University of Applied Sciences Hamburg
Faculty of Life Sciences

Dilemmas in connection with the antiretroviral treatment program in South Africa as experienced by the involved personnel

Master thesis
in partial fulfilment of the requirements
of the academic degree of a
Master of Public Health

submitted
by
Dr. med. Dirk Thomas Hagemeister

Prof. Dr. Dr. Karl Wehkamp	Prof. Geoffrey Setswe DrPH MPH
University of Applied Sciences	Human Sciences Research Council
Hamburg, Germany	Pretoria, South Africa

God give me the serenity to accept what can not be changed,
the courage to change what can be changed,
and the wisdom to know the difference.

Reinhold Niebuhr

Gott gebe mir die Gelassenheit, Dinge hinzunehmen, die ich nicht ändern kann,
den Mut, Dinge zu ändern, die sich ändern lassen,
und die Weisheit, das eine vom andern zu unterscheiden.

Deutsche Übersetzung von Theodor Wilhelm alias Friedrich Oetinger

Abstract

Background: HIV/ AIDS is the most important public health topic in South Africa at the beginning of the 21^{st} century. With the implementation of a nationwide antiretroviral treatment program, health care workers are entering this specialised field of medical care.

Methods: Using the available literature the importance of the cultural influences is established and the potential burdens and dilemmas for the personnel are identified and related to the fields of ‘the individual health carers situation’, ‘the health carer/ patient interaction’ and ‘the third persons’ interests’.

A qualitative study containing nine semi-structured in-depth-interviews with health care professionals from the Rustenburg provincial hospital’s HIV/AIDS clinic, empirical data are collected to verify the relevance of the factors found in the literature.

Results: The main emphasis in the health carers’ experience focuses on the two problems of workload and patient compliance, though a number of other concerns are expressed as well, particularly in connection with traditional medicine and with the ethical dilemma surrounding disclosure of the HIV status.

By the involved health carers a number of valuable suggestions is made how to improve the situation both for the patients and for the personnel, touching the ‘structure of the program’, ‘management topics’, ‘dedication to work’ etc.

Conclusion: The author concludes that the local health care have to face a significant burden of problems and dilemmas though the general attitude is one of hope risen by the dramatic improvement of the state of health of many HIV/ AIDS patients. Nevertheless the needs and worries of the health care worker in their particular field of expertise should be listened to, the suggestions made by them should be applied and the research should be extended to other provinces and clinics to learn more about the typical dilemmas these professionals have to face.

Keywords: Dilemmas – health care personnel – treatment of HIV/AIDS – South Africa

Hagemeister, Dirk Thomas; Dilemmas in connection with the antiretroviral treatment program in South Africa as experienced by the involved personnel.
Hamburg, Univ. of Applied Sciences, Fac. Life Sci., MPH Thesis, VI+93 pages, 2006

List of abbreviations

AIDS	Acquired ImmunoDeficiency Syndrome
ANC	African National Congress
ARV	AntiRetroViral (drugs)
HAART	Highly Active AntiRetroviral Treatment
HIV	Human Immunodeficiency Virus
HPCSA	Health Professions Council of South Africa
KS	Kaposi Sarcoma
MOPD	Medical Out-Patient Department
MTCT	Mother to Child Transmission
NGO	Non-Governmental Organisation
PEP	Post-Exposure Prophylaxis
PMTCT	Prevention of Mother to Child Transmission
RPH	Rustenburg Provincial Hospital
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
VCT	Voluntary Testing and Counselling

Table of Contents

1 Introduction: Pandemic situation

1.1 The AIDS pandemic and South Africa

The infection with the Human Immunodeficiency Virus (HIV) and the resulting disease, the Acquired ImmunoDeficiency Syndrome (AIDS) has become a serious threat to the lives and the future of millions of people, particularly in sub-Saharan Africa. Some regard it as “the world’s most serious public health problem” (Evian 2000:3), without doubt it can meanwhile be considered “as the leading cause of illness and death in sub-Saharan Africa” (Colvin 2005:336).

The ‘HRSC Study of HIV/AIDS’ in 2002 estimated the HIV infection rate to be 12.8% and 17.7% for women and men respectively in the ‘reproductive’ age group between 15 and 49 years of age in South Africa (Shisana and Simbayi 2002). Other authors warn that e.g. the prevalence amongst female teenagers seems to be five times higher than that of their male age mates and expect round about 6 million people living with HIV/ AIDS in South Africa in the year 2005 (Pelser et al 2004). This pandemic, as it is called meanwhile (e.g. Benatar 2004:586ff), has dramatic effects on various fields of daily life in South Africa, and these effects must be expected to increase even further with the growing number of people progressing from HIV-infection towards suffering from the clinical manifestations of AIDS and finally dying. The suffering and loss of human life by this disease does take its toll from the society by leaving many children orphaned by the disease, leaving them with little hope for a prosperous future. From within the ranks of the countries work forces, many people die during their most productive years, including many teachers and health care professionals, resulting in gaps that can hardly be filled. This might affect the economic growth and the transition of the society and thus fewer resources might become available in the future to finance the countries health system (Whiteside 2005:408ff). Yet on the other hand, exactly this health system is increasingly coming under strain by the extremely growing need and demand for medical care by those who suffer from HIV/ AIDS (Colvin 2005).

The current South African political leadership had been widely and wildly criticised[1] for its – at best reluctant – stand towards fighting this threat to the health (and in consequence to the wealth) of the South African population.

The misunderstandings and controversies caused by political figures like the current president Thabo Mbeki, the minister of health Manto Tshabalala-Msimang, or the (late) presidential spokesperson Parks Mankahlana, have fuelled political and legal confrontations within the society of South Africa, which on the other side were especially spearheaded by the Treatment Action Campaign (TAC). For many years, the government had supported 'alternative treatment' approaches for AIDS, such as the drugs 'Virodene' and 'Oxihumate K' that both lacked scientific evidence of effectiveness and the nutritional immune booster using beetroot, garlic, lemons, African potato and other ingredients (Deane 2005:539f) and at the same time the governments representatives publicly doubted the effectiveness and safety of antiretroviral (ARV) drugs as developed by international pharmaceutical companies and registered for treatment and prevention of transmission in many other countries. It wasn't until the above mentioned TAC succeeded in court rulings to force the government to change its stand on the issues and to implement a nation wide program for prevention-of-mother-to-child-transmission (PMTCT – legal fight end 2001 – mid 2002, implementation 2003). After another long lasting political struggle and a lot of pressure from a wide variety of social groups, the government finally adopted the plan for a nation wide ARV roll-out, that was published on November 19th 2003 [2] and was to be implemented soon thereafter, effectively opening the first 'wellness clinics'[3] during the course of 2004.

Yet, with these achievements the real struggle was rather to start than to end, as the South African health system is still suffering from extreme inequalities both regionally and between different social groups within the same region, often contributed to the heritage of decades of oppressive Apartheid politics. So despite the granting of licences for generic ARV drug production by the patent holding international pharmaceutical companies (what significantly reduced the expenses of the program), the current task is to implement a nation wide network of well trained and equipped

---

[1] Benatar 2004:589f the author speaks of "(...) irrational (some would say 'criminal') government behaviour (...)" and South African Nobel-laureate of literature Nadine Gordimer was cited on the front page of the 'Pretoria news' Dec. 1st 2005 saying: "I've seen how they've battled against government's long time indifference to this terrible epidemic"

[2] the aim was to have at least one antiretroviral service point in each district within one year and to have 1.4 million people on treatment within five years (Deane 2005:544)

[3] Clinics for free HIV counselling and testing, ARV drug roll-out and treatment monitoring

facilities that help to achieve drug adherence by the patients, as this is highly essential for a sustainable success of the program. Aggravating factors are the ‘brain drain’ of skilled workforce that the country experienced and the persistently higher attractiveness to work in a private health care facility.

1.2 Focus on the health care worker

Despite of the vast presence of the disease and the frequency and intensity, health care workers in South Africa have to face the problems caused by this pandemic, very little has been published so far to highlight the dilemmas these groups of professionals are confronted with in this country.

As early as 1986, only a few years after the new medical phenomenon of HIV/ AIDS came to the attention of the scientific world in the early 1980s, the first studies had been done to examine the psychosocial impact of the new disease on both the patients as well as the health care worker in the United States (Baumgartner 1986; Geis and Fuller 1986). Since then a number of authors have engaged to discuss such different topics as ‘HIV and health carer burnout’, ‘HIV and legal conflicts’, ‘religious and/ or cultural backgrounds and HIV’ or ‘HIV and reproductive medicine’. With a focus on the situation in Eastern Africa a study has been conducted in Kenya to investigate the role of HIV in the development of ‘burnout’ in health care workers (Raviola et al 2002). In the chapter on ‘Health care worker burnout’ a recent South African ‘Handbook on HIV medicine’ (Wilson et al 2002:451) states that

> “(c)aring for people in need is both rewarding and uniquely draining work. In particular, it can be highly exhausting in the HIV/AIDS arena”

and in a very comprehensive book on ‘HIV/ AIDS in South Africa’ the authors discuss such topics as ‘the health care burden’ as well as the impact of AIDS on the community, on democracy in South Africa, on ethics and on the economy (Abdool Karim and Abdool Karim 2005)[4].

---

[4] the chapter by Colvin on the health care burden gives a brief bibliography about South African studies and papers concerning this topic

1.3 Significance of the Study

As outlined above, the HIV/AIDS pandemic has a tremendous importance for the people in South Africa. Though there is clear evidence from literature for specific emotional burdens and ethical dilemmas in connection with the treatment of this disease, little research has been done so far on the question whether and in what way the health care personnel involved in the antiretroviral rollout program in South Africa is affected by the above mentioned factors or by additional influences.

The main aim of this study will be to establish an overview over locally prevalent concerns in this group of health care givers. In the centre of interest shall be the emotional part of the experience: Not the potentially occurring practical shortfalls of the daily work setting in the clinics shall be reported, but the question shall be in what way the involved personnel suffer from the conflicts and deficiencies they have to face. To reach this goal, firstly the available literature shall be reviewed in regard to this topic, trying to identify topics and clusters for these burdens.

The focus of the qualitative, interview based study then will be very narrow (and the population under examination very small), consisting of the in-depth-interviews with physicians and nurses from only one health care facility in Rustenburg, North-West-Province. Therefore the possibility to generalise the findings for the whole of North-West-Province or even South Africa will be limited. Nevertheless, this approach seems to be the most appropriate, given the fact that little is known about this special topic for the local setting. Based on the results of this research, a broadened foundation of knowledge should be laid by both applying the qualitative approach to other local settings and probably by using a quantitative approach trying to establish the significance of the issues found in the interviews for a bigger population of health care workers, e.g. by using a questionnaire-based survey.

1.4 Structure of the paper

As indicated in the above sketch, the next chapter shall give a comprehensive idea of the topics that have been discussed in the literature so far in connection with problems, difficulties, burdens or dilemmas for the health care workers involved with the treatment of HIV/AIDS. As outlined above, this literature review will depict an extensive discussion of the available publications and therefore might be regarded as one of the main parts of this paper. But this part will also serve as a theoretical foundation for the practical part of collecting empirical data through interviews, providing an idea of what topics might be relevant from the interviewees' point of view and probably should be 'screened' therefore during the interview. The methodology of this research will be discussed more thoroughly in the third chapter, including the more technical aspects like the selection of the sample and the actual performance of the interviews.

In the forth chapter then the collected data will be used, after extensive analysis, to draw a picture of what in fact worries the interviewed nurses and doctors from this particular clinic. Presenting the results of the interviews, broad space shall be given to the spoken word of the interviewees, depicting in their own words what matters to them.

Potential confounders that might influence the results shall be discussed in the fifth chapter, where factors like the interviewer/interviewee relation or the locally limited source of the data will be highlighted, with an attempt to summarise the main important findings from the interviews as well.

In the concluding sixth chapter the implications of the previously mentioned findings shall be addressed, i.e. the identified needs for supportive action and changes of structure within the antiretroviral treatment program as well as the outlined suggestion for additional research activities to gain a more comprehensive picture of the national situation of the personnel involved with the antiretroviral treatment rollout.

2 Dilemmas and burdens in HIV/ AIDS care in the literature

In a dilemma (an expression derived from classical Greek philosophy) the acting person has a choice between two options that seem equally good or equally bad. Discussing dilemmas for the health care provider, these options of choice can involve such different objects as financial factors, ethical and social values, health outcomes or even emotions. To result in a dilemma, the two options don't have to belong to the same group: If the medical person for instance, is afraid of an infectious disease at the workplace but can't avoid the exposure, the emotion of 'fear' (to get infected) competes with the social value of 'helping others' or simply with the economical benefit of a paid job, thus creating a dilemma. Similarly, if the patient refuses to undergo a treatment that the doctor recommends, the expected health outcome 'to benefit physically from the treatment' competes with the ethical value of the patient's autonomous right to refuse. In this way, very often, the problems or burdens that health carer experience due to their work result in a dilemma, because the health care worker does not only experience the problem, but has to acknowledge it in the process of decision making and has to weigh it against other factors or values.

The aim of the following passage is to give a brief review of what has been recognised as to significantly affect the health carer working with HIV/AIDS. Given the overwhelming impact of HIV/AIDS on the society as well as the resourceful - but increasingly demanding - medical situation there is a plenitude of emotional and ethical conflicts possible in connection with the treatment of HIV/AIDS.

For well understandable reasons, the first perspective used in health science usually, is that of the patient's needs and worries, as the main aim of medicine since the days of Hippocrates is to help the patient. Following this approach, Garcia et al. (1999) established a list of eight categories of 'ethical dilemmas related to counselling clients living with HIV/AIDS', which includes 'disclosure, vocational, legal, health, family/ social, sexual, death and counsellor/client relationship'. Many of these fields will be dealt with below, yet since the focus here is more on the situation of the health care worker than on that of the patient, they will appear according to the role they play in causing problems for the personnel dealing with HIV/AIDS patients. Obviously, the situations of health care workers and patients are closely related and interfere strongly with each other, but they are clearly distinct from each other, too.

Taking a closer look at the burdens for the health care worker, there are certainly many ways to group these problems (and the resulting dilemmas) into clusters of topics. Therefore, the following structure is not meant to be *the* definite clustering, but rather one that should be operational to list and discuss the individual health care provider's concerns. The approach to structure the observed dilemmas, will extend from the narrow focus on the individuals concerns about his own personal situation, continuing to discuss the problems of the health carer and patient relation and towards the broader perspective of the involvement of third persons' interest.

As will be elaborated further in the following, the first group of topics to be assessed is the one concerning the individual *health carer's own situation*, including such things as the 'setting of mind', the social position, the cultural background as well as scientific ideas and political opinions. These problems include the personal fears of the health care workers and the emotional responses to the suffering and deaths they experience, but as well such topics as the overload of work and the possibly resulting 'burnout'.

Originating from the interaction between the *health carer and the patient*, additional problems can occur, e.g. the lack of cooperation (refusal to give consent to the treatment) or the lack of adherence by the patient. A mental impairment of the latter, disabling the patient to act responsibly, can cause the health carer to face additional burdens. Further can the social position impair the patient's chances to receive the best possible care.

A third group of conflicts can be described where there are additional *third persons' interests* at stake. Such 'stake-holders' could be the patient's spouse who might be at risk of contracting the infection in the case of discordant couples or the children who face numerous potential risks from getting infected during birth or breastfeeding to a possible future as being orphaned and socially deprived. The topic of disclosure often causes the most significant problem in this cluster: Should the information about the HIV status be forwarded to sexual partners, parents or employers who might be affected by the patient's situation?

As this approach focuses more on the individual health carers perception than on abstract headlines, it might happen that topics that could be summarised under one headline may occur in different clusters, e.g. could the topic 'resource allocation' show as a problem of *patient/ carer interaction* (micro allocation – 'refusal-to-treat') and as well as a *reflected concern* (macro allocation – 'sense-of-program'). In the same way the ‘religious background’ might affect the individual health carers own approach to the pandemic (e.g. reluctance to recommend the use of condoms), might complicate the patient’s adherence to the provided treatment (e.g. through the patient’s belief into competitive traditional or spiritual treatments) and might influence the health carer’s considerations about the responsibility towards third persons’ interest (e.g. principle of charity). Given the special and exciting cultural situation in South Africa, with a large variety of different religious and cultural backgrounds being prevalent, the potential impacts of these backgrounds will be discussed in a separate introductory section (chapter 2.1).

Of course none of the aforementioned factors or clusters of topics can be regarded as independent from the others or solely relevant, as it is the same individuals they have effects on and they interact in many ways. This should always be kept in mind: It is single aspects of a whole (the health carer’s situation) that are being described.

Within the last twenty years since the HIV/AIDS problem was first recognised, there has been extensive research in connection with this new disease, resulting in a plenitude of academic writing and publishing. In the following section the specific literature is to be reviewed with regard to the specific subject of this study, the dilemmas for the health care worker and the order will grossly reflect the above mentioned clustering.

