reminded that the counsellors fulfilled the interpreting role in the clinic. The terms *interpreter* and *counsellor* were thus used interchangeably to refer to the counsellors in discussions related to interpreted communication in the clinic.

In paediatric health care doctors' communication is often directed more to the caregiver than to the child (Van Dulmen, 1998). In this study the doctors almost solely discussed their communication interactions with caregivers as opposed to children. Therefore the term *patient* was often used to refer to the caregivers when discussing the caregivers' experiences as communication partners to the doctors.

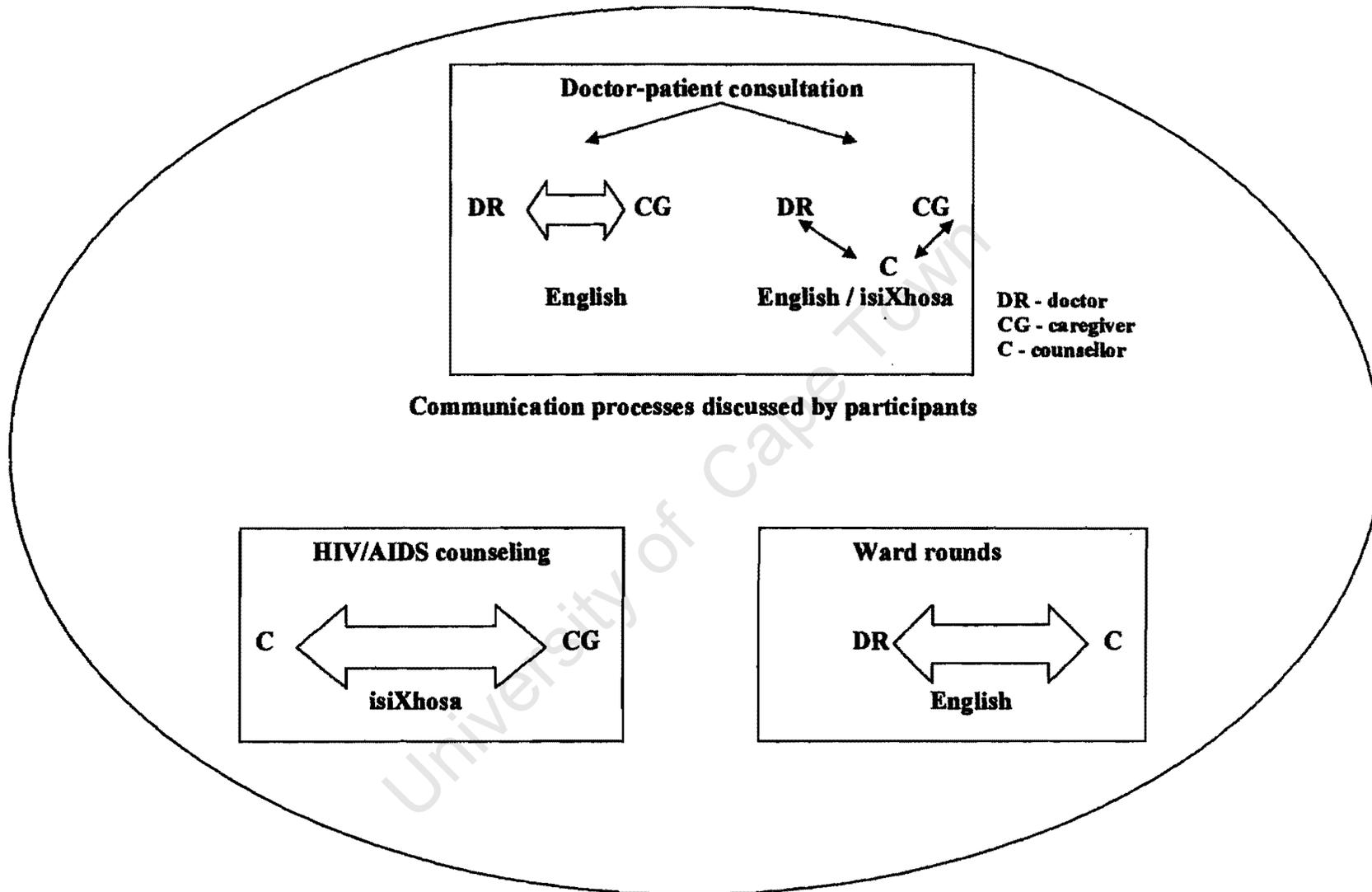


Figure 4: Diagrammatic representation of the communication processes discussed by the participants

3.1.4 Organisation of the Results and Discussion section

A diagrammatic representation of the organisation of the Results and Discussion section of this thesis is provided as Figure 5 below. The experiences of the three groups of participants will be discussed separately. The discussions are all introduced with a tabulated summary of themes related to the communication experiences of the particular category of participants. Every theme will then be discussed separately. The discussion of themes is consistently introduced with tabulated examples from the interview transcripts. Verbatim examples are supplied so that the reader can place him/herself in the situation and the thoughts of research participants (Patton, 2002). The quoted examples also serve as evidence for the emerged themes. Key words within the quoted examples were highlighted to clearly illustrate the themes to the reader. Key words have not been highlighted in examples that were sufficiently succinct. Summaries of lengthy themes are provided throughout the text. Where the description and discussion of themes are limited in terms of content summaries are not included to avoid unnecessary repetition.

The results and discussion related to the caregivers' experiences of communication in the HIV/AIDS clinic is presented next. The counsellors' and the doctors' communication experiences will then be described and discussed respectively. This section is followed by an integrated description of the nature of communication in the clinic.

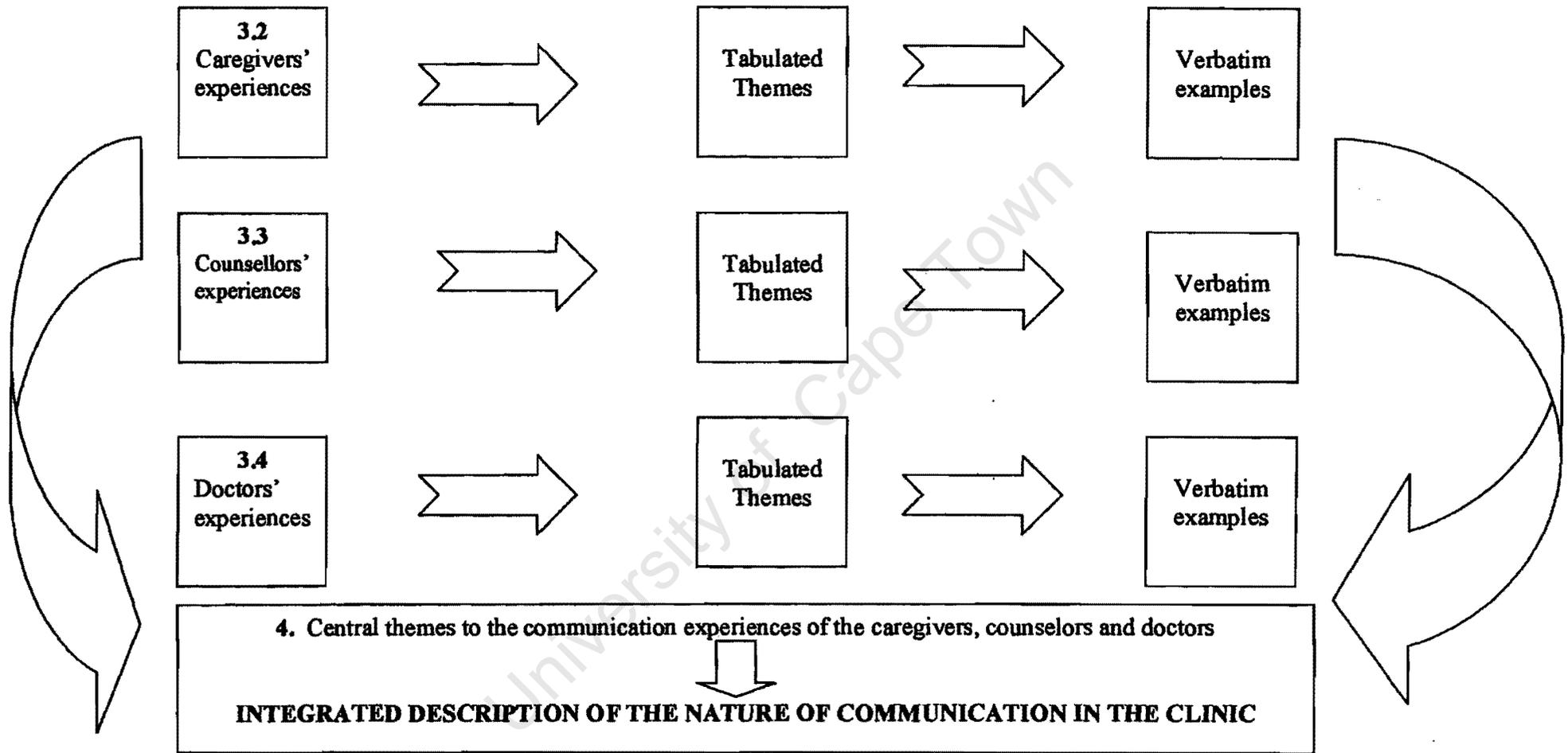


Figure 5: Overview of the Results and Discussion section.

3.2 DESCRIPTION AND DISCUSSION OF THE CAREGIVERS' EXPERIENCES

Eleven caregivers of HIV positive children were interviewed about their experiences of communication in health care in general, and more specifically their communication experiences related to HIV/AIDS care and the specific HIV clinic. A summary of the themes of the caregivers' experiences is provided in the Table 3.1 below. Each of the themes appearing in Table 3.1 will then be illustrated with verbatim examples from the interview transcripts and subsequently will be described and discussed

The caregivers communicated overwhelmingly positive experiences regarding communication with doctors and counsellors at the clinic. However, their experiences were multiple, as some caregivers reported no experience of communication difficulty "*I never have any problems*" while others reported occasional misunderstanding "*sometimes that happens to me that I don't understand what she (the doctor) is saying...*". The caregivers were also very satisfied with the services offered by the clinic on the whole. One participant articulated her preference for the clinic above the services available in her area: "*...there is nothing wrong (at XXX⁶) it is always alright. There is nothing. The doctors are alright everything and the nurses and they are much better than at our clinics there... in the townships. The treatment is alright*". According to anecdotal information shared by one of the staff members, many caregivers preferred the urban clinic to the health care centres in their areas of living, as greater anonymity existed further away from home. Due to the stigma attached to HIV/AIDS many caregivers probably wished to conceal their status from their home communities, and therefore sought HIV/AIDS care further away from home.

The caregivers' experiences of communication with doctors are discussed next.

⁶ XXX was used whenever a participant used the name of the research site. This was done to ensure that the data remained confidential.

Table 3.1: Summary of the themes of the caregivers' experiences of communication in the clinic

<p>3.2.1 Caregivers' experiences of communication with doctors</p> <ul style="list-style-type: none"> i. Doctor-caregiver consultations in English ii. Conversational accommodations made by doctors iii. Inhibiting doctor conversational style iv. Doctors respond to caregivers' questions and expressed concerns v. Miscommunication: words or terms that caregivers do not know or understand vi. Doctors' use of communication repair strategies vii. Improper communication procedure: no counselling prior to diagnosis viii. Doctors as custodians of poor communication in the bigger health care system
<p>3.2.2 Communication behaviour and characteristics of the caregivers</p> <ul style="list-style-type: none"> i. Caregivers' communication repair strategies ii. Caregiver's lack of communication repair strategies iii. Emotional consequences of not understanding the doctor iv. Caregiver responses to an inhibiting doctor conversational style by doctor v. Contrasting views on HIV/AIDS
<p>3.2.3 Caregivers' experiences of communication with interpreters</p> <ul style="list-style-type: none"> i. Need versus dislike ii. Positive experience of communication with interpreters iii. Inconsistent availability of interpreters
<p>3.2.4 Caregivers' experiences of communication in counselling sessions</p> <ul style="list-style-type: none"> i. Positive communication experience ii. Communication breakdown in isiXhosa counselling sessions iii. Counselling as helpful
<p>3.2.5 Caregivers' overall experience of HIV/AIDS health care delivery at the clinic</p> <ul style="list-style-type: none"> i. Satisfaction with the service delivered by the bigger health care team ii. Discontinuity of care

3.2.1 Caregivers' experiences of communication with doctors

Table 3.2.1: Caregivers' experiences of communication with doctors

i. Doctor-caregiver interactions in English
ii. Conversational accommodations made by doctors
CG 3: <i>"Sometimes, it happens to me that I don't understand what she (the doctor)⁷ is saying, but the doctor usually tries to accommodate a person"</i>
Appropriate level of language
CG 9: <i>"...their (the doctors') English is easily understandable and they can also understand you"</i>
CG 10: <i>"Some things (I do understand in English) but she didn't ask me things that are difficult for me to understand...She didn't ask me things that would be difficult for me".</i>
Facilitative doctor conversational style
CG 1: <i>"I haven't experienced any problems, otherwise they (the doctors) sympathise with a person....they sympathise with you, they sometimes give you advice, you see."</i>
CG 3: <i>"She (the doctor) then asked if his getting any physical therapy. I did make an appointment at physio before. I then told her that I have not yet received it, I am still on the waiting list, I was going to get it in June. Then she said I must do this... she asked if I have been given a date. I then just said they did not give me, they just said they are going to phone me. She said I must not wait for them to phone me....When I come here again I must ask there".</i>
CG 5: <i>"The doctors here at XXX are kind, really... They are very kind. They care... When you need something you explain and they help you"</i>
CG 6: <i>"... like when they said the child is also positive, like first they comforted me, you see, they told me it's not the end of the road, like it is the beginning of life... they told me on Monday, Wednesday, Friday. Then after that every day. The medicine is given to boost his immune system and for me to see him grow".</i>

⁷ Words appearing in brackets (in regular / non-Italic font style) in the transcript excerpts were not part of the participant's actual words but have been inserted by the researcher to clarify issues for the reader. Words appearing in brackets in Italic font style were somewhat difficult to identify on the audio and video recordings due to poor sound quality. The Italic word in brackets is the word that was most likely used by the interviewee based on the auditory and contextual cues.

iii. Inhibiting doctor conversational style

CG 3: "...when he is doing this he will just tell, not in a clear way, and will just talk".

CG 7: "He talks and talks".

CG 10: "Last time that doctor was not there and we went to this other one and this doctor was not attentive. That other doctor said that I may ask anytime if I see that she (the child) is not alright. That other doctor was not attentive, she just told me that... I thought: 'hey anyway'".

iv. Doctors respond to caregivers' questions and expressed concerns

CG 1: "I have never left here unsatisfied, thinking that... because I ask questions. And at this point I have asked questions from the other doctor and I wanted him/her to explain everything"

CG 6: "Like it (the communication) is alright because the doctor explained everything to me".

CG 4: "That one (the doctor) spoke English but I understood her. I asked her everything I wanted to know and she answered me too. I showed her the sore on my child's head and she told me exactly what to use on it".

v. Miscommunication: word or terms that caregivers do not know or understand

CG 9: "You'd be hearing what he (the doctor) is saying, but you'd think: 'this word...I've never heard before'".

CG 10: "A word like disease, I would not know what they mean (laughs shyly)... With those words... I would admit that I do not know what disease means... like the other thing that I did not understand was the CD 4 counts, understand? They would say your CD 4 count is like this. But I did understand it eventually as I asked there at the support group."

vi. Doctors' use of communication repair strategies

CG 3: "When it happens that I don't understand, she (the doctor) will try to explain to me until I understand".

CG 7: "...there were times when I had problems (in understanding the doctor) but he explained everything to me".

CG 10: "...it's not easy but if I get stuck she finds someone for me... Yes, she'll find someone else if she sees that I am struggling, she will find someone to explain for me".

vii. Improper communication procedure: no counselling prior to diagnosis

CG 2: *"I don't know how it happened, she (the child) was sick and I took her to the clinic. They said she was HIV. They said I must bring her here" "... the time I discovered my child was HIV, I was never counselled first, I was told my child was HI ntoni-ntoni (Xhosa: translatable with what-what)".*

CG 7: *"When I went to this doctor to do a blood test, ... when I came for the results he just told me that I have this. I thought: 'No ways, how can this be?' I usually hear from other people talking that there are usually people who are there to explain to you, but he just put it like that...just like I was, I thought that...I didn't know if he was telling me the truth, if he...In what way has this doctor taken me?...What kind of person am I? I was not feeling OK and I thought I that I didn't understand him. But the other day when I went there again he then apologised and said I was right he has taken this lightly, there should have been a person who counsels you in all of this and I did not get it".*

viii. Doctors as custodians of poor communication in the bigger health care system

CG 6: *"Yes, I got it once (doctor-caregiver misunderstanding), when I was admitted in ...Like, they fed him baby formula 1... and they said they'll change him back to baby formula 2. I did tell the one doctor that the baby formula 2 is making his tummy run. Then he understood. Although ...he didn't understand. Now at night time round about eleven they gave him baby formula 2 and his tummy ran".*

CG 8: *"I got that the first time my child got sick in...two thousand and two. Uhm. The doctor took blood tests, and then when it was time for results, he said what they looked at was not right. When I got back he said it was still not working so he must take another test and that was when I didn't understand".*

i. Doctor-caregiver consultations in English

All of the caregivers' interactions with doctors occurred in English. None of the caregivers had English as a first language. Ten of them were isiXhosa first language speakers and one had Sesotho as mother tongue. In contrast and typical of the South African health care sector the physicians were all English or Afrikaans first language speakers and were not fluent in any of the other nine official South African languages (Drennan and Swartz, 2002). The caregivers all possessed varying levels of proficiency in English and/or Afrikaans. This can be explained by the fact that according to their chronological ages, all the caregivers (with the exception of caregiver 1 who is the child's grandmother) received secondary level education in the post-1976 era which required English and an African language as matriculation subjects (Mesthrie, 2002).

It was thus often the caregiver's multilingualism and knowledge of English that facilitated doctor-caregiver communication in the clinic, as can be seen from the following quotation:

Caregiver (CG) 2: *"We (caregiver and doctor) understood each other when he asked questions and I answered him...I spoke English. I can speak both English and Afrikaans, since I used them at school"*

The caregivers who participated in Levin's (2004) study on communication in the hospital similarly reported that 94% of their previous discussions with doctors were conducted in either English (92%) or Afrikaans (2%), languages relatively unfamiliar to the caregivers. Levin reported that interpreters were present in only 21% of the interactions where doctors were unable to address caregivers in isiXhosa.

ii. Conversational accommodations made by doctors

The caregivers' positive experiences of communication with doctors should not be mistaken for trouble free communication without any breakdowns. The caregivers' stories suggested that intercultural communication surrounding HIV/AIDS could be complex, and that accommodations by both conversational parties were needed. The caregivers indicated that the doctors made certain accommodations to meet the caregivers' informational and interpersonal communication needs.

The caregivers perceived the doctors to use a level of language that accommodated their understanding. The quoted comments indicate that the content (vocabulary) and structure (sentence formation) of the doctors' language facilitated the caregiver's receptive English ability. In addition to facilitative language use, was the notion of an encompassing facilitative style of communication used by doctors. As one caregiver put it: *"...it depends on the kind of person one (a doctor) is"*. Aspects of a communicative style that the caregivers experienced as facilitative to a positive communication experience included sympathy and kindness shown by doctors, as well as indications that the doctor cared about the caregiver and patient and wanted to help, even beyond pure medical

issues. The doctors were thus perceived to be performing affective communication behaviours and adopting a biopsychosocial approach towards their duties versus the more traditional bio-medical approach. Biomedicine is primary disease-focussed, whereas the biopsychosocial model includes the person and the disease (Engel, 1977, 1980).

Coyle and Sculco (2003, p. 214) found that patients suffering from chronic and life threatening diseases benefit from communication that indicated “interest, concern and affirmation of one’s self as a unique human being”. They also reported that doctor conversational style and the patient’s relationship with the doctor influence the way in which the patient receives information.

Caregiver 3’s story regarding the doctor’s concern over the child’s physiotherapy furthermore indicates that the doctor was aware of the need for a continuum of care in the treatment of HIV/AIDS (Hughes et al.; 2004) and realised that medical as well as physical rehabilitation services were needed by this child.

iii. Inhibiting doctor conversational style

In contrast with the description of a facilitative conversational style the caregivers also described a certain dominating and insensitive doctor conversational style which inhibited effective doctor-caregiver communication. The caregivers described an inhibiting doctor conversational style as insensitive to the communicative needs of the caregiver, who “*talks and talks*” without adapting the level or content of his/her language (being unclear) and without verifying the caregiver’s understanding. The physician thus dominates the conversation and probably doesn’t allow the caregiver space to ask questions or express her concerns.

An inhibiting doctor conversational style involves high control by the doctor indicative of a paternalistic bio-medical approach where the disease is more important than the person suffering from it and the doctor is the expert who instructs and makes decisions on behalf of and his/her patients (Steward and Roter, 1989, in Ong et al., 1995; Engel, 1977). An inhibitive doctor conversational style creates a monologue in contrast with the dialogue

advocated by patient-centred methods (Moodley, 2000) and executed through a facilitative doctor conversational style. The absence of an accommodating and sensitive conversational style can have serious negative effects on the medical interaction and caregiver satisfaction with the medical service (Smith, Polis and Hadac, 1981 in Ong et al., 1995; Korsch et al., 1968).

Ong et al. (1995, p. 910) summarised literature on the cause of high controlling physician behaviour and reported that “patients’ limited understanding of medical problems and treatment” and “heightened uncertainty” might be responsible. An inhibiting conversational style in the public HIV/AIDS care sector is likely arise from like factors. Doctors’ exercise of control over medical information and the institutionalised roles dictated to doctor and patient might also lead to doctors assuming high control in doctor-patient interactions (Ong et al., 1995).

iv. Doctors respond to caregivers’ questions and expressed concerns

Various caregivers expressed a need and expectation for doctors to provide thorough and clear explanations regarding the child’s condition and treatment. The caregivers reported positive communication experiences and satisfaction with the health care service when doctors responded to their informational needs by providing complete answers to their questions and by attending to their concerns regarding the children’s health. Caregiver 1 made it clear that satisfaction of her expectations of the medical encounter was equally dependant on her ability to formulate questions and concerns as it was on the doctor’s responses and style of responding, to such needs. The caregivers were sufficiently assertive and linguistically competent to ask questions and express needs during medical consultations. At the same time the conversational style of the doctor facilitated the caregiver to ask questions. This balance formed part of the caregivers’ positive experience of communication with the doctors in the clinic.

Despite the caregivers’ positive comments regarding thorough answers and explanations to their questions, the doctors (see 3.4.4. iii) and the counsellors (see 3.3.5) both reported a limited use of questions by the caregivers. Moreover, the two studies that involved

conversation analysis of doctor-caregiver interactions at the clinic found that caregivers mostly used their conversational turns to answer the doctors' (or interpreters' in the case of interpreted consultations) questions and rarely initiated questions (Garcia, 2004; Steenkamp, 2004). Levin (2004) similarly reported that 39% of the caregivers he surveyed (in the same hospital as the setting of the current study) admitted to refraining from asking the doctors questions they wanted to ask due to anxiety over asking questions.

The majority of patients' contributions to medical consultations consist of information provision in response to doctors' questions (Roter, 1989, in Ong et al. 1995). In their literature review of doctor-patient communication research, Ong et al. (1995) reported that several studies have indicated the reluctance of patients to ask questions in interactions with doctors. In their pioneering study of doctor-patient communication in the journal *Paediatrics*, Korsch et al. (1968) found that most paediatricians viewed themselves as providing sufficient opportunity for caregivers to ask questions. However, analysis of the paediatrician-caregiver interactions revealed that 10% of caregivers made no use of questions and that a further 27% asked only one or two, including medically unrelated, questions. Moreover, Korsch et al. (1968) found that doctors frequently ignored the caregivers' questions, provided vague answers or changed the conversational topic in response to caregivers' questions. One hundred and ninety three of the 800 caregivers who have participated in Korsch et al.'s study have indicated that they would have liked to ask the doctor more questions. Cicourel (1985) stated that doctors' disregard for patients' questions may reflect the status and power differences between the two parties.

Similar to the findings of the current study Korsch et al. (1968) reported that caregivers had expectations for the doctor to take time and trouble in addressing questions and providing explanations. Patients have a need for intelligible information on the nature and the cause of their illness and need to feel accepted and understood by doctors (Billings-Gagliardi et al., 2001; Ong et al., 1995). Doctors often underestimate the amount of information required by patients. However, patients need sufficient information in order

to participate in decision making (Ong et al., 1995). Research further shows that patient satisfaction and compliance increase when patient expectations are met during the medical encounter (Like and Zyzanski, 1989, in Ong et al., 1995; Korsch et al., 1968).

It has been reported that patients who ask more questions, appear more anxious and express more concerns within clinical interactions receive larger amounts of information than patients who ask fewer questions (Street, 1991 in Ong et al., 1995). Patients thus need to ask questions in order for their informational needs to be met. In the context of the pronounced unbalanced power relations and linguistic differences between doctors and caregivers in the current study it is likely that the caregivers will have anxieties over asking the questions that they need to ask. Caregiver gender might further affect the ability to ask doctors (especially male doctors) questions as women might not often be listened to or be expected to speak in communities where gender inequality is rife (Duffy, 2005). Despite the realisation that patients and doctors are both responsible for effective communication Ulrey and Amason (2001) state that doctors carry a larger proportion of the responsibility due to their training and competence in the development of interpersonal relationships. In intercultural situations where interactions are conducted in the doctors' as opposed to the patients' first language and the power balance strongly favours the doctor, the doctors responsibility to elicit caregivers' questions and address their concerns seem especially important.

v. Miscommunication: word or terms that caregivers do not know or understand

It is predictable from the context of intercultural doctor-caregiver interaction and evident from some of the quoted examples that despite the overall positive view of clinical communication, the caregivers had various experiences of not understanding the doctor's message. The most frequently quoted reason for these miscommunications was the doctors' use of words and terms that the caregivers did not understand. The counsellors (see 3.3.6.ii) and the doctors (see 3.4.1.C) have also mentioned that medical terminology and concepts specifically related to HIV/AIDS has caused difficulty in communication in the clinic.

Levin (2004) similarly reported that the caregivers in his study most frequently cited difficulty in understanding English and specifically medical terminology, as reasons for poor communication with doctors. Patients have a better understanding of the doctor's message when an everyday language (EL) is used as opposed to the specialised medical language (ML) register (Bourhis et al., 1989).

vi. Doctors' use of communication repair strategies

Caregivers have experienced specific communicative actions from doctors to repair the communication breakdown when a caregiver didn't understand the doctor's message. Caregivers described how doctors would provide explanations that are thorough ("*explained everything*") and persistent ("*until I understand*"). Doctors were also reported to call on the services of an interpreter to bridge the communication gap between him/herself and the caregiver. The doctors indicated correspondingly that they relied on interpreters to facilitate caregivers' understanding in interactions where communication breakdown occurred or is likely to occur (see 3.4.1.E and 3.4.4.iv). It thus seems that interpreters are sufficiently included in difficult doctor-patient interactions, unlike the underutilisation of interpreters that has been reported in other parts of the hospital (Levin, 2004). However, an occasional unavailability of interpreters has been mentioned by the caregivers and will be discussed under 3.2.3.iii.

vii. Improper communication procedure: no counselling prior to diagnosis

Two caregivers reported dissatisfaction with doctors' communication of their own and their children's HIV positive diagnoses. These incidents did not occur at the research site. Caregiver 2 and 7 relayed stories of not being counselled before receiving their own or their children's HIV positive blood test results. It is not clear from the caregivers' stories whether they have received pre-test counselling or whether they have provided informed consent for the HIV tests to be conducted. However, it is clear that the caregivers did not receive the support and information, including risk reduction strategies, which are required from post-test counselling in the case of an HIV positive diagnosis (Bekker, 2002; Schrooten et al., 2001).

Even after caregiver 7 has received an apology and validation of her feelings from the doctor, the abrupt announcement of her HIV status remained a difficult memory. The improper and unsupportive procedure made her doubt the authenticity of the information she has received. Her uncertainty about her HIV status did not only threaten her own well being, in that appropriate medical and nutritional care might not have been followed, but also the well being of her loved ones, as the disease could have been transmitted due to improper precautions. Furthermore the caregiver felt unvalued and upset. She found it difficult to understand why she did not receive counselling since she has knowledge of others routinely being counselled prior to and following HIV tests. The delivery of a life threatening and chronic diagnosis signals the start of the relationship between the patient and the health care system. When communication missteps occur during the delivery of such diagnoses, the adverse effects on the patient's relationship with the doctor and the bigger health care service seems immense.

It is a very stressful life event to receive an HIV positive test result with physical as well as significant psychological and social implications (Schrooten et al., 2001). When HIV positive test results are delivered without proper counselling patients do not receive the support they deserve and may be left with feelings of worthlessness. When patients perceive doctors to treat them without respect their individual vulnerability is exposed and conflict in communication ensues (Coyle and Sculco, 2003). The current study indicated similar consequences of missteps in communication to those reported by Coyle and Sculco (2003, p. 209) namely, "loss of hope, sense of abandonment, and a diminished feeling of personal worth and dignity". Difficulties regarding the communication of HIV test results have also been reported in literature from the developed world (Schrooten et al., 2001).