2.1 The social, cultural and religious background

The Republic of South Africa has as many as eleven official languages and the cultural and ethnic diversity is often expressed by the term ‘rainbow nation’. Despite the surprising fact of a peaceful transition from white minority rule (‘apartheid’) to a democracy that saw Nelson Mandela being elected as the country’s first black president in 1994, the people(s) of South Africa might still have to go a long way towards mutual understanding, both in terms of the others’ languages and of their culture and beliefs.

Though it might be obvious, the complicating effect of different cultural backgrounds on the implementation of broader community based public health actions as well as on the individual patient/ health carer relation is often ignored.

2.1.1 The language barrier

As a first barrier the problem of language can easily be recognised: If the health carer and the patient don't share at least good knowledge of one common language, direct meaningful communication is impossible, and assistance by an interpreter will be needed. But even with this assistance available the communication will lose some of its effectiveness - a problem that might similarly occur if either the health carer or the patient makes use of a foreign language that is not his mother tongue:

In the specific wording as well as in the intonation much additional information is given as part of the speaking persons (non-verbal) communication, information that is easily 'lost' by either using an interpreter or by limited command of the language used – not to mention the simple misunderstandings.

2.1.2 'How to talk to my patient' – cultural barriers

But in addition to the mere language barrier a cultural barrier might add to the problem. Sometimes both participants in the health carer/ patient relation have completely different ideas about what causes – or even what 'is' – the specific disease. Where 'modern western' medicine has a sophisticated system of diseases as clinical entities and theories of their individual pathogenesis, people of other cultural background may have an - often much more 'holistic' – understanding of what makes them sick and of how to treat this condition. Approaching a patient with the 'western' understanding of patients' rights, the 'informed consent' has been shown to cause some dilemmas for American physicians dealing with patients from differing cultural background: The Navajo Indian e.g. will fear that the bad events are being willed by the mere mentioning of potential negative outcomes of a surgical procedure during the information of the patient, since 'bad words' in their belief have a spiritual power to cause these things to happen. Further, it is reported to be completely within the traditional moral understanding of Japanese or Chinese people for the relatives to withhold a severe and fatal diagnose from the person affected (Betancourt et al 2000).

For South Africa with its vastly different cultures and beliefs the barriers of understanding are certainly not less, maybe just less well described. Yet the different concepts of disease have been the issue of research, particular from the psychosocial disciplines. For psychological/ psychiatric disorders, it has been shown that traditional healers might come up with strikingly similar assessments of the patients, compared to the ‘western diagnoses’, especially if one bothers to find the equivalent expressions in the local language (IsiZulu in this case) – and the patients’ perception of helpfulness of either group of ‘healer’ (western or traditional) was reported to have been similar, too (Edwards 1986). On the other hand, a recent study by anthropologists in the lowveld of South Africa’s Northern province found a range of ‘unconventional’ theories on HIV/AIDS amongst the local rural population: The women in general tended to have a more biomedical understanding and to think positively about condoms still had some theories about nurses intentionally spreading the disease and the men expressed a wide variety of conspiracy theories involving an Apartheid time chemical weapons specialist, the Americans, bestiality and the breech of other sexual taboos (Niehaus and Jonsson 2005, with the genderised perception attributed by the authors to the differing scopes of life experience). Though they didn’t find witchcraft to act as a major explanation for the population in their research, the authors discuss

> “Evans-Pritchard’s classical theory that, as an ideational system, witchcraft provides a logical explanation for the particularity of misfortunes and answers the central questions, “Why me? Why now?” As he so convincingly demonstrates, this theory of witchcraft does not exclude empirical knowledge about cause and effect, but supplements theories of natural causation:” (p. 180)

In other publications, witchcraft is given a far more prominent role, with the symptoms of AIDS seen as signs of a slow poisoning with “isidliso” (IsiZulu name of a poisonous concoction that causes a small creature to slowly consume the bewitched person from inside – p. 181) and it is estimated that e.g. in the Northern Province between 1990 and 1999 587 people were killed as alleged witches (Jolys 2005 with reference to Ashforth, A (2005): Witchcraft, Violence and Democracy in South Africa. Chicago). In accordance with the aforementioned theory, it should be understood that the need to find explanations, especially for personal catastrophes is human, even in ‘modern western’ societies this urge is preserved, e.g. considered a highly skilled professional in Germany a direct local contusion suffered while playing with his children to be the cause when he was diagnosed with testicular cancer, a causal relation that has no scientific background (personal experience of the author) – thus not the attempt to construct a causation is culturally determined but only the set of ‘possible explanations’. Yet this differing repertoire of ‘metaphysical’ ideas might create a high barrier for effective communication: Despite the fact that possibly both sides, patient and health carer, generally accept a biomedical explanation of virus and drug therapy, they might use different frames of reference with a physician talking of ‘random controlled studies’ and ‘statistical evidence’ while the patient refers to ‘disapproval by the ancestors’ or ‘jealousy of the ex-girlfriend’. If the partners in communication, and particularly the health carer, lack understanding for these problem, this might put an end to any meaningful communication, resulting in the withdrawal of the partners and the statement that the other ‘doesn’t understand’. Almost two decades ago, during the years of Apartheid, a South African social scientist discussing the fate of a black psychiatric patient in a paper entitled “Ethics and the social responsibility of health workers” stated:

> “The basis for the misunderstanding is complex but must be acknowledged to include ignoring the impact of political inequity as well as language barriers and lack of understanding of the beliefs and values of people from different cultures.” (Manganyi 1987)

Unfortunately, not only the interaction between health carer and patient is affected by religious and cultural ideas, these ideas can have a direct effect on the individual’s actions, too: The almost ‘classical’ example for this problem is the stand of the Catholic church on the use of condoms. Since according to Roman Catholic teaching sexual intercourse serves the sole purpose of creating (god’s) children, any intercourse that does not bear this option is against the will of god, i.e. homosexual intercourse as well as the use of barrier methods or other means of contraception in heterosexual activities. As sexual transmission is on of the main routes of spreading the HI-Virus and as it has been acknowledged that abstaining, what certainly biologically is the safest way of avoiding both pregnancy and infection, can not always be achieved, it has generally been started to recommend condom use, thus a contribution to ‘social reality’. The even more delicate part of this discussion is that obviously in a faithful relationship of two, the use of condoms for prevention of infection is not necessary (once it is established that both partners are healthy), thus leading to the accusation that the recommendation to use condoms would promote promiscuity – or at least make it seem more acceptable. Against this background, it might become more difficult for the Catholic health care worker to propagate condomisation, since he faces the dilemma that this attempt, to protect people from infection, comes at the price of committing a sin (e.g. for Brazil: Arruda 1994). On the other hand of course such religious reservations can show on the patients side as well, with sometimes fatal effects, as it does not seem convincingly ‘Christian’ to refuse the use of Condoms as against the will of god and thereby putting others at risk of contracting an infection - a motion that is nevertheless welcomed by those who oppose condoms in general - often the men. These attitudes against condomisation have been shown to have numerous reasons that are linked to traditional thinking about fertility, the role of the sexes etc. (Preston-Whyte 1999:142f; Niehaus 2005: 189/194; Varga 1999).

Furthermore even the ethical rules of health care might be affected by such religious considerations, as Christian Authors argue with the obligation towards the neighbour and suggested therefore that in some circumstances the right to confidentiality is secondary to other needs like e.g. to protect the unborn child of a minor – statements in clear opposition to legislation South African and many other countries, a dilemma recognised by the authors as follows:

> “(…) remember that there may be times when the professional must obey God's law if human law is in direct contradiction (…)” (Rutecki and Geib 1991:14).

2.1.3 Poverty and health – the social situation

Very often and in many countries the separations caused by culture and language (and often ethnicity, too) coincide with significant differences in social status and economical wealth. This is true for the US (‘white Anglo-Saxon protestants’ versus Blacks, Asians or Hispanics), Europe (e.g. in Germany: those with ‘Central European roots’ versus Turkish immigrants, Russian born ‘Spaetaussiedler’ or asylum seekers from Africa) and obviously for the segregated South African society, harmed by the consequences of decades of Apartheid policy.

Usually the economic disadvantage results in an equally reduced health and life expectancy (WHO-Europe 1998). For the South African situation it has been shown that the life expectancy of black people (60 years in 2001) is far below that of whites (74 years, Pelser 2004:183). This had already been the case even before the impact of HIV/ AIDS showed (as it might otherwise be argued that this is a mere sign of the pandemic, though the life expectancy is expected to drop to 40 years (!) by 2010 due to the pandemic, Redelinghuys and van Rensburg 2004:222) and might be partially attributed to the vastly differing coverage with medical care for the two groups of population as reflected e.g. by the doctor per population rate for the Western Cape

(1:654 in a province with high percentage of white population) and the Limpopo or Northern Province (1:6747, i.e. one tenth of the previous in a province with very little white population, van Rensburg 2004:353).

The observed disparities of HIV infection rates - blacks 12.9%, whites 6.2% (Shisana and Simbayi 2002) - between the ethnic groups thus might be regarded as both result and (future) reason of social and economic disadvantage: The higher rates amongst blacks can be seen as a consequence of the lack of proper health care and education due to the effects of Apartheid as well as they will be a source of further deterioration of the social and medical situation of this part of the community, leaving many children orphaned and without perspective for proper education and economic success (Frohlich 2005).

The goals of the democratic transition are, as the then deputy president and now president of South Africa, Thabo Mbeki, listed:

> "to create a non-racial society; to build a non-sexist country; to heal the divisions of the past; to achieve the peaceful coexistence of all our people; to create development opportunities for all South Africans, irrespective of colour, race, class, belief or sex; and to improve the quality of all citizens." (Mbeki 1998:185)

But at the same speech president Mbeki expressed his impression that "South Africa is a country of two nations", a "white, relatively prosperous" one and "the second and larger (…) is black and poor" (p. 188).

To overcome this situation, it is essential that health care professionals recognise this kind of impact of the cultural diversity and that they actively try to heal these divisions of the past. Since the distributions of ethnicities in the general population (35.2 million/ 78,7% blacks vs. 4.5 million/ 10.1% whites, Pelser 2004:174) and amongst the medical doctors (e.g. medical specialists 71% white, 13% black, van Rensburg 2004:329) are contrary, and thus for a long time the disadvantaged groups of the population will not find enough physicians who share their own socio-cultural background, it will be the task of the medical professionals to overcome these barriers and to enable themselves to interact successfully with their patients.

To summarise the above, it can be stated that the social, cultural and religious background can affect the situation of the health carer and his interaction with the patient in at least three ways: The language barrier, the distinct cultural and religious beliefs and the social situation that might be related to the cultural and religious belonging. These topics might be mentioned again in the following chapters.

2.2 The health carer's loneliness – infectious threat and overload of work

HIV/AIDS is known to be an infectious disease and therefore poses a potential risk of contracting the disease to those who deal with the patients. In addition to the HI-Virus, AIDS patients are susceptible to other infections (tuberculosis, meningitis) and some of these germs are spread easier than the virus, e.g. the mycobacterium causing tuberculosis.

As early as 1986 a study on the psychosocial response of American hospice staff to the emerging 'AIDS care dilemma' had been conducted (Geis and Fuller 1986). Finding that the interviewed staff is caught in an ethical and emotional dilemma between their personal fears and the expectation to act 'professionally', the authors state the need for the society to openly face the growing problem of AIDS in order to help both the patients and the care givers:

> "In spite of the fact that AIDS is a growing health problem, society as a whole does not want to deal with AIDS. It tends to isolate both the patients and their caregivers. Isolation only adds to the difficulty of coping with fears; it does not solve problems for either the staff or the patients:" (p. 241f)

– 20 years down the line, this could probably still be found to be a good description for the situation in many areas in South Africa.

Lack of knowledge about the disease adds to the fear, as a component of 'anxiety of the unknown'. In the same year as the previous paper, 1986, thus quite at the beginning of the scientific discoveries about the disease, another American author collected reports of personal experiences from different kinds of health care worker involved with HIV/AIDS. A physician told him:

> "We've had nurses refuse to work with AIDS patients. The problem is, no one knows who may get the disease, (…)" (Baumgartner 1986:55)

– a motion that certainly occurred amongst medical doctors as well. In addition to that, the reality of stigma and denial in a society deprives the individual health carer of the necessary support structures, as a social worker and leader of an AIDS support group stated (asked about the impact of the deaths of four of the members):

> "It means that I'm aware of my isolation professionally doing this, (…)" (p. 60)

especially since the suffering and death caused by AIDS constituted a new experience for him:

> "I had never worked with a lot of terminal patients. This is a whole different ball game …" (p. 61)

And a nurse involved in support and hospice work for AIDS patients even reported direct impact of the stigma of the disease onto his personal life:

> "I was kicked out of my apartment because I was seeing clients who where KS AIDS patients. I had a room in which to do therapy, and as soon as the landlord found out I was seeing KS AIDS patients, I was given a notice of eviction. He left me without hot water for 10 days. It's hard enough to deal with all of the crap associated with KS AIDS, but … well, I got tired of being the forerunner." (p. 63)

Such personal offences against the health carer as well as the experience of suffering, the identification with the suffering and the inability to safe/ cure these patients adds to the phenomenon of 'burnout', as the nurse cited above continues:

> "I have stepped back tremendously within the health care in the gay and lesbian community since I moved to Houston, because I'm tired. One of the things that personally happened with me is a strain that results from getting patients with whom you can identify. I'm 38. The same age as many of these patients. (…), and when these patients die it's very hard." (p. 63)

The AIDS pandemic in Southern Africa does not only confront the medical personnel with patients with whom they can identify: Due to the large numbers of children being infected at birth, there might be a new dimension of emotional burden to the personnel caused by the large amount of children suffering and dying from the disease. Whilst the exposure to dying children in countries with a different epidemiological situation and higher socioeconomic standards might be limited to specialised areas such as paediatric oncology and maybe traumatology, now there is a vast number of children in severe health conditions.

Concerning strategies to counter the problem of 'burnout', a good social support system and the opportunity for a 'break' seems essential, as a director of an AIDS hospice stated on stress:

> "I have to get away as often as I can. A large segment of the end part of our training weekend deals with burnout. It creeps up on you. You can't totally prevent it. I have to keep telling myself and my friends have to keep telling me that this is my job now, and at times I have to get away and leave it. Also I have a fairly good support system, and that helps." (p. 67)

and about the topic of fear and stigma director of another hospice that had extended its program to include AIDS patients had experienced:

> "We had programs that every employee in every department had to attend, which ran all day. I think that now that the fright and panic are pretty well over with, our staff and aides are really getting attached to the patients. Really being good to them." (p. 68)

More recently an extensive study by local and US American researchers in Nairobi, Kenya, using participating observation, interviewing techniques and questionnaires found that in the given setting many of the medical professionals suffer from symptoms of burnout. This is contributed to an excessive workload with little therapeutic option for the HIV patients, the fear of the infectious diseases as well as the lack of support by superiors and of adequate financial remuneration (Raviola et al. 2002).

For South Africa itself a study showed a high rate of exposure to HIV positive blood amongst the less experienced practitioners in medicine (students and interns) at Johannesburg teaching hospitals as well as a significant underreporting of these events (Raviola et al. 2002). And Colvin (2005) concludes from the existing studies that the main impact of HIV/ AIDS on the adult sector in South African medicine appears to be an increase in hospital admissions, yet he notes with regret a “scarcity of data on the impact of HIV on health care services” (p. 336f) and complains:

> “Unfortunately there are little additional non-anecdotal data on the impact on health services but impressions are that the services are under strain” (p. 339)

In some regional hospitals young and relatively inexperienced doctors are reportedly making life or death decisions “simply because of the lack of consultants” (p. 345). For the paediatric sector it has been estimated that in 2002 89,000 children (6.7%) were born HIV positive – without ART 50% of these could be expected to die within 3 years and 90% before the age of nine (p. 340), and Colvin sees statistical evidence for a rationing already taking place whilst hospitals are reported to run for extended periods at 120% over capacity. This paper is ending with the quotation of an Acting Head of Medicine for Edendale, Grey’s and Northdale Hospitals:

> “People are dying prematurely because we are so stretched. Medical patients who don’t have HIV/AIDS are being severely compromised because we have to discharge them prematurely – everybody is being compromised – the system just can’t cope.” (p. 348)

Certainly not the ideal conditions to prevent South African health care worker from burnout.

To summarise the above, it can be said that the health professional dealing with HIV/AIDS in this pandemic is or might be exposed to a number of stressors in the vocational situation: The fear of getting infected, the experience of suffering and death in an unknown dimension and the helplessness against it, a severe overload of work and sometimes even social stigmatisation for working with HIV/AIDS. Other factors could ease the situation if they are existent (or worsen it if absent): Good social support (family and friends), advice and training by senior colleagues, financial security (remuneration) and the opportunity to take breaks from the exhausting experiences.

2.3 The ‘difficult patient’ – dilemmas from the patient/ health carer relation

> “(…) you see a lot of denial, anger, “why me”-ing. Often these men are unprepared to negotiate their way through the medical system, they don’t know how to talk with physicians and nurses, how to demand things, and as a result are usually frustrated at what’s going on, and consequently may act out by doing such things as throwing trays at aides.
> Confidentiality is a major issue with these patients. Many become social isolates after the diagnosis.” (Baumgartner 1986:59)

– what was reported from the personal experiences of an American social worker working with gay AIDS patients in the mid 1980s might be the case in nowadays South Africa as well, given the still strongly existing social stigma of the disease and of those suffering from it.

The experience:

> “They feel like lepers. They think they’re treated like lepers. They really do!” (Baumgartner 1986:68)

unfortunately is confirmed by the stand of some groups in society, as expressed by the abovementioned ‘Christian’ authors:

> “Leviticus 13 can serve as a paradigm concerning limits of confidentiality, since Old Testament communicable diseases such as leprosy are analogous to modern day "plagues" such as acquired immune deficiency syndrome.” (Rutecki and Geib 1991:12)

Sic! - to make things worse, Lev 13,45-46 gives rules for the segregation of lepers!

Therefore the social and cultural background, as discussed above, might result in a serious stigmatisation, what in return will have a severe effect on the patients’ behaviour in terms of the willingness to make use of health care, in terms of his or her openness and compliance.

The principle of patient autonomy can be considered a worldwide ethical standard in medical care for patients. This includes the necessity to obtain the patients informed consent (Beauchamp and Childress 1996:142ff) and can end in situations where the medical practitioner has to accept a patient’s rejection of treatment despite of this therapeutic option being ‘the best’ for the patient. To accept this might sometimes be difficult for the health carer, especially if his or her approach is to some degree paternalistic (like: “I know best what is good for my patients”), a real dilemma thus occurs if the patient’s competency for decision making is in doubt (as above:132ff; Carney and Hopper 2003). Often it will not be easy to decide whether an ‘unreasonable’ objection by the patient is due to his ‘a bit strange but healthy’ character or whether it is due to a mental impairment as a result of HIV encephalopathy or other disease related conditions.

Specific to HIV/AIDS is the fact that already the diagnostic procedure (HIV test) needs the explicit consent of the patient and therefore a pre-test counselling has to be done (Evian 2000:37). Thus an HIV patient can potentially ‘frustrate’ the health care affords in at least three stages: by not being tested (not visiting the health care facilities or refusing to have the specific test done), by refusing to agree to the initiation of treatment or failing to fulfil the criteria (as given in the “National Antiretroviral Treatment Guidelines”, South African Department of Health 2004:3ff) or finally by dropping out of the treatment program at a later stage after initially starting the medication. Particularly, the last point results in risks that affect more than the individual patients future, as the failure to comply with the necessary application schemes for the antiretroviral drugs has been reported to promote the selection of resistant virus strains and thereby, diminish the treatment options for those infected with these strains. Recognising the more difficult situation in the region as compared to e.g. the US or Europe, it has been written about “Preventing antiretroviral anarchy in sub-Saharan Africa” (Harries et al. 2001).

There is a plenitude of factors motivating or reducing the patient’s adherence, some of which were mentioned above as being linked to the cultural background. In general, it can be said that the process of obtaining the patient’s informed consent for testing and treatment as well as maintaining a high level of adherence for the continuous and most likely livelong treatment is a very demanding task for the health care worker and thus can lead to disappointment and frustration if failed, whilst these emotions again can negatively affect the relation between health carer and patient (Ojascastro 2000).

One of the fundamental dilemmas for a health care professional might arise from the need to deny a patient special treatment. The medical system in South Africa is far from being as well funded as those in Western Europe or the US and even there, the situation is common that certain procedures or drugs are not being paid for. With even more limited resources, the South African medicine in general and HIV medicine in particular will probably have to face some kind of rationing. This might result in the decision not to provide everybody who is eligible for it with antiretrovirals. The term ‘micro allocation’ is used to describe the process that happens in such situations: it has to be decided which specific patients will receive the treatment – and which will not, thus leaving the health carer with the need to communicate the denial of treatment to these patients. An example for such a situation might be seen in the case that a certain patient does not fulfil the abovementioned criteria and is therefore by the multidisciplinary team found not to be eligible for the treatment (South African Department of Health 2004).

A more specific dilemma might arise in the field of sexual and reproductive health. In this area, the main attention is not on the general health or maybe life expectancy of the HIV infected, but on the interest to be sexually active or to have (biologically) own children. The moral sensitivity thus and the source of dilemma for the health carer in this subject arises from the fact that HIV/ AIDS is reported to be mainly a sexually transmitted disease. Therefore, on the one hand the fact of being HIV positive is often attributed to the infected person’s promiscuity and by this way giving him an own responsibility (and guilt) for being infected. On the other hand, the HI-Virus could be transmitted further if the HIV infected practises intercourse (for its own sake or for the purpose of having children) and thus affect both the sexual partner and the potential offspring. Kell et al (2002) considered the decision whether or not to treat erectile dysfunction in the HIV positive patient to be “(a)n ethical dilemma” and recently it has been demanded not to deny HIV positive patients the necessary treatment from the fields of sexual and reproductive health to fulfil their ‘sexual and reproductive rights’ (Myer and Morroni 2005), what might be open for discussion in a setting that experiences an ever increasing demand for live saving treatment on the one hand and serious shortfalls in funding on the other.

To summarise the topic, it can be said that problems in the health carer/ Patient relationship usually result from difficulties in communicating and agreeing on expectations between the two parties. This can be caused by an underlying lack of trust (due to e.g. stigmatisation), by general problems of communication between the two parties (e.g. due to language or cultural barriers – as discussed under 2.1) or by a difference in what the one side is demanding and the other side is willing or able to offer (e.g. offer of treatment versus unwillingness to adhere; recommendation of treatment versus refusal of it, demand of sexual health treatment versus denial of moral right to claim for it). All these factors may lead to a difficult or even failed interaction between health carer and patient, often resulting in the assessment of a ‘difficult patient’, failure to achieve the possible medical/ therapeutic benefit and frustration for the health care personnel.

2.4 “I can’t tell her, she will kill me!” – the interests of third parties

Though the health carer/ patient relation usually focuses on the direct contact between these two people, the world doesn’t end at the borders of this micro cosmos, as a lot of expectations, demands, needs and rights are usually touched by the simple dialogue between e.g. a medical doctor and the patient: The patient has family (parents, spouse, children etc) and friends who might be affected, an employer who pays for the work or others who may be at risk due to the patient’s disease, either because it is communicable or because it impairs him to a degree that causes a danger for others, e.g. epilepsy and car driving – to name just some of the most obvious examples.

Discussing dilemmas for the health carer in HIV treatment it can easily be seen that this area is particularly prone to cause such dilemmas when e.g. the patient’s interests have to be weighed against other (‘third’) persons’ interests.

On of the traditional obligations of the health carer since the days of Hippocrates has been the confidentiality, i.e. that the medical practitioner abstains from disclosing any information gained by treating the patient without the latter’s consent (Beauchamp and Childress 1996:418ff). From the patient’s point of view this obligation to the health carer reflects the right for ‘informational self-determination’, with this perhaps regarded as a part of the principle of patient autonomy.

How difficult it might be to keep one’s positive HIV status secret if social support is being organised and distributed publicly has recently been described using the example of Ugandan food supply for those infected – where some people abstain from receiving these goods not to disclose their status (Whyte et al. 2005).

2.4.1 ‘To tell or not to tell’ – the problems of disclosure

Voluntary disclosure of the positive HIV status is regarded as an important psycho-social factor to qualify a patient for the antiretroviral treatment in South Africa (South

African Department of Health 2004:3). The many factors and difficult considerations that are being made by HIV positive patients have been described for African American women (Black and Miles 2002). Ideally this act of disclosure will result in finding support and understanding for the difficult situation that the HIV positive person is in, but as has been described, it can also go horribly wrong:

> "I had a case recently where a professional here in town came to me and said, "I've been diagnosed, and I've secretly gone to work, and I've secretly gone here and there, with my friends thinking I was away on business. I don't know who to tell except my lover." We talked about some important people in his life, a psychologist friend who would be supportive, a priest who works with gay people, and his lawyer. Sounded reasonable. The first thing that happened was that the person who did the biopsy told others, and word got out that this person was going to die. The attorney got a hysterical reaction. Everyone the patient would see at a bar or party would become angry and call him and ask what he was doing going out, warning him he couldn't pick up people. Essentially his attorney buried him. The patient is now at the stage of not telling anyone." (Baumgartner 1986:55f)

The health carer often is asked to advise the patient on how to proceed, and not only in medical and pharmaceutical matters but with regard to the psychosocial situation, too. If additional topics come into sight, this role of the health carer might become even more difficult. One of these problems could be that the patient in respect is a minor (Adams 1994), a situation where the delicate decision between the minor's confidence as an essential prerequisite for the relation with the health carer will have to be balanced against the parental responsibility and right to be informed and the respective legal regulations. Again religious background can lead to a different result of the considerations:

> "Information given to health care workers by minors is to be handled differently by Christians because of Biblical mandates related to the authority of parents, sanctity of marriage and importance of the family." (Rutecki and Geib 1991:14)

2.4.2 'Duty-to-warn'? – responsibility to the spouse

Another 'classical' conflict of rights (and a dilemma for the health carer) is the situation that a person with positive HIV status is unwilling to either disclose this status or to initiate protective methods in the sexual relationship[5]. This topic of 'partner notification' has been highlighted from a number of perspectives. The special

---

[5] In the US, this situation often is discussed together with the topic of needle sharing, yet the transmission amongst iv drug abusers does not constitute a major route of transmission in South Africa

role of family physicians has been emphasised (Toomey 1990), as this group of medical practitioners often has a genuine knowledge of the patient's social surrounding, which puts them into a unique situation once they learn about the patients HIV status: Unlike the personnel e.g. at an HIV clinic, where often only the patient himself is known and information about e.g. sexual partner would have to be given by the patient voluntarily, the family practitioner immediately has an idea who else might be affected by the infection. Different approaches to inform such stakeholders about the need that they too should undergo HIV testing have been described and named: 'patient referral' means that the health carer tries to motivate the patient to disclose his status and the necessities for the partner himself, 'provider referral' involves the health carer, who will either contact the stakeholders himself or make use of other facilities, e.g. public health institutions. The latter approach usually aims at obtaining the 'index patient's' consent and the health carer will thus act as a kind of assistance for the patient who feels incapable of fulfilling this task of notification himself. If the patient and the surroundings are unknown to the health carer, the patient's cooperation will be as essential as it is in the case of the 'patient referral' to achieve anything. But in certain rare situations the health care provider might have to consider disclosing information out of a 'duty-to-warn' against the patient's will. The legal aspects of this dilemma have been discussed under the experience that in an extreme course of events the health carer might even be held responsible for damage suffered by the partner, yet in her 'HIV partner-notification plan' the author advocates a program of voluntary notification, assisted by mandatory training about this topic for the involved health carer and legal regulations that ensure indemnity to the health carer if the procedures are followed (Bernstein 1995). Out of their religious perspective Rutecki and Geib speak of an "obligation to practice "limited" confidentiality", discussing a similar case this results in the conclusion that:

> "Since a risk to life exists (wife-AIDS, unborn child-abortion) select dissemination must occur." (1991:13)

- and they advise that generally:

> "The Christian health care worker should volunteer his/her Biblical views regarding the protection of and love of neighbor prior to the verbalization of any confidential information. In fact, one can argue that Christian health care workers should publish a statement for both patients and colleagues that presents a philosophy of limited confidentiality according to Biblical revelation." (p. 14)

For the health carer in this country the Health Professions Council of South Africa has issued a handbook on good and ethical practise that contains one chapter entitled “Guidelines for the management of patients with HIV infection or AIDS” (2002). Here it is stated that

> “(i)n the management of the HIV positive patient, the health care worker has a primary responsibility towards the individual patient. The health care worker also has certain responsibilities towards other health care workers and other parties that might be in danger of contracting the disease from the patient.” (p. 89)

Unfortunately, it has been found that the peculiar issue of confidentiality still lacks clear legal regulations:

> “The principle of confidentiality applies in respect of the patient. The decision whether to divulge the information to other parties involved must, therefore, be in consultation with the patient. If the patient’s consent can not be obtained, ethical guidelines recommend that the health care worker should use his or her discretion whether or not to divulge the information to other parties involved who are at clear risk or danger. To date, we have not had legal clarity regarding whether this situation is an acceptable limitation of the right to confidentiality.” (p. 94)

To say it in brief: Law and jurisprudence are not clear on this topic and it remains to the health carer’s discretion to decide – far from an ideal situation for such a delicate issue. At least the HPCSA continues with practical recommendations how to proceed in such a case: Counsel the patient on the importance of disclosure – provide support to the patient to make this disclosure – if the patient is still refusing, counsel him on the health carer’s ethical obligation to disclose and request consent to do so – disclose such information.

2.4.3 “I will lose my job!” – HIV, occupational health and the employer

In a study from the Senegal, this dilemma was one amongst others, as the authors examined the problems that HIV/ AIDS causes for occupational physicians (Mbaye et al 2004). Some of the medical practitioners confirmed to have forwarded information about the HIV status of the employees to the employer. The employer’s knowledge can, as it was already described for other disclosures, have positive or negative effects for the patient. On the one hand, an employer might offer additional health care funds to support the patient, as South African mining companies e.g. run their own antiretroviral treatment programs, not for altruistic reasons but to keep their skilled but HIV positive workers alive and fit for work. On the other hand, the HIV infection or the pharmaceutical treatment with its side effects may reduce the patients fitness to perform certain tasks: Who would wish to board an airliner that is being flown by an HIV positive pilot who's vision is impaired by CMV retinitis and who's vigilance is affected by the sedating effects of antiretrovirals – in the German Armed Forces e.g. everybody who is HIV positive is considered unfit to pilot an aircraft.[6] These vocational restrictions might threaten the patient as he might lose his job or at least significant parts of his salary – reason enough to 'hide' such impairments from the employer, leaving the health carer with the dilemma to decide whom to protect, the patient or those potentially endangered by his behaviour.

2.4.4 "If I don't breastfeed, they'll know I have AIDS!" – mother and child

A completely different kind of stakeholder is affected in another often and intensively discussed area – the mother-to-child-transmission (MTCT). The 'third person' here sometimes (or at least at some stages) is not yet a person, and as Flagler et al. (1997:1730) state the woman during pregnancy is not yet a mother either. Nevertheless, it is commonly expected from the mother-to-be to act in a way that prevents the foetus from harm and this would include e.g. the intake of antiretroviral drugs to prevent the transmission of the virus from mother to child (PMTCT, van Niekerk 2004), where it has been shown that the consequent application of optimal methods can reduce the risk of transmission by a factor greater 10, from about 25% to 1-2% (Coovadia 2004). After birth the risk of infection is still given since breast-milk contains the virus and has been shown a potential way of infection - a factor contributing to the fact that the rate of transmission in developing countries stays at 15-25% despite the application of single dose regimens of antiretrovirals to reduce perinatal transmission.

To lower this risk, different methods have been suggested, e.g. the mother can be advised to bottle-feed only to avoid any risk or one can try to make the breastfeeding safer. There is some evidence that exclusive breastfeeding would result in a lower rate of transmission – and to feed only expressed breast-milk that has been heat treated would reduce the risk further (Coutsoudis 2005:957f).

But breastfeeding, as a part of motherhood, is a very important experience and is affected by many cultural rules and traditions – thus causing problems in the implementation of these interventions, as helpful as they might seem 'in vitro'. As breastfeeding is the norm, almost without exceptions, in rural South Africa, the

---

[6] personal communication of the author with the German Airforce's Institute for Aviation Medicine

decision of the mother not to breastfeed her baby would immediately disclose her as being HIV positive (p. 958; Dohrn 2005) and possibly expose her to social stigmatisation and isolation. To make things worse, in many rural areas there is no continuous supply of clean drinking water, a necessary requisite to prepare formula bottle milk. Finally, the idea of exclusive breastfeeding might be an illusion as well, since very often children of only a few weeks of age are being fed additional porridge – to deny this might come at the expense of disclosing one's HIV status, too. Therefore the health care worker is often left with the dilemma to choose the lesser ill: Recommending the use of formula milk to the mother might end in the child being malnourished because of the lack of formula or fresh water, or the benefits of certain concepts will be lost because the mother has to fulfil the traditional expectation of breastfeeding behaviour.