An explanation of the cause of improper communication in the delivery of HIV test results needs to take various factors into account. When health care professionals have to deliver news that patients do not want to hear "both parties...are engaged in a communication dance of vulnerability. The physician is vulnerable because he/she must deliver the facts whatever they may be, and the patient is vulnerable because he/she

doesn't want to hear any... bad news" (Coyle and Sculco, 2003, p. 212). Furthermore the doctor must face the patient's raw emotions in such situations and may not have received appropriate training in this regard. Communication of an HIV positive test result is a resource intensive task that requires training, experience, talent, HIV/AIDS specific knowledge and time (Schrooten et al., 2001). If any of these resources are lacking improper procedures may result. Moreover, negative stereotypes and stigma exercised by health care providers may lead to improper delivery of HIV test results.

viii. Doctors as custodians of poor communication in the bigger health care system

The caregivers also related communication experiences that suggested miscommunication amongst members of the health care team or within the bigger health care service. Despite the true origin of these miscommunications it might be that the caregivers perceived the cause as directly attributable to the doctor. (Refer to Table 3.2.1 for examples from caregivers 6 and 8's interviews in this regard). It is quite possible that the miscommunication regarding the formula feeding of caregiver 6's child occurred between the doctor and the nightshift nursing staff, or amongst members of the night time nursing staff and not necessarily between the doctor and caregiver. Similarly, caregiver 8's blood test account probably indicated miscommunication between the doctor and the laboratory personnel. These experiences seemed to be upsetting to the caregivers involved, who might have correctly or perhaps misguidedly attributed the miscommunications to the doctor. It is thus possible that the doctors became the custodians of poor communication within the bigger health care system from the caregivers' point of view.

Summary of the caregivers' experiences of communication with the doctors

Communication between caregivers and doctors in the clinic was conducted in English. The caregivers had overwhelmingly positive experiences of communication with doctors in the clinic. They perceived the doctors to facilitate their communication needs by adopting an appropriate level of language as well as a conversational style characterised by sympathy, kindness and a willingness to help. The caregivers were satisfied with

communication when doctors responded to their questions and expressed concerns. Miscommunications between caregivers and doctors were reported, mostly due to the doctors' use of terminology unfamiliar to the caregivers. The doctors were reported to make use of thorough and persistent explanations to repair communication breakdown.

In contrast with the description of a facilitative conversational style the caregivers described a certain dominating and insensitive doctor conversational style which inhibited effective doctor-caregiver communication. Two caregivers shared experiences of improper communication procedures followed by doctors when they were informed of their seropositive diagnoses. These improper procedures resulted in doubt over the authenticity of the doctor's information as well as feelings of diminished self worth and dignity. Finally, it seemed that doctors were often perceived to be responsible for miscommunication in the bigger health care system. The doctors were thus at risk to become custodians of poor communication within the bigger health care system.

3.2.2 Communication behaviour and characteristics of the caregivers

Table 3.2.2 Communication behaviour and characteristics of the caregivers

i. Caregivers' use of communication repair strategies
CG 6: <i>"I ask him to repeat what he means exactly"</i> .
CG 11: <i>"But I don't leave if I don't understand something. I'd say that I don't understand"</i> .
CG 8: <i>"...if I don't understand I ask the doctor to call someone in"</i> .
CG 5: <i>"...you know what I usually do, I would write them down as she (the doctor) is saying them and I would ask someone else"</i> .
ii. Caregivers' lack of communication repair strategies
CG 7: <i>"I would just keep quiet as I wouldn't know what to do... I would go on though I have not understood what has been said"</i>
iii. Emotional consequences of not understanding the doctor
CG 3: <i>"Usually I don't feel okay, but I would understand that it has to be like that"</i> .
CG 7: <i>"That made me worry a bit, because I wanted to understand everything that he was saying"</i> .

iv. Caregiver responses to an inhibiting doctor conversational style

CG 3: *"In such a way I am sometimes unable to ask, maybe the child has something wrong with him and I won't be able to say"*

CG 7: *"It makes me unhappy, then I am less interested to go back there because I find that I leave there not understanding and I can see that I do not understand"*.

v. Contrasting views on HIV/AIDS

CG 3: *"... they (the doctors) normally take it as if it is an easy thing...I would be seeing it as the very thing that will bring me down"*

CG 5: *"Because, I did not take this in a hard way. I took it that everyone is sick mos, everything kills, people are killed, mos you understand. The doctor took it as that it is difficult for her, but I did not take it the hard way...I took everything easy, you see"*.

Cg 6: *"...like when they (the doctors) said the child is also positive, like first they comforted me, you see, they told me it's not the end of the road, like it is the beginning of life...they told me on Monday, Wednesday, Friday. Then after that every day. The medicine is given to boost his immune system and for me to see him grow"*.

i. Caregivers' use of communication repair strategies

The caregivers mentioned various communication repair strategies that they have used when not understanding the doctor's message. These strategies included requests for repetition, clarification or an interpreter. Caregiver 5 reported a rather sophisticated and literate means of dealing with unknown technical terms, namely to write such terms down and to enquire about their meaning from "someone else" after the medical consultation has ended. Levin (2004) found similar solutions to communication breakdown employed by caregivers in other parts of the hospital. Caregivers in his study reported that they requested an interpreter or asked the doctor or a nurse for explanations when a communication breakdown occurred.

A necessary question to ask is why caregiver 5 did not ask the doctor about the meaning of the words that she has not understood? And why did caregiver 10, who was quoted earlier (see 3.2.1.v) as not knowing the word 'disease' or the meaning of a 'CD 4' count, learned these meanings from a support group and not her doctor? Caregiver 10 gave some clue in the following statement: *"... no, I did ask it from this child's doctor. I did ask her doctor but I forgot the name of the doctor there at XXX. Yes."* The answer is probably that caregiver 10's doctor provided an unintelligible explanation of the words the

caregiver did not understand in the first place. Caregiver 5 might have had a similar experience or might have been aware of this possibility and therefore wrote troublesome terms down in order to enquire about the meanings later from “*someone else*”. Caregiver 5 might also have been compensating for the limits of the human memory with her written notes (Glascoe et al., 1998, page 2 of 8). Patients often have difficulty recalling the doctor’s message (Ong et al., 1995) especially if it contains specialised terminology (Gablehouse and Gitterman, 1990 in Glascoe et al., 1998, page 2 of 8). Caregivers’ ability to remember the doctor’s message is also negatively affected by stress. Many caregivers arrive at the medical encounter with worry over their child, their own abilities and other life stressors (Glascoe et al., 1998, page 2 of 8). A high prevalence of anxiety and depression has been reported amongst HIV positive individuals (Hughes et al., 2004; Freeman, 2004; Olley et al., 2003). HIV positive individuals who fulfil a caregiver role are exposed to even more stressors (Freeman, 2004). Caregiver 5’s strategy to understand and (possibly) to remember the information delivered by the doctor is considered to be well motivated and extremely adaptive.

ii. Caregiver’s lack of communication repair strategies

Despite the communication repair strategies reported by some caregivers, caregiver 7 admitted that she did not know how to, nor attempted to repair a communication breakdown in an interaction with a doctor. In the quoted example she specifically referred to miscommunications due to the doctor’s use of specialised medical language. The doctors (see 3.4.3.iii) and counsellors (see 3.3.5) who were interviewed in this study similarly mentioned the lack of communication repair strategies by some of the caregivers. Levin (2004, p.78) similarly found that 21% of the caregivers he surveyed did nothing to repair communication breakdowns occurring in interactions with doctors. Levin concluded that this “probably reflects the extent of the disempowerment and frustration felt by patients due to the inequalities between them and their doctors”. He further stated that an individual’s expectations of medical encounters are shaped by his/her politicisation, past experiences of the medical system and other components of general society.

It is also important to consider the emotional experiences of poor, black, disabled, female caregivers in the current South African era, and the influences of those experiences on relationships (Marks, 1999) within the health care sector. It is likely that the caregivers have experienced exclusion, marginalisation and/or rejection in a society with a history of racism, where gender inequality and ableism is still rife, and HIV/AIDS is severely stigmatised. Social exclusion and denigration often leads to internalised oppression that affects self-esteem, thoughts and actions (Marks, 1999). It is thus possible that some caregivers have internalised the denigration and exclusion that women in their situation often experience, and feel “tainted and devalued” (Siegel and Lekas, 2002). This internalised oppression serves to keep them submissive and disempowered in situations of unequal power. Caregivers who suffer from internalised oppression are unlikely to be sufficiently assertive in interactions with doctors to make use of communication repair strategies.

iii. Emotional consequences of not understanding the doctor

Miscommunication between doctor and caregiver had emotional consequences for the caregivers. The caregivers reported feelings of unhappiness and worry when not understanding the doctor. The influence of doctor-patient interactions on patients' health outcomes and psychiatric morbidity is often studied (Ong et al., 1995). Ong et al. (1995) cited various studies that confirm that psychological difficulties may arise in the diagnosis or treatment phases of terminal conditions when patients receive a lack of information. Examples of such psychological difficulties are uncertainty, anxiety, depression and problems with coping.

iv. Caregiver responses to an inhibiting doctor conversational style

The caregivers have also explained their reactions to an inattentive, domineering doctor conversational style. A domineering doctor conversational style inhibited the caregivers to express their complaints and concerns regarding the children's health. An inhibiting doctor conversational style might also prevent caregivers from using communication repair strategies to overcome communication breakdown in doctor-patient interactions. The caregivers indicated that an inhibiting doctor conversational style might cause them

to leave the health care setting without understanding the information conveyed to them. It might also lead to the decision not to return for follow-up medical services that are crucial in the treatment of chronic diseases such as HIV/AIDS.

Other authors have also reported that a perceived lack of interest by the doctor may result in anger amongst patients (Coyle and Sculco, 2003) and/or patients deciding not to adhere with instructions, to seek alternative remedies and not to return for follow up services (Ong et al., 1995; Cicourel, 1985). Ironically doctors may perceive such patient behaviour as negligence on the patient's part without recognising their role in eliciting the behaviour. It is clear that poor doctor-patient communication might adversely affect the quality of health care and the health care outcomes of patients. Levin (2004) found that 45% of the caregivers who have participated in his study were concerned over the possible negative effects of poor communication on them or their children. Twenty two percent of the caregivers reported specific adverse consequences of poor doctor-patient communication on their children's health, including incorrect administration of medication and misdiagnosis.

v. Contrasting views on HIV/AIDS

The caregivers as well as doctors seemed to have varying perceptions of and emotional responses to HIV/AIDS. Whereas some caregivers had perceptions of doctors considering the disease in a "light" manner, another felt that the doctor had a much more troublesome view of the disease compared to her own view. The comment by caregiver 5 indicates a fatalistic outlook that was also noted in an earlier quotation caregiver 3 ("*Usually I don't feel okay (misunderstanding the doctor), but I would understand that it has to be like that*"). Caregiver 6's story of receiving her child's diagnosis illustrated a doctor who had a hopeful and optimistic view of the child's illness and who was able to comfort the mother. Furthermore a sense of the doctor's awareness of and concern for the child and mother with the disease was felt. The doctor thus seemed to be adopting a biopsychosocial and patient centred approach.

Another instance of the caregivers' perceptions of HIV/AIDS was that the infected child of an HIV positive mother had a greater problem than the mother herself. CG 10: *"I will refer mostly to the child, as she is the one who has a bigger problem"*. Finally, there was an example of a caregiver who tearfully explained that the first thing she would have changed about her situation if she was able to would be the fact that her child was HIV positive. Caregiver 2: *"If I was to start? The fact that my child has HIV"*. The caregiver's wish to erase the child's HIV positive status may be connected with what Korsch et al. (1968, pg 863) calls the "almost universal tendency for parents to blame themselves for their child's illness and other shortcomings". In this case of HIV/AIDS the mother must be painfully aware that the child most possibly contracted the virus from her, which often leads to guilt (Wiener and Septimus, 1998 in Ross and Deverell, 2004) and consequently to intense emotional upset. Furthermore, this mother faced the dismal situation of mother and child both being infected with a life threatening chronic disease with poor treatment opportunities in South Africa, especially at the time that this study was conducted. HIV positive caregivers often experience deep feelings of guilt and worry at the dependants who are left behind when the caregiver dies (Special Assignment, 2003, in Freeman, 2004). The mother also has to live with the pain of knowing that her child might die from this disease. The death of a child is often more tragic than losing a loved one who has lived a long and fulfilled life (Freeman, 2004). Finally, Caregiver 2 may wish to spare her child the discrimination and social ostracism faced by HIV positive individuals (Siegel and Lekas, 2002).

Differences in doctors' and caregivers' perceptions of HIV/AIDS have the potential to complicate doctor-caregiver interactions beyond the more obvious challenges of multilingualism and cultural diversity. A biomedical approach may fail to recognise the "many dimensions of meaning – psychological, moral or social – which characterize the 'illness' perspective of the patient, and those around him or her" (Helman, 1994, p. 137). Medicine's focus on the diagnosis and treatment of physical malfunction, may also fail to take into consideration emotional states experienced by the patient, e.g. "guilt, shame, remorse and or fear" (Helman, 1994, p. 138). However, effective communication

between doctors and patients can enable recognition of and negotiation between the various views, resulting in better outcomes for patients and doctors.

Summary of the communication behaviour and characteristics of the caregivers

The caregivers reported to use communication repair strategies such as requests for repetition, clarification or interpreters. However, not all caregivers had the knowledge, or the courage, to use such strategies. The caregivers indicated that misunderstanding the doctor or an inhibitive doctor conversational style could lead to negative psychological and health outcomes. Differing perceptions of HIV/AIDS among caregivers and doctors have been identified. Contrasting perceptions set an expectation for communication to recognise and successfully negotiate between the participants' views.

3.2.3 Caregivers' experiences of communication with interpreters

Table 3.2.3: Caregivers' experiences of communication with interpreters

i. Need versus dislike	
Need	<p>CG 2: <i>"It (interpreting) helps... Or some other words you don't understand, you see...or the doctor would not speak the way a black person would, ... the way they explain it you see"</i></p> <p>CG 8: <i>"What can I say, she's (the interpreter) a nice person. She's alright, she speaks nicely. If something is not clear she explains it to me"</i>.</p>
Dislike	<p>CG 3: <i>"I don't like it (interpreter's presence), but it happens as it has to happen... Because, she is going to be hearing about my problems"</i></p> <p>CG 9: <i>"I wouldn't like that. Sometimes I would like to talk for myself...to the doctor. Even if the interpreter is there I don't mind, but sometimes I wish I can... speak by myself to the doctor. It must not be like I have to pass this to this side and she also have to pass this to my side"</i>.</p> <p>CG 5: <i>"I always communicate in... I can communicate with them (doctors) in English"</i>.</p> <p>CG 11: <i>"I never have anything that I do not understand"</i>.</p>

ii. Positive experience of communication with interpreters
Facilitative conversational style
CG 2: <i>"... Or some other words you don't understand, you see...or the doctor would not speak the way a black person would, ... the way they explain it you see"</i>
CG 8: <i>"What can I say, she's (the interpreter) a nice person. She's alright, she speaks nicely. If something is not clear she explains it to me"</i> .
Accurate interpreting
CG 8: <i>"She (interpreter) also speaks what I tell her to speak"</i> .
Formal interpreting
CG 7: <i>"If it can be a person working hereworking with the doctor, not anyone who passes by"</i> .
iii. Inconsistent availability of interpreters
CG 2: <i>"The translator is not always here, it is only some days"</i> .

i. Interpreting services: need versus dislike

An additional aspect to the caregivers' experiences of communication with doctors in English is the use of interpreters. Caregivers were divided regarding whether they would appreciate or dislike an interpreter's presence in a medical consultation. Caregivers who have experienced or who would appreciate interpreted medical consultations saw the interpreters' explanations of poorly understood words and concepts as the biggest advantage of interpreted interactions. Caregiver 2 indicated that the interpreter did more than merely explain terms that were not understood. The interpreter delivered the information in a manner appropriate to the culture of the caregiver. An interpreter role of cultural brokerage is thus suggested (Swartz, 1998). In contrast, caregivers who disliked the presence of interpreters in medical consultations explained this view with the following reasons: threatened confidentiality, altered dynamics of the dyad-to-triad, compromised ability to *"speak for oneself"*, loss of direct contact with the doctor and superfluity.

Caregiver 9's ambivalent comment about acceptance of an interpreter's presence, yet preference for direct communication with the doctor is interesting. Caregivers' perceptions of the presence of interpreters in medical consultations are probably largely influenced by their educational level and degree of proficiency in the doctors' language. All caregivers and patients would probably prefer direct doctor-patient contact without

any third parties present, especially in interactions regarding sensitive issues such as HIV/AIDS. Caregivers who do not have sufficient receptive or expressive proficiency in the language of the doctor do not seem to benefit from a doctor-patient dyad and are grateful for the presence of an interpreter to bridge linguistic and cultural gaps. The need for privacy, direct contact with the doctor and self-expression thus seems to be overridden by the need to understand and to be understood, albeit in an indirect manner.

ii. Positive experience of communication with interpreters

The caregivers who did make use of interpreting services had positive experiences of the interpreted consultations. They described the interpreters as using a facilitative conversational style, characterised as clear and culturally appropriate. Furthermore the caregivers felt they were well represented by the interpreters and did not suspect mistranslation of their messages to the doctor.

The caregivers were satisfied with the situation at the research site where counsellors and thus members of the health care team acted as interpreters, as opposed to informal *ad hoc* arrangements. The fact that the current clinic has assigned specific experienced individuals to the interpreting function may be largely responsible for the caregivers' positive communication experiences of interpreted consultations. *Ad hoc* interpreting is often relied upon in other parts of the hospital (Levin, 2004; Schwartz, 2004) and in the public health care sector generally (Drennan, 1998).

iii. Inconsistent availability of interpreters

Caregiver 2 mentioned the inconsistent availability of interpreters in the clinic. The unavailability of interpreters in situations where caregivers do not understand the doctor and/or are unable to express their concerns predicts negative doctor-patient communication outcomes. Interpreter unavailability is an issue related to the general provision of resources to and within the bigger health care institution. The clinic was probably in a much better position than most clinics in the hospital as far as the availability of interpreters is concerned. Only two trained interpreters were employed (in nursing posts) at the hospital. Doctors in the larger hospital made use of the trained- as well as *ad hoc* interpreters (Schwartz, 2004). Forty percent of the doctors interviewed by

Schwartz (2004) reported that they most often used nurses as interpreters. Nurses often resent being used as interpreters as it is time intensive not part of their formal duties. Interpreting is thus perceived as an unpaid and unappreciated part of their jobs.

Summary of the caregivers' experiences of communication with interpreters

Caregivers were divided regarding whether they would appreciate or dislike an interpreter's presence in a medical consultation. Reasons for disliking interpreters' presence in medical consultations included threatened confidentiality, altered dynamics of the dyad-to-triad, compromised ability to "*speak for oneself*", loss of direct contact with the doctor and superfluity. The caregivers who did make use of interpreting services had positive experiences of the interpreted consultations. They described the interpreters as using a facilitative conversational style and felt they well represented by the interpreters. These caregivers regarded the interpreters' culturally appropriate explanations of unfamiliar words as the biggest advantage of the clinic's interpreting service. Inconsistent availability of interpreters was also reported.

3.2.4 Caregivers' experiences of communication in counselling sessions

The caregivers all had access to the counselling services that were provided at the research site. Counselling sessions were fully conducted in isiXhosa, which is the first language of the counsellors and of the majority of caregivers visiting the HIV clinic. Caregivers 1 and 11 were the only participants who did not make use of or intended to make use (referring specifically to caregivers who were first time visitors, that is caregivers 7 and 8) of the counselling services offered. Caregiver 1 did not visit a counsellor as she spoke Sesotho and not isiXhosa and caregiver 11 did not attend counselling sessions as she regarded them to be of little use to her.

Table 3.2.4: Caregivers' experiences of communication in counselling sessions

i. Positive communication experience
CG 5: <i>"Very nice, it (the counselling session) was very nice"</i> .
Cg 10: <i>"I have never had a difficult one (counsellor), I only have an easy counsellor"</i> .
CG 4: <i>"... they say the real thing. Even when they tell you things, they don't just tell you, they speak to you nicely. They help you"</i> .
CG 7: <i>"It was okay. She explained everything"</i> .
ii. Communication breakdown in isiXhosa counselling sessions
CG 5: <i>"...and you'd think now you don't understand what she is saying, because they speak fast and suddenly you don't understand"</i> .
CG 6: <i>"...you know, we as Xhosa people, we like to speak English when we speak to each other... Xhosa is difficult at times"</i> .
iii. Counselling as helpful
CG 10: <i>"I never had a difficult one. I just have an easy counsellor. She's also from here at XXX, but she referred me to a place that I must go there in my area"</i> .
CG 9: <i>"It (the counselling session) was okay, in such a way that I even gained more knowledge of things that I didn't know about. I didn't know that (unintelligible, but most likely referring to a specific service) about the one that's nearby"</i> .
CG 6: <i>"Counselling helps me a lot. I am strong"</i>
CG 7: <i>"It was okay...she explained everything...At least I felt alive from where I was sitting"</i>

i. Positive communication experience

The caregivers' experiences regarding communication with counsellors in the counselling situation were overwhelmingly positive. Caregivers described the communication in counselling sessions as pleasant and unproblematic. Furthermore the caregivers experienced the counsellors as adopting a facilitative conversational style in counselling sessions. Caregiver 4's comment regarding the counsellor *"say(ing) the real thing"* points out that she experienced the counsellor(s) to be truthful, trustworthy and credible. The fact that the caregivers and counsellors were both HIV positive and belonged to the same linguistic, cultural, socio-economic, gender and seropositive groups probably contributed

greatly to caregivers' positive experience of communication within the counselling sessions.

ii. Communication breakdown in isiXhosa counselling sessions

Although the counselling sessions were conducted in isiXhosa, the language that all caregivers who made use of the counselling services were most comfortable in, experiences of communication breakdown were reported by the caregivers. Miscommunications due to the counsellors' high rate of speech, and also the caregivers' unfamiliarity with certain isiXhosa terms, were mentioned. Various Xhosa dialects exist, where some include Zulu or Sotho terms. Such dialectal diversity has been reported to cause problems amongst isiXhosa first language speakers (Kaschula and Anthonissen, 1995). It is thus possible that various isiXhosa dialects are represented by the caregivers and counsellors in this study, since most of them have moved to Cape Town from various other areas, mostly in the Eastern Cape and the former Transkei and Ciskei.

Caregiver 6's comment regarding isiXhosa being difficult and a preference for English was the only such comment that was made by the caregivers. The comment seems different from the overall positive experience and appreciation that the larger group of caregivers had of the isiXhosa counselling services. Caregiver 6 was however the only caregiver with a tertiary level training (in information technology) and is probably part of the "urbanwise 'modern' (black) people, who speak English and non-standard urban varieties of African languages, showing extensive borrowing of vocabulary, code-switching and neologisms" (Meshtrie, 2002, pg 16). Communication between health care workers and patients in isiXhosa is thus not necessarily unproblematic, due to linguistic variety based on the backgrounds of individuals.

iii. Counselling as helpful

Various caregivers described the counselling services that they received as helpful on a practical and informational level, as well as on an emotional level. Caregiver 7's profound statement is interesting when paired with her disturbing description of being diagnosed with HIV without receiving counselling. Recall her story: "*When I went to this*

doctor to do a blood test,... when I came for the results he just told me that I have this. I thought: 'No ways, how can this be?' I usually hear from other people talking that there are usually people who are there to explain to you, but he just put it like that...just like I was, I thought that...I didn't know if he was telling me the truth, if he...In what way has this doctor taken me?...What kind of person am I? I was not feeling OK and I thought I that I didn't understand him. But the other day when I went there again he then apologised and said I was right he has taken this lightly, there should have been a person who counsels you in all of this and I did not get it".

The caregiver's previous feelings of being treated as worthless and without respect are in stark contrast with her "*feeling alive*" during counselling. The most obvious explanation for the different feelings evoked during diagnosis and counselling is probably related to the orientation of health care worker towards the caregiver and her disease. The caregiver might also "*feel alive*" by mere virtue of the fact that she is receiving and not denied counselling. The timing of the two occasions must also be considered as being diagnosed with HIV is a very stressful event (Schrooten et al., 2001). By the time that patients are receiving follow-up counselling they might have started to develop coping strategies in response to the disease. Olley et al. (2003) reported adaptive coping strategies (such as religion and planning) in a sample of recently diagnosed, HIV positive, female public health care patients in Cape Town.

Summary of the caregivers' experiences of communication in counselling sessions

The caregivers reported overwhelmingly positive experiences regarding their communication with counsellors in the context of counselling sessions. The counsellors were perceived to use a facilitative conversational style. Miscommunication within counselling sessions was reported and was attributed to the counsellors' high rate of speech or use of unfamiliar terminology. The counselling services were described as helpful on practical, informational and emotional levels.

3.2.5 Caregivers' overall experience of HIV/AIDS health care delivery at the clinic

The caregivers' experiences of other aspects of the HIV/AIDS care at the research site were also shared. Their experiences were overwhelmingly positive. All but three caregivers (the first time attendees who were not in a position to make a statements regarding satisfaction/needs provision) stated that their needs were met and that they were satisfied with the service. In fact, caregiver 5 expressed her preference for treatment at the urban research site over the clinic in her area: "... *there is nothing wrong... it is always alright. There is nothing. The doctors are alright everything and the nurses and they are much better than at our clinics there... in the townships. The treatment is alright*". Patient satisfaction is associated with the nature of the interaction between doctor and patient (Ong et al., 1995).

Table 3.2.5: Caregivers' overall experience of HIV/AIDS health care delivery at the clinic

i. Satisfaction with the service delivered by the bigger health care team
CG 1: " <i>They (caregiver's needs) are met because last year I told the doctor otherwise I wanted a grant for the child... I went to the social worker</i> ".
CG 6: " <i>Like, the medication is given to boost his immune system and for me to see him grow</i> ".
Cg 9: " <i>...I wanted something for the child, he has as rush... and she has this mouth. So the doctor looked at her and I wanted her to look at her and then check her. Then she told me to go fetch something (medication) for her there (dispensary).</i>
CG 10: " <i>She (the child) was a weak child see, who did not like to eat, most of the time see, a month would not end without me coming here to XXX. But they managed to make her better... since she has been taking this treatment... she took this treatment in October, she started in September... So she seemed... that doctor also said it now, that she is alright now, she is saying for example that she also saw how she was (before)</i> ".
ii. Discontinuity of care
CG 10: " <i>... like if I brought this child here... the doctors change... it is the first time that she is getting the same doctor</i> ".

i. Satisfaction with the service delivered by the bigger health care team

From the quoted examples satisfaction with the services received within the bigger health care team is evident. Caregivers furthermore seemed satisfied with the access they had to

a wider health care team, including a social worker who assists amongst other things in social grant applications. Caregiver satisfaction was also often related to receiving medical treatment for the children's symptoms and the experience of positive outcomes of the treatment. However, caregiver 2 mentioned that only her child received medication. CG 2: *"You don't get medicine. Only the pills and that green stuff for children"*.

At the time of the study treatment at the clinic was directed and available to children only despite the fact that HIV positive children most often have HIV positive parents who have the same treatment requirements as their children. The fact that the clinic could not attend to caregivers' medical needs had the potential to influence doctor-caregiver communication. It is expected that a sense of discomfort and frustration would characterise doctor-caregiver discussions regarding the child's medical needs.

It must be considered that the caregivers' overwhelmingly positive experiences of communication in the clinic might have been influenced by the generally good and comprehensive health care services offered at the site. The clinic provided caregivers with medication for their children, as well as access to broader support systems such as welfare grants and counselling services. The caregivers possibly did not experience easy access to such services in their local communities and health care centres. Levin (2004, p. 78) very importantly paid attention to the relationship between "the propensity to complain about linguistic and socio-cultural issues" and "the expectations that one has of these needs being met". The South African health care system has never been able to provide caregivers with access to doctors proficient in isiXhosa. Moreover, the health care system is guilty of a lack of awareness and willingness to address the communication difficulties of patients. Caregivers in this study were thus unlikely to have high expectations of communication within the health care system.

ii. Discontinuity of care

Caregiver 10 pointed out that she and her child were not always consulted by the same doctor. This discontinuity of attending doctors posed a challenge to the establishment of strong doctor-caregiver relationships. An intimate relationship between doctor and patient

is of great importance and often diagnosis, treatment and the way that information is perceived are directly dependent on the doctor-patient relationship (Coyle and Sculco, 2003; De Villiers, 2000). Increased duration of the doctor-patient relationship is associated with better communication in HIV/AIDS care settings (Wilson and Kaplan, 2000). Continuity of care is advantageous to important health outcomes for HIV positive patients (Wilson and Kaplan, 2000). Discontinuity of care can thus inhibit effective doctor-caregiver communication. The counsellors' and doctors' perceptions of discontinuity of care are respectively described under 3.3.4 and 3.4.3.iii.

A thick description of the counsellors' experiences of communication with caregivers and doctors and other related matters is provided next.

3.3 DESCRIPTION AND DISCUSSION OF THE COUNSELLORS' EXPERIENCES

Four lay HIV/AIDS counsellors were interviewed about their experiences of communication in health care in general, and more specifically their communication experiences related to HIV/AIDS care and the specific HIV clinic. The counsellors' experiences were extremely rich and valuable considering that they engaged in various types of communicative interactions in the health care setting. The counsellors shared various cultural influences with the caregivers, namely geographic location, language, health status, parental status, gender, age and race. Besides being from a similar cultural background as the caregivers, the counsellors were also in a position to identify with the doctors, in the sense that both parties were involved in delivering health related services to caregivers.