2.4.5 'Justice'? – the other patients

To conclude the considerations of third party interests, one last group's concerns should be mentioned: the other patients'. It can easily be understood that it is an important task for the health care worker to protect other patients from being exposed to the virus at health care facilities (Isaacs and Jooste 2004). But there is another, more indirect way by which the other patients' interest is affected. When discussing the health care burden and the stressors acting upon the health care worker it has already been shown that the HIV/AIDS pandemic is threatening to overstretch the already struggling South African health care system. This, of course, comes down to the expense of the quality of care for patients who suffer from other diseases. In a system with limited resources (basically every health care system) the health carer always shares some responsibility for the allocation of these resources. He or she does this on a micro level, on a daily basis, by prescribing a certain therapy to a specific patient. They may, however, have to do this on a higher (macro) level as well – the questions "Does it make sense what we are doing here?" "Is the money spent well?" "Are we winning the struggle?" or maybe even "Should the money rather be spent on prevention instead of treatment?" are considerations that the health care worker has the privilege to have special insight into from his or her daily work. And Therefore the health care worker has the obligation to answer whether the allocation is fair with regard the other patients' interests, which might cause a dilemma.

To summarise the above, third party interests are regularly involved in medicine, particularly in HIV medicine in connection with disclosure of the status. Family members, spouses and employers can justify their interest in learning about the HIV status, either out of responsibility or because they are personally endangered. The prevention of mother to child transmission seems to be complicated by the local traditions and social norms. Finally, the assessment of whether or not the given health care approaches ‘make sense’ is also a field where the health carer might have to consider such third parties’ interests.

2.5 What do we know, what do we need to know?

The aim of the above discussion was:

- to establish that HIV/AIDS is one of the most important medical and social factors in today’s South Africa (chapter 1.1).
- to make aware of the fact that the high number of patients presenting with HIV/ AIDS related conditions as well as the creation of special ‘wellness-clinics’ (the sites for specialised HIV/AIDS testing, care and drug roll-out) brings into existence a kind of ‘extra branch’ of medicine with potentially own problems and rules (chapter 1.1/1.2).
- to show that a plenitude of problems and burdens might be present for those health carers who accept the task to stem the pandemic (chapter 2), that these problems are either due to the specific situation with HIV/AIDS (e.g. 2.4.3) or due to the specific situation in South Africa (e.g. 2.4.4) – and with these problems resultant in difficult decisions or ‘dilemmas’ for the health carer.
- to emphasise that seemingly so far little effort has been put into investigating, describing and – hopefully – improving the situation of these health carers in South Africa, a gap that certainly will have to be filled to ensure the sustainability of the HIV/AIDS treatment program.

3 Research question and methodology

3.1 Research question and hypothesis

As it is visible from the literature HIV/ AIDS is an important factor in South Africa nowadays and the health care workers in this country are heavily involved in the treatment of this disease. Since recently the national treatment program was started, it is the aim of this study to examine the situation of the South African health care worker in this particular field of medicine. Therefore, the guiding research question will be:

What are the specific problems, emotional burdens and ethical conflicts that the health care workers involved in the antiretroviral rollout program experience and which might cause dilemmas for them?

The underlying hypothesis is that there are specific, identifiable and communicable burdens for this group of health care personnel and that these burdens affect the personnel emotionally.

3.2 Methodology

3.2.1 Type of study

The study is performed as a qualitative study, using semi-structured in-depth-interviews.

3.2.2 Theory building

No research, neither qualitative nor quantitative, is free of underlying assumptions or applied theories. Therefore it is important to reflect and analyse what theories might be used and how they have been built (cf. Meinefeld 2004). In preparation for this work, a number of conversations have been held with health care personnel working at the wellness clinic. In these talks, certain concerns were expressed by the staff. Based on these first impressions and equipped with a brief list of concerns, an extensive literature review was exercised. This review used both internet based sources (Medline, google.scholar, inventory of the university library of UNISA – screening for ‘HIV’, ’AIDS’, ’treatment’, ‘dilemma’, ‘burden’, ‘personnel’ in various combinations) as well as ‘manual’ work, identifying further relevant literature from bibliographies/ resources list in some of the acquired papers and monographies and amongst the physically present publications at the relevant shelf mark at a university library (UNISA). The topics evident from the relevant publications were then grouped into clusters as described above. The scheme used to create these clusters is basically meant to reflect the degree to which the contact with patients and other stakeholders contributes to these conflicts: Whether it is merely the working situation involving the fears and worries the health carer experiences, whether it is conflicts caused in the interaction between health carer and the patient or whether it is the triangular situation between health carer, patient and another stakeholder. In each of these groups a number of topics were present in the literature and it was obvious that the cultural diversity and division of South Africa might play a significant role in causing such problems. As can be seen, the targeted topics might be considered to belong to different fields of sciences: the workplace problems may be considered ‘sociological’, some of the conflicts and dilemmas are clearly ‘ethical’ and much of the influence of cultural and traditional believes could be assigned to the realms of ‘anthropology’ thus causing this research to be – as has been stated – a ‘chimera’.

3.2.3 Methods of data collection

For the specific field of this research, little has been published on the situation of the South African health care worker. Therefore, no established theory could be used to compose a questionnaire and collect data in the manner of a quantitative research. Instead, as described above, an original theory had to be deduced from the literature available on the relevant burdens for the South African health care worker. In obtaining data from involved personnel, these concepts have to be validated – are the topics derived from the literature relevant for the South African setting? The research focuses on personal experiences and the personal perception of problems rather than on structural or procedural shortfalls. While participating observation is an adequate tool to identify examples of the latter, the usage of interviews offers better opportunities to collect spoken word statements from the affected people as well as evidence (open and indirect) on how relevant the particular topic is deemed and felt by the interviewee. According to these considerations it was decided to use a semi-structured interviewing technique – a narrative interview technique would probably have allowed somewhat more insight into single topics as chosen by the interviewee but would not have allowed to evaluate the relevance of the other factors identified from the literature.

Well in advance of the interview (at least one day prior to the appointment) the interviewees received an information leaflet containing information on the kind and purpose of the research. Some examples of very general questions that could be asked were also included, as well as two vignettes (short case descriptions of potentially troublesome patients): a child that for social reasons does not qualify for the antiretroviral treatment and an older TB patient who shows clear evidence of non-compliance.

As a location for the interviews, a private place was agreed upon, either at the interviewee's or at the interviewer's domicile. The interview would commence with a few brief biographical questions to gain details about age, home language, amount of professional experience and prior experience with HIV/AIDS. The very topic of the research would then be addressed with an open question "What do YOU consider to be the most important problem that you experience working at the wellness clinic", giving the interviewee the opportunity to express his or her gravest concern. Following this the different topics, as defined from the literature, were covered, using the case examples to focus on topics like e.g. 'suffering of children', 'justice', 'fear of own infection' or 'lack of adherence'. To ensure that all the identified topics would be covered, a printed interview guide listing these items was used and those topics that had been mentioned were ticked (cf. Hopf 2004:352). The interview, however, was not structured by this guide but followed the topics as they were brought up by the interviewee. Also included was a request to suggest ways to improve the situation at the clinic. At the end of the interview the health care professional was asked whether he or she could think of anything else in connection with the field of dilemmas/ burdens for the health carer involved with HIV/ AIDS, giving opportunity to add possible items that had not been considered so far. In addition to this, internal validation was attempted by either summarising the most important topics for approval by the interviewee or by asking the interviewee what he or she himself considers the most relevant topic. Each of the interviews would take between 30 and 60 minutes.

3.2.4 Study population/ Interviewees

As was mentioned in the introduction, the source of personnel to be interview was one ‘wellness clinic’ in Rustenburg in the North West Province’s Bojanala District in South Africa. It was decided only to include health care worker from the two professional groups of registered nurses and medical practitioners. Though there are a number of other professions and lay worker involved in the HIV/ AIDS treatment, e.g. pharmacists, dieticians, social worker, lay counsellor etc. the two aforementioned groups are those who usually cover the main part of diagnostic and therapeutic conversations and decisions. Given the limited time frame and resources of this study, the inclusion of other groups would have made it impossible to collect a couple of interviews to compare and analyse whether certain problems are individually caused or more general features. Since the ‘population under investigation’ is working in a specialist field and location, the purposive selection of the sample would have to focus on these locations viz. the wellness clinics. Since the South African administration expects that research proposals are forwarded from the local level to the level of district administration (so far usually only one rollout-site/ wellness clinic per district had been established) sampling from more than one site would have necessitated the time-consuming application to and involvement with more than one district administration. Therefore the limitation to one site as a kind of convenience sampling had to be decided upon.

Prior to the research, it had been targeted to collect approximately five interviews per professional group, though this number was to be reassessed according to the findings from the interviews (whether still new ideas appeared as mentioned above) and according to the external circumstances as well (cf. Mertens 2004). To select the professionals for an interview, they were to be registered with the respective South African professional board and had to have gained at least three months of experience in the field of HIV/ AIDS care in the rollout program. In the end a total of nine health care workers (4 nurses, 5 medical doctors) were interviewed, covering basically the entire staff in the two categories at this one facility.

The physicians, two men and three women, represented different African cultural backgrounds, two where native Nigerians, one from the Democratic Republic of Congo and two were South African nationals, each of the five having a different African mother tongue. They were aged between 28 and 38 and had between 3 and 10 years of professional experience (6 to 12 months at wellness clinic).

The five female nurses, all native Tswana (the local African language) speakers were aged between 32 and 47 and had gained between 8 and 24 years of experience in their profession, including between 12 months and two years (since the very beginning of the program) at the wellness clinic.

3.2.5 Methods of data analysis

After obtaining consent from the interviewees, all interviews were recorded digitally and subsequently transcribed verbatim by the author (cf. Kowal and O'Connel 2004; Henning et al. 2004:162ff). This process served as an aid to improve the interview technique as well as a first analysis of the content. On reviewing the interviews, sections were coded for content, using both colour coding to indicate certain predefined clusters from the literature review, as well as topic related naming of the sections. After this procedure more attention was paid to the complete interviews, trying to assess what topics were particular important for the interviewee as expressed by wording, repetition, time and emphasis and other 'nonverbal' indicators, e.g. signs of nervousness (pausing, laughing etc.). Reviewing all the interviews, when it was found what topics or codes appeared as most relevant, both in terms of frequency and of emphasis of mentioning, those topics or coded sections were grouped into clusters that roughly resembled those suggested in the literature review with some additional clusters to be defined as well (cf. Mayring 2004; Böhm 2004; Henning et al. 2004:101-124).

Transcription and analysis were performed as an ongoing process during the period when the interviews were done to be able to learn whether new aspects were still appearing.

3.2.6 Ethical assessment and confidentiality

To assess potential ethical conflicts that could be encountered by this study, it is important to consider the population under investigation as well as the data or information that is being processed. As should be obvious from the above description, no patient contact or access to patient data was intended or obtained for the research. Yet the study involved personnel who is directly and daily involved with patient care and who gains the experiences expressed usually exactly from these patient contacts. Therefore, it was taken care that no information about individual patients that might have been mentioned during an interview would be cited or used in a way that could lead to the identification of an individual patient or his/ her details.

But independent from the ‘patient issue’ that traditionally is of utmost concern discussing research ethics in medicine, this study is one using social sciences techniques including personal statements and narratives about personal experiences that could potentially be linked to individuals amongst the health carer. To avoid any negative impact for these individuals, again the highest attention was paid to the avoidance of citing, directly or indirectly, personally identifiable data of these individuals. Nevertheless, it has to be acknowledged that qualitative research lives from the very ‘human input’, the individuals’ stories, resulting in the fact that potentially not all ‘typical’ features or ideas could be avoided, particularly where the spoken word is to be quoted.

In advance the individual health care workers to be interviewed were, as described above, informed about the concept, the topic, the intentions and the focuses of the research by using an information leaflet. In addition it was pointed out that despite the efforts of the researcher, complete anonymity in the given situation (nine interviews from one location) could potentially not be guaranteed. Before commencing the interview, the leaflet was discussed and the interviews consent for the research as well as for the audio recording was obtained. The interviewees were informed that they could terminate the interview at any stage.

The CEO of the provincial hospital, the clinic is attached, to was informed about the intended research and handed over a written concept of the study including the research proposal. These were forwarded to the district research committee and no objection was expressed.

4 Results: HIV medicine – something special?

During the interviews one of the questions gave the health carers the opportunity to explain whether they experience special emotional burdens in the field of HIV medicine. In addition to that, many of the interviewees used comparisons to other fields of medicine whilst discussing other topics like the behaviour of the patient, the chronicity of the disease etc. The general motion amongst both professional groups (nurses and doctors) was that since the introduction of HAART HIV/AIDS has become a treatable though not curable disease which in its chronic nature and perpetual need for medication is comparable to other chronic conditions, as two nurses put it:

> “(I)t should be taken as any chronic disease. I don’t understand why it’s taken so … why it’s so special compared to others, because I think it should be treated like any chronic disease.”
>
> “(F)or now what we say, we … we just tell them like they should take their HIV medication like diabetic, like hypertensive. Because once you are a hypertensive patient, it takes long for you to say that you are no longer a hypertensive patient. Some few of them they will even die on those hypertensive medications, not necessarily meaning that they are not taking the medication well. So we just relate that HIV to the other conditions, it’s just that we explain to them that like the introduction of HIV and AIDS, it was scary in the first. But for now, we have medication just to suppress the virus, so people can live for longer. They do understand when we relate it to the other conditions. (…)
>
> Because if you ask relating to the grandmother: ‘How long did your grandmother take medication for high blood?’ they will tell you: ‘Twenty years’ ‘And then, how long did she live?’ ‘You know, twenty two years, thereafter she died.’ ‘Why?’ ‘Because of diabetes mellitus.’ So it was time. They just have to accept that if it’s time it’s time, but with the medication, if you take it well, something is going to go alright.”

and a doctor states about the fatality:

> “If you have got a heart problem, it is going to kill you; it is the same as in HIV.”

whilst another colleague addresses the lack of cure:

> “(H)ypertension has no cure, asthma has no cure, sickle cell has no cure, epilepsy has no cure, you can go on and on and on. The only difference I guess is that … that people say it is an adherence thing, that because the patient has … they don’t miss one day of their drug.”

The last point mentioned above, the need for adherence and the potential for (fatal) failure of the treatment is the one special feature of HIV medicine the health carers agree upon, as strict adherence is clearly more important with antiretroviral drugs than with for instance antihypertensives. Unlike in all the other chronic diseases, the treatment in HIV medicine is all about controlling an infection that is established in the body of the patient and the causing agent, the HI virus is constantly reproducing itself if not prevented from doing so. Thus once a resistance has developed and especially with the limited number of drugs available in South Africa in the public sector[7] after loosing the effect of the available drugs little more than ‘supportive therapy’ is left to be offered to the patient, as one doctor said:

> “That’s very worrying, you know, in all the chronic diseases, when the patient decides to stay on treatment, even if he messes around, he can stay. You either increase the dose (…) or you do (…) multiple therapy, you give more than one drug. *In HIV, when you blow it you blow it.* That is just the problem.”

The fact of dealing with an infectious disease certainly has other implications, too, since the fact of the pandemic has to be contributed to this very nature of the disease – and a distinct affection of the health care workers, the fear of infection is caused by this attribute of HIV/AIDS as well. From the statements of the interviewed health care workers clearly emerged two main concerns, the exhaustion by an unbearable workload and the frustrations caused by the ‘special’ patients – probably another factor that distinguishes HIV medicine from other fields of medicine. These two ‘main factors’ will, alongside others, be discussed in the following chapters, trying to systemise the information a bit in accordance with one doctors comment[8]:

> “Ah, what sort of problems, I think there are different species – what you’d call dimensions. Especially is it problems to the patient, problems within the patient, problems you as a doctor coping with the system, problems with the management – all sorts of problems.”

4.1 The health carers’ situation – the threat of burnout

Since this whole research is centred on the health care worker, the first question shall be how the individual workers have experienced their situation. As has been described when discussing the literature, a couple of factors potentially affect the work-satisfaction and cause in the worst case a burn out syndrome. These contributing factors include the amount of work that has to be managed, special fears

---

[7] in the roll-out program two regimen are offered: regimen 1 with Stavudine, Lamivudine and either Efavirenz (1a) or Nevirapine (1b) and as second line regimen 2 with Zidovudine, Didanosine Lopinavir/Ritonavir

[8] actually a counterquestion to the question about the gravest difficulty that indicates that the health care practitioners do experience these distinguishable ‘dimensions’

arising from the work (occupational hazards) and the financial remuneration as well as the nonmaterial appreciation of the work done.