A summary of the themes of the counsellors' experiences is provided in Table 3.2 below. Each of the themes appearing in Table 3.2 will then be illustrated with verbatim examples from the interview transcripts and subsequently will be described and discussed.

Table 3.2: Summary of the themes of the counsellors' experiences of communication in the clinic

<p>3.3.1 Counsellors' job description</p> <ul style="list-style-type: none"> i. Pre- and post HIV test counselling ii. Interpreting
<p>3.3.2 Counsellors' training</p>
<p>3.3.3 Counsellors' experience of their counselling function</p> <ul style="list-style-type: none"> i. Counsellors' experience of caregivers' emotional responses to HIV/AIDS ii. Counsellors' experience of caregivers' knowledge of HIV/AIDS related issues iii. Managing caregivers' emotional issues iv. Counsellors as most appropriate individuals to perform HIV test counselling in the paediatric setting v. Counsellors' source of support
<p>3.3.4 (Dis)continuity of care</p> <ul style="list-style-type: none"> i. Caregiver preference for a continuous counsellor-caregiver relationship ii. Improper communication procedure: inappropriate pre-test counselling
<p>3.3.5 Counsellors' experiences of communication with caregivers</p>
<p>3.3.6 Counsellors' experiences of their interpreting function</p> <ul style="list-style-type: none"> i. Caregivers' satisfaction with the interpreting service ii. Problems caused by medical terminology in interpreted consultations iii. The interpreter's difficulty with delivering bad news iv. Difficulty explaining the caregiver's message to the doctor v. Counsellors as emotional brokers vi. Role of family members as interpreters
<p>3.3.7 Counsellors' perception of doctor-caregiver communication</p> <ul style="list-style-type: none"> i. Conversational accommodations made by doctors ii. Caregiver's inability to comprehend the doctor's message iii. Inhibiting doctor conversational style
<p>3.3.8 Cultural factors influencing communication surrounding HIV/AIDS</p>

The first two themes (3.3.1 and 3.3.2) are not findings as much as they are providing context by describing the counsellors' job description and training.

3.3.1 Counsellors' job description

The counsellors described their occupational functions according to the specific tasks performed as well as the skills needed to perform these tasks.

Table 3.3.1 Counsellors' job description

i. Pre- and post HIV test counselling
<p>C 1: <i>"My job is counselling. My counselling deals with HIV/AIDS. What happens at the hospital... we work especially in the clinic... IDC, the one next door to (unintelligible). What happens is that when you come here to the clinic for the first time, or the hospital, maybe your child is suspected that, a blood sample will be taken, he will first need to go for counselling. That is our first job. We will give you your results when they are back. Whether they are negative or positive, we will give them to you. We also go to the wards".</i></p>
<p>C 3: <i>"Like, what I know is to work together with people, what the person is saying, how you face someone's problem when you are in contact with her. What advice do you give her, where to go, and everything else. What she wants to understand so that someone leaves with full information".</i></p>
ii. Interpreting
<p>C 1: <i>"Many times we get people (caregivers) who can't speak English. Maybe you'll have to translate to the doctor. Others do know English. When we have met those people they go out satisfied with what we have talked about".</i></p>

i. Pre- and post test HIV test counselling

Pre- and post HIV test counselling were the counsellors' first priority in the clinic. Counsellor 3 talked about the skills and activities associated with HIV/AIDS counselling. A skill that was repeatedly referred to by the counsellors was that of dealing with an individual experiencing a problem or crises (this aspect is described in more detail later in this section). Other tasks associated with counselling according to counsellor 3 were the giving of advice and practical information as well as facilitation of caregiver comprehension.

ii. Interpreting

Interpreting also formed part of the counsellors' formal activities in the clinic. The fact that the counsellors were trained for counselling and not interpreting, and were generally referred to as *counsellors* by other clinic staff members, reinforced the notion that the counsellors were primarily fulfilling the task of counselling and that interpreting was considered as an add-on or secondary function of these individuals.

During the data collection phase of this research project the isiXhosa speaking interviewer noticed a caregiver who was crying whilst waiting to see the doctor. The caregiver was the grandmother of two ill children whom have lost their mother to AIDS. The children were regular patients at the clinic who were attending follow-up medical consultations and have thus been diagnosed for a period of time. The isiXhosa interviewer approached counsellor 4 and asked her whether she could counsel the caregiver. Counsellor described her response in the following quotation.

C 4: *"So what I said is that I don't have enough time. Because I was busy with the first (inaudible). She (the caregiver) stays in Khayelitsha and Mitchell's Plain. So, and we do have our counsellors who are working. We got a container there in in in site B, site, site, site B of the day hospital... In Khayelitsha. So I referred her to the container there for further counselling... Really I didn't ask (why she was upset). In I just said to her whatever that is bothering her. I didn't want to go into asking her. Because if I ask her I must go further with this... I can't just ask her and leave it there. Because the only thing the time, the time, for me it's the time. So I don't want to talk to her for I want the information. I want to talk to her as a person that I want to help. I want to help her. I don't want to hear her story. I want to help her. So I don't have enough time. The time to do this you know. And you know the other thing there are counsellors there who are used now and there is a social worker... So it is not really my counselling now... But I think she did have counseling because now they are waiting for the social workers, the social worker to see her. She is going to the social worker".*

Counsellor 4 has thus not counselled the upset grandmother but has referred her to counselling services in the area where she lives. The counsellor's decision to refer the caregiver for counselling was partly due to time constraints, as well as the fact that the caregiver was referred to the social worker for counselling. It also seemed that the counsellor was not scheduled to perform counselling at the time of the request. The counsellors at the clinic were responsible for pre- and post test counselling as well as interpreting. Counselling of caregivers with more serious emotional difficulty was dealt with by professional counsellors, such as the social workers employed by the hospital, and/or counselling services outside of the hospital. The social workers were responsible for a big case load and the caregiver appeared to be on a waiting list for the social work counselling services. The counsellor seemed to view communication with caregivers as meaningful and serving a specific purpose. Counselling is delivered through communication (the talking cure). Unless the counsellor had the time and skill required to effectively counsel caregivers, she refrained from entering into in-depth communicative interaction with the caregivers.

Although counsellor 4 has not agreed, or could not agree, to counsel the grandmother she displayed a responsible and ethical attitude towards her professional task. Because counsellor 4 did not have time to spend with the caregiver she did not enquire about her problem. She realised that opening up a sensitive and emotional conversation required time to work through the issues that were raised. Counsellor 4 made it clear that she wanted to help as opposed to wanting to know, and thus denied a mere inquisitive agenda regarding the caregiver's problems. Counsellor 4 referred the caregiver to a counsellor who could accompany her thoroughly through her emotional difficulty, whilst she was waiting for the services of a social worker. Counsellor 4 was thus actively pursuing the best care for the caregiver despite not being available or assigned to deliver the services herself.

3.3.2 Counsellors' training

C 1: *"I personally think we got everything that we were supposed to get (from our training)"*.

C 2: *"There was nothing bad in our training, like it was just enjoyable. Like, we were taught like, the person who was teaching us had experience and would try by all means what she is doing, maybe like what she was teaching us, what it is done like in other words. A person must be like he is feeling the pain in what you are doing...We were taught well"*.

C 3: *"My training was easy and I understood everything. I just did well"*.

The counsellors were all employed by a non-governmental organisation (NGO) that was hired by the hospital to provide counselling and interpreting services to caregivers with HIV positive children. All the counsellors received training regarding counselling practices at the hospital where the research site was situated. As can be seen from the quotations above the counsellors were largely satisfied with the training they have received as well as with the training provider, who was considered as well experienced. Counsellor 3's comment indicated that the training was presented at an appropriate level and enabled this particular counsellor to succeed in her course.

3.3.3 Counsellors' experience of their counselling function

i. Counsellors' experience of caregivers' emotional responses to HIV/AIDS

The counsellors mentioned the caregivers' emotional responses in situations of pre- and post test counselling, as well as ongoing counselling. The counsellors reported caregivers' anxiety over receiving test results, their difficulty in accepting and talking about an HIV positive status, and their concern over the welfare of the child with HIV/AIDS and the desire to remove the child's disease. The difficult emotional issues faced by the caregivers influenced the counsellor-caregiver communication.

Table 3.3.3: Counsellors' experience of their counselling function

i. Counsellors' experience of caregivers' emotional responses to HIV/AIDS
<p>C 3: <i>"Sometimes you don't know where to start with the fact of the results. One person, you would see that she is already scared. She's not ready for these results. She's scared to hear what is going on. To her if you could just say nothing... So most of the time people...are afraid of their results so it is a must that a person must know her child's status"</i>.</p>
<p>C 3: <i>"I did see someone (for counselling this morning). Like I was telling someone about her results, child's results. She did not accept them, she's worried about her child...if only it was only she who has this, this virus, and not her child. So she was crying"</i>.</p>
<p>C 4: <i>"... she (the caregiver) was crying today too...I only see, pick up from her that she's too much, too emotional. She's very upset and she's down"</i>.</p>
<p>C 1: <i>"With some people there are problems but with others there aren't, or for example, when someone gets the results, it is hard to accept them. While others know their status they have problems talking about it"</i>.</p>
ii. Counsellors' experience of caregivers' knowledge of HIV/AIDS related issues
<p>C 3: <i>"... she did not know where to go, like she doesn't know anything"</i>.</p>
<p>C 3: <i>"Perhaps someone has tested before and tested negative by the time she was pregnant and now it comes as a shock that her child ...is now positive. So now we would tell her that there is a window period..."</i>.</p>
iii. Managing caregivers' emotional issues
<p>C 3: <i>"I tried to comfort her, and I advised her, and I told her about help that is available here at the clinic. I told her not to lose hope, they can take care of the child and give her treatment. At least she'd be able to grow up like other kids. I tried to give her strength. I gave her information..."</i>.</p>
<p>C 4: <i>"So I said to her in the running. She must just be strong. Whatever that she is going through. Whatever. Because she is not alone. She's not the only person who is going through this. And she must see how the world is outside, there is a lot of disease, there is a lot of crime, there is a lot of things that is happening. So you cannot just be, feel down whenever you find out there is something wrong, you feel down. You have to be strong. Because whatever happens to you, it happens for you to learn from this and to become strong, you know. And she must look after herself, because nobody is going to. And, if like she was trying to talk about whatever, like I was going to give an example of myself, whatever I am going through. Even with my child and AIDS, and whatever I am going through, I know that there is nothing I can do for myself and the only person that can help me and can call upon is God. And so when I call upon God, and think everything for me, like become okay. And even if nothing go to, is going to change. But I will be like accepting that thing and feel much better"</i>.</p>

C 1: *"I see maybe...it's (the counselling style preferred by caregivers) the way you approach a person ...maybe for example if you meet a person who has an HIV positive child, I'll make an example about myself...I'm HIV positive so when I'm counselling a person that I see that it's difficult with her, I like to disclose my own status...But I don't disclose to everyone".*

C 2: *"What I can say is that a person must feel the person's pain. Like when you are a counsellor...you put yourself in the person's shoes so that you can feel the person's pain as if it's happening to you...so that you can advise better".*

iv. Counsellors as most appropriate individuals to perform pre-test counselling in paediatric setting

C 4: *"...I came across someone who is, and then the sister called me inside back and said '...this woman, the child was diagnosed with HIV in inpatient hospital, but she was denying it'. You know, so she was denying, didn't want to hear anything, didn't want to test, didn't want anything. And she was so rude to the nursing. The nurse was start talking about AIDS and she'd raise her voice and (clicking fingers). And the nurse said to me 'Can you talk to her?' and I said fine. So I get inside and I see and I ask her 'What's wrong with your child', and she said 'They said she's HIV'. So I said 'What do you say?'. And she said 'I, I, I...'. And I said 'Do you trust, do you trust what this statement is?'. You know, do you believe what they say about this child with HIV? And she said 'Yes I. Ja, I do believe, because you know, the sickness that the child is having. Keep being nauseous, go to hospital in Mowbray'. And I said 'Where do you think the child gets this? Where do you think this child gets the HIV?' And she said 'I don't know and was like uncertain, but I have AIDS. I have AIDS'. She called the sister and told her 'I want to go for tests'...She was in denial. So I got that out. I got it out...And the doctors they have such, maybe they have busy schedules you know. They don't have time. I think it is better when there is someone, people outside to do counselling and to take it to the doctor...Because the doctor is like most concerned about the child, and not about her, understand".*

v. Counsellor's source of support

C 4: *"...Monday to Thursday we are at the community. Friday we are in supervision...Every week Friday...There we share our casework, we share our personal lives, uhm problem, and uhm yeah, then you pray and meditate, you know, so just to bring the balance back before the next week. That's why uh, even if we come across clients, like in that one, for me it's ok. Because I know, you know how toThen at the end of the week if something have touched me, I will keep it up till Friday, but not later than Friday. Even if I am sick I will wake up and go to supervision because I got something to share".*

The counsellors' description of the caregivers' emotional difficulties confirms the reported negative mental health consequences and stress of receiving and living with an HIV positive diagnosis, being an HIV positive caregiver or caring for an HIV positive child (Freeman, 2004; Hughes et al., 2004; Olley et al., 2003; Siegel and Lekas, 2002; Schrooten et al., 2001).

ii. Counsellors' experience of caregivers' knowledge of HIV/AIDS related issues

Counsellor 3 indicated that a specific caregiver whom she has counselled on the day of the interview had very little knowledge regarding the HIV disease, its management and available support structures. It is reasonable to assume there were other caregivers with similar limitations to their knowledge. Counsellors might assume caregivers to have some prior knowledge regarding HIV/AIDS before entering the counselling situation. Incongruence between the counsellor's expectations of caregiver knowledge and the actual state of a caregiver's knowledge might lead to miscommunication. Counsellors might also be somewhat desensitised to the caregivers' informational needs as a result of their daily task of conveying HIV/AIDS related information to patients.

The second comment by counsellor 3 referred to the confusing experience caregivers undergo if they have previously tested negatively for HIV and then test positive at a later occasion. The counsellor attributed this experience to the effects of the window period in HIV infection - a period of 3-4 months after infection, during which HIV antibodies may not be detectable in the patient's blood. An infected patient might thus test negative in the window period. Individuals who test negatively after known exposure to the HI virus are often requested to attend a follow-up confirmatory test within 3 to 4 months (UNAIDS, 2000 in Ross and Deverell, 2004). The window period is one of a number of complex disease and treatment related concepts in the field of HIV/AIDS. Other examples are CD 4 blood counts and viral load tests. Communication regarding HIV/AIDS is thus complicated by various semantic (terminology) and conceptual issues. These complicated issues coupled with many caregivers' lack of related knowledge increase the possibility of misunderstandings and are potentially inhibiting to effective communication in the health care context.

A recent knowledge, attitudes, beliefs and practices (KABP) study conducted at an outpatient clinic in Soweto (in South Africa's Gauteng province) found good knowledge surrounding the cause and transmission of HIV as well as the importance of ARVs amongst a sample of 105 HIV clinic patients (70% of whom were not on ARVs)

(Nachegea, Lehman, Hlatshwayo, Mothopeng, Chaisson and Karstaedt, 2005). The patients have all received pre- and post test counselling. The authors attributed the patients' high knowledge scores to the counselling as well as exposure to HIV education through the media. HIV counselling may thus improve the caregivers' HIV related knowledge, provided that information is appropriately delivered and understood.

iii. Managing caregivers' emotional issues

The counsellors employed various techniques to manage the caregivers' emotional responses to HIV/AIDS. Counsellor 3 reported to comfort, advise, inform, and empower caregivers. She also provided the caregivers hope. Counsellor 4 described the approach that she has used to comfort the upset grandmother caregiver referred to earlier. Counsellor 4's approach differed from that of counsellor 3. She advised the caregiver to be strong as she was not the only person suffering and that a depressed mood or to "*feel down*" was not an acceptable response to suffering. Counsellor 4 motivated her standpoint by trying to indicate to the caregiver what the meaning of her suffering might be, i.e. "*it happens to you to learn from this*". She further seemed to empower the caregiver by urging her to "*look after herself*". The counsellor then used her personal situation as a mother who lives with HIV/AIDS to comfort the caregiver. She testified that she found her help from God, and that she has achieved acceptance of her circumstances and comfort from God. Women often use religious practices as a coping strategy to deal with the diagnosis of HIV/AIDS (Olley et al., 2003).

Although counsellors 3 and 4 seemed to differ in their approaches to emotionally upset caregivers, they both referred to the objectives of delivering hope and to empower. The counsellors further described empathy towards the caregivers as a key element of their counselling approach. They were of the opinion that caregivers appreciate a counsellor's empathy and that empathy is necessary for effective counselling. The counsellors were in an ideal position to empathize with the caregivers' difficulties, since they shared a positive HIV status and various other characteristics with the caregivers. They had first hand experience of undergoing HIV testing and receiving positive results and have been faced with the associated emotional challenges of living with HIV/AIDS. Counsellors 1

and 4 indicated that they disclosed their HIV status to caregivers who displayed emotional difficulty. They were thus willing and able to use their own difficult experiences and disease status to assist others in similar situations. The caregivers' perception of counsellors as truthful, trustworthy and credible, and their experience of counselling as being truly helpful on a practical and emotional level, indicated the appropriateness and effectiveness of the counsellors' approach.

The counsellors' described goals of HIV test counselling correlate with the literature, namely that counselling should provide information and support and facilitate decision making after the testing (Bekker, 2002; UNAIDS, 2000 in Ross and Deverell, 2004). These goals necessitate counsellors to fulfil technical as well as emotional communicative tasks. Technical communication in this context involves providing the caregiver with practical information, such as how to have safe sexual practices and the importance of exercise and adequate diet and rest. Emotional communication seems a lot more complex and involves management of the caregiver's emotional difficulties, such as relationship problems. HIV positive individuals who are properly counselled may feel better and be better able to discuss fears and emotions and plan for the future (Bekker, 2002).

iv. Counsellors as most appropriate individuals to perform HIV test counselling in the paediatric setting

Counsellor 4 shared an experience of being successful in convincing an at-risk caregiver to undergo an HIV test in a situation where health care professionals were not able to do so. According to counsellor 4, specifically appointed counsellors who were not part of the medical health care personnel, were the most appropriate individuals to perform HIV test counselling. In her opinion doctors were not the best suited individuals for the counselling task, due to their limited time and apparent disproportionate concern for the mother compared to concern for the child.

It is important to understand the emotional experiences of at risk individuals who are unsure of their HIV status. Persons may avoid HIV testing due to fear of the stigma and

consequences of an HIV positive test result, especially in settings with inadequate health care resources (van Dyk and van Dyk, 2003, in Freeman, 2004). Sadly, HIV positive individuals are often discriminated against in health care settings due to the stigma held by health care workers, such as nurses and doctors (Meel, 2005; Siegel and Lekas, 2002; Groenewald, 1993). Testing might also be avoided out of fear for the emotional distress accompanied with knowledge of an HIV diagnosis (Freeman, 2004). Furthermore women are often wrongly accused of introducing HIV/AIDS to a family, especially if they are diagnosed or become symptomatic before the partner does (Tlou, 2002).

There are various factors that might lead to communication barriers between individuals and health care personnel in HIV testing situations. A counsellor who shares various characteristics, including an HIV positive diagnosis, with the caregiver might thus be in a better position than health care professionals to communicate with an at-risk caregiver about HIV testing. Counsellors supposedly also have more time available for HIV test counselling compared to doctors and nurses. Counsellor 4's comment that HIV test counselling was best performed by counsellors holds merit. However, to comply with requirements for ethical counselling practices counsellors' communication of patients' HIV status to colleagues without the patients' consent, should be strictly guarded against.

v. Counsellors' source of support

The counsellors received regular support in the form of weekly group supervision sessions provided by the director of the NGO they worked for. The director was a social worker by profession. The entire group of counsellors working at the clinic, as well as affiliated counsellors working in other settings attended these group sessions. A total of 34 counsellors, of which one was a male, attended the weekly session. Counsellor 4 described the group supervision sessions as an environment where the counsellors could share and find support for problems they encountered in their personal and professional lives. The prospect of a supervision and support session at the end of the week helped counsellors to cope with difficult situations during the work week. Counsellor 4 explained that the regular supervision sessions helped her not to repress difficult

emotions for too long. The weekly supervision sessions could thus fulfil the counsellors' needs for communication related to their emotional and information needs.

The counsellors were especially vulnerable to the burnout and mental health difficulties associated with the HIV/AIDS care work environment. They were also confronted with the stresses and emotional consequences of being a patient and a caregiver. Support groups that facilitate the expression and discussion of work related experiences are vital for counsellors and may decrease the potential negative effect of the work environment on their mental health (Ross and Deverell, 2004; Hedge, 1999 in Freeman, 2004). Indirectly the counsellors' support system and subsequent improved emotional well-being may have lead to greater emotional availability for caregivers and thus more effective communication within counselling sessions.

To conclude the current discussion of the counsellors' management of the emotional issues experienced by caregivers, an interesting quotation by counsellor 3 is provided. Counsellor 3 talked about the manner in which she measured caregiver comprehension of the conversation that took place in the counselling session:

C 3: "I understood everything she said and her too as I was telling her. After I told her the results, she cried and did all that. But by the time we finished she came out fine. That tells that she has understood. I gave advice about other things...I did not experience any problems. She quickly understood me".

It seemed that counsellor 3 considered the ability to calm an emotionally upset caregiver down as an indication of the caregivers' comprehension. Once the caregiver has knowledge about her diagnosis, important other functions can be provided through counselling (Bekker, 2002). Success in the communication around test results and diagnoses is thus seen as a crucial step in continuing the important conversation between an HIV counsellor and patient.

Summary of the counsellors' experience of their counselling function

The counsellors had to manage the emotional responses of caregivers in the situation of HIV/AIDS counselling. The caregivers were reported to be anxious about receiving their test results and had difficulty to discuss and accept a HIV positive diagnosis. HIV/AIDS counselling was further complicated when caregivers' knowledge regarding HIV/AIDS was perceived as insufficient. Furthermore the complexity of disease and treatment concepts posed a challenge to effective communication in counselling situations.

The counsellors have described individual approaches to the management of caregivers' emotional difficulties. Their counselling strategies had the shared objectives of communicating hope and empathy to caregivers and to empower these women. All of the counsellors attended weekly supervised support group meetings where they could share and find advice for their personal and work-related problems. The regular supervision sessions enabled the counsellors to manage the emotional stresses posed by their work environment and broader life circumstances.

3.3.4 (Dis)continuity of care

i. Caregiver preference for a continuous counsellor-caregiver relationship

Counsellors perceived the caregivers to prefer continuity of care in the counselling context. It seemed that a relationship and understanding developed between counsellor and caregiver during the first counselling session, and that this session signalled the start of the process of support to caregivers by the counsellors. Counsellors therefore experienced that caregivers prefer to continue counselling with the counsellor whom provided their first counselling session at the clinic. The caregivers did not speak about continuity within relationships with counsellors but did mention discontinuity in their relationships with doctors (see 3.2.5.ii).

Table 3.3.4 (Dis)continuity of care

<p>i. Caregiver preference for a continuous counsellor-caregiver relationship</p>
<p>C 3: <i>"Sometimes one person (a particular counsellor is favoured by the caregiver) since she spoke to you the first time, if she could always see you. Her problem now perhaps...it seems like you understand it better. If she has seen you the first time, then you again...The person she has seen at the beginning".</i></p>
<p>ii. Improper communication procedure: inappropriate pre-test counselling</p>
<p>C 2: <i>"Like ... problems I encounter, you find a person maybe she's never, maybe she has not come to me so that I can explain to her that they are asking to draw blood from the child, understand. So you'll find she's now getting results, understand. And it would happen that they are bad. So you find that the person is shocked that she...or maybe you find the person, maybe the doctor told her, maybe she did not understand that the doctor has asked to draw blood, maybe she did not understand English, there was no person to interpret for her, understand? So when she goes to the doctor and all of a sudden I'm called and told to give the results, and that person has not understood from the beginning what the doctor was going to do, see. So if there could be something that is signed, like a consent form you see. Like a person should write down that I give consent for my child. The person must not be made to give consent verbally, because a person can say I did not agree though she had agreed because she knows that nothing was written down. So if there could be a consent form she signs that she gives consent that blood can be drawn from her child. So that when the results come back we don't get any problems".</i></p>

Counselling in any health care environment involves a supportive relationship between the care provider and patient (Bekker, 2002). HIV test counselling is a continuous process consisting of three stages namely, pre- and post test counselling as well as follow up counselling and support (Bekker, 2002; Schweitzer, 2000). One of the aims of the first counselling session is described as establishing a relationship between counsellor and patient that is "characterised by trust, confidentiality, and ongoing care" (Schweitzer, 2000). HIV counselling is thus a continuous process that ideally happens within an established counsellor-patient relationship, implying continuity of care. Counsellor-patient communication is thus ideally continuous and builds on information shared over a period of time.

ii. Improper communication procedure

The counsellors had experiences similar to the caregivers' stories about not receiving proper counselling prior to receiving their own and/or their children's HIV test results. Counsellor 2 relayed her experiences of communicating test results to caregivers who did not receive appropriate pre-test counselling from the doctor before a blood sample was taken from the child. According to counsellor 2 a caregiver's poor understanding of the reason for a blood test might be due to the fact that an interpreter was not involved in the pre-test counselling, when an interpreting service was truly needed by the caregiver.

Counsellor 2 reported that caregivers reacted with shock when they were confronted with test results without proper understanding of, or consent for an HIV test. It is evident that counsellors occasionally performed post-test counselling when they were not present at the pre-test counselling of the particular caregiver. This discontinuity of care clearly places the counsellor in a very uncomfortable situation, as they haven't had the opportunity to establish a relationship with the caregiver before having to perform the difficult task of delivering HIV test results. The caregivers' shock reaction to an unsuspected diagnosis is very understandable considering the fact that the aim of pre-test counselling, namely to prepare the caregiver for the child's diagnosis, was not reached (Schrooten et al., 2001; Bekker, 2002).

Counsellor 2 made the suggestion of instituting a protocol where caregivers are requested to formally sign a consent form to indicate their permission for an HIV blood test to be performed on either themselves and/or the child in their care. It seemed important that the form is signed, in order to indicate the significance to the caregiver. Such a process was predicted by Counsellor 2 to lead to better reaction by caregivers when receiving HIV test results, and consequently to fewer problems for the counsellors during post-test counselling. A formalised procedure will likely reduce instances of caregivers feeling uninformed when receiving an HIV diagnosis and will result in greater caregiver satisfaction regarding the quality of information that was provided before undergoing an HIV blood test. Ultimately the ethical requirement of proper communication between

health care worker and patient (Moodley, 2000) might be fulfilled by a formalised consent procedure. Of course it cannot be assumed that all caregivers who sign a consent form *have* truly understood all the information presented to them. What seems more important than a formalised consent process is to assure that caregivers with poor English ability have access to interpreters during this process. Continuity of care regarding HIV counselling should also be a priority. Furthermore information needs to be communicated to the caregiver in a style that is facilitative to caregivers expressing their questions and concerns. Ethical health care practice depends on effective communication with patients.

3.3.5 Counsellors' experiences of communication with caregivers

Table 3.3.5: Counsellors' experiences of communication with caregivers

C 2: *"...I never experience any problems with communication. Like the problem arises when you are counselling the person and maybe for example you find that you have spoken to her and she will say she has understood see, but maybe for example, when the doctor asks her again, you will find that she does not know what you have just told her, but you did tell her. But the problem, I don't know whether it is caused by forgetting or when you were talking to her she was not with you in what you were saying. But when you say she must ask a question when you finish or where she did not understand you'll find that there are no questions and she has understood but you'll find that as time goes when she's asked again by the doctor you'll find out that she does not know that then".*

C 2: *"...like it becomes interesting if you counsel a person that...like sometimes mos you would be with a person that sometimes just says 'yes' (nods), just says 'yes', and would say 'yes, yes'...Like it is interesting if it is a person that speaks...like an open person...a person who speaks, like who asks questions...like if she doesn't understand something or she has not heard you...instead of 'yes'. Instead of a person who would say (nods) 'yes, yes'. Did you understand? She'd just say (nods) understand...So you don't feel okay. You don't know what is happening".*

The counsellors referred to certain caregiver communicative behaviours as either facilitating or inhibiting effective communication. Inhibiting caregiver communication was described as an indication of comprehension and non-utilization of question asking opportunities, when it later (during doctor-caregiver interactions) became apparent that caregivers did not comprehend the counsellor's message.