4.1.1 Overwhelming workload

The one problem that was consistently and by all interviewees without exception complaint about was the excessive workload in the clinic. Both groups acknowledge that the workload at the clinic is far to high and this topic is often mentioned as to be the most relevant difficulty experienced at the clinic, with a significantly negative impact on the working relationship between the health carers:

> “The other thing is workload basically; we are seeing just far too many patients. I don’t know how we can avoid it, because we are the only clinic in a very large area, but the workload is far too much. It’s exhausting. And it has a tendency as well of creating disharmony amongst the staff. It is obviously if one works too much you are thinking that the other colleagues are not working and they are actually working equally as much, so it’s a situation that really can create a nasty atmosphere, basically.” (a doctor)

This problem results in patient numbers per health carer that are far beyond reasonably manageable scales, what is sometimes contributed to the early stage of the development of the program:

> “But there is a lot of human resources; we are short staffed, so like we are only one site in Bojanala[9] right now, so we are catering for 46 clinics that are referring to us. So if we have to return the other thing, take the other thing it’s draining to us, we end up seeing plus minus 120 to 160 only with sometimes two doctors or three doctors and two nurses or three nurses.” (a nurse)

As additional explanations for the exhausting situation, some people see specific conditions of the local setting. These would include the social and economical structure of the region with its consequences for risk behaviour and infection rate amongst the population:

> “For what I know it’s that we have a potential to be very busy and given our country statistics and the nature of our town, our town is very industrialised, lots of mining, migrant labour system, so we have, maybe not the highest, but our numbers are not insignificant and it is expected that we are going to see huge numbers and hopefully, ehm, there will be strategies to, to handle the big numbers, not only leave it to one clinic but look at ways of getting everybody involved to ease the burden. So the numbers are high and we are not reaching a significant number of them and, ehm, ya, we just need strategies to ...” (a doctor)

---

[9] name of the administrative district Rustenburg belongs to

The fear and expectation that only a little of the ultimate disease burden has already become visible is widely shared and can be estimated from the data given for the infection rate and the population numbers compared to the number of HIV positive patients currently registered in the local clinic (ca. 4500), though the following probably rather expresses the general concern and not exact statistics:

> "And then the whole pandemic is for now it's still under controlled, it still not controlled. You know, those who are lucky are on the board, but I think it is still just one percent of them, and then the other, you know, 99 percent are still outside with the treatment. So the treatment is behind a lot. " (another doctor)

4.1.2 Working together

This overload of work and the perspective of the situation getting even worse definitely causes a lot of friction amongst the health care workers. This can be observed within the respective groups of professionals when one individual gets the impression that he or she has to work more than the fellows do, as it was mentioned above and is confirmed by another colleague:

> "(…)because of workload in the clinic, ehm, I was talking to one of the colleges recently, who mentioned 'What was the harass between you and one of the colleagues?' I think the pressure of the workload was taken on one person, I mean he was feeling what we have all felt and I have tried to do something about. Somebody said the things you can not change, you just ask god the grace to bear them. So may be he hasn't gotten into that stage yet, he is still personally not sustaining with some of the things that occur there.
> The workload could affect you so much now, you didn't know where to direct the problem to. You see now, you feel that the other colleague is not doing his work, is not seeing as many patients as you see, the mere fact that when you see them, the average time you have to see them is maybe two minutes, I don't know how you see a patient in two minutes."

But in addition to the tensions amongst e.g. the doctors, the extreme workload causes criticism of other professional groups as well. This starts with the cleaners, who work on a voluntary basis and therefore can not be requested to work at the right times, thoroughly and reliably. What is probably of more of concern than this problem is the fact that quite often criticism from the medical doctors is directed towards 'the nurses' in general, a problem probably found in health care all around the world, but nevertheless detrimental to the working atmosphere:

> "So you see, in terms of satisfaction, where the work comes in now, we'll be fighting with the nurses. The nurses sometimes don't know what their job is. They just go pick …

> retrieve files. Why should they go retrieve files, it's not the work of a nurse. They should have somebody in records gets the files. The nurse has to assess the patient, see the patient, know how sick he is even before he sees me.
>
> She should know whether the patient needs an admission, put up a drip, whether he is anaemic, should even have done the blood test before I get there. So if you don't know what you are doing as a nurse, there's a problem with roles … (…)
>
> You know what I mean. So you feel overburdened, the doctor will have to do everything."
>
> "That are procedures that we need them immediately to be done from nurses, you know, like I need this patient to get this injection for me as my treatment, you struggle to get the patient to be given buscopane or whatever. You don't know what the nurses are doing here."
>
> "That is why at the end of the day I feel that the doctors are more overworked and overloaded here because where I come from (…), once you started treatment you can leave it with the nurses. That's after one visit then from second month up to the fifth month are the nurses, you know. And then the doctors can start new patients in all the time. It's not structured like that here. Here it's every visit the doctor should see. So at the end of the day I end up asking: What are the nurses doing?"
>
> "Well, in general we do work well together, but every now and then especially with this workload problem if one feels, you know, that some others could take a bit more than they are already taking, like the sisters could scan more patients and then the doctors don't have to see so many, so that creates a lot of problems. So if one feels that the counsellors are not doing a proper job of counselling and now the doctors have to go an extra mile to make the patients understand, that can be quite strenuous and that does affect the relationship amongst staff members and ..., yah, quite negatively."

The other 'target group' of widespread criticism from within the ranks of the doctors were the counsellors, as can be read in the last quotation. This group of lay personnel is often employed at the HIV/AIDS clinics or by NGOs on a salary base to assist with the process of counselling. Counselling includes giving the patient a general idea of what behavioural changes might be necessary, but what is particularly important for the success of the antiretroviral pharmacotherapy is that the patient understands the need for strict adherence and practises it. The lay counsellors usually only enjoy a brief training (approximately two weeks) for their task. Nevertheless, they occupy a crucial role in the system. The above experience is echoed by others:

> "but then the counsellors, I think they need to go for a refresher course or, you know, I don't know where they trained for the counselling, but I don't think they are up to date …"
>
> (a doctor)
>
> "I don't know what is happening during training but the counsellors are not doing well. Because you see the rate of defaulter and then some of them you talk to them and tell

> them: ‘But you shouldn’t do this and this and this’ and they say: ‘But they didn’t tell me.’” (another doctor)
>
> “I gave them an example, I took a session with one of the counsellors every time I would take one of them and try to show them the physiology and everything surrounding, you know, why are we saying you must take it from 8 to 8?” (a nurse)

More generally professionals from both groups complain about a lack of dedication or ‘professionalism’ by some of their co-workers, as these fellow workers show a tendency of avoiding work, extending tea breaks and arguing rather than helping the patients, resulting in the impression that some of the people who are working at wellness clinic seem not to know what they are being paid for:

> “When I got there, I realised that when I see the public sector, there is a lot of mediocrity for our people, we don’t love our people if we can improve their fate, why can’t people try to improve if they can? (…) Okay, what I have realised, you know, the professionalism at our clinic is very poor.“ (a nurse)
>
> “To improve the situation, I want everybody to realise that we have to work, from the cleaner up to the doctor, up to the super. You understand? Everybody must know that we – this time I am not talking about the patients – I am talking about the workers: We are going there to work. And each and everyone must know: What is my job description, my daily job description? Because somehow, most of us sometimes we don’t know what we are supposed to do and that is creating a mess, you know.” (a doctor)

These problems with the other fellow health workers certainly may increase the difficulties the individual experiences at the clinic, but to a distinct degree these tensions may just be caused by the difficult working conditions. In addition to the extreme workload a number of other obstacles had been named by the interviewees: Deficiencies in communication that resulted in blood samples getting to old for analysis, difficulties having the patients’ files available in the consultation rooms on time, the lack of a dedicated paediatric HIV clinic and – as a point of concern shared by many interviewees, particularly nurses - the infrastructure of the clinics building:

> “About the infrastructure I can comment, I am not happy with it. If you go to wellness clinic, it is so packed. Rooms - no counselling rooms, everywhere it is so packed. Just imagine, we started in 2004 with wellness clinic, it’s 2005 and with HIV, I don’t know what will happen in 2008. So that building is too small.”
>
> “The wellness clinic is small as well … in terms of space. They had promised us another building nearby, but nobody is talking of it anymore.”

4.1.3 The negative impact of the situation – patients and families suffer

As can be expected, an unfulfilling, or even exhausting, situation at work will have negative effects on the individual workers private life, affecting those living with him or her:

> "You know, the thinking of works and what people are doing when they are thinking how miserable your working conditions are and how much underappreciated you are. I always complained to my girlfriend, and I still complain. (…) the frustration you actually took home with you." (a doctor)

In addition to these harmful effects on the personal relations, the permanent stress might as well negatively influence one's health. It is especially evident in the immune system, as the main stress hormone is known to be one of the most powerful immune suppressants – certainly not the ideal condition for health care workers who are exposed everyday to infectious agents that may make advantage of an impaired immune system, like e.g. the bacilli that cause tuberculosis:

> "But then you see all these people again then you think: 'Oh I am so tired, I don't want to do anything'. And I think it is also affecting our … health also, and I think also our children are suffering. Because when you come back, you are just so tired, the kids must go and be patient, at that time you are so tired, you just want to sleep. And you wake up at eleven o'clock when you thought you go to sleep at four just for two hours. And you wake up you are tired for the whole day." (a nurse)

And apart from the detrimental results 'at home', the overload of work and especially the inadequate number of staff in relation to the number of patients (those already in included in the program and even those still to be included) goes with a negative impact on the quality of care these patients receive. After all they should be the very focus of this program:

> "And you as a doctor, you need (…) to give the best care to the patient."

Yet the overload of work affects the delivered care at a number of points like the counselling:

> "Especially in this place, there are a lot of people on ARV, so the counselling sessions are very short. You know, you find that you do one session and start on ARV and not all of the people are … are, I would say 70% of them are not acquainted to do one session and start." (a doctor)

The patients are also forced to spend a lot of time in the clinic whilst waiting to be seen. In this time they crowd the clinic, complain to the staff and of course sometimes get upset about the long waiting periods (as mentioned by a nurse asked about satisfaction):

> "Yah, so yah, with the patients, it becomes … they spend a lot of time, waiting time, waiting period, it's not acceptable, because they come 7 o'clock or 8 o'clock and then they'll only go home round about two or three o'clock. So we can not work well with the waiting time, so for us it is disturbing."

Obviously the quality and extent of the consultation between the patient and the doctor will suffer from this situation, which will lead to the risk of the doctor missing important facts from the history or complaints of the patient. On the one hand, potentially severe complications will not be discovered, and on the other hand an experience of dissatisfaction by the patient, who might not feel fully accepted. The patient may get the impression just to be seen as one of many who have to be pushed through and given the essentiality of adherence in the case of HIV/AIDS pharmacotherapy, this weakening of the patient/doctor relationship (one of the main sources for the patient's belief in and commitment to the therapy) might have disastrous effects on the outcome of the treatment affords:

> "What started as a problem recently is that the doctors saw seventy patients in a kind of four hours. When you divide that as I said, seventy patients in four hours it comes at 2.2 minutes per patient. That is not even acceptable ethically. This is even HIV patients, not just ordinary. In an HIV patient, you look at this … you go over again. At each time, there are things to look at. You want to reassure with words, you want to assure the patients dedication. We don't ask them, some people don't now that just discussing with the patient makes him happy: 'How was your Christmas? You know, I know it is not easy to take drugs again on Christmas.' And issues like that, it is like the patient can feel that you understand that these things are not that easy. But you don't have time to talk about that kind of 'nonsense', you don't take your peers, you just point finger at the patient, sometimes you don't even have time to talk to the patient. In two minutes, how do I talk to the patient? I just have to write my notes and finish."

In connection with these experiences it was mentioned that originally a number of approximately 20 patients per doctor and day had been considered to be the upper limit of what could reasonably be handled with acceptable results – a vast difference to the situation which has developed. There is worse to be expected as the pandemic has not yet reached its peak, nor has the treatment program successfully penetrated to all those who are in need of it.

4.1.4 The emotional part of HIV medicine (1): Fear of infection

The emotional problems are not as often and as voluntarily mentioned (or 'admitted') as the above problem of workload, and the nurses generally seem more willing to express their emotions, compared to the medical doctors who'd rather like to discuss the problems on a more abstract level. Nevertheless most health professionals describe their, sometimes very strong, fears and emotions when these topics are addressed directly. Only one professional, a nurse, named the fear of infection as the main difficulty in connection with work at wellness clinic, while the other health care practitioners would address either the workload (4.1.1) or the difficulties with patients (see below, 4.2) when asked about the heaviest burden:

> "My fear, one of my main fears working with HIV, people who are infected, when I have to insert a drip, I just am cautious and try not to accidentally prick myself with the needle. It's so … every time I think about that because I think we are under stress, we are few, and if you are under stress, okay it affects your immunity and you can get this meningitis and … TB."

Another sister remembered an own experience of how she felt after exposure when she had reason to suspect that she could have been infected:

> "And the risks are there, sometimes, not that far, I used to worry, I started coughing, I was having a strong cough, and I thought I had contracted HIV … TB. And we used to take some blood from the patients and one day I pricked myself, I was so sad, the patient was HIV positive, fully proven, and she had only started the treatment for a week. But fortunately it was OK, I stayed negative. This is very scarring."

Medical doctors would tend to discuss the topic rather from a more technical point of view, trying to describe or quantify the risk instead of talking about their own fears – asked "Do you feel a fear caused by the risk of infection" one doctor answered:

> "Well, the risk is always there of occupationally acquired infections, but, yah, it is there. You are working with a patient population that is high risk for tuberculosis and everybody is HIV positive, but, well, it is better now since we got our ultraviolet lights, probably one's a little more relaxed, you know, to 'burn' the HIV – [click] the tuberculosis bacilli. And we don't take much blood ourselves, we have a phlebotomist. Every now and then we do invasive procedures, but it's not so common. So we just have to comply with the international standards of ... avoiding occupational injuries, but otherwise ... yah, the risk is there."

Apart from their hygienic efficiency, the mentioned technical devices for prevention of infection at the clinic have (like the described special light sources for the rooms or a special ventilation system) a distinct psychological effect, especially if they don't work, as another doctor admits the fears:

> "You know, I was complaining the other day, there are these extractor fans that should extract whatever [laughing], it had stopped working and like I had this Patient who was coughing so I though: My god. So, you know, all the time you expose yourself to risks and it is so scary, you know! I mean, you can tell the patient as much, but every time you go

> to test, you know, I freak out all the time, so I don't know [laughing]. I think it's a problem, it's so scary. Yeah."

Certainly the habit of introspection – and of suspecting severe disease – as it has been expressed by a nurse above is imminent in the ranks of the medical doctors, too, having learned about all these dreadful threats one is prone to find the symptoms in oneself:

> "When I was to travel to X in July, there was this cough I had. Hey god, I don't know whether I got flu because it was peak of winter. I was coughing, honestly, because we have been asking them to put this infrared light to handle the TB story, they were delaying and delaying, we don't know whether it was ever coming. So I boarded the plane in mind that I was coughing, I came to X I was still coughing, the only thing that kept my mind upright was the fact that I had a nasal congestion. So I convinced myself [laughing] … I convinced myself that since my nose was blocked, it's unlikely to be TB."

Some of the medical practitioners might even demand certain vaccinations or procedures that are thought not to be effective in adults, like the BCG vaccination for tuberculosis. Due to the fact that BCG is still recommended for newborns in South Africa, people who grew up in other countries might think they would benefit from it – and if only psychologically – what would probably be a subject for additional occupational health affords:

> "Yes, I have fears. Tomorrow I am going to take my last dose of my hepatitis vaccination. I was also supposed to take a TB vaccine before I started at wellness clinic, but the hospital refused to give that. Because I wanted one, I wanted on, but the hospital refused to give it. They say that … that … I don't know what they say. Either they don't give it or they only give it to children …" (a doctor)

The fears and the uncomfortable feeling in dealing with HIV/AIDS patients might not only be derived from the health carers own perception, sometimes his surrounding and especially the spouse might contribute to it – possibly with ideas that seem quite abstruse to medical professional. Nevertheless, they are human and particularly in the highly stigmatised field of HIV/AIDS a lot of superstitions show their strong effects:

> "The major fear that we face it's … sometimes it is not just your fears, you see, it's all the fears other people confronting you with, maybe in the family sector, your people are not … your wife is not a doctor or something and she sometimes thinks: 'He is working with HIV, has he washed his hands?' - all this kind of non-statistic things. [laughing] So you have to be extra cautious towards you. And even if you convince the person: 'Look there is no way I touch somebody who is HIV positive, to get infected, even if I examine them', because some of them I touch with my bare hands and when I finish, I go and wash my hands. It's not so much … sometimes it is not your personal fears." (another doctor)

What always should be kept in mind as well – apart from how to deal with the own and others' fears at home – is the question how the fears of the health carer change the interaction with the patient:

> "You'll be a doctor whose behaviour would be like rejecting patients, you know.
> Patients will feel that you are scared of what they have and it is going to affect your relationship with the patient. They won't trust you, they won't like you. And if the patient doesn't like the doctor, you can imagine what next. [laughing]"

But as one of the doctors suggested, remembering experiences from the anatomy classes: In the beginning everybody would be strictly protected when doing the sections, after three months one would eat his sandwich next to the corpse – so mere habituation might help to find the right state of alertness between the extremes of panic and of carelessness.