3.3.6 Counsellors' experiences of their interpreting function

Table 3.3.6 Counsellors' experiences of their interpreting function

i. Caregivers' satisfaction with the interpreting service
C 1: <i>"Many times we get people who can't speak English. Maybe you'll have to translate to the doctor. Others do know English. When we have met those people they go out satisfied with what we talked about".</i>
C 3: <i>"There is a problem because most of the time the mothers usually don't understand what the doctor is saying. That is why most of the time we are needed, so that we can explain to the mothers what the doctor is saying now, see. So that you can explain to her and she can come out understanding what has been said by the doctor. Because there is difficulty. You'd find out that she couldn't understand totally".</i>
ii. Problems caused by medical terminology in interpreted consultations
C 2: <i>"It is very difficult (to find Xhosa equivalents for some of the English medical terminology), as you want this person to...perhaps that person doesn't know English...maybe she doesn't even have a clue...it's better when a person has a clue...Maybe she doesn't have a clue. I'd wish to explain to this person in my own isiXhosa language that she knows. You'll find then it's difficult...to pass the word then so that she understands it..Yes, she ends up not understanding what you are saying. Especially in this illness mos, you see...there are lots of terms in this illness".</i>
C 2: <i>"...the problem...you'd find that the doctors' terms sometimes here at the hospital...because let me say perhaps we were not trained here at the hospital. We are just working as counsellors. You'll find that some other terms you don't know, you don't know, you don't understand until you ask the doctor to explain to you what she has meant perhaps in some other way, understand, before you are able to know it. Our problem is the terms".</i>
C 3: <i>"There are some difficult terms that the doctor would use, I'd find out that I haven't understood. But I would try to ask her to repeat and put it in a way that I would also be able to explain. We do come across difficult words...It does give us some difficulty but does not give us so much difficulty because you'd tell the doctor that you didn't understand so that she tries to make you understand. You don't leave there not understanding what she is saying. The doctor tries that you'd understand what she is saying, she'd try by all means that you understand so that you can pass the correct message to the person you are interpreting for".</i>
iii. The interpreter's difficulty with delivering bad news
C 1: <i>"If perhaps the doctor is telling that the child is in his last stages it's hard for me to tell the parent but I have to tell them".</i>
iv. Difficulty explaining the caregiver's message to the doctor
C 1: <i>"There are times when you don't know how to put what the person is saying to the doctor. It happens".</i>

v. Counsellors as emotional brokers

C 3: "...we do get mothers, like there are mothers, the doctor would perhaps think that she has just said something light, and she sees the mother crying maybe. Now the doctor is wondering: 'No! What now?' ...Perhaps (thinking) what has been so sensitive to her (the mother)?...Perhaps one would say, 'No she's just sad that her child is sick'. Perhaps the child is going to be admitted, she's going to be admitted at the hospital. Now the doctor is saying that (to the mother), and so on. You'd find that the mother is crying. You were just talking and explaining and all of a sudden. Now you find out that the doctor is wondering about what is happening now...She has not taken it as something that would make her (the mother) cry...perhaps the doctor is asking me why this is happening...'What have I said?' ...It has bothered her, see. So you'd tell her then perhaps, she (the mother) has said 'No I'm just sad that that my child is not going to live, that's what I'm worried about'."

vi. Role of family members as interpreters

C 3: "I don't see it as the correct thing to do (requesting caregivers to bring a family member along for interpreting purposes) like...perhaps a person is not yet ready...perhaps a person has not yet even disclosed at home...to her family. So it is difficult to just disclose and say no, it's like this now. It takes a person some time to disclose, perhaps she starts by getting...like we tell people about things like the support groups...a person would visit those and see that I am not the only one who is living with this virus and eventually get the strength and see no, now I can talk with my family...So it won't be easy for a person to just bring her family member, things like that".

i. Caregivers' satisfaction with the interpreting service

The counsellors experienced the caregivers as being satisfied with the interpreting service that they received. The counsellors perceived their interpreting services as enabling the caregivers to understand the doctors' message. The caregivers' positive account of the interpreting service, including their perception of the interpreting as being accurate, validates the counsellors' perception.

ii. Problems caused by medical terminology in interpreted consultations

The counsellors have mentioned some problems that they encountered during communication in their role as interpreters. Their biggest problem seemed to be related to doctors' use of medical terminology. One problem with interpreting doctors' medical terminology is that various English terms do not have word-for-word equivalents in isiXhosa (Schwartz, 2004; Westermeyer, 1990, in Wood, 1993). The counsellors found such terms to be especially prevalent in the HIV health care context. The counsellors had

difficulty describing these terms to caregivers in isiXhosa, especially when the caregivers have very limited English proficiency. Furthermore the counsellors were unsure of the meaning of various English terms used by the doctors. Counsellor 2 ascribed the interpreters' problems with terminology to their lack of training in this field.

The counsellors' unfamiliarity with the doctors' terminology thus lead to communication breakdown within the doctor-interpreter-caregiver triad. Both the counsellors and the doctors were reported to be able to remedy this breakdown with appropriate communication repair strategies. The counsellors indicated that they would request the doctor to explain the unknown terms in a manner that would enable them to deliver the meaning accurately and effectively to the caregiver. The interpreters were satisfied with the doctors' attempts at explaining the unfamiliar terminology. The strategies used by the counsellors and the doctors to overcome the barrier of medical terminology seemed to improve the effectiveness of communication in interpreted consultations, and indicated a commitment by both parties to good quality communication with and adequate information provision to caregivers.

The complexity of the interpreting function was illustrated by the counsellors' experiences. Specialised terminology often causes difficulty in medical interpreting, amongst trained and untrained interpreters (Fish, 2001; Smit, 1999). The interpreter often has to convey meanings to the patient despite the unavailability of equivalents for many English terms in the patient's language (Walker et al., 1995, in Lesch, 1999). Similar to the translators of text under these conditions, the interpreter has to develop strategies to explain concepts and terms from the source language to the patient. This requires linguistic skills as well as good knowledge of the source language and the subject of the conversation as well as the ability to manipulate the interpreted message for the target group (Lesch, 1999). In this specific clinic the interpreters were not trained regarding field specific medical issues and thus requested the doctors to formulate messages in a manner that they as well as the patients would understand. The interpreters seemed satisfied with the doctors' assistance in this regard.

iii. The interpreter's difficulty with delivering bad news

The counsellors also experienced trouble in delivering bad news to the caregivers. It seemed that the counsellors took on a certain part of the doctor's responsibility and role during interpreted medical consultations. The counsellors found the content of certain messages difficult to deliver and seemed aware of the meaning of such messages to the caregivers. It is also possible that the doctor could avoid some of the unpleasantness and difficulty of delivering bad news when it was delivered to the caregiver via the counsellor.

iv. Difficulty explaining the caregiver's message to the doctor

In addition to the problems experienced in delivering the doctor's message to the caregiver, the counsellors also at times experienced difficulty in delivering the caregiver's message accurately to the doctor. This problem was however not experienced by all the counsellors, as can be seen from the following statement by counsellor 2:

C 2: "From this person (caregiver) no I never find that (it is difficult to deliver the caregiver's message to the doctor)."

Just as medical concepts are not easily directly translated from one language to another, direct translation of a patient's understanding of his/her disease process is problematic (Westermeyer, 1990 in Wood, 1993). Certain African cultural issues may be very difficult to put across in a different language, especially if the language is 'non-African' such as English or Afrikaans (Mtuze, 1995, in Kaschula and Anthonissen, 1995).

v. Counsellors as emotional brokers

The counsellors' stories made it clear that the caregivers' emotional state influenced the communication process between caregiver and health care professional and/or interpreter. Counsellor 3's account illustrated how a caregiver might react emotionally to the information received by the doctor via the interpreter. According to counsellor 3 the interpreters and/or the doctors did often not anticipate the caregiver's emotional response. Counsellor 3 described how doctors were not always aware of, or sensitive enough to

realise the emotional impact of their message on the caregivers. Counsellor 3's description that she as interpreter might be "*just talking and explaining and all of a sudden*", indicated that the counsellors were also sometimes surprised by a caregiver's emotional reaction. Several topics may be addressed in medical interactions of which many may be emotionally laden (Cicourel, 1985). It has to be considered that the doctor's message alone might not always be the sole reason for a caregiver's emotional reaction. The caregivers have to deal with very complex issues and various aspects of interpersonal interaction may remind a mother of her difficulties and therefore spark an emotional reaction.

An image of the counsellor acting as the doctor's access to the emotional life of the caregiver with limited English proficiency was created. It was thus possible that besides acting as a cultural broker for the caregivers, as was pointed out by the caregivers' stories, the counsellor also acted as a type of emotional broker. Schwartz (2004) similarly reported that effective interpreting implied interpretation of words as well as emotional issues for the medical doctor. The counsellors in the current study identified with the caregivers on many levels. The shared characteristics of motherhood, disease status and living arrangements were probably the most important in making the counsellors appropriate emotional brokers for the mothers. Despite this fact it is somewhat concerning that counsellor 3's comment might be interpreted as the counsellor answering the doctor's question regarding the reason for the mother's emotional behaviour without consulting with the caregiver. Ideally the counsellor would allow the caregiver the opportunity to answer the question herself, as individual factors beyond the shared characteristics of caregiver and counsellor might be responsible for the caregiver's behaviour. This would prevent the substitution of the counsellor's assumptions and interpretation for an authentic explanation of caregiver's difficulties.

Furthermore, it has to be considered that the doctors' and counsellors' failure to anticipate the caregivers' emotional response indicated desensitization to the caregivers' difficulties. It is possible that being faced with the same and difficult issues everyday doctors and interpreters were less sensitive to the caregivers' emotional vulnerability.

This creates some questions about the image of empathetic communication between caregivers and doctors and counsellors at the clinic that has been described previously. The fact that the doctor enquired about the reason for the caregiver's emotional upset, as opposed to ignoring or treating it as irrelevant, probably indicates that the communication wasn't non-empathetic. The impression is rather that the doctors and counsellors weren't, and could not ever be, fully prepared for every possible caregiver response. The doctors and counsellors did however seem prepared and willing to learn about, and possibly assist, in individual caregivers' emotional difficulty.

vi. Role of family members as interpreters

Family members of limited English language proficiency patients frequently act as interpreters in medical facilities where trained or formal interpreters are unavailable (Wood, 1993). The counsellors who participated in the current study were not of the opinion that such an arrangement would be appropriate in the HIV/AIDS care context due to the sensitive nature of the disease.

The literature is consistent in reporting family members and relatives of patients as very unsatisfactory interpreters due to the influence of their relationship with the patient on the information obtained (Wood, 1993). Counsellor 3's perception correlates with the reports in the literature that many HIV positive women in African countries are often forced to keep their HIV status secretive for as long as possible due to gender inequalities and fear of social stigma, physical injury, isolation, loneliness and/or abandonment by the family and community (United Nations, 1995, in Tlou 2002; Duffy, 2005). In this study the caregivers who needed interpreting services reported a preference for formal interpreters over *ad hoc* interpreting arrangements, which resonated with the counsellors' perception that clinic staff was the most appropriate choice for interpreters in the South African HIV health care sector.

Summary of the counsellors' experiences of interpreting

The counsellors perceived the caregivers to be satisfied with the interpreting service. The counsellors also viewed their interpreting function as providing the caregivers access to the doctors' message. The doctors' use of medical terminology was a source of difficulty for the interpreters. Medical concepts were difficult to explain to caregivers, especially since many terms do not have equivalent forms in isiXhosa and because the counsellors were at times unfamiliar with the meanings of the English terminology. The counsellors and doctors were able to successfully repair communication breakdowns resulting from medical language in interpreted consultations. The interpreters also occasionally experienced difficulty in relaying the caregivers' message to the doctor. Another difficulty for interpreters was the delivery of bad news to caregivers. The counsellors acted as emotional brokers for the caregivers and were required to interpret the caregivers' emotional issues for the doctors. The counsellors were satisfied with the current situation in the clinic where formal and not *ad hoc* interpreting procedures were followed. The use of family members as interpreters in South African HIV/AIDS care was not recommended.

3.3.7 Counsellors' perception of doctor-caregiver communication

Due to their dual role in the clinic the counsellors had direct and indirect experiences of doctor-caregiver interactions. In a direct manner the counsellor actively participated in the doctor-caregiver interaction in her capacity as interpreter. Indirectly the counsellor often learned about the doctor-caregiver interaction process in fulfilling her counselling role. The counsellors commented on their perception of doctor-caregiver interaction. Their perceptions are discussed next.

Table 3.3.7 Counsellors' perception of doctor-caregiver communication

i. Conversational accommodations made by doctors
<i>C 3: "The doctors are different. Some are trying Xhosa. You'd see that yes... they try so that a person can understand. Even though she's (doctor) not speaking Xhosa... but she would just speak so that a person understands".</i>
ii. Caregivers' inability to comprehend the doctor's message
<i>C 2: "... you find that you need to go back to the doctor to ask for her (the caregiver) what the doctor has said, so that you can explain to her again".</i>
iii. Inhibiting doctor conversational style
<i>C 2: "Like when you are with this person and the doctor, understand, you'll find that the doctor just asks what concerns her, she doesn't want to like what usually happens like she won't explain exactly to this person, or well enough, like to ask neh, for example, to ask a person what the child has, things like that and.... like I wish she goes deeper".</i>

i. Conversational accommodations made by doctors

The counsellors reported that individual doctors differed with regards to conversational style. The counsellors also noted the accommodations that the doctors made during doctor-caregiver interactions, in order to facilitate caregiver comprehension. Counsellor 3 cited the example of an appropriate level and choice of language used by the doctors. The perceptions of the counsellors regarding the doctors' communication with caregivers thus corresponded with the caregivers' reports in this regard. Similar to the caregivers the counsellors had various examples of caregivers not understanding the doctor's message. This issue will be discussed next.

ii. Caregivers' inability to comprehend the doctor's message

The counsellors had experiences of caregivers arriving at counselling sessions without a clear understanding of the doctor's message delivered in the medical consultation prior to the counselling session. It is possible that caregivers, like the woman referred to by counsellor 2, did not make use of communication repair strategies during the medical consultations. The caregivers admitted to such behaviour (see 3.2.2.ii). It is also plausible that the caregiver did request clarification from the doctor, but failed to comprehend the doctor's attempt at repair. Again this possibility has been confirmed by the caregivers in their individual interviews. Furthermore, it is possible that the doctor left most of the explanation of his opinion in the hands of the counsellor, whom he knew would meet

with the caregiver following the medical consultation. Similarly, the caregiver might have preferred to ask the counsellors for explanations as opposed to the doctor towards whom she might have felt uncomfortable due to language barriers and perceived power differences. This last explanation paints a picture of various communication roles played by different members of the health care team. The doctor's role can be described as scientific expert who provided information, while the counsellor fulfilled the role of explaining the doctor's opinion to the caregiver.

iii. Inhibiting doctor conversational style

The counsellors were aware of an inhibiting conversational style employed by some doctors. Counsellor 2 explained such a conversational style as serving the doctor's agenda and as considering only one aspect of the caregiver or patient's life. She furthermore felt that doctors at times provided caregivers with insufficient explanations. The counsellors' perception of an inhibiting doctor conversational style was consistent with the caregivers' description, namely a domineering and insensitive doctor who does not allow caregivers to ask questions, voice their concerns and therefore to obtain adequate explanations. As in previous discussions (see 3.2.1.ii) an inhibiting doctor conversational style seems connected to a bio-medical philosophy of medicine, where only the biological dimension of the patient's illness is taken into account.

3.3.8 Cultural factors influencing communication surrounding HIV/AIDS

C 2: "Like it happens that a person you are counselling maybe for example like the doctors would have diagnosed the child with HIV, and she, the parent, does not believe that. She sees that this child has been bewitched. She'll tell stories that when the child was still young or this happened to her, things like that so she expected this would happen anyway. Sometimes the other one would say, I'll accept this as it happens, I expected that it would happen anyway...She will tell herself that she doesn't believe that it is this HIV, see, this child is bewitched...And the doctor would be telling her about the HIV factor".

Counsellor 2 used an example of a caregiver's particular cultural perception of HIV that differed from the doctor's bio-medical understanding of the illness. In this example the caregiver rejected the doctor's explanation of the cause of the child's disease as an

infectious disease caused by the HI virus (Essex and Mboup, 2002). The caregiver's causal explanation was based on beliefs in supernatural powers. It seemed that certain behaviour of the mother of the child has led to the bewitchment and that the caregiver was in some sense aware that ill health awaited her child. This perception seemed to be responsible for a fatalistic view of the child's disease. Cultural beliefs regarding HIV transmission as a result of witchcraft or non-observance of social norms and taboos have been reported in the literature (Freeman, 2004; Tlou, 2002). According to Tlou (2002) such misinformed cultural perspectives of HIV transmission may lead to fatalistic behaviour and may be responsible for the failure of HIV/AIDS awareness programmes to translate into action.

Doctors and their patients view ill health in different ways. The philosophy of scientific rationality that forms the basis of medical training treats caregiver beliefs regarding the cause of disease, e.g. bewitchment, as less real since it cannot be objectively observed or measured. Doctors' explanation of the cause of HIV thus stands in contrast to caregiver's explanation of HIV as being caused by superhuman forces. Medicine as philosophy is more concerned with the consequences of illness than the causes. A discrepancy seems apparent between the doctors' traditional focus on treatment and the apparent preoccupation with the cause of the disease by caregivers with a belief in witchcraft. The caregivers' accompanying fatalistic view may be explained by the emphasis placed on disease causation (Helman, 1994).

A successful consultation is dependant on consensus between the doctor and patient regarding the "cause, diagnostic label, physiological processes involved, prognosis and optimal treatment for the condition" (Helman, 1994, p. 136). Although consensus is no assurance of an appropriate diagnosis and ensuing treatment decisions, the contrasting doctor and caregiver explanations of the disease cause will lead to difficulty in doctor-caregiver communication. Another potential source of difficulty in doctor-patient communication in this context is the patient's use of folk terminology that may be unfamiliar and confusing to the doctor, especially if the clinician is unaware and unfamiliar with the caregiver's theory of disease causation (Helman, 1994). The

caregivers' perceptions of the doctors in this particular clinic as being caring, kind, sympathetic and helping indicate that the doctors have been able to integrate some of the wider aspects of the caregivers' lives into their management approach. This possibly explains to a large extent the positive perception of the caregivers regarding communication with doctors at the clinic.

Another factor that needs to be considered, is the effect that the CG's explanation of the child's disease as the consequence of her (the caregiver's) past behaviour and the symbolization of the disease as divine punishment, has on the caregiver's perception of her own condition and the way she is responded to by the community (Helman, 1994). The CG consulted the doctor regarding the child's illness. It is not certain that she would treat her own condition in a similar manner. Helman (1994, p. 119) wrote that the view of HIV/AIDS as 'moral punishment' has the danger of preventing "patients from getting the compassionate care and medical treatment that they deserve". It is also possible that she will suffer discrimination in her community due to the stigma attached to HIV/AIDS, and the specific lay explanation of the disease cause as bewitchment.

The process of communication between caregivers and health care professionals should negotiate between the lay and medical worldviews. Communication in HIV/AIDS care also needs to manage issues of morality, as it is a significant part of the patients and caregivers reality.

A thick description of the doctors' experiences of communication with the caregivers and counsellors and other related matters is provided next.

3.4 DESCRIPTION AND DISCUSSION OF THE DOCTORS' EXPERIENCES

Four doctors working in the HIV clinic were interviewed regarding their experiences of communication with patients and counsellors. A tabulated summary of the themes of the doctors' experiences is provided in on the next page in Table 3.3. Each of the themes appearing in Table 3.3 will then be illustrated with verbatim examples from the interview transcripts and subsequently will be described and discussed.

3.4.1 Factors that influence doctor-patient communication directly

The doctors have identified five factors that affect doctor-patient communication directly. Each of these factors will be discussed separately.

A. Language and culture

i. Nature and meaning of the language gap between doctor and patient

The doctors confirmed the caregivers' (see 3.2.1.i) description of doctor-patient consultations as mostly conducted in English at the clinic (see 3.2.1.i) due to the doctors' limited proficiency in isiXhosa and the isiXhosa speaking caregivers' relative ability in English. The doctors considered the caregivers' English ability as an "*enormous help*", whereas they viewed their poor isiXhosa abilities as limiting and frustrating. The doctors' isiXhosa skills seemed to enable them to obtain very basic information from the caregivers and to initiate a relationship, but do not allow counselling or in depth history taking. This finding corresponds with the perceptions of doctors interviewed by Levin (2004) and Schwartz (2004) in the same hospital. The majority of medical doctors at the hospital viewed themselves as having very limited expressive isiXhosa language skills. The doctors were mostly able to pose simple questions or hold basic conversations in isiXhosa.

Table 3.3: Summary of the themes of the doctors' experiences of communication in the clinic

<p>3.4.1 Factors that influence doctor-patient communication directly</p> <ul style="list-style-type: none"> A. Language and culture B. Awareness of unequal power relations C. HIV specific issues D. Time constraints E. Doctors' experiences of interpreted consultations
<p>3.4.2 Doctors' experience of working with and perception of counsellors</p> <ul style="list-style-type: none"> i. Doctors' perception of the counsellors' role ii. Doctors' perception of the counsellors competence and training iii. Problems regarding counselling by counsellors
<p>3.4.3 Doctors' experiences regarding the practice of medicine at the clinic</p> <ul style="list-style-type: none"> i. Multiple duties ii. Doctors' experience of their counselling function iii. Discontinuity of care iv. Compromising quality due to pressure of numbers and urgency v. Child directed treatment
<p>3.4.4 Doctors' general experiences of communication in the clinic</p> <ul style="list-style-type: none"> i. Communication as no different across clinics ii. Communication issues specific to Paediatric medicine iii. Caregivers' lack of questions and repair strategies in communication with doctors iv. Facilitative strategies used by doctors
<p>3.4.5 Doctors' perception of a doctor with good communication skills</p> <ul style="list-style-type: none"> i. Appropriate level of language ii. Listen and be gentle: moving away from paternalism iii. Personality and Orientation towards the caregiver and child iv. Experience in counselling v. Facing sensitive topics / going to the difficult places vi. Build bridges across cultural, language and power gaps
<p>3.4.6 Doctors' experiences regarding communication skills training for clinicians</p> <ul style="list-style-type: none"> i. Learning an indigenous language ii. Need for communication training iii. Communication training and the medical curriculum
<p>3.4.7 Planned strategies and suggestions to address problems</p> <ul style="list-style-type: none"> i. Team based family clinic ii. Development of a communication protocol iii. Professional counsellor assigned to clinic

Table 3.4.1 A: Factors that influence doctor-patient communication directly

A. Language and culture
i. Nature and meaning of the language gap between doctor and patient
<p>Dr 2: <i>"I don't, I'm not fluent in Xhosa. About seventy percent, probably eighty percent of our patients I think would be most comfortable speaking Xhosa directly. A lot do speak English, or Afrikaans but I don't know if that is actually their chosen language. I think there are actually a few who are quite comfortable speaking English or Afrikaans and I'm comfortable with that. I speak a little bit of Xhosa so I try to use that as a way to sort of bring them in but I can't get into serious counselling issues with that".</i></p> <p>Dr 1: <i>"I think the most...obvious barrier is...the language barrier in actually...wanting to and cannot communicate...Even with a little bit of (day) patients speaking a bit of English. It's usually an enormous help if you can get basic communication. And those who cannot speak a word. And my limited, Xhosa. Usually you tend to take shortcuts. To spend time you know to actually go through in detail, so you are just trying to get the essential information, basically".</i></p>
ii. Cultural differences in perception of medical concepts
<p>Dr 3: <i>"Uhm, communication makes up a large part of it but there is a whole, whole other dimension to it which is probably more cultural. Uhm, which comes in with language obviously. But, but, just that certain concepts don't seem to be clear to them and they. She, she was complaining of a headache, and she couldn't explain to me what, why she's. The child has been complaining of a headache for four years. And she couldn't explain to me why she's now complaining of a headache, for four years. And it is, and first of all she didn't perceive it as a problem previously, or people didn't take her seriously. And now once again I didn't seem to really meet that expectation that she's come with. Because I couldn't answer the question either. She couldn't explain her problem to me. So it is probably language, but certain medical concepts which they perceive or understand they can't always explain to you...She couldn't even explain to the interviewer what the problem was. And I was left this complete sense of frustration right at the end. That she asked me for something and I couldn't offer her what she was trying to ask me for".</i></p>
iii. Frustration caused by language and cultural differences
<p>Dr 3: <i>"I find it incredibly frustrating when I can't communicate with the patients..."</i></p>

Dr 1's honest comment about a tendency to "take shortcuts" in collecting information from caregivers with poor English skills is concerning as such practice might have led to important medical or other information never being shared between caregiver and doctor and thus a compromised standard of medical care offered to the caregiver with limited English proficiency. Similarly the doctors in Levin's (2004) study viewed the language barriers between themselves and their patients as a significant problem that affected the doctors' ability to obtain accurate medical histories, explain the nature of the

patient's illness and provide adequate counselling. Furthermore the doctors believed that poor communication had the potential to negatively affect the quality of health care and therefore the patients themselves.

Ideally time and personnel resources would allow that a formal interpreter be present in all consultations where doctors are not able to collect sufficiently in-depth information from the caregiver. Similarly doctors would have to value communication to the extent that the service of an interpreter is requested the moment the doctor feels that the quality of information collected from the caregiver is insufficient due to the language barrier between him/herself and the patient.

ii. Cultural differences in perception of medical concepts

"Communication issues make cultural differences apparent" (Kelly and Brown, 2002, p. 1650). Doctor 3 described some of the difficulty and frustration she experienced in her interactions with caregivers due to what she describes as "*cultural*" influences on the caregivers' perception of illness related concepts. Doctor 3 used an example of not understanding the caregiver's current complaint in the context of the child's chronological medical history, and had a perception that "*certain medical concepts don't seem to be clear*" to the caregiver. She also felt that the caregivers "*can't always explain*" their medical complaints to doctors, or even to interpreters. The doctor's frustration regarding the situation mentioned in the quotation above is better understood when one considers that she has failed to comply with the instruction of medical textbooks (written in the developed world with Western culture in mind) to elicit the "*sequence of events leading to the present complaints*" from patients during history taking (Gill and O'Brien, 2003, p. 16; Talley and O'Connor, 1996). Doctors in South Africa, especially in the public sector, have to understand that developed world theory and everyday practice often differ vastly (De Villiers, 2000). There is also the possibility that the caregiver has sought advice in the folk sector, for instance from traditional healers, before consulting with a doctor in the professional health care sector about the child's headache (Mfenyana and Mash, 2000). Kelly and Brown (2002) have interviewed

non-Native⁶ Canadian doctors regarding their experiences of work in Native or First Nations communities. The doctors who have participated in their study similarly reported frustrations related to cross-cultural communication.

Dr 3's comment indicated that it is not only the language barrier that causes misunderstanding between doctors and caregivers, but that differences also existed between doctors' medical and the caregivers' lay perspectives of illness. Such differences in perspective complicate doctor-caregiver communication (Helman, 1994). Misunderstanding of cultural influences may lead to erroneous diagnosis and treatment (Brant, 1990, in Kelly and Brown, 2002).

The caregivers and counsellors have similarly mentioned differences between lay and medical perspectives in the clinic. It is thus clear that the doctors' and caregivers' differences in perspective complicate doctor-caregiver communication in the clinic.

iii. Frustration caused by language and cultural differences

Doctor 3 also expressed her frustration regarding difficulties in communication with caregivers. She felt that linguistic and cultural barriers at times prevented doctors from addressing their patients' needs, and thus ultimately from performing their duty as medical doctors. Linguistic and cultural barriers can thus challenge doctors' professional ideals, and "assumptions about medicine as a system of knowledge as well as a helping profession" (Good et al., 1998, p. 171). Doctor 3's quotation illustrates the way that "language combines with cultural qualities of communication to influence effectiveness" of cross-cultural medical interactions (Erzinger, 1991, p. 91) and also the understanding of each participant within the consultation (Cicourel, 1985).

Dr 3's awareness of the differences in illness perspective between herself and the caregiver and of the ensuing difficulty to exchange information and to provide an appropriate service suggests cultural sensitivity on her part. Ulrey and Amason (2001) found effective cross cultural doctor-patient communication and cultural sensitivity to be

⁶ Non-Native, Native and First nations are the terms used in the original article by Kelly and Brown (2002).

related concepts. Their study also indicated that improved cultural sensitivity and intercultural communication effectiveness may relieve health care professionals' anxiety in cross-cultural interactions which may lead to better quality care to the patient. It is ironic then that Dr 3's displayed cultural sensitivity lead to frustration of feeling unable to assist caregivers appropriately. However, her cultural sensitivity brought about a consciousness of the potentially dangerous consequences of misunderstandings, such as misdiagnosis and violation of patients' ethical convictions. Her efforts to understand the caregivers' complaints, through the use of interpreters or otherwise, was thus likely to impact positively on patient care. Other factors influencing the doctors' experiences of practising medicine at the clinic are discussed under 3.4.3.

B. Awareness of unequal power relations between doctors and caregivers

Awareness of unequal power relations between doctors and caregivers

Dr 2: "...I think just the natural sort of power relations between a doctor and a patient. So you dealing with sort of a white middle class male and a poor black female or a teenager. Uhm, in fact it is often quite nice to relate, because there is often a bit more (somehow) in common than speaking to, for example with a sixty year old makholo⁷ from the Eastern Cape... So, there is always those immediate power relations. I think in Paediatrics we are a little bit maybe more in tune with that. To some extend we kind of don't have white coats and ties so there is some element of that"

Dr 2 's comment above indicates his awareness of the asymmetrical nature of the doctor-patient relationship, with the professional usually having more power than the patient or his/her caregiver (Aita et al., 2005; Ong et al., 1995; Northouse and Northouse, 1992; Welch, n.d.). This situation of unbalanced power is exaggerated when doctors and patients are from different socio-economical groups and educational backgrounds (Welch, n.d.). In the context of South Africa's political history "*White middleclass males*" are generally powerful in relation to "*poor black females*" who are relatively powerless. AIDS in South Africa is an unequal epidemic reflecting the racial disadvantage of the past (Johnson and Budlender, 2002 in Schneider and Fassin, 2002). The unbalanced doctor-patient power distribution is thus exacerbated in cases of cross

⁷ *Makholo* is an isiXhosa word meaning grandmother.

cultural medical encounters, especially when patients are from disadvantaged groups. The paediatric context might be more sensitive to such unequal power relations.

C. HIV specific issues influencing doctor-caregiver interaction

Table 3.4.1 C: HIV specific issues influencing doctor-caregiver interaction

<p>i. Stigma, caregivers' limited knowledge and insight, and the complexity of medical concepts as barriers to effective communication.</p>
<p>Dr 2: <i>"I think also just the whole HIV stigma, knowledge type issue is quite a big thing, uhm in that trying to open up a discussion there is a lot of complexity... So it just sets up, there's quite a lot of barriers to cut through quite quickly and try and open it all up, before you can really try and talk in a sort of close way"</i>.</p> <p>Dr 1: <i>"Uhm, but I uhm, think that more of a barrier to me is the patients who, the level of patients' insight into their, uhm, how much they know about HIV standing...Because to try to explain to someone they've got some particular illness and they don't have a good understanding of that. Even if you, if you speak the same language, there's an immediate barrier there, in terms of concepts, uhm"</i>.</p> <p>Dr 3: <i>"Not necessarily with the day-to-day follow up, but when it comes to especially the investigations. Things like the CD 4 and viral loads, those are difficult concepts to carry across. And with the initial consultations where a counsellor uses a lot of them. I mean they don't even have Biology at school, so a concept of what a blood cell is. What a white cell count, a red cell count does"</i>.</p>
<p>ii. Expectations in a specific era of HIV/AIDS treatment</p>
<p>Dr 2: <i>"And the expectation of patients I think at least previously was of HIV, for example disclosure was a bit of a uhm, like that's that you know, you can't really do anything, a death sentence kind of issue. But now I think for me what makes it easier is that the next step after is what are we gonna do about it. And the treatment. 'And this is the clinic, this is where you should feel at home. This is your place you know. And I am telling you this diagnosis but so that I can help you' as opposed to 'here is HIV, sorry it is terrible', you know? Uhm, so I think that adds quite a positive start to work. The potential now"</i>.</p>

i. Stigma, caregivers' limited knowledge and insight, and the complexity of concepts as barriers to effective communication

The doctors' comments regarding the impact of HIV specific knowledge and terminology on communication resonate with those of the caregivers and counsellors in this regard. All three categories of participants have indicated that the complex terminology and concepts related to HIV/AIDS and the caregivers' limited knowledge regarding these

issues lead to difficulties in communication. Dr 3 pointed out that concepts, such as CD 4 counts and viral loads, were especially troublesome. Caregiver 10's comment that she "*did not understand... the CD 4 counts*" corresponds perfectly with Dr 3's observations. This is a significant finding as these concepts are likely to be discussed and to cause communication difficulty at critical points in the doctor-caregiver relationship, such as during the initial consultation after diagnosis, as well as during consultations discussing the onset of anti-retroviral (ARV) therapy. Difficulty in communication surrounding these concepts may impact negatively on the short and long term health outcomes of patients.

Dr 2 also talked about the stigma surrounding HIV/AIDS as a factor influencing communication. HIV positive individuals experience stigma in various social arenas including the health care sector (Meel, 2005; Ross and Deverell, 2004; Siegel and Lekas, 2002; Schrooten et al., 2001; Groenewald, 1993). Dr 2 was aware of the stigma and discrimination suffered by the caregivers and the potential distance that this may cause between doctor and caregiver. The fact that the doctor was aware of this barrier and confessed to attempts to "*cut through*" and "*open up*" these issues in order to communicate in a "*close sort of way*" predicted effective interactions between himself and his patients. It is heartening that the doctors interviewed did not seem to contribute to the stigma and discrimination the caregivers are likely facing in other areas of their lives. Negative interactions with health care professionals can have significant effects on the health and quality of health care of people living with AIDS (Meel, 2005). It is possible that Doctor 2 had an awareness of and has addressed his own prejudices of and discomforts with HIV infected patients. It is also possible that doctors considered the caregivers and children as innocent victims of HIV/AIDS (Helman, 1994), realising their biologic, sociocultural and economic vulnerability to HIV infection (Tlou, 2002). The women's partners might have been seen as the guilty parties in the pandemic (Helman, 1994) and might have been treated differently.

The caregivers, as black, poor, HIV positive women, are expected to be especially negatively affected by social stigma. The context of the HIV clinic places them in a

vulnerable position as their stigmatising attribute becomes visible as they enter the clinic and all related interactions as 'discredited' individuals, i.e. their HIV status is disclosed before every encounter (Goffman, 1963, p. 14 in Gillespie and Gerhardt, 1995).

ii. Expectations in a specific era of HIV/AIDS treatment

The powerful quotation from the interview with Dr 2 illustrated the moral and ethical dilemma of health care professionals in developing countries in the era of HIV/AIDS treatment post the approval of ARV medicines. Dr 2 pointed out that the possibility of treatment has restored his potential to help his patients and thus has boosted his morale. The meaning that the clinic carried has also been transformed from an ineffective space where deadly news was broken without a possibility of hope, to a caring home to which the caregivers are offered ownership. The availability of ARV medication has been described elsewhere as "reinserting the word 'hope' into the discussion about AIDS" (Kobayashi, 1997, p.161, in Siegel and Lekas, 2002) and as offering HIV/AIDS patients "the opportunity for a 'second life' " (Rabkin and Ferrando, 1997, in Siegel and Lekas, 2002, p. S69). The increasing ability of the clinic and its staff to provide caregivers with treatment for their children had a positive influence on doctor-caregiver relationships and interactions as it added in the words of Dr 2 "a positive start to work".

D. Time constraints

Dr 2: "I mean the other (problem with communication) is time obviously. I mean you can see by the patient list. I, I have probably seen today between, we have only been going from about nine, between nine and one thirty, what is that? ... Four and a half hours I have probably seen I think only five patients. Four or five patients. And I probably need or should be seeing more patients in terms of the list of patients that we have. But today was a relatively quiet day. So, depending on the kinds of patients that I see and the issue is whether they are new ones or regular follow-ups, the time that you can give to a patient is often quite constrained".

The doctors admitted that the ever growing patient numbers limited the time they had available to communicate with caregivers. The type of consultation, in terms of first-versus follow up visits, largely determined the amount of time that a doctor could spend with a patient at the clinic, where first visits generally required more time than follow up visits. The medical culture's values of speed and efficiency were probably another source

of pressure on the doctors' use (Renshaw, 1998). The effect of these time constraints on the doctors' counselling function will be discussed under 3.4.3.ii.

E. Doctors' experiences of interpreted consultations

Table 3.4.1.E: Doctors' experiences of interpreted consultations

i. Doctors' perception of interpreters: competent, helpful and familiar
<p>Dr 2: <i>"I think given that they (the caregivers) are talking through an interpreter obviously there is a natural loss of immediacy that you get, uhm, but to be able to communicate I think quite well. We are using very good interpreters who we know quite well, and I think they are doing quite a good job as interpreters in giving information to us and feeding back information".</i></p> <p>Dr 3: <i>"But by and large you quickly understand if the patient doesn't comprehend what you are saying...the misguided responses that they do give you to questions that you would expect a different response. And the interpreters for that particularly help enormously. Because by and large they do understand".</i></p>
ii. The nature of interpreting and the doctors' perception of the interpreter role
<p>Dr 2: <i>"Sometimes adding a bit of their (the interpreters') own element because of their counselling training. But it is sort of not fully counselling and not straight interpreting, so a bit of a mixture...Which is good but at the same time we are not getting the full counselling side that we want".</i></p> <p>Dr 3: <i>"Certain counsellors you'll sit and you'll expect them to translate for you then you'd actually hear them adding on a whole lot of stuff, which you know is relevant it is just that you are going past it and they have heard it so many times. I mean they do the stuff for so many people. So I mean in some aspects they can actually be a help and be better than what we are ...I mean if I get to a situation where I think she is more than capable then I'll let it go. But it also has to do with the type of personality and probably that individual. Some people I would trust more than others, and with experience".</i></p>
iii. Determining when to use an interpreter
<p>Dr 1: <i>"It depends on the patient. To determine how much they can (read) and can talk"</i></p> <p>Dr 4: <i>"...we ask them 'do you speak English?' we do not ask them 'do you understand?'... We should ask whether they understand English, not if they speak English".</i></p> <p>Dr 2: <i>"But, I mean, by and large if it gets to the counselling part I actually have to ask the counsellors to come and help because they seem to have that much more of a grasp of what the patient can understand or not".</i></p>

iv. Miscommunication between interpreters and caregivers

Dr 3: *"She (the caregiver) couldn't even explain to the interviewer what the problem was"*.

Dr 3: *"But you do get situations where, either the patient isn't necessarily Xhosa speaking. She might be from somewhere else and she is Sotho, or Zulu even and there is a communication barrier within"*.

i. Doctors' perception of interpreters: competent, helpful and familiar

Doctors 2 and 3's comments clearly communicated their perception of the interpreters as competent to perform the interpreting function. It seemed that the doctors experienced the interpreters as understanding the messages of both the doctor and the caregiver during interpreted consultations, and therefore they were regarded as an effective link between doctor and caregiver. The caregivers reported a similar perception of the interpreters as providing accurate information to the doctor. The finding of the interpreters as accurate and effective is thus well supported.

ii. The nature of interpreting and the doctors' perception of the interpreter role

Due to the dual role that the counsellors were fulfilling in the clinic, as well as their counselling training background, the nature of their interpreting was described as a "*mixture*" of interpreting and counselling. Doctors experienced the interpreters to do more than merely translate messages back and forth between the doctor and caregiver. The interpreters also expanded on issues that they were familiar with during interpreted consultations due to their training and experience of working in the clinic. Steenkamp's (2004, p. 29) conversation analysis of interpreted doctor-patient interactions in the clinic illustrated the interpreters as active partners to the doctors. Interpreters' assumption of the role of active partner in medical consultations is regarded as a factor that facilitates effective communication between all parties of the triad (Steenkamp, 2004, Friedland and Penn, 2003). Furthermore the doctors who participated in the current study seemed to appreciate the fact that the interpreters take on more than the role of an invisible interpreter.

The ideal interpreting model of partnership seemed to be followed at the clinic where the doctor and the interpreter functioned as a team in order for the caregiver to benefit from the specialised knowledge of each party (Westermeyer, 1990 in Wood, 1993). The doctors were thus willing to relinquish control of the consultation to the interpreters. The doctors' comfort with the interpreters' participation in the consultations seemed to be related to their familiarity and experience in working with the particular interpreters. An interpreter's personality and the doctor's ability to trust the interpreter are also considered as important aspects in this regard. Although the interpreters were not primarily dedicated to interpreting at the clinic, the relationship that was able to develop between doctors and interpreters over time seemed to lead to effective interpreted communication practice. This corresponds with the observation by Friedland and Penn (2003) that familiarity between interpreter and health care professional facilitates effective communication.

Schwartz (2004) made a similar discovery regarding doctors' relationships with interpreters in primary, secondary and tertiary health care centres in the Western Cape. She found that a doctor's ability to hand over power to an interpreter depended on trust, the interpreter's training and field specific knowledge, as well as the doctor-interpreter relationship. Formal interpreting arrangements are widely preferred in the literature over *ad hoc* arrangements where relatives or family members act as interpreters for patients (Wood, 1993).

The importance of a continued doctor-interpreter relationship becomes clear when one considers the comments of Dr 1 below. Dr 1 has been interviewed on his second day of work in the clinic, and has thus not been able to establish a working relationship with any of the clinic's interpreters by the time of the interview. Doctors usually enter multilingual health care centres without specific knowledge and experience in working with interpreters (Kelly and Brown, 2002).

Dr 1: "... *their (the interpreters') role is to translate whatever you are saying. I think what is frustrating sometimes, is many of them, will only... ask exactly what you ask to say. They don't take, have any ... initiative in asking the appropriate questions. So you have to prompt them every single thing. And they, that someone who has any medical training are understanding. So they're literally just channel interpreting, they don't actually have insight into illnesses...If someone who had medical training, some medical training background it would be far more effective... "*

Doctor 1's description of the interpreters as ineffective channel interpreters with little understanding of illnesses and in need of medical training, is in stark contrast with the comments of his colleagues with more experience in general and in the clinic specifically. It seemed that Doctor 1 was expected to work in the clinic and the hospital without an introduction and orientation into issues related to communication. Doctor 1's comment suggests that a doctor-interpreter relationship of trust and mutual respect for each other's specialised knowledge might be necessary for the interpreting model of partnership to develop. It is also possible that doctor 1's views of the interpreter role was merely in contest with those of his colleagues and not related to a lack of experience or training. It is interesting to consider the reason(s) for the interpreters' contradictory behaviour in Dr 1's consultations compared to the consultations of the more experienced doctors. Dr 1's doubt about the interpreters' competence and training possibly kept him from relinquishing power to the interpreters which placed the interpreters' in the role of invisible or channel interpreters.

iii. Determining when to use an interpreter

The doctors spoke about the ways in which they determined whether the help of an interpreter was needed or not. They have reported that they were lead by their own and the caregivers' rating of caregiver expressive English language ability. Dr 4 came to the realisation during the interview that it might be more appropriate to ask caregivers whether they understood English as opposed to whether they could speak English in determining the need for an interpreter. The ideal practice in this regard would probably be to ask each and every caregiver before the onset of the medical consultation whether they would like to have an interpreter present or not. Resources in the form of personnel

and time would determine the feasibility of such an approach. Health care professionals should also be careful to assume that because a patient admits and appears to be able to speak the language of the clinician, the patient will entirely understand the doctor's message.

Dr 3 commented that she usually asked an interpreter to assist when she performed counselling functions, as the interpreters were knowledgeable about the caregivers' understanding of particular information. This correlates with Levin's (2004) finding that doctors in other parts of the hospital called on the help of interpreters when an in-depth history or parental counselling was required. Dr 3's comment further suggested that the interpreters acted as cultural brokers as she relied on their knowledge of the caregivers' culture and background to illuminate aspects of the caregivers' comprehension (Swartz, 1998). The role of interpreters as cultural and emotional brokers for the caregivers in this clinic thus becomes evident once more.

The availability of interpreters in the clinic as well as the doctors' good sense to call on the interpreters' assistance, were viewed as predictors of effective communication at the clinic. The benefit of the interpreters' close understanding of, and even identification with, the caregivers' background for communication in the clinic was a strong theme in the doctors' interviews and will be discussed further under 3.4.2.ii and 3.4.3.ii.

iv. Miscommunication between interpreters and caregivers

Although the clinic offered a formal interpreting service, and the doctors and interpreters seemed to have formed a good working relationship, difficulty in interpreted consultations still occurred. Doctor 3's example of a difficult interpreted consultation where the caregiver could not explain her problem to the interpreter was very similar to the interpreters' comments of occasional difficulty in delivering the caregivers' message to the doctor. Another factor that complicated caregiver-interpreter interactions at the clinic was the fact that exact matches between the language of the caregiver and that of the interpreter were not always possible. The majority of patients at the hospital (Schwartz, 2004), as well as all of the counsellors working in the clinic were isiXhosa

first language speakers. Interpreters may not necessarily be fluent, or as fluent in one of the other eight South African indigenous languages as they are in their mother tongue, isiXhosa. Approximately 10% of the population served at the hospital were speakers of South African indigenous languages other than isiXhosa, or speakers of languages spoken elsewhere on the African continent, such as Swahili or French (Schwartz, 2004). It is thus expected that interactions between doctors and caregivers from the described indigenous linguistic minority will be especially troublesome.

Summary of the factors that influenced doctor-patient communication directly

The linguistic and cultural differences between doctors and caregivers complicated communication between these parties. These factors influenced the doctors' ability to address their patients' needs and were therefore perceived as a source of frustration for the doctors. There was an awareness of the unequal power distribution in the doctor-patient relationship in the clinic. The paediatric context generally might be more sensitive to such inequalities. Certain HIV/AIDS specific issues were identified as influences on communication in the clinic. Complex terminology and concepts related to HIV/AIDS and the caregivers' limited knowledge regarding these issues lead to difficulties in communication. The doctors' ability to provide their patients with ARV medication was seen as providing a positive start for the doctor-patient relationship. Time constraints were also reported to affect doctors' communication with caregivers.

The doctors viewed the interpreters as competent, effective and accurate. The ideal interpreting model of partnership seemed to be followed at the clinic where the doctor and the interpreter functioned as a team in order for the caregiver to benefit from the specialised knowledge of each party. The active participation of interpreters in the medical consultations was probably related to the familiarity and established working relationships between the doctors and interpreters. The doctors reported difficulties regarding interpreted consultations due to language differences between caregivers and counsellors.

3.4.2. Doctors' experience of working with and perception of counsellors

Table 3.4.2 Doctors' experience of working with and perception of counsellors

i. Doctor's perception of the counsellors' role
Pre- and post HIV test counselling, HIV related advice, and treatment counselling
Dr 1: <i>"All the counselling around tests. Which should, should boil down to their main function, testing. Pre-test counselling, post-test counselling. Advice, or what to do next about things, you know. And about disclosure and medication. Then also the other role is we start children, or want to start children on anti, anti-viral treatment. There is a lot of counselling involved in that, in adherence to the medicine."</i>
Difficult dual role
Dr 2: <i>"The way they act in the clinic actually is as interpreters but they are also counsellors. Now the extent to which they do their own counselling, is a little bit, we're not sure how much that happens. Uhm, and they do have to do this quite difficult dual role. Whereby at one point they are just interpreting. We also do hope then that they will sometimes take the patient away and speak to them further and counsel a bit more. But we don't often get a sense that that is always happening. Or we don't maybe get much feedback on that'.</i>
Dr 3: <i>"Because often in this situation, I mean we really don't have that much time. So I'll call her in, and...she'll be acting as an interpreter saying a whole lot of the almost medical stuff that you want her to say and then I'll turn around to her and say 'you now have to go and counsel the patient about all the other aspects'. So I know that she is gonna be repeating a whole lot of the things I have said'.</i>
Serious counselling
Dr 1: <i>"But when you have to tell someone that the child is likely going to be dying and you want to give, want to get someone to. We usually refer those kids to the social worker...mothers who need emotional support... they (the social workers) are very good but they are very busy".</i>
ii. Doctors' perception of the counsellors' competence and training
Counsellors' personal experience and insight
Dr 2: <i>"I think they are amazing women. The majority of them are HIV positive or maybe all of them. Uhm, so I think they bring into it a lot of feeling, I mean a lot of personal feeling experience. They can sit down and talk to the mother from the heart you know".</i>
Dr 4: <i>"...they (the counsellors) have got a lot of first hand experience with HIV, because some of them have HIV and are on ARVs so they know what they are talking about. A couple of them are very insightful, they know quite a bit. They have a lot of insight into the disease. And I think they would actually be doing a much better job than, when you (Dr 4 points to himself) would counsel'.</i>
Competence regarding pre- and post test counselling
Dr 1: <i>"...pre- and post-test counselling. I think that they are fine with. I think that's still okay, it works well. It's really a simple and straight forward formula".</i>

Competence regarding counselling on treatment related matters
Dr 1: <i>"But I think to go into counselling about treatment and other problems, I don't think they're equipped. See now, I don't know if they have much insight into how to take drugs... I don't think they have...been trained"</i> .
Dr 4: <i>"But that (counsellors' training regarding ARVs) is what I am concerned about as well. I mean we are all concerned about it"</i> .
iii. Problems regarding counselling by the counsellors
Lack of feedback from counsellors
Dr 2: <i>"...it is difficult for me to know what actually happens when they counsel patients. Now the only way that I could get a sense of what was happening is the extent to which they feed back and report it to me...But, uhm, so I think they probably do do good work, but somehow we need to formalise it. Because for us you see the process of putting a child on treatment. We like the child to be counselled, but we need to know sort of how it went you know. So it is difficult. Apart from sitting in in counselling you don't know what is really happening there...And language wise. I mean they would be speaking Xhosa with the patient. Ja it is difficult, you know. I don't know whether the answer is to kind of have, some sort of, stick to professional counsellor, psychologist people doing it. Because that removes some of the contact, the kind of connection that I think these women do have with the women in the clinic. And the counsellor wouldn't have...But what we need to encourage for them is to try and give us the whole picture of what happening in the sessions and with the patient. Because we don't really have that..."</i>
Need for vocal patient advocates
Dr 2: <i>"You know, we don't really, we don't find them (the counsellors) ...being for example very sort of active vocal sort of advocates of their patients. So when we have a sit down in a ward round, where the patient for example the patient is in a ward and had to be counselled by the doctor and the counsellor. We would ideally like, uhm, kind of vigorous feedback from that counsellor to tell us what actually happened in that session. You know with this mother. It this the sort of mother who we think is gonna get the treatment. Does she understand about HIV, does she, is she going to inform her child about the HIV. All those kind of issues. And at the moment we are not getting that from them. So that is a bit of a frustration for us"</i> .

i. Doctor's perception of the counsellors' role

The doctors' description of the counsellors' main function as the provision of pre- and post HIV test counselling was in agreement with the counsellors' view of their role and function. Similar to the counsellors themselves the doctors viewed the counsellors as providing advice to caregivers on HIV/AIDS related matters such as disclosure. The development and availability of ARV AIDS treatment at the clinic has added aspects of counselling regarding medication to the counsellors' original role. The doctors'

perception of the appropriateness of the counsellors' competence and training to perform the listed functions are discussed under 3.4.2.ii.

The doctors have also discussed the counsellors' "*difficult dual*" role of interpreting and counselling. Although the counsellors have been reported to include some counselling aspects when they were providing interpreting services, time constraints did not allow thorough counselling during interpreted medical consultations. The counsellors were required and sometimes requested to provide further counselling to a caregiver *following* the interpreted medical consultation, on matters that have arisen in the medical consultations. Although the counsellors might thus have to repeat a lot of the information that was shared with the caregiver during the interpreted consultation, the way in which the information will be discussed during the counselling session might differ, as the counsellors' role would be counselling as opposed to interpreting.

It is clear from Doctor 2's comment that the doctors did not receive sufficient feedback regarding the counselling that took place following the interpreted consultations. The issue of limited feedback was a problem strongly expressed by the doctors regarding their working relationship with the counsellors. This issue is discussed more thoroughly under 3.4.3.iii.

A distinction existed between the counselling services provided by the clinic's appointed counsellors, and professional counselling offered to patients with more serious emotional difficulty or even clinical psychological conditions. In this clinic caregivers with emotional difficulty that surpassed the skill and scope of practice of the counsellors and doctors were referred to professional counselling services offered by hospital appointed social workers. The doctors' perception was that the social workers were highly skilled but not readily available due to large caseloads and patient waiting lists. Doctor 1 has offered a suggestion to this problem that is discussed under 3.4.7.iii.

ii. Doctors' perception of the counsellors' competence and training

The doctors' perceived the counsellors' personal experience of HIV/AIDS and ARV treatment as factors qualifying them to provide counselling services even superior to what the doctors themselves might be able to offer. The caregivers confirmed the doctors' belief with their expressed appreciation for the availability of counsellors with whom they could identify and have described the counsellors as truthful, trustworthy and credible (see 3.2.4). More specifically, the doctors perceived the counsellors to be fully competent and appropriately trained for the provision of pre-and post test counselling. However, the doctors were concerned about the counsellors' ability and training surrounding counselling on ARV treatment. The doctors' reason for this scepticism was the lack of feedback they received from counsellors. This issue will be discussed next.

iii. Problems regarding counselling provided by the counsellors

The doctors have mentioned two specific problems that they encountered regarding the counselling provided by the counsellors working in the clinic. The first was that the doctors did not receive feedback from the counsellors on counselling performed with caregivers after the interpreted medical consultations or after the delivery of HIV positive test results. The practice at the hospital was that a doctor as well as a counsellor would counsel a caregiver in the wards to determine whether the child was a good candidate for ARV therapy or not. Certain social criteria apply in selecting children for ARV treatment. Public health care clinics often evaluate the degree to which a patient's domestic environment is conducive to adherence to treatment, the implications of ARV therapy is understood and a long term commitment is made before the patient is accepted for therapy (Eley et al., 2004; Kapp, 2004). Doctors thus needed the counsellors to provide them with extensive feedback on the caregivers' social and family background as well as the counsellors' personal interpretation of the information received from the caregivers. This information is vital to the doctors in determining the nature of treatment a child will receive. Due to the doctors' limited time and isiXhosa language proficiency the only access to the information shared during counselling sessions was through feedback from the counsellors. The doctors admitted that formal feedback structures were not in place at

the clinic at the time of data collection for this study, and felt that this was partly to blame for the lack of feedback from the counsellors. A communication protocol to solve this problem was being planned and is discussed under 3.4.7.

The second issue regarding the problems that doctors experienced with the counsellors' counselling function is closely related to the first. The doctors experienced a lack of advocacy for the patients on the side of the counsellors. Swartz (1998, p. 38) described a particular view of the interpreter role, namely the "interpreter as client advocate". This view regards patients who are not fluent in the dominant language of the health care institution as having far less power than the doctor. The role of the interpreter is seen as "to assist the client with access to resources – essentially to empower the client", and often the interpreter would form a close and continuous relationship with the patient. Although the doctors were referring to the counsellors' *counselling* function with the comments surrounding advocacy, it seems reasonable that the doctors had difficulty with the counsellors' lack of fulfilment of the role described by Swartz (1998) as the *interpreter* as patient advocate. The doctors' comment stemmed from the fact that counsellors gave little feedback to doctors surrounding the counselling performed with caregivers. It is interesting that the counsellors have indicated that they support and empower caregivers during individual counselling sessions, and that the caregivers have experienced these individual sessions as helpful on an emotional and practical level. The counsellors thus seemed to act as advocates for the caregivers in their individual interactions, but failed to be advocates for the caregivers during their interactions (or lack thereof) with doctors. This is an important finding as the potential of the counsellors and the doctors to truly serve and empower the caregivers is limited if an effective feedback mechanism between doctor and counsellors does not exist.

3.4.3 The doctors' experiences regarding the practice of medicine in the clinic

Table 3.4.3: The doctors' experiences regarding the practice of medicine in the clinic

i. Multiple duties
Dr 2: <i>"A number of visitors to this clinic, for example from overseas, have commented on the fact that... the doctors here are, is actually performing medical duty, quite a lot of the nursing duty, in the sense of blood taking, some of the measurements, some of the routine type admin nursing type paperwork duty and even nursing stuff and counselling. So, you know, I don't say that to sort of... that I am such a great person... But I think that quite a lot of clinics, well chronic disorder clinics and these kind of HIV clinics and others in in in. Well, okay in a lot of developed countries they tend to have resources, time, fewer patients and so forth. But some of their counselling would be done pre and post the medical consultation, you know so maybe by a counsellor or afterwards"</i> .
ii. Doctors' experience of their counselling function
Doctors do counsel
Dr 2: <i>"Maybe we (the doctors) tend to our patients too much, but I think we feel that it is not been done so therefore we do... We do a lot of counselling"</i> .
Setting not suited for doctors to perform a counselling function.
Dr 2: <i>"... it is just in terms of the numbers and resources and staff burn outs and all those other kinds of issues... I think that (counselling) is their (the counsellors') job, that is their training, that is what they do. And, although I do quite enjoy it and I see it as part of my sort of responsibility I think ultimately it should be done by a counsellor. So by the time the person comes to me they've gone through some of that and one can then proceed with some medical things... But I would like, in order for me to go and proceed to do that, I'd like, well I need feedback from that counsellor"</i> .
Counselling duty best performed by counsellors
Dr 3: <i>"...by and large if it gets to the counselling part I actually have to ask the counsellors to come and help because they seem to have that much more of a grasp of what the patient can understand or not... And just to be able to open up a little more (with counsellor's presence during counselling by doctor). I find that the patients are very reserved. Especially with something really sensitive like this, and more like when they need... the first time share issues just with you"</i> .
Dr 4: <i>"We (the doctors) were never taught to counsel and you still do not have counselling skills. And what we see our job is imparting information. Now I think there is a complete different concept between sitting here and saying da-da-da-da, ABC of anti-retrovirals and... taking that information and putting it across in a sort of a counselling..."</i> .

iii. Discontinuity of care

Dr 2: "...we don't see our own patients each time...we uhm generally pick up the next folder. So now we would all over time see the patient. And in some ways it is good because you get different kind of input from different people and all have different degrees of experience in HIV. In managing (roll out of) anti-retrovirals and stuff. But other than that there isn't that familiarity, and maybe that trust, the kind of responsibility issue also..."