4.1.5 The emotional part of HIV medicine (2): Suffering and death

Many of those interviewed confirmed that the experiences of HIV related suffering and death does have a significant emotional impact for them, though again it could be seen a general reluctance to articulate personal emotions and a greater willingness of the nursing staff to do so than the doctors would show.

Despite the fact that all of the interviewed staff was more or less well experienced in the health professions, the fate of HIV/AIDS patients seems to contain a special potential to affect the personnel emotionally, as one nurse experienced:

> "And another thing is sometimes you feel for them and *that problem affects you emotionally and sometimes it can be psychological*. Because in most cases – I am staying in Rustenburg – there are people that are coming there that I know and sometimes I feel for them and I feel bad and sometimes you meet a patient who is very poor and he or she is HIV positive and she needs to get the antiretrovirals. This patient doesn't have money to buy food and maybe he or she is staying far from the clinic and has to travel. So that's the most problem that you come across at the clinic."

Obviously the emotional burden is bigger where there is no success of the therapy or a later, secondary failure:

> "And if we see that person, talk to them, and you find out: ah, conditions are becoming worse, or maybe that person has improved and then after three months he or she is down again, *it's really hurting*."

The emotional affection seems to be a result of the health carer getting ‘to much involved’ with a case, particularly where the patient offers some attributes the health carer can identify with or if there is a basis of sympathy, as another nurse points out:

> “But there are those cases, you know, okay that you empathise with them, but there are those that *you end up sympathising*, *you feel like crying*. There we also see the PEP[10]; those are the rape cases, so it is sad to see those twelve year olds who were raped and even if we test them immediately, so when their results come, you find that they are positive. And it’s difficult for the parents to understand that if the results are reactive, it means the child has been positive, she didn’t contract it from the … (…) So, it’s sometimes you end up sympathising with them, it’s different hence from other patients. But basically in most cases it’s just empathy …”

Sometimes the emotional affection might reach such levels the following nurse describes to be depressing, definitely a potential risk to end up in burnout if there are no supportive surroundings:

> “Yeah, the suffering of the patients sometimes … it makes you depressed sometimes … it makes you depressed sometimes, when you look at their emotional suffering, you end up saying: ‘You become strong for the patient.’ But at the end of the day, you see - when you go for the debriefing sessions, then you look back on these patients and you see these patients – something is affecting you. So it is emotionally draining, you get some depressions, sometimes …”

This emotionally draining effect is experienced to be somewhat special to the wellness clinic, as this sister continues with the answer to the question whether these experiences differ from those at other work places like the MOPD[11]:

> “IT DOES! Because mostly patients that come into MOPD, it will be ambulant patients, like that … that you can relate well to and then you give medication and then they can go home. And then those ones who are coming, it’s people that come without hope, and you see that they are … some you see that they are just about to die and then there is nothing that you can do for them. So you feel useless at sometimes.”

In addition to that, the fact that sometimes the external social circumstances prevent a patient from receiving the medication, as he or she might not fulfil the requirements according to the guidelines of the department of health. Such conflicts cause a certain degree of frustration as well, as one doctor expresses it:

> “So just because of external forces, things that I feel that can be controlled, that I feel if there is one person who can understand, who can and try and administer, we don’t even give them the chance to the drugs home, it is so unfair, it’s so unfair.”

---

[10] = post-exposure prophylaxis

[11] = medical outpatient department

But sadness is not the only emotion the personnel is confronted with at wellness clinic, sometimes the behaviour of the patients causes mere anger, as in the following case where a nurse describes how an HIV infected patient had lied to his girlfriend to persuade her to have unprotected intercourse with him:

> "I don't know, sometimes, you know, you get emotional. But I always tell my subordinates, if you feel that you are about to loose it, just leave and call somebody else to attend to that chap. So I did in that case, because I felt, and even when he comes, you know he was there yesterday, I say: 'I hate him for what he did.' I really hate him, when he comes, I can't take him, it's really … … it's … depressing …"

4.1.6 The lurking burnout

As a result of the exhausting working conditions, some of the health care workers may just develop signs of burnout. Overload of work and tensions with the fellow workers are but some of the causing factors for this syndrome. The effect on the workers motivation to work and even worse the reduction in the ability to perform the work properly might results in bad outcomes for the patients treated. Of course this is not the only detrimental effect of the burnout syndrome, as the worker's own health suffers significantly from this condition, both psychologically and physically.

In the spoken statements cited above every once in a while expressions like 'depressed' and 'frustrated' occurred, but in some of the responses given by the interviewees more severe signs of a possibly developing burnout were expressed.

The experience to have to compromise own values has been identified as one of the reasons for burnout, something one of the sisters has to face and that results for her in 'feeling useless':

> "Now the difficulties we only encounter is that we … maybe we don't reach our patients well and we can not do the follow up and check on our patients, especially those who are defaulting, because of the workload, we are just so few and if somebody doesn't show up it is as if we don't care, even if you do, because there is nothing that you can … that we do that much. (...) Yah, you feel … you feel useless. You know when you feel useless as if whatever you have started, you can not carry on what you have started."

For another nurse the extreme exhaustion results in tiredness:

> "You find that on Thursday, ooh, you are so tired when you think about coming to work."

Others might feel that the whole effort doesn't make sense, like a third sister said:

> "Hmm, yah, it's sad, but we were saying the other day: 'Sometimes you feel you are fighting a loosing battle."

One of the doctors got thoughtful about the efficacy of their work:

> "I have such feeling sometimes that say: 'We are not doing enough, we are not doing what we are supposed to be doing really and I used to complain. Sometimes, yes you can also sometimes feel frustrated, yeah, certainly."

Another doctor expressed signs of resignation and withdrawal that could be interpreted as a first stage of burnout, the withdrawal is shown by the loss of affection towards the suffering that one experiences in the clinic:

> "You know, as a doctor you ... you tend to become immune to certain things that people shouldn't become immune to. You get used to dying, you get used to being sick. So, probably the first few times you see it, you feel bad for the child. But by the time, you have seen so many, you just ... it's just another day, *it's a job ... a job*! So you feel bad initially. When it happens, you might feel bad, but just when you have seen the next few patients, you forget about this one. It's just a sad fact ... a sad fact of human nature, you know, you help those that you can."

A little later in the same interview this doctor shows more signs of resignation and clearly describes the lack of energy and the effect this has for the treatment – no more engagement for the patients needs and a kind of defensive withdrawal that allows only to manage the basic treatment tasks:

> "I know that, but there is just no time, there is just no energy, there is just no enthusiasm. So you just hope that they do what they should. We give them treatment and that's it. Initially yes, people can tell you, they go out of their way to tell them a lot, but now …"

These expressions indicate that at least the last health care worker might have entered some stage of burnout syndrome - this kind of resignation might be accompanied by other signs of burnout, physical and psychological, like gastric problems, sleep disturbances and anxiety. This alerting finding should motivate for thorough examinations and considerations about what needs to be improved in this clinic.

4.1.7 Ways out of the crisis

> "Too many patients, you feel you are not being paid enough, you feel you are not being appreciated, you feel the hospital is working you to death. They're not making use of your clinical skills, the CEO is not listening to your own ideas, it's just pushed to the ground."

This brief description of an unsatisfying work situation by one of the interviewed doctors does not only express frustration, but gives as well an idea what approaches could be used to improve the situation. Besides efforts to reduce the workload, such improvements could involve the financial remuneration as well as the immaterial compensation, to give the workers the perception of fair treatment:

> "When you ask what affects one's family life, in terms of every working environment if you don't … if you don't feel cared for, if you don't feel the workplace is … if you feel the work is only taken away from you, it's not given you back, it will affect you emotionally."

Like this doctor most of the colleagues in the clinic felt. And whilst of course an increase in payment might raise the moods, many of the interviewees reported frustrating experiences in connection with the mere recognition of their work, like the following one:

> "You know it is good to make somebody work hard, but it is also … it is better when that person who is working hard feel also … feels also that now people are recognising I am doing my job, I am working very hard. But when you work hard and you realise that people doesn't mention, they just don't care about what you are doing, frustration is coming."

In an a little more pronounced way, the following doctor recalled his perception of certain shortfalls the management might have show when it received suggestion from the 'workforce':

> "It's a kind of a monarchy system. [laughing] Sorry to say that. (…) If people listen to people on the job, there are two types. There are people on the job with pictures and others who are manager. And they look at the things from a management point of view. And as long as you don't have a diploma in management or a master, you are not supposed to know."

Therefore it should be kept in mind that the time those in charge spent to listen to the ideas of the employees could pay off in at least two kinds of beneficial results: On the one hand those who are given the opportunity to present their suggestions may find their motivation boosted and on the other hand the suggestions are not unlikely to contain some valuable approaches for future improvements.

Such suggestions as they were expressed during the interviews included measures to reduce the workload like the need to get primary care nurses more involved in the later stages of the treatment when the patients are stable and the option of down referring to primary care centres once such sites have been properly trained and equipped. The limitations of such options are seen and discussed very clearly, too, but whilst the training of the local clinics will be strenuous, there is being seen little opportunity to extend the wellness clinic either, due to the building infrastructure. As further possibilities to make the work easier, the use of forms with tick boxes was suggested to reduce the time needed to write, contacts to other clinics (nationally and internationally) were suggested to exchange experiences and a pooling of the data of the different centres to get a proper statistical basis for the nationwide situation. Finally, ward rounds and other teaching events were demanded to make the work more satisfying and to offer opportunities to improve the delivered care, as one doctor put it in brief:

> “People in the clinic like research, I want to do some research, people in the clinic like field work, I want to do some field work, people in the clinic like different aspects, I just want to do that.”

One institution should finally be mentioned, which is appreciated by both the nurses and the doctors: the regular debriefing sessions with a psychologist twice a month, which are meant to offer the personnel a forum to talk about their experiences, emotions and fears, especially if their private surroundings don’t give such opportunity. One doctor summarised the benefits in the following way:

> “I think it helps somehow to get the people to talk and share the emotions and see actually that they are not alone and to see that they are actually normal. So the debriefing sessions are quite a good thing that is happening now at the moment.”

4.1.8 Who can do it?

Discussing the multiple burdens and difficulties to be faced in the field of HIV medicine, some of the interviewees expressed as well their opinions what a HIV health carer should be shaped like. He or she should not be too anxious:

> “If you live in fear, it is better not to work in HIV medicine because your fear is going to affect your patients’ emotions.” (a doctor)

and the health carer should have some special talent to comfort the patients and motivate them for their treatment:

> „Now we can settle a person’s emotion and then, you know, talk and make the patient feel better. So it’s special, not everyone can do it, even not every doctor without a special training can do it. It is so special because I think we are in a high level of, what can I say, of the health care system. So it’s very special. (…) it requires certain people with certain characters … maybe, if I can … characteristics, if I can say it like that. Because I think you can teach somebody but there is somebody who is telling very badly: ‘You know that you are going to die, just take the medicine …’ you know, it doesn’t go like that with the … with all the ARVs. So I think the emotional aspect is for certain people, not everyone can do it.” (another doctor)

These suggested special character qualities of the health carer are extended by another doctor even to the spiritual field:

> “The spiritual well is very important, because there are some patients that ... you can not treat them physically, but you can treat the inner man, so that you can prepare them to go past what they are going through. Some people are saying: ‘I don’t want to get involved with that, just call the pastor,’ …”

4.1.9 The impact on personal life: Hope, caution and ‘inner mission’

An amazing and very reassuring finding was that apart from all the problems linked to this particular work, it can be stated without doubt that by almost all of the interviewees an impressive feeling of hope and satisfaction was expressed – especially for those with prior impressions of the impact of HIV/AIDS, the new therapeutic options that are now offered to a broad population are very motivating. One doctor contrasted this describing his own experiences:

> “But the first thing I would say is that before the antiretrovirals were rolled out, you see a patient diagnosed HIV positive, he just comes with one opportunistic infection after the other, then subsequently he stays in the hospital, you keep treating, you know the guy is not going to get better. You just ... you just feel helpless. If you look at some of the notes that are written, they just write: ‘HIV positive – continue management’ There is nothing, there is no other thing you can do. Now, at the very moment when you sit with an HIV patient, we feel a little bit, I would say, we have a little sense of hope.”

Another colleague enjoys the unbelievable improvements under the therapy:

> “Sometimes you start and see them when they come, so like: My god, are we going to win here? And then after three months they are walking and happy – like: Wow! [laughing]“

While a third colleague sees more of the public health benefits of the treatment program:

> “And the fact, ehm, that we are bringing the viral load quite significantly down to an undetectable level as well contributes to decreasing the rate of transmission. But the main point, the main thing is to teach patients to actually use barrier methods. And so we do all that in addition to just giving treatment. And it does have a great significance in controlling the epidemic.”

These perceptions are being shared in the same way by nurses:

> “It’s not like before when you were … when they said you were positive you’d like … you feel you are going to die. At least now there is hope”

Many even express their mere happiness to participate in this kind of work:

> “I’m happy, I’m happy working and helping the patients.” (a nurse)
>
> “Maybe for me now to add, personally, I mean for now I am happy, I’m really happy. You know my problem’s like ‘but what triggered you to chose this field?’ or whatever. For me,

> it's still new basically, so it's something that's new, you know, that's interesting. And I feel it is not like the general medicine, you know, it's a different medicine." (a doctor)

and another doctor with a little bit of scepticism:

> "The work itself, I must say, is potentially very satisfying, if ... especially when you see patients improve from a point where you yourself thought that nobody would ever save them. It is satisfying that some patients actually can be saved, but there are a lot of interpersonal clashes that arise from increased workload and that can interfere with one's job-satisfaction. But it is quite a satisfying job, I must say."

The fact of gaining new insights and exploring new horizons motivates another nurse as well:

> "Yah, for me I have learned a lot about wellness, and I have learned a lot about HIV and AIDS, okay, and they send us sometimes outside for the in service training and we have learned a lot about special patients as well and I'd wish that I could still learn more. (…) I have learned a lot about the treatment, the medical and different types of patients or of people …"

Answering on the question what impact the experiences at wellness clinic had had for the personal life, there were two main groups of answers. On the one hand under the impressions from the clinic the health care worker developed an awareness of the "fragility" of life (as one doctor called it) and draw the consequences from the fact that small events can have these dramatic results by becoming cautious, e.g.:

> "So for me personally, you know, it influences me a lot, like to be careful about lots of things and also about sex, you know when it comes to sex, to be careful about sex and to test, especially when you are married, there is just one way … [laughing]"

On the other hand especially the nurses explained how the task of fighting the pandemic and teaching about HIV/AIDS has become an important part of their lives. All the interviewed nurses show – in the spoken word and in their compassion – something one might call an 'inner mission' and what might become visible from the following statements:

> "A lot, hey, it did. Yah, it did, because I mean in a way outside many people … I have educated a lot of people, those who know that I am at the wellness clinic. You find people asking a lot of questions and you can see that they are asking for themselves, maybe they want to know. You know, you educate and it's nice to use that as a teaching moment, the people to know what to do, where to go. And like in funerals, like when my uncle died, I used that as a teaching moment. So I taught people, told what killed my uncle, he was HIV positive. I used that teaching moment."
>
> "So always when I'm in that transport there are always people talking like that, judging about people. And I always ask them: 'Do you know your status?' Then they keep quiet and become thoughtful."

> “Yah, it changed a lot, … it changed a lot, if you go outside and if you see that person is like … is sick … is HIV positive, even if you see a personal friend, you can do counselling, you can talk to them: ‘You are sick, please go and do the test!’ If even … it’s like you are preaching it outside, you are working in the hospital, but outside you are still doing HIV/ AIDS, you counsel them, you do everything. (…) even at home you find that the person asks you: ‘You did help me, can you please talk to that guy, he is sick, can you please go and talk to him?’ It’s like sometimes you are doing home visits, even though you are off, because the person asks you: ‘Can you please … ‘“
> “They call me the ‘AIDS sister’, even at church, when there is AIDS day or whatever, they know: She is going to talk a lot about the HIV and what ever.”

4.2 Our special patients – interaction between health carer and patient

In this chapter the focus will be on the trouble the health carers are experiencing as caused by the patients. Together with the burden by the workload, these patient-caused problems were regularly and with high priority mentioned by all the interviewees. Such topics include the phenomenon that HIV/AIDS patients are somewhat special patients in terms of behaviour and expectations, that motivating and maintaining good adherence is very difficult, that the existing stigma is interfering with the attempts to diagnose and treat those affected by HIV/AIDS and the fact that traditional healer, African churches and other beliefs can hinder the successful treatment with ARVs.