Dr 3: "And the problem with this clinic... is that we don't necessarily see the same patients over and over again. And I find that the patients that I do tend to see regularly are much more forth coming in terms of giving a history the than patients you are just seeing once off".

iv. Compromising quality due to pressure of numbers and urgency

Dr 2: "...we all know that theoretically before someone goes onto treatment which is lifelong, which is uhm, which adherence is absolutely essential, that they should really be informed, really counselled, really have a close relationship. That they should have access to me, that they should have a team looking after them all those things. And we by necessity, by urgency of wanting to put kids on treatment, by the pressure of numbers we don't always achieve that degree of quality that we could, and we should, and would like to...Uhm, but, the...need is such that we really, really want to put those kids on treatment. So we do sort of the best we can. But there is a cost to us, there is a cost to the patients in the sense that they are not as fully, uh, maybe ready for it or informed".

v. Child directed treatment

Dr 2: "The other big frustration I think is that, although we got a few mothers on treatment, uhm treatment is directed at the children. We do not have an active programme for the mother. So you are in a situation where you are putting the child on treatment and you really can't be sure if the mother is going to treatment".

i. Multiple duties

Dr 2 pointed out that the doctors at the clinic performed several duties in addition to their medical duty, including nursing and counselling activities. Medical literature indicate that counselling, including pre- and post HIV test counselling as well as ongoing counselling, is considered part of the role of the doctor (Botes and Levay, 2004; Bekker, 2002; Schweitzer, 2000). However, Doctor 2 mentioned that better resourced chronic disorder clinics, as in the developed countries, made use of counsellors to provide counselling to the patient before and after the medical consultation. This clearly differs from the situation in the clinic under investigation, where the appointed counsellors have limited training and perform mostly pre- and post-test counselling, and doctors fulfil a reasonable

amount of counselling and even nursing activities as part of their medical duty. The doctors' experience of their counselling function will be discussed next.

ii. Doctors' experience of their counselling function

The doctors counselled their patients, and admitted to enjoying this task and viewed it as part of their responsibility. This is in line with the biopsychosocial medical model's holistic perspective of the patient which "requires that the physician accept responsibility to evaluate whatever problems the patient presents and to recommend a course of action...Hence the physician's basic professional knowledge and skills must span the social, psychological, and biological, for his decisions and actions on the patient's behalf involve all three" (Engel, 1977, p. 133). However, the doctors were of the opinion that the nature of the clinic as well as the relative background and training of the counsellors and doctors made the counsellors the ideal staff members to perform the counselling function. The doctors reported that the shared background characteristics of the counsellors and the caregivers at the clinic often lead to improved communication between these parties compared to communication between the doctors and caregivers. The counsellors confirmed this observation with examples of how their communication with caregivers was successful compared to attempts by health care personnel. Doctor 2 felt that the counsellors had a better sense of the caregivers' comprehension and that caregivers were more ready to share personal information in the presence of a counsellor than would be the case in a doctor-caregiver dialogue. Although counselling is a recognised part of primary care physicians' professional role (Botes and Levay, 2002; Schweitzer, 2000) doctors do not necessarily receive specialised instruction on counselling as part of their professional training. Doctor 4 emphasised an important distinction between the mere conveyance of information, which he saw as the doctor's role, and the delivery of that same message through counselling. It is the former role that doctors felt were most suited to counsellors at the specific resource limited clinic, especially since the counsellors had particular success in communicating with caregivers.

However, the doctors did indicate that the counselling function could only be fully taken over by the counsellors if there was a formal feedback system between the doctors and

the counsellors in place. It has been discussed earlier that the doctors were concerned about counselling surrounding ARV medicine. Due to the limited training of the counsellors the doctors felt that counselling surrounding medication should be undertaken by both the doctor and the counsellor. Doctor 4 said the following in this regard: “... *not only do we counsel, but the... counselor does the counseling independent of us. And they take us out of the equation and they go and sit with the mothers, the parents and mothers and often they can get more out of them*”. Again it is apparent that the counselors were often more effective in communicating with the caregivers than the doctors. The double counseling regarding ARV treatment seemed to be effective considering the results of an evaluation study of the clinic’s early experience of a highly active antiretroviral therapy (HAART) programme. The results indicated that the majority of the 80 children that were enrolled in the programme achieved greater than 85% adherence. The researchers speculated that the high adherence percentage was responsible for the benefit that the child participants received from the HAART (Eley et al., 2004). The clinic was in the process of planning a system to set an effective feedback between doctors and counselors in place. The planned strategy is discussed under 3.4.7.ii.

iii. Discontinuity of care

The doctors reported that they did not have their “*own patients*”, but rather “*pick up the next folder*” as a method of assigning patients to doctors. Doctor 2 pointed out that a system where patients were seen by various doctors over time had the advantage of offering the patient a range of the skill and experience available at the clinic. Experience in the administration of ARV therapy increases the confidence and efficiency with which doctors perform this clinical responsibility (Eley et al., 2004). However, similar to the counsellors the doctors felt that this discontinuity of care had a negative effect on the relationship and interaction with caregivers. Plans to address this problem will be discussed under 3.4.7.i.

iv. Compromising quality due to pressure of numbers and urgency

Dr 2 described the dilemma the doctors were facing by having to balance a big caseload in dire need of ARV therapy, with the requirement of excellence in the preparation of

patients for this lifelong treatment. He talks about a cost to both the patients and the doctors. The cost to patients was serious as it means that they may not be sufficiently prepared before they start ARV treatment, which might lead to problems with adherence and thus ineffective treatment with the risk of resistance creation. On the doctors' side cost was related to the theme of frustration when the reality of the practice situation contradicted theory and professional ideologies of medicine as an all-knowing and technically proficient science were challenged. The cost to the patient was thus the basis of the sense of loss and frustration experienced by the doctors. Similar frustration was reported over communication difficulty caused by language and cultural differences between doctors and caregivers (see 3.4.1 A. iii). Another related frustration is discussed below.

v. Child directed treatment

At the time of the study treatment at the clinic was directed and available to children only despite the fact that HIV positive children most often have HIV positive parents who have the same treatment requirements as their children. It is easy to understand the doctors' frustration in providing a mother with hope and care for her child, while at the same time not being certain that the mother's medical needs were met. An integrated family model is regarded as the best option for the comprehensive management of HIV infected children (Eley et al., 2004). The doctors had a plan developed to address this important frustration, which will be discussed under 3.4.7.i.

Summary of the doctors' experiences regarding the practice of medicine in the clinic

The doctors at the clinic performed several duties in addition to their medical duty, including nursing and counselling activities. The doctors saw counselling as part of their responsibility but were of the opinion that the nature of the clinic as well as the relative background and training of the counsellors and doctors made the counsellors the ideal staff members to perform the counselling function. However, the counselling function could not be fully taken over by the counsellors before an effective feedback system between the doctors and counsellors were developed. Due to the limited training of the counsellors the doctors felt that counselling surrounding medication should be undertaken

by both the doctor and the counsellor. Three frustrations regarding the practice of medicine at the clinic were described by the doctors. Firstly, the doctors were concerned over the effect of the discontinuity of care on their interactions and relationships with patients and caregivers. Secondly, the doctors described the dilemma of having to balance a big caseload in dire need of ARV therapy, with the requirement of excellence in the preparation of patients for this lifelong treatment. Finally, the clinic's ability to provide treatment for children but not for their families was a source of frustration for the doctors.

3.4.4. Doctors general experiences of communication in the clinic

The doctors' commentary on their experiences of communication, as well as their perception of ideal communication skills (discussed next under 3.4.5) gave evidence of their adoption of the biopsychosocial medical model and the patient centred clinical method. This statement is clarified and illustrated in the following two sections.

Table 3.4.4: Doctors general experiences of communication in the clinic

i. Communication as no different across clinics
Dr 1: <i>"But it's (communication) no different to...any other clinic..."</i>
Dr 4: <i>"We (the doctors) were never taught to counsel and you still do not have counseling skills. And what we see our job is imparting information. Now I think there is a complete different concept between sitting here and saying da-da-da-da, ABC of anti-retrovirals and... taking that information and putting it across in a sort of a counseling uh, uh, so. But I think this is an issue that cuts across the whole of medicine".</i>
ii. Communication issues specific to Paediatric medicine
Dr 2: <i>"And you know with Paediatrics it is always a, it's always a sort of two level thing because on the one hand you've got the patient and on the other hand...you have the caregiver, whether it is the mother or somebody else. And sometimes you sort of really tune in very well to the patient and not the mother or the mother and not the patient... And so you are dealing with two people and uhm, I mean obviously it applies strictly with the older children, so the young adolescents and that, where it is very important that you get on well with their caregiver, but ultimately it is actually them you've got... With the younger children the mothers are everything. You really have to focus on the mom."</i>

iii. Caregivers' lack of questions and repair strategies in communication with doctors

Dr 3: *"But by and large you quickly understand if the patient doesn't comprehend what you are saying...the misguided responses that they do give you to questions that you would expect a different response"*.

Dr 4: *"Patients don't ask us questions and that is the problem. That is the problem. Patients don't ask questions...When I say us I mean the doctors... They talk to the social workers, they talk to the. But they don't talk to us. That I can't understand...I think that that is why it (communication) doesn't run on a smooth basis"*.

iv. Facilitative strategies used by doctors

Dr 2: *"I really enjoy communicating with the patients. It actually makes my job good and interesting, so I do put quite a bit of effort and time into it...whether it is one-on-one or whether it is through an interpreter"*.

Dr 3: *"...I find that visual cues often help a lot, so I end up drawing at the back of stuff for the patients all the time and they seem to understand that. And I just make things quite simplistic at times, by using garden and household items so that it is simpler. That sometimes does do the trick. But, I mean, by and large if it gets to the counselling part I actually have to ask the counsellors to come and help because they seem to have that much more of a grasp of what the patient can understand or not"*.

i. Communication as no different across clinics

The doctors and counsellors have both talked about HIV specific issues that influence communication. Similarly the limited literature on communication in HIV care frequently highlights disease specific issues that challenge communication in a clinical setting. However, the doctors noted that certain aspects of their communication experiences were comparable to communication with patients in other clinics within the context of South African public health care. Examples of 'generic' communication difficulties were related to the language and cultural differences that frequently exist between doctors and patients and to the doctors' limited training regarding communication skills.

ii. Communication issues specific to paediatric medicine

Doctor 2 mentioned communication issues specific to the paediatric health care context. Paediatric medical interviews are quite different from adult interviews. Paediatric interviews involve a triad of doctor, caregiver and child, compared to the doctor-patient dyad of adult interviews (Mendelsohn, Quinn and McNabb, 1999). Dr 2 noted that the doctor who works with children needed to communicate on two levels, that of the child

and the caregiver. The age and maturity of the child ultimately determined the distribution of focus in interactions between the caregiver and the child. According to Doctor 2 the caregivers of young children, like the caregivers who have participated in this study, were the doctor's main focus during paediatric interviews and related interactions. Literature on communication in paediatric health care contexts indicates that children of school age are capable of reporting their health complaints to doctors with parental confirmation of certain points (Gill and O'Brien, 2003; Van Dulmen, 1998). Increasing attention is being paid to children's right to adequate information regarding personal health matters, especially in the field of HIV/AIDS. Receiving and delivering information from and to children is challenging in multilingual contexts where doctors have poor verbal skills in the patient's language and vice versa.

Steenkamp's (2004) conversation analysis of interpreted paediatrician-patient interactions lead to an interesting finding regarding the doctors' use of their limited isiXhosa skills to build rapport with their young patients. An example was used of a doctor greeting an isiXhosa young boy in his mother tongue. In a self-administered survey of paediatricians regarding commonly used interview techniques, Mendelsohn et al. (1999) found that paediatricians reported various linguistically independent strategies of building rapport or calming the young patient, such as touching or holding the child, vocalisations, and the use of toys. However, as children matured doctors relied more on verbal strategies to calm and to establish a relationship. The limited isiXhosa abilities of the doctors who have participated in this study are thus not expected to affect their ability to establish rapport with or to calm the young patient from a non-English or Afrikaans speaking family. Sufficient communication between doctors and older children might however be a considerable problem in this clinic.

iii. Caregivers' lack of questions and repair strategies when communicating with doctors

Doctors in this study have commented on caregivers' lack of questions or repair strategies in doctor-caregiver interactions. The counsellors have also related experiences of caregivers who did not make use of opportunities to ask questions.

Few studies have however aimed to identify factors that influence whether patients attempt to obtain verbal information from their doctors or not. Situational or socio-demographic factors might be associated with patient information seeking (Beisecker and Beisecker 1990, in Ong et al., 1995). Bourhis et al (1989) suggested that, patients might be embarrassed to ask the doctor all of their questions due to the patients' status position within medical consultations. Furthermore, interactions of longer duration might be necessary for patients to actualise their desire for verbal information seeking and participatory decision making.

Health professionals' and patients' behaviour and communication in HIV clinics are largely shaped by social, economic and historical factors. Although the doctors who were interviewed in this study have not or were not able to give explanations for the caregivers limited use of questions it is argued that unequal power relations probably play a large role in this phenomenon. The time pressure and the relative short duration of consultations, as well as the current discontinuity of care, probably also contributed to the caregivers' limited use of questions in doctor-caregiver interactions.

Very NR

iv. Facilitative strategies used by doctors

The doctors referred to communication approaches or strategies that facilitated effective communication with the caregivers. The caregivers have corroborated this claim with their comments regarding various communication behaviours employed by the doctors to facilitate their understanding.

Doctor 2 made a very important statement regarding enjoying and appreciating communication with caregivers and therefore investing time and effort into the process. The fact that doctor 2 described communication with caregivers as *interesting* probably indicates his appreciation for the essential skill of the physician "to elicit accurately and then analyse correctly the patient's verbal account of his illness experience", according to the biopsychosocial medical model (Engel, 1977, p. 132). Doctor 3 discussed more practical issues namely the use of visual materials such as drawings, and commonly known household and garden materials to make information accessible to the caregivers

and to facilitate their understanding. The caregivers as well as the counsellors testified to the doctors' attempts to make accommodations in terms of the complexity level of their language use. The caregivers reported that the content and structure of the doctors' language facilitated their understanding within the medical consultation. The doctors' adaptation to the language register of the caregivers, namely everyday language (EL), rather than to maintain their specialised register of medical language (ML) during medical consultations, might signal the doctors' willingness to balance the differences in power and status that existed between themselves and the caregivers (Bourhis et al., 1989).

The fact that the caregivers and counsellors in this study confirmed the doctors' claimed communicative accommodations, gives evidence that the doctors were successfully employing convergence to the caregivers language register despite possible implicit knowledge (see page 3). Convergence has been reported to improve intelligibility between speakers (Berger and Calabrese, 1975 in Bourhis et al., 1989) and to promote interpersonal liking between conversational partners (Giles, Mulac, Bradac and Johnson, 1986, in Bourhis et al., 1989). In the case of the current study the caregivers' positive regard for the doctors might thus be related to the doctors' adaptation of register during medical consultations.

Another important strategy used by Doctor 3 was to request a counsellor to take part in consultations where difficult concepts which were crucial to the caregiver's understanding and management of her child's and perhaps her own illness, were discussed. In doctor 3's opinion the interpreters were most able to explain certain concepts to the caregivers and also to gauge the caregivers' understanding of these concepts. Doctor 3's use of assistance from interpreters thus indicates that she recognised the skills of the counsellors in the clinic and applied a team approach in situations where language and cultural differences influence communication negatively. The fact that the interpreters made judgements about the caregivers' understanding during such interactions indicates that the interpreters were functioning as junior colleagues in these situations (Swartz, 1998).

It is interesting that the caregivers cited 'request for an interpreter' (see 3.2.2.i) as a communication repair strategy applied when they have not understood the doctors' message. The fact that the doctors used a similar strategy might have encouraged and reinforced caregivers to request the help of interpreters in situations where communication was problematic.

3.4.5 Doctors' perception of a doctor with good communication skills

Table 3.4.5: Doctors' perception of a doctor with good communication skills

i. Appropriate level of language
Dr 2: "... I think it is... a lot to do just with uhm just really trying to talk at a simple and plainer level, almost a day-to-day level".
ii. Listen and be gentle: moving away from paternalism
Dr 2: "And putting the person you talk to at ease and trying to get away from 'I'm the doctor and you are the patient and I will tell you what to do'. But rather to... try and listen to what is coming out and to say in a sort of a gentle way. Trying to sort of tease out information. It is almost a bit of an extension of the way you deal with a child, the way you see a child... just as an analogy... I mean you, when you examine a child, you can't ask them to sit up and breathe. Now, you know, you actually have to play and go into it a bit and get their confidence and listen to their chest while they are not upset, and then do something else when they are a bit upset, and so uhm build up a picture. And I think, I mean it is just an analogy, but uhm I think somehow with mothers a bit".
Dr 3: "And the ability... to just actually switch off and listen to the patient. Because I think in a hospital set up you are probably almost thinking, the next patient and you must hurry up. Uhm and a difficult counselling session is, I guess is, almost your escapism".
iii. Personality and Orientation towards the caregiver and child
Dr 2: "You gotta to love the child and the mother and actually want to do something for them. You've got to uhm spend the time as opposed to just seeing them right here on the bed".
Dr 3: "Well, I think personality to a large extend is involved... a caring personality...".
iv. Experience in counselling
Dr 3: "a lot of the people who seem to be doing well (with regards to communication) are experienced in counselling".
v. Facing sensitive topics / going to the difficult places
Dr 2: "You got to go to the difficult places that you don't feel like, like uhm disclosure".

vi. Build bridges across cultural, language and power gaps

Dr 2: *“Uhm, in terms of sort of frustrations and a bit of uhm whatever cultural histories... I think the constraints are usually communication constraints and time and effort and input constraints. And I think if you sit down and spend time with somebody those things fall away, you know you talk together as human beings, not as. But I, I am not unaware of all those kind of power relations that are already in place. And to, to try and get through some of those. I don't assume that those go away, I mean they are there. But I think you can actually come through that quite a bit”*.

Dr 2: *“You have^{*} to sort of build bridges and not try and speak English to people who don't understand English. But also try and muddle your way through Xhosa so that people know that you care. Try”*.

i. Appropriate level of language

The doctors valued the ability to use an appropriate level of language when communicating with the caregivers. Doctor 2 talked about having conversations at a *‘simple and plainer level’* which was interpreted as accommodations pertaining to the content and structure of the doctor's language. Doctor 2's statement regarding talking at a *‘day-to-day’* level, probably referred to convergence from ML to EL. The doctors' view of ideal communication as being in line with the register of the caregiver correspond with Bourhis et al.'s (1989) finding that doctors and nurses consider EL as more suitable for communication with patients compared to ML. Bourhis et al. (1989, p. 340) are of the opinion that “convergence from ML to EL by doctors with their patients should be expected” since convergence makes information easy for the patient to remember and understand (Silverman et. al, 1998, in Blitz, 2000). Convergence can therefore maximise the effectiveness of doctor-patient communication, may increase patient compliance with medical advice and may lead to the patient experiencing a greater sense of ease during medical interactions. The provision of information to the patient in a clear and simplistic manner also enables the doctor to establish common ground between his/her own ideas and goals and the ideas and expectations of the patient (Steward et al., 1995, in De Villiers, 2000). Furthermore, a doctor can facilitate the patient's participation in clinical decision making by delivering information in a clear and simple way (Elwyn et. al, 1999, in De Villiers, 2000). Mutual decision making is an important component of the patient-centred clinical method (De Villiers, 2000).

ii. Listen and be gentle: moving away from paternalism

“The most important attribute of any good doctor is to be a good listener”. This is how Gill and O’Brien (2003, p. 13) open their chapter on history taking in paediatric examinations. The quotations in the table above indicate that the doctors interviewed in this study shared the authors’ opinion. Listening is considered as one of the key skills of a doctor with good communication ability (General Medical Council, 2001, in Dacre et al., 2004; Gill and O’Brien, 2003; Blitz, 2000; Tally and O’Connor, 1996). Blitz (2000, p. 68) advises that the doctor should prepare him/herself for every consultation by adopting an attitude that says: “I am ready to listen to this story” and that all distractions and interruptions should be removed so that full attention may be paid to the patient. Doctor 3 expressed similar views. Patients have appreciation for a doctor who pays them undivided time and attention, and the doctor is often well repaid for the time spent on communication (Gill and O’Brien, 2003). Similar to other health care facilities in South Africa time was a limited resource in the current research setting. De Villiers (2000) urges clinicians to add value to the little time they have available by, for instance, focussing on the patient’s needs regarding explanation of the disease and suggested treatment.

Doctor 2 mentioned another very significant aspect regarding ideal doctor-patient communication, namely a shift from the traditional paternalistic medical model view of the doctor-patient relationship, to the favoured model of partnership, such as advocated by the biopsychosocial model and the patient-centred clinical method (De Villiers, 2000). Whereas the bio-medical model “encourages bypassing the patient’s verbal account by placing greater reliance on technical procedures and laboratory measurements”, the biopsychosocial model pays close attention to patients’ verbal reports in order to deliver appropriate and holistic health care (Engel, 1977, pg 196). Post modernism has brought about a change in the doctor patient relationship from “one of monologue to one of dialogue” where the doctor no longer instructs the patient, but rather negotiates the management plan with the patient (Moodley, 2000, p. 313). The present-day doctor-patient relationship has been referred to as a meeting between experts, where the doctor is

the medical expert and the patient the expert regarding his/her illness experience (Barker, 1998, in Moodley, 2000).

iii. Personality and Orientation towards the caregiver and child

Doctor 2 made the point that good communication skills did not merely refer to the mastery of a certain conceptual framework and practical skills, such as the biopsychosocial and patient-centred methods' emphasis on listening and allowing the patient to talk. He stated that effective communication stemmed from compassion for and willingness to help the caregiver and child. The caregivers have confirmed Doctor 2's statement by expressing their appreciation for the sympathy, kindness, care and help that they have experienced in their interactions with the doctors at the clinic (see 3.2.1.ii).

The awareness of the importance of conversational style by the doctors who have participated in this study is a further indication of their adoption of the patient-centred clinical method where the patient is viewed as more important than the disease (McWhiney, 1989, in De Villiers, 2000).

iv. Experience in counselling

Doctor 3 made the observation that the colleagues whom she regarded as good communicators usually had experience in counselling. Good communication skills by doctors are not considered an innate ability, but rather a skill that can be learned and enhanced (Maguire and Pitceathly, 2002). Observation of more senior clinicians as well as personal experience and feedback from skilled individuals or patients are needed for doctors to feel comfortable in their discussions with patients and/or caregivers (Gill and O'Brien, 2003, Blitz, 2000). Experience might be of even greater importance in cross-cultural settings. Kelly and Brown (2002) found that doctors needed a 2- to 5- year period to acculturate in community contexts. Changes in doctors' communication behaviour and understanding of the patients' culture develop over time.

v. Facing sensitive topics / going to the difficult places

Care for patients with HIV/AIDS implies the discussion of stigmatising and painful topics (Wilson and Kaplan, 2000). Doctors are often hesitant to discuss these sensitive topics with patients (Kelly and Brown, 2002), often despite additional training in general communication skills (Epstein et al., 1998). Since patients do not often determine the topic of discussion in the medical interview (Epstein et al., 1998), the onus is on the doctor to introduce these sensitive yet important topics. Wilson and Kaplan (2000) have found longer visit length and less advance disease stage to be associated with better communication regarding HIV specific topics. Trust and acceptance of the doctor are also needed for patients to discuss important issues with doctors in cross-cultural contexts (Kelly and Brown, 2002). Sensitive topics that are discussed with non-judgemental acceptance of the patient establish a sense of trust and safety that the patient finds very valuable (Blitz, 2000).

vi. Build bridges across cultural, language and power gaps

Doctor 2 made a very powerful statement in saying that the barriers to effective doctor-patient communication in terms of differences in culture, language and power can be largely overcome by spending time and effort on doctor-patient interactions. He also placed attention on that which doctors and patients have in common, membership to the human race, instead of accentuating the differences between them. He admitted that the difficulties of differential power distribution and differences in perception did not disappear with longer and more rigorous interactions, but suggested that more attention to the human aspect of health care went a long way in resolving the barriers that are perhaps too frequently used as excuses for substandard doctor-patient communication. Doctor 2 was thus promoting a biopsychosocial and patient-centred model of health care that incorporates the psychosocial aspects of patients' lives (unlike the traditional bio-medical model) and includes patients as partners in the health care system.

Doctor 2 made a practical suggestion regarding overcoming the language barrier that frequently existed between doctors and patients in South Africa. He advocated that

doctors use of the limited expressive ability that they possess in the patients' first language when patients cannot speak English. In his opinion and experience a doctor's attempt to address a patient in his or her first language communicated concern and a willingness to overcome communication difficulties to the patient. Willingness by the doctor to '*muddle his/her way through Xhosa*' might also leave the caregivers feeling that their inability to speak English is not the problem within the clinical interaction, but rather that the problem is a shared one and that the doctor and the bigger health care system also has certain flawed abilities. Attempts by a doctor to address a patient in a language other than the doctor's most comfortable language, might thus move the power scale more towards equilibrium.

Doctor 2 did not imply that interpreters were not needed in situations where caregivers have very limited English abilities, but rather made the point that limited direct interaction with the caregiver in her/his mother tongue established important components of a therapeutic doctor-patient relationship. The counsellors reported their experience of the doctors' use of isiXhosa in interpreted consultations and have interpreted it in the way intended by the doctors, namely to assist the caregivers' understanding (see 3.3.7.i).

Summary of the doctors' perception of good communication skills

The doctors discussed various factors that they associated with good communication skills in a medical doctor. Their perceptions agreed largely with recommendations on communication skills in the medical literature. The doctors valued the ability to use an appropriate level of language when communicating with patients. Doctors viewed the ability to set competing agendas aside in order to listen to the patient's story as very important. The doctors considered an ideal doctor-patient relationship to shift away from the traditional paternalistic medical model to a model of partnership. Experience in counselling and a willingness to address sensitive topics were also mentioned. It was felt that barriers to effective doctor-patient communication in terms of differences in culture, language and power could be largely overcome by spending time and effort on doctor-patient interactions. Ultimately good communication ability meant more than adopting a

particular philosophy of medicine or practising certain skills. The personal values and orientation of the doctors towards his/her patients were crucial.

3.4.6 Doctors' experiences regarding communication skills training for clinicians

Table 3.4.6 Doctors' experiences regarding communication skills training for clinicians

i. Learning an indigenous language
Dr 1: <i>"I used to learn a little in school in Zulu. I learned it at school and University. There was a course offered in Zulu... It was quite helpful... it's useful in communication".</i>
Dr 3: <i>"But the problem is, you learn maybe the language that is indigenous to the area of your University and then you end up somewhere else. So it is not always that helpful"</i>
ii. Need for communication training
Dr 3: <i>"I definitely do (think health professionals will benefit from more training in communication skills)... Because you leave medical school and your head is full of this medical terminology and suddenly you try and communicate with a patient and you realise but they don't understand what hypertension, or diabetes is. You have to now know what the common garden name is and what patients perceive and understand by it.. I think that is a very good idea, and it has to start at medical school already".</i>
iii. Communication training and the medical curriculum
Dr 3: <i>"...the problem is there is obviously so much to try and fit into your medical curriculum in only so much time. It is probably something that we should routinely make sure our students can do. History taking is supposed to be part of their evaluation. And I think that is where communication emphasis should be placed".</i>

i. Learning an indigenous language

The doctors in this study found the basic language training in an indigenous South African language useful in basic communication with patients. They have however noted that the usefulness of the training was largely limited to interactions in the area of their training University. For example, Doctor 1 received his training in the province of Kwa-Zulu Natal and has therefore acquired basic isiZulu skills. Although isiZulu is the language spoken by the greatest number of people in South Africa, only a small group has isiZulu as first language in the Western Cape (Statistics South Africa, 2001).

In South Africa medical students are often expected to complete a course in an indigenous language as part of their undergraduate training. Such courses aim to enable students to develop some basic proficiency in the indigenous language spoken by most people in the geographic area of the medical school. For example, the medical schools

in the Western Cape require undergraduate medical students to complete courses in basic isiXhosa, as isiXhosa is the most commonly spoken indigenous language in the province (Statistics South Africa, 2001). Knowledge of the patient's language improves doctor-patient communication and also enables the doctor to understand the patient's culture in more depth (Ellis 1999, in De Villiers, 2000).

ii. Need for communication training

The quotation in the Table 3.4.6 illustrates the apparent difficulty that Doctor 3 experienced in interacting with patients regarding their illnesses after completing medical school. Billings-Gagliardi et al., (2001) pointed out that medical students often need to explain complex medical and scientific concepts to peers and educators during their training and examination. After graduation these students will be in the position of explaining similarly complex concepts to patients. Scott and Weiner (1984, in Billings-Gagliardi et al., 2001) report that students may in fact lose the ability to provide intelligible explanations to patients in the course of their medical training. Doctor 3 suggested that students receive communication skills training to sensitise them to the patients' lay perspective of disease and to appropriate communication with patients regarding medical concepts. A similar suggestion was made by Bourhis et al. (1989). The doctors and nurses who participated in Bourhis et al's (1989) survey have also indicated that communication skills courses for health professionals would be of great value. Similarly Schwartz (2004) reported an expressed need for education regarding communication, language and culture by the heads of medical departments of the hospital where the current data was collected.

iii. Communication training and the medical curriculum

It is not until recently that under- and postgraduate medical training started paying attention to students' communication skills (Maguire and Pitceathly, 2002). It is thus likely that the doctors who participated in this study have not received communication skills training as part of their formal medical education. The suggestion to include communication skills training in the undergraduate medical programme has to take the well known constraints of the medical curriculum into account, namely large volumes

of learning material and restricted time. Doctor 3 made the suggestion that communication skills training should receive attention throughout students' medical training, and that communication skills should be evaluated in the clinical training arena. The literature advises that three components of learning be included in all communication skills courses, namely cognitive input (such as written notes and/or lectures), modelling by experienced trainers and finally the practice of key skills (Maguire and Pitceathly, 2002). In addition to Doctor 3's suggestion to use history taking (information gathering) as an opportunity to teach and evaluate communication with patients, the task of information giving should also be included in training curricula (Dacre et al., 2004). It is also important that feedback from skilled and experienced trainers follow the practical component of communication courses, as feedback predicts more effective transfer of learned skills to real life situations (Dacre et al., 2004; Maguire and Pitceathly, 2002).

Doctor 3's suggestion to include communication skills in students' assessments is very valid considering the famous saying in medical education that 'assessment drives learning'. The inclusion of communication skills in students' examinations will provide students with the opportunity to "reflect on and enhance their own communication" (Dacre et al., 2004, p. 711).