4.2.1 HIV patients are different (?!)

All of the interviewed health care workers described certain features by which the HIV/AIDS patients are different from ‘normal’ patients in the one way or the other. Again a tendency could be observed that the doctors would lay more emphasise on certain ‘technical’ topics (effects of the disease, requirements of the treatment whilst the nurses would focus more on the emotional part of the interactions as well as on social aspects. In the perception of the nurses HIV/AIDS patients are particular difficult because of their attitude, as they are often described as aggressive or angry whilst they think they are somewhat special:

> With HIV, I think it’s more difficult, if I compare it with let’s say medical OPD, you see other conditions like diabetic and, okay, asthmatic patients. But with HIV it’s so different, it’s so different, those people they are so … it’s like they are angry, and that anger they

> don't know what to do, the person comes complaining, they do complain about lots of things compared to those who suffer from diabetes and they need that attention from us, they are expecting a lot from us, especially with ARV, they expect to be cured. They expect a lot from us.

This idea to be special results in a very demanding behaviour of the HIV/AIDS patients, who e.g. don't feel the need to keep appointments (what further worsens the organisation of work in the wellness clinics):

> "They don't want to take responsibility for their health, that's my main problem. They are too dependent, you know, it's like they feel they are the only people on earth who are sick, others' conditions are not serious, theirs is the-e illness. That's my problem. (…) in OPD they knew, when they say I have to come on the twentieth, I have to come on the twentieth. If they don't come they will call: 'I can't come because of 1/2/3, I want to change my appointment', but they come and they will tell you: 'So do I have to die?'"

But it is not only the demanding presentation that makes these patients special; they may have a special 'offensive' way:

> "The patients, some of them are very much emotional, some can be rude and then some can be aggressive, you know and some are suffering. (…)"

Yet this sister has an explanation of the strange behaviour:

> "Wellness patients are really spoiled, they are rude. You are trying to help them and they don't give a damn. But I always think, I tell myself that maybe the situation, the condition they are in has spread to the brain."

This potential brain condition/encephalopathy is pointed at by the following doctor, too, who warns about the difficulties to prepare such a patient for the complicated and continuous pharmaceutical treatment – and not to let them down to easily:

> "And you see, because the question is, some people come and say 'I don't want counselling' and let's say they already have a problem understanding what you tell them. But you realise, I use to tell, HIV itself has some damaging effect, you don't actually reason at the level you should. It affects you up to the level of dementia. So you should understand that it is also an immunologic effect or probably the disease itself. So you don't expect the person's answering that question to be as good as yours if you are not HIV positive, lucky you."

One of the medical colleagues puts the facts of social and mental limitation of the patients in less empathetic words:

> "The main difficulty for me is that you are working with poor people, you're working with ignorant people, you're working with people who don't have an income, don't have a home. So you are working with the homeless, the helpless, the desperate of the society. You know, these are people that can't even eat and they now have this dreadful disease."

In opposition to that another colleague sees the main difficulties in the emotional task of calming, comforting and reassuring the patients:

> "The most is the patient, especially the newly diagnosed, when you have to start the treatment, telling them about the treatment, you now. Depending where they come from, if the counselling was done properly, that's the difficult part actually with the patient. They come to us just feeling that they are going to die. They start crying, and then you must wait, let them cry and then start to comfort them."

The next doctor looks for rational explanations of the special behaviour of the patients and finds them in an ongoing process of denial:

> "Yah, we know about the benefits of adherence and we have seen patients recover quite dramatically, those who are adherent, and sometimes, you know, one gets the feeling that the patient is just taking the medication to please us. You know, it is quite a battle to get them to understand that what they are doing is for their own good and they're doing what they are doing for them and not for you. And I think it difficult for the patients as well, some of them are still in denial and that interferes a lot with how they react and take home advice, but, yah, that's frustrating."

In a similar motion, the following doctor understands the patient's failures very benevolently as an expression of the human wish to return to normality:

> "Yeah, the patients, you know, like anybody else, they want to go back to their normal life. Even though we can't tell them at the beginning, we tell them that really from now on you have to use condoms always, from now on don't drink alcohol, don't do this … They can do it at the beginning, after six months, they start getting better, they see the CD4 is going up, and then somehow, it looks like the counselling is going away [laughing] and then suddenly they just realise that they are normal, hey they can go to parties and drink with friends. And then they start feeling: This matter of taking medicine everyday is disturbing. And then, that is where we get the patients who are now no more adherent to the treatment, you know. They start forgetting one by one … evening pills for example they forget or they go back to alcohol …"

With these last comments the topic of adherence has been tackled already. Here the need to strict adherence to the timing and dosing of the medication collides with the (sometimes) particularly difficult patient – it should not be ignored that many of the HIV/AIDS patients do their very best to comply, but however …

4.2.2 Poverty and 'ignorance'? – the obstacles to adherence

As had already been mentioned above (introduction to chapter 4), the necessity for an extremely strict adherence to the therapy regimen is more or less unique amongst the chronic diseases, being comparably demanding to the patient as probably the intensified insulin therapy for diabetes. But the significant difference between these two therapies is still that in the case of diabetes the failure to apply the therapy properly will show immediate effects like hypo- or hyperglycaemia, whilst with HIV and the HAART the patient will not experience any short term negative implications if he or she fails to adhere – the more dramatic will be the long term results if the effectiveness of the regimen is lost due to resistance and the patient is once more condemned to the mere awaiting of opportunistic diseases and death. Therefore the guidelines for the antiretroviral therapy put a lot of emphasis on adherence and the health care workers involved do their utmost to ensure the patients' compliance – to prevent the patient and the community from the devastating effects of the spreading of resistant viruses.

Adherence has been named as one of the major problems by most of the health care workers who were interviewed and a wide range of aspects have been mentioned that could influence the adherence. Apart from merely medical reasons, like the sometimes quite strong and disabling side effects, often other factors such as the social situation, literacy or the mere duration of the treatment are being named.

As first obstacle to the adherence often the financial situation of the patients on the one hand and on the other hand the need to travel far distances to reach the treatment sites for the regular follow-up consultations is seen, as one nurse stated:

> "He or she is HIV positive and stays very far from the clinic and she can't afford to pay the transport, she can't afford to buy food for herself or the family can't afford to help"

and a doctor emphasised the importance of these factors:

> "In the area we are the only clinic and everybody comes to the clinic and some people really have to travel long distances to come to the clinic, which is not good for adherence"

The impact of the social situation might be worsened by the lack of literacy, like one other doctor recalled:

> "You know that in Africa the percentage of people who are illiterate is … is a bit high. Then for instance I will give an example, the patient must be responsible, knowing that this medicine, he has to take it at this time and that and then you face … you face for example a patient who is illiterate, who doesn't have anybody around to take care of him, to help him to live …"

One of the problems for the motivation is obviously the duration of the treatment, or better the fact that there is no end to it but the perspective of a life long treatment:

> "The treatment is a life time treatment, but after they have started taking treatment, and they start getting better, they'll ask you again: 'Doctor, don't you think that I can end it one day because my CD4 count is rising and is it not possible that one day I can stop it because it is OK now.' They tend to forget what you have told them at the beginning and then it is just an ongoing counselling [laughing] …"

This doctor's experience is confirmed by similar ones of a nurse:

> "Patients they take their antiretrovirals maybe three, four months, when she realises that 'Now I am OK' she stops taking the antiretrovirals. Some are defaulting their appointment, they stay away for a month or two, they don't come for the treatment, then she realises that she is starting to be sick, they come back to the clinic: 'I have been away, I have been to Transkei, I went to see my family, so I didn't get a chance to come to get the treatment."

And another doctor confirms that the patients are actually continuously expecting cure:

> "You know it is like you are dealing with patients where the success of the treatment is based on compliance and that is a very big problem, because every patient accesses you over there and some of them walk in and ask 'when do you think there will be a cure for this' – is a frequent question."

But there is a good share of understanding for the weaknesses of the patients, as this doctor admits own problems:

> "Even me as a doctor I don't keep to term when I take my drugs and I am educated, I have an alarm clock, I can wake up that time, I should be more structured with my stuff, you know, I don't seem to do, I forget some, sometimes I don't feel like taking it, you know, so I don't see how the patients, how people can be that stringent day in day out and take the drug everyday and not miss one."

Nevertheless the goal must be to achieve good compliance and adherence and this requires, according to this nurse, informing the patient properly and understandably:

> "But I think if they really understand why they are taking the treatment, and then what the treatment is doing, it's not difficult. I think most of them were defaulting because they didn't understand why. (…) So when you show them what's happening if they don't take it on time, then you can even see it in their faces: 'Ooh, this is what's happening.' Then I think it's getting easier."

So quite often the problem might not (alone) be with the patient, he or she might just not have been properly prepared as this doctor knows:

> "The counsellors are not doing well. Because you see the rate of defaulter and then some of them you talk to them and tell them: 'But you shouldn't do this and this and this' and they say: 'But they didn't tell me.' So you see that it is really lack of information …"

Sometimes one might, even as a doctor, feel forced to become 'rude' to make the patient understand:

> "I think there basically you have to interact like some common person, you have to change the way of interacting with them, in fact you just have to become rude [laughing]. For them to get the message, you know, you just have to put the message the other way, I don't know, just to reinforce the message, what is important for the patient. For me it is important that they should always be on treatment. Yeah, so I say anything, I do anything to knock some common sense into them. So there I think I just get so rude."

And certain patients are a big problem as they don't adhere at all – probably they have other ideas about treatment, influenced by other sources, as this doctor explains:

> "We have other … other patients who are not adherent from the beginning. This one also is another big problem, from the beginning they don't adhere, they don't trust you, they trust other people outside the hospital."

4.2.3 Traditional medicine, churches and HIV – the power of beliefs

An interesting and remarkable finding is that certain local traditions and beliefs seem to affect the patients' compliance to the antiretroviral treatment. As such sources of interference with the 'western' way of pharmacologic therapy specific local traditions after the death of the spouse have been identified as well as certain influences by local churches.

Nurses and doctors alike report a typical problem for the adherence that is related to a specific local tradition as explained by the following nurse:

> "When it comes to cultural issues, like you find it with Africans, especially Tswanas, after … when they lose the husband, when the husband dies, there is this traditional concoction they are supposed to take for a year whilst they are mourning. You know, and we are preaching that they shouldn't combine ARV with traditional medication, you know, the interaction and all that, liver damage and all that. So you find that it is a problem. Because others feel they would rather stop the ARVs and concentrate on that, you know, there is that thing that they're putting into them that when you are sleeping with your husband his blood is mixed with yours. So you are drinking that concoction to take out your husbands …"

This description is similarly echoed by one of the doctors from the same cultural background:

> "You know, the traditional things, I know them, you know, I am a black person, it is our culture. Now you find that maybe the spouse passed away. Then they are demanded traditionally to drink all these traditional things, I mean I grew up like that, I know it should be like that, but then I tell you: Listen, with those medicines it won't work, and give them a fact why, in fact I end up lying to them that this one it won't work, even this one won't work as long as you combine it, just to tell them: Listen, this one is uninterrupted, it can not combine with that. Yeah, so, but it is difficult because these are people who tell you direct: Listen, I rather stop or don't start antiretrovirals, and at that time they are running out, looking all so thin, the clinical picture and the CD4 status of that patient. But we knew, you know, people's beliefs, people's religions …"

The detrimental outcome of this interference is drastically visualised by another nurse:

> „There is another hospice in Phokeng of Mamokwena and the Mamokwena people are defaulting there, they are giving them there traditional muti[12] and they will only send them here when they are very sick and they have diarrhoea and they are dehydrated and the CD4 count is very low and the patient is almost dead, then you can start them on antiretrovirals, because some of the traditional doctors tell the patients not to take HIV antiretrovirals, they tell them: 'Okay, I am going to heal you' but I don't think that they really can …"

As there is no easy solution to this dilemma, different people use different approaches, and though the severe side effects of a combination of both medications are feared, this combination might have to be considered whilst trying to persuade the patient otherwise:

> "You have to sit down and talk to them and explain to them: Okay, we can give the traditional medication, but with the antiretrovirals. (…) But … it's not right to combine the traditional medication with the antiretrovirals. Because they become resistant or their liver functions are going up … the function tests are going up."

In today's South Africa there is a hope to integrate the traditional healer into a comprehensive concept to fight the pandemic:

> "We need to be in partnership with those people, because our people, I mean, they are real, realistic things, they go there, they consult. We should be partners with them; so that they should actually encourage them to adhere (…) our people listen to traditional healers more than they listen to them (the doctors). So if they could do that, I think they would win, because most of them feel that the traditional healers, if they tell them to do it, they will do it, more than if we tell them. So if we integrate with them, be partner, become partners, I think would be good. " (a nurse)

But the controversy about the therapy unfortunately often results in a dilemma for the patient, like in this case recalled by a nurse:

> "There was another lady who came to us, her husband passed away and she was on ARV. So the granny said: 'You must take those herbal medications.' So it was a … a dilemma that we said this, the granny said this."

Certainly this topic holds potential for a lot of research that still will have to be done. Such investigations would on the one hand have to learn more about the herbal medications used and their potential side effects and interactions, on the other hand the social function of the traditional healers need to be better understood – if the application of traditional herbal medication is the main function (and source of income

---

[12] = traditional medicine

and respect) for the traditional healers, any policy aiming at the elimination of such herbal 'interference' will be unlikely to enjoy their support.

Some local churches seem to be a second religious group hindering the treatment. Such groups may tell the patients that no medication is necessary at all; just prayer would ensure that 'god' is going to help, or they recommend teas and coffees instead of the antiretroviral drugs. Where the doubt is about 'heavenly cure', the health carer usually use a swift approach not to offend the patients religious feelings, like the following two examples, by a doctor and a nurse respectively, indicate:

> "And some come who in terms of religious concept, you know that can be very conflicting also with your faith as a Christian, as with the Christian faith, a patient comes in and tells to you and asks you questions: 'Doctor, I just went to my pastor yesterday, you see, he prayed for me and something happened, I know that'. I had to deal with one like that; he even bought me a book. He said you have been very accommodating and all that, he said all sorts of things. But, my major fear when I was dealing with him was, he shouldn't conflict, he shouldn't have a conflict in himself, because I told him, I said: 'Look, if good heals you, he's not going to play tricks about it. All we need to do is to confirm, which I will be more than willing to talk about. You know, we need to do an HIV-test. If the HIV-test comes out negative, there's it. I know that the only person who can heal you like that is god, but you have to wait for him to do.'"
>
> "And then other people they tell me 'I am born-again and that is going to cure me, I shall pray and that is going to cure me.' And then I tell them: 'Okay, god will cure you only if you take antiretrovirals and you take them regularly and you look after yourself, you protect yourself, then god will help you. Okay, he can help you, but if you don't take the medication to boost your body or to fight the virus, then I don't know.'"

So even with these churches the situation arises that the patients face the dilemma whom to believe about their treatment and medication. But since the teas and coffees, that are being recommended by these religious teachers, are usually without severe side effects, the decision to agree to a combination with antiretroviral drugs is usually made much more easily. As another sister explains her approach:

> "She was there two years ago, she was HIV positive with a CD4 count of 8 and then we put her on the treatment and then immediately the preacher says, the priest says: 'Stop taking the ARVs, I prayed for you, you are now HIV negative'. So they come for confirmation, so during the counselling I tell them that there might be a possibility that they are still positive. I know that whatever the priest might … might have said, it's true, I believe in the same god, I do, they are believing in, but for the HIV, I am not sure, so we will see with the results. And don't be amused when you get the results, saying … still saying positive – the priest was not wrong by saying that, what ever he was feeling, he was feeling because of the prayer. But we have most of those who stopped treatment because of the priest or the church elders saying: 'No, you have to take that tea and stop

> that medication.' It's confusion. (…) So, some with the church elders who will be saying: 'We pray for this tea, you must drink tea ... this tea and then don't take the ART' but we explain to them, even if you have to drink your tea, when you look at the tea, it's just an ordinary Yoko tea. So because they believe in the Yoko[13] tea, we let them drink their Yoko teas and continue with the ARVs, because immediately when you say 'Stop your Yoko tea', they say: 'Eh, eh, eh, the church elder is better than that sister.' So they are going to stop with the ARV and follow their church leader, but if you leave them to drink that, as long as it is not herbal medication, and still with the herbal medication, if you are ready to start with the medication, we will give you the medication, but if you chose to take the herbal medication, we won't combine it with."

4.2.4 "O, then the sister will know my status!" – stigma and the HIV-test

The stigma of HIV/AIDS still seems to be a major obstacle to the successful fight against the pandemic. Despite all programs to de-stigmatise the disease many South Africans still hide their status – or don't even want to know about it. Once somebody's positive status gets know, the infection is often linked to accusations, rumours and prejudices. This poses a serious obstacle to the efforts to fight the pandemic, since people who are unwilling to face the facts about their infection are certainly quite unlikely to go for treatment or to use preventive measures to avoid further spreading of the disease. One of the doctors tries to explain the stigma with the idea that the HIV infection implies some guilt:

> "But then I think the stigma comes in, you know, they think probably the way you have gotten infected, you have done something wrong. So that is the problem, not the disease itself."