3.4.7 Planned strategies and suggestions to address problems

At the time that the participants of this study were interviewed, the clinic staff was planning certain changes to the everyday administration of the clinic. These changes probably reflect the overall change in the nature of HIV/AIDS care in the current era of ARV provision in the South African public health care sector. The planned changes, as well as the problem(s) addressed by each strategy, are described in the doctors' words in the Table 3.4.7 below and are discussed thereafter.

Table 3.4.7: Planned strategies and suggestions to address problems

Problem addressed	Planned strategies and suggestions to address problems
Creates continuity, a feedback system and treatment of caregivers	<p style="text-align: center;">i. Team based family clinic.</p> <p>Dr 2: <i>"We looking at some stage, it's probably not quite possibly just yet, but is to develop a team. A team would be a doctor, a nurse, a counsellor, or two counsellors. Which would take responsibility for a family. You know, so for the child, the granny, the mother, the father...At least by that, by doing that, that sort of team approach we can say well this patient falls under my group. You know, so when they come I should see them and they should be seen by either one or two counsellors only. Not any counsellor who's free. Uhm, and that count I get to know the counsellor, they should get to know me. Such that they can feedback to me what I need to know and I can feedback to them what they ... so then it works well"</i>.</p>
Creates feedback system and control over counselling on ARVs	<p style="text-align: center;">ii. Development of a communication protocol</p> <p>Dr 2: <i>"...we are developing a form, a counselling form with a checklist of information they (the counsellors) should cover in the counselling session...and also a checklist for doctors to know what they should cover in their consultation. Which is more maybe more medically orientated but also counselling orientated. But the counselling thing is actually a specific checklist that is a counselling thing before testing for HIV and a counselling thing for treatment. Ja, they might well be covering those things but maybe not as formally. Not ticking them off formally...I am actually putting it together, you know with (name of Doctor 4), with... the social worker, with (name) who is going to be coordinating the counsellors I think and also the CAB which is a community advisory board which is a board consisting of community people who try and help us prioritise what we do...it is kind of getting there, but there are constraints"</i>.</p>
Immediately available professional counsellor for serious cases	<p style="text-align: center;">iii. Professional counsellor assigned to clinic</p> <p>Dr 1: <i>"I think it would be nice to have someone assigned to the clinic where you could refer, ... where counselling needs to be done"</i>.</p>

i. Team based family clinic

The doctors were planning to transform the clinic to a team based family clinic where a health care team would be assigned to provide continuous care to entire families. A team- and family based model would solve several of the problems the doctors have reported

and that have been mentioned earlier in this text. Firstly, continuity of care would be offered to caregivers and their families. Doctors would thus be able to develop a more long term relationship with the family, which predict positive outcomes in terms of communication effectiveness and patients' health (Wilson and Kaplan, 2000). Dr 2 expressed the following in this regard: "... *continuity would be ultimately the best thing... you have to see someone in the passage and say 'Hi, how are you doing?' and they gotta come to you and know that you are (first name of the doctor) and you are their doctor. And so that they can just say hi, you know and they can ask you what they want to ask you...*".

Furthermore the doctors' frustrations regarding treatment provision for the child without certainty about the availability of treatment for the caregiver(s), would also be addressed. A team-based model of service delivery would also allow the doctors and counsellors to form better working relationships and to provide each other with feedback regarding individual interactions with caregivers. It has been pointed out earlier that certain aspects of the doctors' current interactions with counsellor / interpreters suggests elements of a team approach. Examples are the doctors' appreciation of the counsellors' personal experience and insight into the caregivers' life world and disease status, as well as the doctors' realisation that the counsellors might be more suited to engage in certain interactions, such as counselling, with caregivers than the doctors themselves. The doctors and counsellors would thus probably work well as formalised teams, and will be able to take advantage of the opportunities that such an approach offers, for example case discussions before and/or after medical consultations or counselling sessions (Swartz,1998).

It is likely that the continuity of care offered by a team-based approach will improve the doctors' and counsellors' job satisfaction. Dr 1 has pointed out that continuity within counselling services "*would probably, certainly from a counsellor's point of view, make their work life, their work group more interesting. You can develop some sort of rapport*". A team based family clinic would thus be to the benefit of the doctors, counsellors and ultimately to the caregivers and their children.

ii. Development of a communication protocol

Although the doctors appreciated and recognised the important function and skill of the counsellors, a need was expressed for control over the topics and the outcomes of interactions between the various clinic staff members and caregivers. Doctor 2 was commissioned with the task to develop, in collaboration with various role players, a checklist of topics to be covered by counsellors during pre-test HIV counselling as well as counselling regarding ARV treatment. The counsellors would be expected to tick off on the checklist the topics which were discussed with the caregivers and also to provide feedback on the outcome of the discussion. A similar checklist was being developed for doctors regarding information required to be covered in consultations. The aim of the described checklists is thus to formally ensure that all important topics are discussed with caregivers and that feedback on the various discussions is available to all clinic staff members.

iii. Professional counsellor assigned to the clinic

Doctor 1 made the recommendation to have a professional counsellor permanently assigned to the clinic. The role of this professionally trained counsellor would be to perform counselling to caregivers with serious emotional or clinical psychological needs. This role is currently fulfilled by the hospital's social workers. The social workers' large caseloads often required that caregivers in need of their services be placed on a long waiting list. The high prevalence of psychological difficulties in patients with HIV makes access to mental health services a needed goal (Hughes et al., 2004; Freeman, 2004; Olley et al., 2003).

The themes that were identified as issues central to the experiences of caregivers, counsellors and doctors regarding communication in HIV/AIDS care will be discussed in the next section.

Important chapter

4. INTEGRATED DESCRIPTION OF THE NATURE OF COMMUNICATION IN THE CLINIC

Five themes were identified as issues central to the study participants' experiences of communication in the clinic, and are presented in Table 4.1 below. Each theme is described and discussed in the following section.

Table 4.1 Themes of the structural description of the study participants' experiences and perceptions of communication in the clinic.

4.1 Communication is more than words
4.2 Communication is shaped by context
4.3 Communication is collective
4.4 Communication as transactional process
4.5 Communication is powerful

4.1 Communication is more than words

The caregivers, counsellors and doctors were all aware that a conversational style accompanies words in clinical communication (Erzinger, 1991). All three categories of participants were aware that health care workers could use facilitative or inhibiting conversational styles when communicating with caregivers. Various characteristics of a facilitative conversational style were identified, namely:

- accommodations made by the doctor or counsellor to facilitate caregivers' understanding (examples of such accommodations were use of an appropriate level of language, visual materials and interpreters);
- listening and responding thoroughly to caregivers' questions and concerns;
- a display of sympathy, kindness and a desire to help.

More specifically a doctor facilitative conversational style was characterised as:

- showing concern beyond the biological and pure medical aspects of a child's disease;

- appreciation of the complexity of communication and an investment of time and effort in the process;
- incorporating personal values of compassion for the caregiver and child; and finally
- an attempt at overcoming the various differences between powerful doctors and often disempowered caregivers.

In contrast to the facilitative doctor communication style, the caregivers, counsellors as well as the doctors have described an inhibiting doctor conversational style. An inhibiting doctor conversational style was characterised as:

- unaccommodating in terms of the level of language used;
- providing insufficient explanations;
- serving the doctor's agenda and addressing only one aspect of the patient's disease; and
- domineering and insensitive, that is not allowing the caregiver to express concerns and needs or to participate in decision making.

It became clear that the style that has accompanied the doctor's words reflected his/her philosophy regarding the practice of medicine. A facilitative conversational style signalled a person-centred and biopsychosocial approach whereas an inhibiting style reflected a bio-medical orientation. A facilitative conversational style seemed to have allowed doctors to achieve certain aspects of the patient centred method, namely:

- to learn about the patient's illness experience, including ideas, fears, expectations and the impact of the disease on the patient's life;
- to gain a holistic understanding of the patient;
- to establish a therapeutic doctor-patient relationship that includes respect, caring and concern, empathy and more equal power relations (De Villiers, 2000; Steward et al., 1995, in Aita et al., 2005).

An inhibiting conversational style seemed to display values associated with the bio-medical model, where the doctor's focus is the biological aspects of a patient's disease, with no consideration for the psychological and social dimensions of the illness experience. An inhibiting doctor conversational style reflected the following characteristics of the biomedical model:

- little value is attached to the patient's verbal account of his/her experience with greater reliance on objective technical and laboratory methods;
- disease is fully accounted for by biological pathology. The psychological, social and behavioural dimensions of disease therefore falls outside of the realms of the bio-medical paradigm (Engel, 1977; 1980);
- doctors are experts who make decisions on behalf of and in the best interest of their patients (De Villiers, 2000).

This study confirms Aita et al.'s (2005, p.3) finding that the "infinite variety of personality types, values, beliefs, (and) clinical interests...among physicians" plays an important role in the type of interaction between doctor and patient. Whilst patient-centred models recognise the unlimited differences amongst patients the variety amongst health care workers is often not appreciated (Aita et al., 2005). A bio-medical approach does not necessarily equate unsatisfactory doctor-patient communication or relationships. Aita et al. (2005) found that long term relationships were formed between bio-medically centred doctors and their patients, and that patients were loyal to these doctors. However, in this study the participants' description of a facilitative doctor conversational style reflected a holistic view of the patient and compassion for their welfare.

4.2 Communication is shaped by context

The participants' stories have made it clear that not only conversational style, but also the context of clinical interactions influenced communication in the clinic. When one asks the question of whether the same themes would have emerged if a different disease and setting was involved (Penn, C., 2005, pers. comm., 1 July) the answer would be 'No'. The manner in which the disease entity as well as the characteristics of the health care

setting influenced the communication between caregivers, counsellors and doctors will now be discussed.

4.2.1 Influence of disease entity on communication

Stigma

The stigma associated with HIV/AIDS affected the participants' experiences and perceptions of communication. First of all, the caregivers' preference for the clinic over health care facilities closer to their homes might be related to the anonymity further away from home. Caregivers and counsellors have indicated the importance of confidentiality in HIV related-communication, by expressing preference for formal interpreters as opposed to *ad hoc* interpreters and especially family members. Stigma and associated fears about physical injury, isolation, loneliness and/or abandonment by the family and community have been reported to motivate women to keep their HIV status secret (United Nations, 1995, in Tlou 2002; Duffy, 2005).

Doctors were also aware of the stigma that HIV carries and have reported attempts to overcome the stigma barrier. The fact that doctors did not discriminate against caregivers based on their HIV status possibly also shaped the caregivers' positive experiences of communication and health care at the clinic. However, it was argued that internalised oppression, stemming from HIV stigma in the broader community, may have been responsible for caregivers' lack of attempts at communication repair in situations of misunderstanding during interactions with doctors or counsellors.

Historical context of treatment provision

The historical time period in the treatment of HIV/AIDS in South Africa also influenced communication between caregivers, counsellors and doctors. This study was conducted early in the year following the national government's announcement of a HIV/AIDS treatment programme, after the effectiveness of HAART has been reported since 1996 (Siegel and Lekas, 2002). Doctors' felt that their potential to affect their patients' well being was being restored and they experienced a lift of morale. Very importantly the doctors reported that the era of ARV roll out created a positive start for doctor-caregiver

interactions and relationships to build on. However, the treatment was still largely directed at the child patients and did not include HIV positive parents.

Infected mothers

The fact that HIV is commonly transmitted from mother to child was thus another disease specific characteristic that influenced communication in the paediatric health care sector. Doctors felt frustration at not being able to provide the mothers with treatment, which possibly caused discomfort during doctor-caregiver interactions. The counsellors had experiences of being more successful in counselling than doctors. The counsellors perceived the doctor's apparent disproportionate concern for the mother compared to concern for the child, as one of the contributing reasons.

Emotional content of communication

Like all individuals suffering from HIV/AIDS the caregivers were at risk for mental health difficulties such as depressed mood (Freeman, 2004; Hughes et al., 2004; Olley et al., 2003; Siegel and Lekas, 2002; Schrooten et al., 2001). The caregivers' emotional experiences influenced communication in the clinic. The counsellors have reported that caregivers occasionally experienced emotional reactions in interactions with doctors and/or counsellors, without anticipation of such reactions by the clinic staff. The counsellors and doctors thus had to develop strategies to manage the emotional reactions of caregivers. They also had to learn to remain sensitive to the caregivers' psychological vulnerability and to the possible influence of communication on the caregivers' emotional well being. The counsellors reported to be affected by the emotional nature of their communication with caregivers, as they were often responsible for breaking bad news to caregivers. The counsellors experienced weekly supervision and support sessions to be very helpful in managing the stress involved with HIV communication. The doctors did not comment on the emotional consequences of working with HIV positive mothers and children. There were also no structures within the hospital to offer support to doctors regarding the potential negative psychological consequences of their work environment.

Disease complexity and high information requirements

The communication of HIV/AIDS-related information to caregivers was problematic for doctors and counsellors. Explanations of the nature and management of the disease contained complex concepts and large amounts of information. Doctors felt that the caregivers' limited understanding and knowledge of HIV related concepts complicated communication. The caregivers' limited educational background seemed to have played a role in their poor understanding of disease concepts. Furthermore, as in all medical communication the doctors' use of specialised terminology complicated communication in the clinic. The caregivers and counsellors have reported difficulties in understanding the doctors' medical language.

4.2.2 Influence of the health care setting on communication

Demographic characteristics

The demographic characteristics of the clinic regarding the race and culture of caregivers and doctors also formed part of the communication context. A great divide regarding language and culture existed between the majority of doctors and patients at the clinic. However, it is argued that the homogeneity of the caregivers' culture and the doctors' subsequent continued exposure to this culture had a favourable effect on communication. It has been acknowledged that optimal intercultural assistance is dependant on a doctor's general communication skills as well as substantial knowledge of the patient's culture, and that knowledge of a patient's culture is obtained through experience (Shadid, 1993). The caregivers' report of an overall positive experience of communication with doctors suggests effective intercultural communication, which is associated with cultural sensitivity (Ulrey and Amason, 2001). Although increased exposure to a culture doesn't necessarily lead to increased understanding (Tannen, 1985), the argument can be made that the doctors obtained knowledge of the caregivers' culture through continuous exposure and experience, and that they have been able to translate this knowledge into effective and sensitive communication with the caregivers. However, the caregivers and counsellors did report differences in the doctors' and caregivers' perception of HIV/AIDS. The doctors have also experienced and were frustrated by cultural barriers in communication with caregivers. However, the doctors' awareness of cultural differences

as well as their expressed willingness to overcome such differences indicates sensitivity and potential for effective intercultural communication.

Clinic organisation

The clinic's organisation has influenced communication in a number of ways. First of all the availability of counsellors for pre- and post test counselling as well as follow up counselling has made repetition of important information, such as ARV drug use, possible. Secondly, the counsellors' interpreting function made it possible for doctors and/or caregivers to request an interpreter's help in interactions where the linguistic gap between doctor and caregiver was especially problematic. A lack of formal interpreters, as well as underutilisation of interpreters in the hospital has been documented recently by Schwartz (2004) and Levin (2004). The clinic is thus qualitatively different from the rest of the hospital in that five individuals are available to explain information to caregivers during counselling or interpreting sessions or both. The clinic organisation thus seems to prioritise communication in terms of the personnel resources available. However, the caregivers have commented that interpreters were not always available at the clinic. This is probably due to time and number constraints related to the counsellors demanding dual role and the large proportion of patients who do not speak the doctors' languages, English or Afrikaans. Although the clinic's situation regarding interpreting and counselling might thus be more favourable than in other parts of the hospital, sufficient resources to provide sustained effective communication are lacking.

Despite the facilitative effect of the counselling and interpreting services available at the clinic, there are two organisational factors that have an inhibiting effect on communication. The first is the discontinuity of care, whereby a caregiver is not assigned to a specific health care worker for continuous treatment, but may see a different doctor and even counsellor every time she visits the clinic. The counsellors as well as the doctors were concerned about the effect of discontinuity of care on relationships with and the quality and ethical standard of care for caregivers. Discontinuity of care at the clinic has been perceived to affect communication and work satisfaction negatively.

Secondly the doctors have reported that the pressure of time and large patient loads often lead to compromised health care standards, especially in preparing patients for life long ARV treatment, or providing services to caregivers with mental health difficulties. It is clear that resources such as time and personnel are insufficient to manage the diverse needs of this large patient load and to meet the demands for effective HIV/AIDS care. An insight that has emerged from this study is that effective intercultural communication in the HIV/AIDS context is resource dependant and extensive.

Doctor-Counsellor working relationship

The relationships between doctors and counsellors affected communication amongst themselves as well as communication with caregivers. The doctor-interpreter relationship was largely positive and predicted effective interpreted consultations. The working relationship that developed between doctors and interpreters as well as the interpreters' personal and working experience in the HIV/AIDS field has lead the doctors to trust and to relinquish power to them. An image of an interpreting model of partnership emerged, where the interpreter acted as cultural and emotional broker to the doctor. An interpreting model of partnership is considered as ideal for effective communication within the triad and allows the caregiver to benefit from the specialised knowledge of doctor and interpreter (Westermeyer, 1990 in Wood, 1993). A doctor-interpreter partnership has enabled interpreters to address the most frequent problem they have encountered in interpreted consultations, namely medical terminology.

The relationship between doctors and counsellors was more troublesome. Although the doctors viewed the counsellors as competent to perform HIV test counselling they were worried about their ability to provide appropriate counselling regarding ARV medications. The doctors also had a sense of insecurity about the counselling practices as they received no formal feedback from counsellors. However, the clinic organisation does not accommodate doctor-counsellor feedback, as no formal feedback structures exist. A paradox is evident between the roles of interpreter and counsellor. Whereas interpreters are successful brokers between doctors and caregivers, the counsellors are not. The difference and therefore the intervention seem to be located in the clinic

organisation. Whereas interaction occurs naturally between doctors and interpreters during interpreted consultations, no organisational structure exists to facilitate doctor-counsellor interaction.

This study thus reflects the growing recognition that not only doctor and patient characteristics, but also contextual factors influence doctor-patient communication, including the cultural context (Kelly and Brown, 2002); practice organisation (Aita et al., 2005; Brown et al., 2002) and working relationships (Crabtree et al., 2001).

4.3 Communication is collective

Time pressures and cultural and linguistic barriers have developed separate and overlapping communication roles for doctors and counsellors. Doctors viewed counselling as an important part of comprehensive HIV care and as part of their responsibilities. However, they felt that the nature of the clinic as well as the relative background and training of doctors and counsellors made the counsellors the most appropriate candidates for the HIV test counselling function. Counselling regarding ARV medicine was not solely entrusted in the hands of the counsellors, but was performed by both the doctors and counsellors in their separate interactions with caregivers. The critical importance of caregivers' understanding regarding ARV treatment as well as the counsellors' limited training regarding medical AIDS treatment, prevented the doctors from completely entrusting treatment related counselling to the counsellors. However, the doctors did have an appreciation for the potential power of the counsellors' intimate knowledge of HIV and ARVs based on their personal experiences as women living with HIV/AIDS. The counsellors were also better able to determine the caregivers' comprehension of HIV related concepts. Furthermore the doctors as well as the counsellors reported that the caregivers seemed more comfortable and forthcoming in discussing HIV specific issues with counsellors as opposed to doctors. One reason might be the closeness that the caregivers felt to the counsellors, who were HIV positive women themselves.

Doctors' and counsellors' communication with caregivers also necessarily overlapped during interpreted consultations. However, time pressure often necessitated the counsellors to counsel caregivers on information shared by the doctors, after the medical consultations have ended. Counsellors were also occasionally required to discuss some of the information shared by doctors with caregivers after medical consultations which they did not attend. The overlap in the communication roles of the doctors and counsellors seems like an effective way to ensure that caregivers receive and comprehend necessary information. A potential weakness in this system is the counsellors' limited training background in medical issues. Again it seems that communication between doctors and counsellors is crucial in optimising communication in the larger clinic.

4.4 Communication as transactional process

Transactional communication implies that individuals in an interaction affect and are affected by each other (Wilmot, 1979, in Northouse and Northouse, 1992). A transactional view of communication looks at the relationships that develop and are maintained between individuals through their reciprocal influence on one another (Northouse and Northouse, 1992).

The participants' stories have highlighted the transactional nature of communication in the HIV care context. Transactional communication was specifically clear between doctor and caregiver. The caregivers have described two distinct doctor conversational styles that have been referred to as either facilitating or inhibiting to effective communication, and which were associated with the patient-centred and bio-medical clinical methods respectively. Patient-centred doctors were sensitive to the language needs, difficult life circumstances and health care expectations of the caregivers. This lead to a facilitative conversational style that accommodated the caregivers needs and attempted to balance the significant power difference between doctors and caregivers in this specific context. When caregiver misunderstanding occurred in patient-centred communication the caregivers attempted repair strategies. The caregiver communication repair strategies in turn gave the doctor the opportunity to rectify the communication

breakdown. Rather than preventing misunderstanding, patient centred communication seems to encourage communication repair.

The adverse was true for paternalistic doctor dominated communication. Bio-medically orientated doctors focussed on the patient's disease and did not allow caregivers to express their concerns or to obtain sufficient explanations. Caregivers often misunderstood such doctors' messages but did not attempt to repair the conversation. A domineering doctor style associated with a bio-medical interest thus lead to submissive caregiver communication behaviour.

4.5 Communication is powerful

Communication in the HIV health care sector had the power to affect the lives of caregivers, counsellors and doctors. A doctor facilitative conversational style lead to caregiver satisfaction. The caregivers felt comforted and cared for and had the perception that the doctors had sympathy for them and wanted to help, even beyond pure medical matters. However, the caregivers frequently had difficulty understanding the doctor, and the misunderstanding was often due to words or concepts unfamiliar to the caregivers. Misunderstanding the doctor caused the caregivers unhappiness and anxiety. An inhibiting doctor conversational style disempowered caregivers and demotivated them to continue the relationship with the health care facility. This finding illustrates the power of doctor-caregiver communication to affect not only patient morale, but also health outcomes, as regular follow-up is crucial in the effective management of chronic disorders such as HIV/AIDS.

The emotional stress of being HIV positive and/or caring for a child with HIV made the caregivers vulnerable to the style and content of communication with doctors and counsellors. Counsellors reported anxiety and emotional upset or depression among caregivers in anticipation of or in response to HIV test results. Caregivers were in some cases perceived as unprepared for and avoidant of the counsellors' message. An unwillingness to discuss a positive test result was also observed. Similarly the caregivers were reported to have emotional reactions during interpreted consultations, sometimes

without the counsellor's or doctor's anticipation of such a response. The content or style of the message might not always be the sole reason for a caregiver's emotional reaction. The caregivers have to deal with very complex issues and various aspects of interpersonal interaction may remind a caregiver of her difficulties and therefore spark an emotional reaction.

Daily communication with emotional caregivers coupled with the anguish of an HIV positive diagnosis created a situation of psychological stress for the counsellors. Although the counsellors admitted to difficult communication situations and emotional experiences they gained strength from participating in weekly meetings of a professional support group. The need and benefit of formal support structures for health care workers in the HIV/AIDS field became apparent throughout this study.

The doctors were also affected by the communication with caregivers. The doctors have described the communication difficulties related to the differences in culture, language and knowledge between themselves and the caregivers. Difficult communication was a source of frustration for the doctors as they felt that it affected their potential to optimally assist the caregivers. On the other hand communication with caregivers enabled doctors to overcome many of the difficulties associated with HIV care in resource limited settings. A facilitative doctor conversational style has enabled doctors to form relationships with caregivers and to overcome the differences between them. Communication was also described as making the doctors work life interesting and satisfying.

A paradox seemed to exist in the doctors' work life. The public health sector in which they were working had limited resources available for effective treatment of HIV/AIDS, including time, personnel and perhaps most importantly ARV drugs for child patients and their families. They felt that their technical proficiency and potential to bring about biological change was severely impaired, compared to colleagues in the private sector and in wealthier nations. Yet, the doctors recognised and addressed the psychological and social aspects of the disease. It was mainly through patient-centred and affective

communication behaviours that doctors were able to affect the caregivers' lives in these areas. The doctors have experienced the caregivers' satisfaction with care through communication, which has in turn gave them a sense of work satisfaction and power to affect their patient's lives for the better.

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5. CONCLUSION

Communication in the clinic meant sharing meaning across differences. The language and cultural divide between caregivers and doctors could be successfully bridged by a doctor facilitative conversational style and the participation of counsellors in communication. Effective communication was dependent on systemic support and infrastructure. Five central themes emerged that described the nature of communication between caregivers, counsellors and/or doctors the clinic. These themes crystallised from thick descriptions of the various categories of participants' experiences of communication in the HIV/AIDS care setting.

Communication between health care workers and caregivers involved more than the words they have spoken. All the participants were aware that a certain conversational style accompanied health care workers' communication with caregivers. Doctors' conversational styles seemed to be related to their philosophy of medicine and personal value systems. Communication in the clinic was shaped by the context created by the characteristics of HIV/AIDS as disease entity as well as the demographic and organisational characteristics of the clinic and the nature of working relationships amongst staff members. HIV/AIDS specific factors that influenced communication were related to stigma, treatment issues as well as emotional and informational demands and complexities. Time and number pressures as well as cultural and linguistic factors lead to the development of separate and overlapping communication roles for doctors and counsellors. Responsibility for the communication of the emotional and informational content of HIV/AIDS care was shared between the doctors and counsellors. Communication with caregivers was thus a collective effort. Communication in the clinic was transactional. Caregivers, counsellors and doctors affected one another's communication behaviour with their own. The conversational style adopted by doctors was especially powerful to influence the caregivers' assertiveness during clinical interactions. It was evident that communication in HIV/AIDS care had the power to affect the lives caregivers, counsellors and doctors. Communication was central to the care offered to caregivers in a time of limited traditional medical treatment resources. The

challenge will be to remain communication centred and sensitive when traditional medical resources become available.

6. RECOMMENDATIONS

6.1 Practice organisation and broader health care context

The clinic's planned strategies to address the systemic difficulties are highly commended. Plans for a team based family clinic and development of a communication protocol for counsellors and doctors have the potential to address the problem of discontinuity of care successfully and to improve and assure the quality of counselling. Furthermore, the finding that communication is resource dependant and extensive indicates the need for sufficient allocation of personnel and time, especially in contexts with high communicative demands such as HIV/AIDS. Resource allocation would have to be addressed at the national, provincial and institutional levels of health care.

However, the doctors' problem of counsellors who did not provide them with sufficient feedback when requested, might not be fully addressed by the implementation of a team based model. It might be possible that the counsellors, due to their language and educational status, perceive themselves as powerless relative to the professionally trained health care personnel working in the clinic. It might thus be unreasonable to expect individuals who feel disempowered themselves, to act as advocates for others (namely the caregivers). An appropriate intervention for this problem would thus probably have to start with the empowerment of the counsellors through ongoing training opportunities and integration into a team of health care professionals.

6.2 Support

HIV/AIDS places patients and health care workers at risk for psychological difficulty and necessitates formal support structures for caregivers, counsellors and doctors. Again, the recommendation from one of the doctor participants is embraced, namely integration of mental health professionals in the clinic's health care team. HIV health care facilities should offer comprehensive and multidisciplinary care that includes attention to the

mental health problems of HIV positive caregivers and children (Freeman, 2004; Hughes et al., 2004). Depression may affect caregivers' ability to care for themselves and their children (Catalan, 1999 in Freeman, 2004). Children of HIV infected caregivers are also at risk of mental health problems (Wild, 2001 in Freeman, 2004). Furthermore, additional stress is placed on children who have to care for ill parents (Barnard, 2003 in Freeman, 2004).

A need for support of all individuals working with HIV patients exists since the work environment poses a risk for burn out and mental health difficulties (Ross and Deverell, 2004; Battegay et al., 1991). At the clinic only the counsellors received emotional support and have perceived this service as highly beneficial to their well being. It is recommended that doctors are offered access to a similar but separate support service. Doctors should be allowed to reflect on their experiences of difficult cases and emotions under the supervision of an external professional (Battegay et al., 1991).

6.3 Education of counsellors and doctors

Support services for counsellors and doctors should include continuous education. The recommendations regarding ongoing education for counsellors will be discussed first.

Since the NGO trained counsellors deliver interpreting services on an ongoing basis at the clinic, it is recommended their training is expanded to include the specialised knowledge, skills and attitudes related to the interpreting function. Although the caregivers and doctors were satisfied with the counsellors' interpreting function, research indicates that the quality of communication is negatively affected when interpreters are untrained (Fisch, 2001). Interpreting training should also address the counsellors' limited knowledge of medical terminology. Increasing knowledge regarding of the formal and informal field specific terminology in both languages, is a recognised goal of interpreting training programmes (Corsellis, 1999). Smit (1999) cites various authors who have concluded that interpreters' knowledge of medical terminology creates a common frame of reference which promotes clear and unambiguous communication between health care provider and patient.

The challenge for medical training in South Africa is to maintain and strengthen the excellence of doctors' bio-medical skills, while assuring that training and practicing doctors are sensitive to the psychological and social aspects of disease and the influence of culture on these aspects. This challenge can be met when systems theory and the biopsychosocial medical model are used as frameworks for teaching (Engel, 1977; 1980). Doctors should also be equipped to function in a culturally diverse country with the necessary sensitivity and adaptability. Several more specific recommendations for the training of doctors regarding effective communication with patients in general and in the HIV sector specifically can be made. These training recommendations require communication skills training at undergraduate and post graduate level, including continued medical education.

First of all doctors need to be sensitized regarding the differences between the specialised and exclusive medical language register and the everyday language register they share with patients. It is recommended that doctors only use essential and relevant terminology, as patients' informational needs often include the need for such terms, for example the medical term for the disease entity (Billings-Gagliardi et al., 2001). Even then, the terminology should be accompanied by explanations in an everyday language (Steenkamp, 2004). Furthermore, doctors should learn to incorporate clarification and feedback processes in their communication with patients, in order to identify and resolve any misunderstandings. Feedback processes are especially important in disempowered patient populations where internalised oppression may prevent patients from participating in interactions to fulfil their informational needs. Doctors can also encourage patients to ask questions and to request repetition where necessary (Levin, 2004). Doctors should also clarify the patient's use of terminology (Levin, 2004; Blitz, 2000), as patients often attempt communication with doctors in medical language in an attempt at effective communication and integration with the powerful health care provider (Bourhis et al., 1989). However, the meaning that doctors and patients attach to medical terms often differ (Blitz, 2000).

Secondly, communication skills training should sensitise doctors to the transactional nature of communication. Doctors should be aware of the conversational style and underlying values that accompany their words, as well as the effect thereof on the patient's communication behaviour, health outcomes and psychological well being. Thirdly, the multilingualism and prevalence of interpreted consultations in the South African health care contexts necessitate that all doctors working in the public sector are trained in effective communication through interpreters.

Fourthly, disclosing an HIV positive test result is a delicate task that requires training (Schrooten, 2001). South Africa's status as world leader in terms of numbers of HIV infected individuals requires that doctors are trained in performing HIV test counselling (Bekker, 2002). The psychological implications faced by patients when communication missteps occur in disclosing HIV test results certainly warrant attention to counselling skills in medical curricula.

Fifthly, communication training should work from the definition of communicative competence as encompassing both linguistic and cultural competence (Kaschula and Anthonissen, 1995). Doctors should thus not only be required to possess certain general qualities within every interaction situation, but should demonstrate substantial knowledge of the patient's culture in order to provide optimal assistance. Such cultural knowledge should be based on general outlines of patients' cultures rather than restrictive and stereotypical lists with information and practical hints on communication with the particular cultural group (Shadid, 1993). Adding to the student's knowledge of the patient's culture should be the objective of obtaining an acceptable standard of proficiency in the patient's first language (Levin, 2004).

Finally, medical education should highlight the broader institutional and contextual influences on doctor-patient interactions. Only when the broader contextual influences on communication are recognised, students will be able to identify and manage such factors that influence their communicative interactions with patients (Aita et al., 2005).

Should these recommendations be implemented by training institutions, their effectiveness will be partly dependant on the organisation of the broader health care context in which students will be expected to work after graduation. In South Africa medical, as well as allied health profession students are required to complete a year's community service before they are allowed to register with the Health Professions Council of South Africa (HPCSA) and practice independently as professionals. The decision regarding the placement of students in communities is determined by balancing the students' expressed preferences regarding areas of placement with the availability of and need to fill community service posts. Students thus often receive community service placements in rural areas outside of their province of training. In these rural areas patients are less likely to be fluent in English or Afrikaans, and students may not necessarily have had exposure to the indigenous language of the area. It seems that greater consideration of the language background and training of the students needs to be taken when decisions regarding community placements are made. The resources spend in the training of medical students regarding indigenous languages might be wasted if students are expected to work in areas unfamiliar to the indigenous language in the area of their training institution.

Furthermore there might be an argument to examine the feasibility of harmonisation of Nguni languages (Xhosa, Zulu, Ndebele, Swati) and the Sotho-Tswana languages (Northern Sotho, Southern Sotho and Tswana) respectively into a single written standard, for use within the South African public health care sector. Harmonisation has frequently been suggested, notably by Neville Alexander, due to the potential regarding education and literacy (Herbert and Bailey, 2002). However, harmonisation has never been considered a popular suggestion, due to threats of loss of 'traditional' ethnic identities and the symbolic value of the indigenous languages (Mesthrie, 2002). Several difficulties are however described in "crafting and promoting a standard that is 'no one's mother tongue' in the language planning literature" (Herbert and Bailey, 2002, p. 68). Language training of health care professionals in South Africa is an area offering great research potential.

7. RECOMMENDATIONS FOR FURTHER RESEARCH

The current study was limited to self-reports by caregivers, counsellors and doctors of their experiences and perceptions of communication. However, the study forms part of a larger research project that includes observational data of the actual communication behaviours of participants. Triangulation of qualitative data sources would thus be possible if all of the qualitative data collected within then bigger research project was viewed together (Patton, 2002). A natural next step for the larger project would thus be to compare the conversation analyses of the interactions between doctors and caregivers (Garcia, 2004), doctors, interpreters and caregivers (Steenkamp, 2004) and counsellors and caregivers (Rust, 2005) with the findings of the current study. Schwartz's (2004) study on the communication practices within the larger hospital can form the context against which the integrated results are interpreted.

Various possibilities for further research in the field of HIV health care communication exist. For example, studies on communication between doctors and HIV infected children from various age groups might be particularly relevant. Especially considering the provision in the health policies, acts and bills that allows children as old as 12 years autonomy over health related decisions. Furthermore the study may be repeated in different health care contexts and under different disease conditions.

Culture determines the qualities that patients desire regarding the conversational style of doctors (Erzinger, 1991). Research on the views of the various South African cultural groups regarding facilitative communication behaviour by health care professionals is lacking. Research results in this regard may have important implications for medical curricula and health care practices. Another recommendation for future research on health care processes and outcomes was made by Crabtree et al (2001). These authors recommend that health care practices act as collaborators in research efforts. For example, the current study may be repeated in a year's time after the clinic's planned strategies as well as the researcher's recommendations have been implemented. Participants' experiences and perceptions of the effectiveness of the new structures and

strategies can be determined and they can participate in designing any further needed adaptations.

8. STRENGTHS

The study was one of the first on communication in HIV/AIDS care in South Africa and one of the few on communication in the multilingual and multicultural South African health care context. The study thus contributes to a much needed locally relevant body of knowledge regarding interaction in the health care sector. The experiences of three separate groups of participants were sought regarding the phenomenon of communication in HIV/AIDS care. The description of communication from the multiple perspectives of caregivers, counsellors and doctors served as a form of triangulation of qualitative data sources (Patton, 2002) and strengthened the findings of the study. The study also accomplished what is rarely observed in communication research, namely investigating both inter-cultural and doctor-patient communication (Ulrey and Amason, 2001). Similar to Kelly and Brown (2002) the current study sought to learn about intercultural communication in health care settings from health care professionals working permanently in the field. This study also aimed to give a voice to isiXhosa speaking caregivers faced by HIV/AIDS stigma, gender inequality and poverty. These caregivers were interviewed in their first language to assure that their stories were not restricted by the same language barrier that affects their communication with the health care system. The caregivers were also more likely to comfortably and honestly relate their communication experiences to an interviewer sharing their cultural and linguistic background.

9. LIMITATIONS

The formerly mentioned strength also resulted in one of the study's limitations. The transcripts and translations of the isiXhosa interviews revealed that the isiXhosa interviewer has at times restricted the participants' responses with interruptions, closed ended questions or failure to explore issues of importance in sufficient depth. Unfortunately these limitations became apparent only after the lengthy and expensive process of transcription and translation of the isiXhosa data. The translated transcripts

also revealed incomplete biographical information on the participants. A recommendation for future research would be to extend data collection over a sufficient period of time and to transcribe and translate data as a process parallel rather than subsequent to data collection. This will insure that limitations in data collection by field workers can be identified and rectified early on in the process. Data from patient folders would also have been beneficial in this study, as missing data could have been accounted for in this manner.

The researcher's passive role in the interview process of English participants might be regarded as a limitation. However, review of the audio and video recordings of the interviews as well as the process of interview transcription has allowed the researcher to become immersed in the data. The researcher could also learn from the expertise and skill of the experienced interviewers. The researcher feels confident that her credibility as qualitative researcher has expanded sufficiently during this study, so that she will be able to independently perform high quality semi-structured interviewing in future research projects.

The restricted time period that the research team was allowed in the setting may also be seen as a limitation. However, the need for research on communication in public health care in South Africa and HIV/AIDS care in particular should urge researchers to become involved in the field, despite structural limitations such as time. The contributions of continued research in this field will lead to better understanding of communication issues central to the delivery of good quality health care.

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University of Cape Town

APPENDIX A:

Examples of consent forms to:

Caregivers,

Counsellors, and

Doctors

University of Cape Town

RESEARCH: COMMUNICATION IN HEALTH
CONSENT FORM FOR CAREGIVERS OF PATIENTS / PATIENTS

Hello. My name is _____,

We are conducting a study on communication in health in South Africa. The purpose of the research is to examine and document in more detail health communication issues around the management of HIV/AIDS patients with the intention of moving towards effective communication in health, which in turn will lead to more effective health care. We are interested in the way that communication occurs between doctors and their patients and we invite you to take part in the study.

We would like to videotape a medical interview with the health professional and / or counsellor. Following this, with your permission, we would like to conduct an interview with you, so as to find out how you experience communication between yourself and the doctor / counsellor. This interview will take approximately 15 minutes of your time.

All information including the videotaped material will remain confidential throughout the duration of the study. All videotapes will be destroyed at the end of the study. None of the participants in this study will be identified in any way, in any reports or publications resulting from this research. We will ask you some questions about the communication you had when you were seen by the doctor / counsellor. This information will be confidential and will not change your treatment in any way.

We hope that the results of this study will help develop some useful materials and guidelines for health professionals working cross-culturally in South Africa. You have the right to decline to participate and the right to withdraw from the study at any time without providing reason.

Thank you

I, _____ consent to participate in this research, which will be recorded. I have read, understood and acknowledged the contents of this consent form. I agree that my response may be used in a report, but understand that there will be nothing to identify me personally.

Signed: _____

Witness: _____

Date: _____

**RESEARCH: COMMUNICATION IN HEALTH
CONSENT FORM FOR HEALTH PROFESSIONALS**

Hello. My name is _____

We are conducting a study on communication in health in South Africa. The purpose of the research is to examine and document in more detail health communication issues around the management of HIV/AIDS patients with the intention of moving towards effective communication in health, which in turn will lead to more effective health care. We are interested in the way that communication occurs between doctors and their patients and we invite you to take part in the study.

We would like to videotape a medical interview with a patient and yourself. Following this, with your permission, we would like to conduct an interview with you, so as to find out how you experience communication between yourself and your patients in general and more specifically to this morning's consultations. This interview will take approximately 15 minutes of your time.

All information including the videotaped material will remain confidential throughout the duration of the study. All videotapes will be destroyed at the end of the study. None of the participants in this study will be identified in any way, in any reports or publications resulting from this research.

We hope that the results of this study will help develop some useful materials and guidelines for health professionals working cross-culturally in South Africa.

You have the right to decline to participate and the right to withdraw from the study at any time without providing reasons.

Thank you

I, _____ consent to participate in this research, which will be recorded. I have read, understood and acknowledged the contents of this consent form. I agree that my response may be used in a report, but understand that there will be nothing to identify me personally.

Signed: _____

Witness: _____

Date: _____

APPENDIX B

Examples of interview guide for

Caregivers,

Counsellors, and

Doctors

University of Cape Town

TOPIC GUIDED POST INTERVIEW
TOPICS FOR DISCUSSION WITH PATIENTS

BACKGROUND:

Our area of interest and focus of research is on issues relating to communication in health. Most of the patients attending Red Cross Hospital are not English or Afrikaans speaking. However most of the doctors are English or Afrikaans speaking. Today I would like to talk about this and get your ideas and opinions to help us to learn what are some of the "good" and "bad" things that doctors, counsellors and interpreters do when communicating with you in the health setting. Then we can use this information to help inform and train health professionals to communicate better with patients, which in turn will allow for more effective health care.

Consent form and explanation that any information shared during this interview is confidential and will not be shared with the health professional and therefore will not have affect their treatment in any way.

First please can you give me the following information which is important for the research

BIOGRAPHICAL INFORMATION:

Age:

Sex:

Urban/Rural:

Residential Area:

Level of Education:

How long have you been coming to this clinic?

GENERAL PERCEPTIONS REGARDING COMMUNICATION IN HEALTH

Lets talk about this in general and then we can speak about this more specifically relating to your medical interview this morning.

Possible leading questions:

Can you tell me about how you have experienced receiving health services in the past from medical doctors that do not share your same first language?

How has it made you feel?

Have you always understood what they are asking or telling you?

Have you been able to convey your message properly?

Do you think they understand you?

In the interview this morning:

Did you experience any difficulties in understanding or conveying your message with the medical doctor?

Can you explain the difficulties you had?

Was there any time you felt the medical doctor did not understand you or you did not understand him/her

In your counselling session, whereby the counsellor is isiXhosa speaking:

How did you find this session?

Even though you and the counsellor are both isiXhosa speaking, did you have any difficulties understanding or sharing information with the counsellor?

FACILITATORS AND INHIBITORS:

Even though some medical doctors cannot speak isiXhosa, do you feel some doctors are better at trying to communicate with you than others? Please can you think and tell me what makes one doctor better than another at communicating and relating to the patient?

There are different counsellors

In your opinion what makes one counsellor better than another?

Sometimes you might have had an interpreter or translator with you in the medical consultation.

Can you tell me if there is anything that some interpreters do that makes it much easier and more comfortable for you in this sort of interview? Or

Is there something that the interpreter does that makes you feel uncomfortable or does not help you to understand?

LANGUAGE AND CULTURAL FACTORS

IsiXhosa and English do not always have one-to-one word equivalents- especially with medical terms there may not be a direct isiXhosa translation. Can we talk about this and how it has affected your understanding of HIV/AIDS regarding the illness itself and treatment?

Doctors and patients, as well as people from different communities and cultures may view illnesses in different ways. Lets talk about how the doctor and yourself being from different cultures may not share the same understanding of the illness and the implications it has for you.

EXPECTATIONS

What expectations did you have when coming here this morning?

Were these expectations met?

If not, why/ how?

SUGGESTIONS

How could we have made communication easier for yourself this morning, e.g. use of pamphlets, having a family member with you, a nursing sister who can speak the same language etc

Any other broader suggestions?

TOPIC GUIDED POST INTERVIEW

TOPICS FOR DISCUSSION WITH COUSSELLORS

BACKGROUND:

Our area of interest and focus of research is on issues relating to communication in health. Most of the patients attending Red Cross Hospital are not English or Afrikaans speaking. However most of the doctors are English or Afrikaans speaking. Today I would like to talk about this as well as the difficulties you as a counsellor may experience in counselling patients with HIV/AIDS. Your ideas and opinions will help us to learn what are some of the facilitators and inhibitors regarding communication in health. Then we can use this information to help inform and train health professionals and counsellors to communicate better with patients, which in turn will allow for more effective health care.

Consent form and explanation that any information shared during this interview is confidential and will not be shared with other health professionals or patients.

First please can you give me the following information which is important for the research

BIOGRAPHICAL INFORMATION:

Age:

Sex:

Urban/Rural:

Residential Area:

Level of Education:

How long have you been counselling patients with HIV/AIDS for?

Have you ever done counselling before?

Brief work history?

Please can you tell me about your training programme?

Do you feel the training programme equipped you well enough to undertake this job comfortably?

GENERAL PERCEPTIONS REGARDING COMMUNICATION IN HEALTH

Lets talk about this in general and then we can speak about this more specifically relating to your counselling sessions this morning.

Possible leading questions:

From your view what are some of the biggest problems resulting from the fact that the doctor and the patient do not speak the same language? Lets talk about your experiences in this clinic or even from before.

In your counselling sessions this morning even though you speak the same language as the patient-

Did you experience any difficulties in understanding the patients' message or conveying your message and information to the patient?

Can you explain these difficulties?

What are some of the most difficult aspects of your job?

FACILITATORS AND INHIBITORS:

Even though some medical doctors cannot speak isiXhosa, do you feel some doctors are better at trying to communicate with the patient? Please can you think and tell me what makes one doctor better than another at communicating and relating to the patient?

There are different counsellors

In your opinion what makes one counsellor better than another?

LANGUAGE AND CULTURAL FACTORS

IsiXhosa and English do not always have one-to-one word equivalents- especially with medical terms there may not be a direct isiXhosa translation. Can we talk about this and how it has affected your job in counselling patients with HIV/AIDS regarding the illness itself and treatment?

Doctors and patients, as well as people from different communities and cultures may view illnesses in different ways. Can we talk about this in terms of HIV/AIDS.

EXPECTATIONS

What expectations did you have when counselling the patients this morning? (discuss individual cases)

Were these expectations met?

If not, why/ how?

SUGGESTIONS

How could we have made communication easier for yourself this morning, e.g. use of pamphlets, having a family member with you,

Any other broader suggestions?

TOPIC GUIDED POST INTERVIEW

TOPICS FOR DISCUSSION WITH HEALTH PROFESSIONALS

BACKGROUND:

Our area of interest and focus of research is on issues relating to communication in health. Most of the patients attending Red Cross Hospital are not English or Afrikaans speaking. However most of the doctors are English or Afrikaans speaking. Today I would like to talk about this as well as the difficulties you as a health professional may experience in counselling patients with HIV/AIDS. Your ideas and opinions will help us to learn what are some of the facilitators and inhibitors regarding communication in health. Then we can use this information to help inform and train health professionals and counsellors to communicate better with patients, which in turn will allow for more effective health care.

Consent form and explanation that any information shared during this interview is confidential and will not be shared with other health professionals or patients.

First please can you give me the following information which is important for the research

BIOGRAPHICAL INFORMATION:

Age:

Sex:

Race:

Language:

Medical status within the hospital:

How many years practising:

How long have you been working within the this field of medicine?

Brief work history?

Have you previously undertaken any courses regarding communication skills? If yes, please can you tell me more about them?

Do you feel sufficient emphasis and training is placed on communication skills in health?

GENERAL PERCEPTIONS REGARDING COMMUNICATION IN HEALTH

Lets talk about this in general and then we can speak about this more specifically relating to your medical interview this morning.

Possible leading questions:

From your view what are some of the biggest problems resulting from the fact that the doctors and patients do not speak the same language? Lets talk about your experiences in this clinic or even from before.

In your medical consultations this morning:

Did you experience any difficulties in understanding the patients' message or conveying your message and information to the patient?

Can you explain these difficulties?

FACILITATORS AND INHIBITORS:

Even though some medical doctors cannot speak isiXhosa, do you feel some doctors are better at trying to communicate with the patient? Please can you think and tell me what makes one doctor better than another at communicating and relating to the patient?

There are different counsellors

In your opinion what makes one counsellor better than another?

LANGUAGE AND CULTURAL FACTORS

IsiXhosa and English do not always have one-to-one word equivalents- especially with medical terms there may not be a direct isiXhosa translation. Can we talk about

this and how it has affected your job in treating patients with HIV/AIDS regarding the illness itself and treatment?

Doctors and patients, as well as people from different communities and cultures may view illnesses in different ways. Can we talk about this in terms of HIV/AIDS.

EXPECTATIONS

What expectations did you have when treating patients this morning? (discuss individual cases)

Were these expectations met?

If not, why/ how?

SUGGESTIONS

How could we have made communication easier for yourself this morning, e.g. use of pamphlets, having a family member present with the patient, interpreters etc

Any other broader suggestions?

APPENDIX C

EPOCHE

University of Cape Town

I will write this section in the first person and not in the passive voice as the methodology section. This decision reflects researcher reflexivity and self awareness as a central theme in qualitative research designs. "Writing in the first person active voice communicates the inquirer's self-aware role in the inquiry" (Patton, 2002, pg 65). The first step of the transcendental phenomenological analysis process was to accomplish a "phenomenological attitude shift". Through introspection and reflection I strove for awareness of the personal viewpoints, assumptions and prejudices regarding intercultural communication and disability, or the various research persona's that I brought to the analysis. Furthermore I aimed to discover the background to and the reason for my particular point of view. The rigorous search for my identities as researcher before and during data analysis was especially important to avoid *othering* of the research participants who are doubly disadvantaged by poverty and disability and thus vulnerable to a power divide from the researcher (Harry, 1996).

"Culture provides the backdrop against which the individual researcher will act" (Harry, 1996, pg 295). Banks and McGee Banks (1993, in Harry, 1996) identified three different structures of American culture to which individuals belong, namely national macroculture; microculture, including race/ethnicity, religion, social class, gender, exceptionality and nationality; social groups formed through professional or political associations that support certain values and beliefs. I followed Harry's (1996) example of identifying personal personas that are likely to influence my analytical decision making by examining my identity on the three afore mentioned cultural levels. After introspection and reflection I was able to identify four different persona. The description of these identities is provided under the heading *epoche* to indicate the first step in the analysis process.

EPOCHE

On a macro level I am a South African. Despite shared symbols, e.g. the flag and national anthem, South Africans do not share a unifying national culture and the country's past reflects a history of conflicts between various ethnic and racial groups and later formal

segregation of white and non-white citizens. On the microcultural level I am better able to construct an identity. The census statistics will identify me as a white Christian female from middle class upbringing with tertiary level education. Here I distinguish my first research persona: the *researcher as Afrikaner*. As is the case with my national non-identity I do not include myself in a universal Afrikaner culture, and I believe that such a collective culture doesn't exist. My identity as Afrikaner represents a journey, from ignorance to painful awareness; from isolation to integration and from fear to gratefulness, hope and optimism.

My story of isolation and ignorance is set in the one town and home where I spent the first twenty two years of my life. The people I attended school with, the people who educated me and provided me with religious guidance were all people who looked like me, spoke my language, and shared my religious affiliation. Importantly, the language that we spoke and the way that we looked represented that of the government of the day. The main television station therefore broadcast in Afrikaans and the main news bulletins were read in Afrikaans by white mostly male presenters. The society in which I grew up in was largely monocultural, and as a result I was never acutely aware of this fact as a growing child, teenager or even student. Later, I learned that Afrikaans speaking white people formed a minority within the total South African population, and that my microculture was one of various within our national boundaries. Later I also realised that the society in which I grew up was never monocultural. I was perhaps monocultural.

It must be hard to understand for outside observers that I was also largely unaware of the political situation of our country during the nineteen eighties and nineties. I had to be aware, however, that black people were mostly very poor, uneducated and working as unskilled manual labourers. In fact, most of the contact that I had with black people as a child was with people working as domestic workers, gardeners, petrol attendants, shop assistants and builders for people like my family and the rest of our community. Reflecting upon my experience as high school pupil of the first democratic South African election in 1994, I realise that I was unaware of the meaning of the event. I remember

that change was anticipated and that the change spread varying levels of underlying fear through our community.

My true cultural and political awakening, and the journey to awareness, integration, hope and optimism came about somewhat surprisingly when I moved to cosmopolitan Cape Town after completing my undergraduate studies in Speech-Language Pathology and Audiology. Here I suddenly became part of a cultural and linguistic minority. The members of my new society spoke a different language(s), and there was a rainbow of faces, practices and beliefs. I was part of a truly multicultural system for the first time in my life. I also became increasingly and painfully aware of my background as rooted in an oppressive system that delivered systematic discrimination against black and other non-white peoples of our country who were now my neighbours and teachers. I also learned about the negative associations and stereotypes attached to my specific cultural background. My fear of change and integration has been replaced by amazement and gratefulness at peaceful transformation, and my guilt is slowly being replaced with the growing sense of a unifying national macroculture of acceptance, tolerance and forgiveness through frequent experiences of embrace by the everyday people of my life who have suffered under my people. The somewhat laborious background to my identity of *Afrikaner* thus illustrates the history of my country's transformation, and my experience of it against the backdrop of my microculture and personal experiences that have transcended my group membership (Harry, 1996).

My second research persona I refer to as *The social and able-bodied speech therapist*. The formation of this identify reflects a journey between my training in the traditional medical model, to the discovery and adoption of a social model of disability. Whereas the medical model's personal tragedy account of disability has taught me to focus on the client's disorder, the social model asks me to entertain the idea of a separation between impairment and disability. Whereas impairment represents instances of communication pathology that I have been well trained to recognise and correct, disability refers to the systematic discrimination suffered by individuals with impairments. The social model therefore demands attention on a societal level, and reconsideration by the allied health

professionals of their roles and ethics (Oliver, 1990). The shaping of my perspective of disability is relevant to this research as HIV/AIDS is regarded as a disability issue (Shakespeare, 1996).

Social model and psychoanalytic theory has enabled me to examine my own responses to disability. Reflecting on my feelings when confronted with HIV/AIDS the overwhelming theme is fear. Fear of being infected with the disease. Fear of physical contact with people who are infected, including contact through sharing of utensils, such as stationary and cutlery. The bodies of people with HIV/AIDS are like fragile vessels carrying a deadly and cruel poison. Considering the knowledge I have regarding the transmission of HIV/AIDS my fears are ungrounded. To understand these fears I had to pay attention to the meaning I subconsciously attach to HIV/AIDS. I found that HIV/AIDS represents a disabling illness that weakens the body and disallows full participation in life. It threatens personal ideals of being considered a dependable, hard working employee. The ability to work hard and well fulfils my personal need for acceptance and self-respect. HIV/AIDS, represented as physical weakness, threatens these personal values and ideals and therefore evokes fear. In a similar manner HIV/AIDS threatens other personal expectancies of life: being a dependable and cherished spouse, becoming a mother of healthy children, longevity and the ability to positively reflect on the activities and achievements of that life. I recognise that my feelings regarding HIV/AIDS are laden with defensive fears regarding disability in the broader sense and that my fears are partly shaped and reflected by the fears and assumptions of an abilist society. Throughout the analysis I have aimed to be aware of influence of these personal feelings and their root cause on my interpretation. My identity as *social and able bodied speech therapist* therefore represents my use of the theoretical tools of Disability Studies and Psychoanalysis to examine personal and social responses to disability and to endeavour professional action towards the goals expressed by people with disability. As *social and able bodied therapist* I thus now have the opportunity to become part of the struggle on the terms of the oppressed people. Perhaps through this identity I will even reconcile some issues regarding my sense of disconnectedness from our nation's past struggle for freedom.

My third research persona was identified through reflection on my personal experiences of intercultural clinical interaction as clinician and as patient, namely *the researcher as English therapist and not so English patient*. In the light of the above description of my socio-cultural and professional background I will begin with an account of my experiences of interacting with clients using English as lingua franca.

My interactions with clients using English as lingua franca has mostly been intercultural interactions with clients from previously disadvantaged backgrounds who are living in poverty. My identity of *Afrikaner* has a definite influence on these interactions. I am aware of taking an unbalanced share of responsibility for communicative success by adjusting my communicative behaviour. I might for example reduce my rate of speech, simplify the sentence structure and vocabulary, make use of gestures, and deliberately verify the client's comprehension. These strategies are truly an attempt to reduce communication breakdown and are not based on assumptions about the client's intellectual ability.

Due to my identity as *Afrikaner*, the interpersonal dynamics of these interactions are often qualitatively different from my relationships with clients who share my background and culture. In these intercultural interactions with clients I often feel very aware of the previous divide that existed between the clients and me and I experience feelings of sadness and guilt over the lost opportunities of these individuals. Of course the difference between the clients' and my economical situations also influences these interactions. I have attempted to overcome the separation between us by giving in a personal and material sense. I will for example display friendliness; I will make physical contact through handshakes, touching a client's arm, even hugging. I will give sweets and/or toys to the children. My behaviour can be explained as an attempt to close the distance between the ethnic groups and to erase the history. In part I am apologising for the past and celebrating the present closeness. I am also attempting to shed the stereotype the client might have of my cultural group. Furthermore I want to share what I have with the people who do not have. Ultimately I have to consider the possibility that, despite the

truthful desire to accommodate and relieve some suffering for the client, I am attempting to make myself feel better. I am coping with the stigma and image of the oppressor, and the guilt of a comfortable lifestyle compared to the hardship surrounding me.

My first experience as *an English patient* was as an adult and the decision was in no manner a forced option, as it is for the public health care patients who have little choice over health care providers with very few doctors sharing their first language. I am fairly comfortable with my spoken English ability in interacting with English first language physicians. I have, however, had experiences of not being able to express myself clearly in my second language. This brought about fear of appearing less intelligent and competent to a person who is socially constructed to possess considerable intelligence and skill. The medical practitioner also represents a colleague with a perceived higher social status than most other health care workers. In situations of communicative difficulty I would often point out to the doctor that I was not communicating in my first language – almost to justify my incoherence and to defend myself against negative perception. Despite occasional discomfort in English clinical communication, I have always been able to understand my physician's use of everyday- as well as medical language, perhaps as a consequence of my training in a health related field. Similarly I have never experienced my physician to misunderstand me, and I have always felt confident that I could correct the doctor if I felt misunderstood, or felt that my main concerns weren't being acknowledged. Furthermore, I do not have any sexist, racial or cultural prejudice regarding the competence of doctors, although I am aware of such notions.

Finally, on the level of professional group membership, I want to discuss my identity as *qualitative researcher and multidisciplinary social scientist*. My status as novice researcher conducting one of my first interpretive research studies may influence my decision making in the research process. Moreover, apart from undergraduate training in psychology, I am new to and not formally trained in the social sciences that gave birth to the qualitative method, e.g philosophy, sociology, and anthropology. I see speech-language and hearing science at "the intersection of the natural and social sciences"

similar to occupational science (Barber, 2004, pg 107). As researcher I am positioning myself on the social science end of the crossing. The new landscape may lead to premature, ignorant or simplified methods and conclusions. As masters degree student I am attempting to grow my identity as qualitative researcher and to be aware of the limitations of my work.

University of Cape Town