The finding that HIV infection is often linked to socially disapproved behaviour is confirmed by a nurse:

> "And you find that maybe in public transport, they talk about somebody that you know or maybe who is a neighbour. 'Did you hear that she is HIV positive?' 'I though that she looked positive, that girl she is sleeping around.' And some other also they say: 'He doesn't look after himself, he is a drunkard.'"

Despite the fact that he sees some improvement of the matter in general, the following doctor criticises the impact of certain regulations and motions in the insurance market:

> „It's much better now, before nobody wanted to know that next door neighbour has died of HIV. So they are slightly now beginning to accept it and go for treatment. So what if you go now for treatment, they are going to inquire on you, you can't tell them what you

---

[13] a local tea brand

> have done. So the patient who is now taking it is trying to keep the drugs out of sight, due to that personal conflict. Now society starts to accept it a little bit now that it is necessary for you to take antiretroviral drugs rather than staying on your own and trying to cure oneself. But what is not helping is still the system. The economic system does not allow you as an HIV patient to get it easy. The … the insurance policies the insurance people once you state that you are HIV positive, this funeral policy and all this, they don't want to pay you when they find out that you die of HIV. So you see they even encourage stigmatisation."

A particularly valuable insight into the problems related to HIV counselling and care for the health care personnel itself allowed the interview with one nurse who is involved with occupational health in the hospital as well. First she describes a problem that has been named by others in a similar way: the closer the social relation to the health carer is (e.g. neighbour), the less willing the patients are to disclose their status, because of the stigma – this phenomenon obviously can be very strong where fellow health worker are involved:

> "I once was a nurse, I am still a nurse. Then it is difficult for some people to come to me, especially staff members, they know me, some of us stay together in Rustenburg North, so when they come for VCT or when they are testing for HIV, it's not easy for them to come to me, to talk to me. Also it's not easy for me, because I know them."

A saddening result of this fear to disclose one's own status is the fact that some of the health care workers miss out on their opportunity to receive PEP, the 'post-exposure prophylaxis' that consists of the intake of antiretroviral drugs for one month after the accidental exposure to HI-virus containing material, like in case of a needle stick injury. Since PEP is not given in cases where the exposed person is already HIV positive (not only that it doesn't have an effect, the termination after one month would additionally generate a risk of induction of resistance), the procedure after an exposure is an immediate testing of the exposed health care worker – and exactly that might cause some of those exposed not to contact the occupational health personnel:

> "Some they say: 'Before they can give me post-exposure prophylactic treatment, they must … I must be tested', so they say: 'Oh, then the sister will know my status!'"

Similarly detrimental the consequences may be if an HIV positive health care worker can't be transferred to a less dangerous environment. Everybody will understand that e.g. a nurse who has a serious condition of the spinal column might not be capable of working in a post where the nurse regularly has to lift and to physically support patients. A health care worker who is HIV positive might be in a similar danger to suffer harm if he or she is exposed to the infectious diseases (TB, meningitis etc.)

that are prevalent in the internal or paediatric ward or even in wellness clinic. Therefore such a health care worker should be transferred to another post as well. But since this is not possible without discussing the item with the employee's superiors, this attempt would basically necessitate the disclosure of the HIV status:

> "I feel like in the hospital I must mention, confidentiality, we are not adherent to confidentiality, so we find that that sister will rather work in a medical ward than telling her supervisor: 'I'm HIV positive'. So you find it's so, it's really frustrating."

In the interest of HIV positive staff members, a change in behaviour amongst the hospital staff is to be wished for, to give these HIV patients an opportunity to enjoy the best possible care instead of having them – due to stigma and fear to disclose their status – hiding until their health situation has reached a serious condition:

> "When somebody is HIV positive in the ward or some of our staff member they can not go to the wellness clinic, they are afraid, they can not show. Our people talk - if somebody goes to the wellness clinic, you find them talking about her in the ward. You find that people are really affected, some don't have medical aid, they must come to wellness clinic for their treatment. They are afraid to come to wellness clinic because of the other people, what will they say. So it is like our staff members they don't care about other people, they just talk."

This should be regarded to be an important discovery for the health care personnel: The stigmatisation is not only a problem outside of the health care sites, it takes place everyday right there in the hospital – and that should be the place to start ending this discriminating behaviour, right in the own behaviour of the health care personnel! The impact could otherwise be quite dramatic, as another nurse warns:

> "At Rustenburg Provincial, because what we have realised, the ones that we are talking about, most of our health care are getting positive … are HIV positive and we are loosing them. Okay, sometimes people are inviting us like at the mines to come and do some visitings there, they organise something so that we can come there with our counsellors and the nurses and when we are visiting they call their community and we find out where there are barriers. But here in our hospital, okay we have got an occupational health sister, so that they can come but as we are talking about it, they are not doing it …"

4.2.5 'Wrong incentives' – the grant

The financial problems many HIV/AIDS patients encounter have been identified as hurdle for the programs to treat the disease and fight the pandemic. Therefore a governmental grant has been introduced to support these patients financially.

Surprisingly this grant – or rather the way it is given – turned out during the interviews to be of much concern for the health care workers, one sister e.g. stated:

> "They get that grant for one year and then back to square one. So they default, they default and just say: 'No, I just want my CD4 count to go to 135 so that I can get my money back.'"

The troublesome mechanism that is referred to is the fact that the grant is depending on the CD4 count – the patients actually need a copy of their results. Thus the patient might face a dilemma when the grant is to be reassessed after a year: His choice is between a high CD4 count, a competent immune system and no money either or the opposite, i.e. receiving the grant but at the cost of 'defaulting' the treatment, possibly developing resistance and ultimately dying, as a doctor indicates:

> "Like this social grant, I say you give a CD4 count and somebody gets it free for seven months, for one year it is now. The person was without a job, very sick, rehabilitated, now he is on treatment, then one day you have to stop the grant. Then I said: What do you want him to do? So what we will be noticing: when you stop the grant, they default the treatment so that the CD4 count can drop. It is that the grant is based on the CD4 count. So if you manage to get the CD4 count down, you'll qualify for the grant, so what will you be doing? (…) Let them be the ones who clean all the streets, the roads. There is not much money you need to do that. Put them on leaves; step down the money you give them from 750 to maybe 400. If the patient does not feel he likes that job anymore, he can look for something else, but not to take them of completely."

Obviously the fact that grant and CD4 count are linked is not ideal for the compliance of the patients and other options should probably be considered. As she shares the above suggestions about creating jobs instead of giving grants, one nurse warns of surprising consequences if the patients are not being kept busy:

> "Their CD4 count is above 200, let's say it is been below, they had been getting these grants, and they know that now they are reviewing them every six months. Some of them even say: 'that I have to stop taking the medication now because my CD4 count is going about … above 200' and they will stop their medication. So the goals to them have changed. (…) What they should do, they should create more jobs for these people to work, so that they can be independent, financially stable so that they can buy their own food. And in that case, I mean if you are not working, their fun is to have sex the whole day and contract that HIV, yeah, that's what most of them do. And as you hear most women saying: 'My boyfriend doesn't want to use a condom, but what can I say, I am not working, he's the one who is buying the pap.'"

Certainly the last point, economic dependency of the women and the abuse of this fact by the breadwinner, is an important factor, but as examples from other areas suggest, there are opportunities for 'empowerment' of these women:

> “What I saw in Cape Town was … like I was saying I wish our patients would be more independent, you know, less dependent on the state. They have projects in the wellness clinic, they have this bead work project, I even saw some of their beads at the airport.”

4.3 The health carer, the patient and the others

The conflict of ‘competing interests’ is the classical scenario for dilemmas. Such conflicts can be found between the health care worker and the patient (as above) or it can be between the patient and a third person, with the health care professional in the unpleasant position to decide in favour of one of the parties. The two cases described to the interviewees in the introductory letter before the interviews served as examples for such dilemmas, with one of the two cases describing an adult male patient unwilling to adhere or to disclose his status to his spouse.

4.3.1 “Your partner is HIV positive” – disclosure and the spouse

The most obvious ethical dilemma where the health care worker might have to decide between the interests of a patient and a third person might be the case that a patient refuses to disclose the positive HIV-status to the spouse and does not use protective measure like a condom during intercourse either. This conflict touches the patient’s right to enjoy confidentiality and the spouse’s right to enjoy freedom from bodily harm, as has been discussed above (2.4.2). A broad consent could be found amongst the health care professionals about the fact that some kind of moral obligation exists towards both of the stakeholders and that the situation depicts some ethical conflict. Most of the doctors and nurses agreed as well that the best way to solve such a problem would be to try to persuade the patient to disclose voluntarily. Less uniform have yet been the ideas about how to proceed if such an attempt fails, often the complaint was to be heard that there is no clear legal regulations whilst one doctor interpreted the ethical guidelines of the HPCSA as such.
On of the nurses at the wellness clinic even knows about the job of the example case, though no profession was mentioned in the paper:

> „Sometimes, actually when you tell them they are positive or when they find out that they are positive, they don’t tell their partner but sleeping around and spreading the disease, not knowing that they are infecting themselves. (…) When I read this case, he is a truck driver, I don’t know whether it is mentioned or not, but he is a *truck driver*. He is going

> around, which means even if … he is married, he is going all over the country and he meets girls and sometimes he sees a chance and then he just goes for it. He is living a dangerous live because he is not staying at home. (…)

Emotionally such cases do cause a burden, but she approaches the problem from the practical ‘nursing’ point of view – "Who is going to care for him once he falls sick?" - as she continues:

> “I get angry with them, there is somebody who is HIV positive and he or she is not telling the partner that she is positive. Because I always tell them like: ‘What do you think, are you going to cope without telling the partner that you are positive? If you get sick, who is going to look after you? (…) So some of them will say: ‘Ok, I will tell my partner’ and some of them will say ‘I will bring him to the clinic so that you can talk to him.’”

In terms of legally possible option to act in such a case, she sees no alternative to persuasion:

> “It’s difficult! … Because you can’t just phone the partner and tell him that the person is positive. They will put you at trial, the person sues you. You must sit down and talk and talk and talk. You can spend hours there talking.”

A doctor shares this interpretation of the legal situation and joins in on the persuasion trail, but not without some emotional input and the attempt to tell the patient about his or her wrongful doing:

> “I keep counselling, I keep counselling the patient, because according to the law, I am not allowed to tell the spouse and tell, so I must keep counselling that patient. I … I don’t get tired of talking to such patients.(…) Sometimes, you know, sometimes I shout at them, yeah, I try to tell them that, you know, I can give an example, I usually give an example of some other countries where the law is so rude, the fact if you do that they’ll put you in jail. There are countries like that, I don’t know too many, but there are countries where they said if you are HIV positive and you know it and you keep going around they’ll take you and put you in jail, because you are a danger for the society.”

Another doctor advocates a more aggressive strategy, suggesting that it is legally acceptable to contact the spouse to ‘recommend an HIV test’:

> “This is one of the … the … the ethics topics, you know, in terms of … in South Africa is concerned. It is generally believed and stated clearly in that ethics book that if a patient comes in and is HIV positive, you tell the patient: ‘You are HIV positive, I would like you to do something about it, is your partner aware, are you married, are you sexually active – the person needs to know!’ If on two occasions you have realised that this person is not disclosing, you have the right, as a doctor, to call the partner and advise him to do an HIV test without necessarily telling him: ‘Your partner is HIV positive’. You are leaving the whole acumen with me, as you present the problem in that way: ‘I also want you to do an HIV test’, you give him the opportunity to make a decision. You may say when a doctor phones me and tells me that, there might be something fishy. It’s not your business to

> drive a layer between them, just to make him know that he needs to. Some people drive it up to the point that you can actually tell that person. But I personally tell them: ‘Now you should do a test as well’. The person can sue you, that’s a breach of confidence (confidentiality) …”

Using an example to make the situation even more emotionally challenging, this doctor yet openly admits that this is certainly not the ideal configuration and that he himself as well would rather try to persuade:

> “I rather don’t want a patient who will make my life miserable. But you can imagine, if, yeah, let me make it probably a little more personal, you happen to know this lady who is not … who’s husband she didn’t know … actually you know, maybe the husband was your former schoolmate and now she didn’t want to tell the husband and she keeps it. It is commoner with the female, women because of economic reasons they don’t want to tell you … tell the man because the man will junk them, so that’s a common thing with women. You find more men sleeping with their wife not knowing that the wife is HIV positive. Now the … the point is, you have never … let me explain to you now … If you have a woman who doesn’t want to tell the husband, I can not be seeing this guy and laughing with him and I know what is featuring around in the home. So the … the best way to go around it is persuasion.”

A third medical doctor thus admits not to know what rules exactly would have to be applied, wishing for more guiding legal regulations:

> “But ethically I am not quite sure if we are allowed to actually to a third party which may be wives or friends about the HIV status of the patients if the patients are opposing to that, because of confidentiality. It is a big problem for us, you know, sometimes we wish that we really could warn the other people, but ethically I am not quite sure whether we are allowed to do that. (…) well the guidelines are not there. I am not sure; I don’t think we are allowed. But yah, even the guidelines are not there how to handle such a situation. It would be nice if there could be some ... legal recommendations for situations like this.”

The sisters emphasised that generally a lot of time and effort is being spent to facilitate the disclosure. Such activities can include the direct assistance during disclosure, e.g. on the phone:

> “Or that person says: ‘I can not … because I cannot tell my boyfriend and explain it because I am afraid, can you please phone him?’ (…) But you will go extra miles for them instead of just telling them.”

Or such assistance can take place at the clinic, during ‘couple counselling’, sometimes even demanding some acting skills if the known patient has to be welcomed as a new one:

> “Sometimes you call them for couple counselling and then we allow the patient to tell them in front of you because sometimes when they are alone they can not do it. So I call

> that couple counselling, and then if they tell you, some … some give you tips and say: 'Now I am going to … go to tell my wife now that she should start now and going for counselling so you should pretend like you don't know anything.' So for their sake they should be knowing, all of them, so we do, we do accept that and then we start them all over again."

A doctor though points more to the known problems with workload and overwork, indicating that they might just not be able to walk such an extra mile:

> "So with the limited resources you rely on that person conveying the information, rely on that person telling that person to come and help. You know I can not personally go and phone but I see it should just be direct, tell the other person to protect the other person if you can."

An additional aspect of confidentiality and responsibility was mentioned by one nurse during the interview: The dilemma that might arise from the fact that the health care worker has access to data about a certain person who e.g. is the spouse of somebody closely related. This example is an intensification of the above example mentioning a former school mate: the health care worker might now be trapped in a situation where he or she knows about the positive HIV status of e.g. the own child's spouse from checking in the hospital computer, yet is legally not in the position (as it is not even an own patient) to disclose this knowledge to the child. Such decisions depict an extreme ethical dilemma – to protect the patients confidentiality or the own child's health - and they happen in reality.

4.3.2 "Who cares … ?" – the orphans and their support

An increasing number of children in South Africa are left orphaned by HIV, depending on the care within the 'family network' to survive. Since the grandmothers play an important supportive role for working families with the grandchildren regularly being 'dropped' at the 'granny's' place, these grandmothers 'inherit' the full responsibility for the children once their mother deceases. One of the introductory vignette cases for the interview was suggestive of such a setting, with the grandmother incapable of regularly attending the wellness clinic as it would be required before including an HIV-positive child into the treatment program. So some of the following responses have been fuelled by this fictional case, but the health carers recall their own experiences and 'real' cases from the clinic. Even in the case of orphaned children the stigma and denial linked to HIV still seem to play an important role, as one nurse (and Tswana) remembers:

> “With the Tswana, I remember now we had a child, okay she was I think five years, the mother passed away, okay, she is staying with … with the grandmother, it’s like the grandmother knows about the status of her daughter, but it is like she was in denial, she didn’t want to bring the child.”

From her social surroundings, another nurse is familiar with a comparable case and has experienced how difficult the social networking and the organising of support can be:

> “Like I was talking about one granny, one of my friends has a granny who has two grandchildren, I mean they are three, the last two are HIV positive, the mother and the father passed away, the granny is a pensioner, she hasn’t got a husband, so the … the first child was getting some grant so that she can have them buy some food. And then she asked me about this little one and how can she prepare … she can get the grant. I explained to her like: ‘Okay, I will organise the social worker for you, so I will get the social worker to help you to get another grant for the baby.’ So she is getting two grants for the two kids. But you can see that she is struggling, she’s an old lady, she’s hypertensive, she’s diabetic, she has to look after two HIV positive kids. It’s a very difficult situation.”

So such a situation definitely can be causative of the inability to regularly attend the wellness clinic, especially if the clinic is some distance away from the home of the children, but the decision whether or not to treat children under such circumstances remains difficult, as another nurse declares:

> “Eish, it’s actually a dilemma, you don’t know … it’s, it’s very difficult, because you know if you give the child treatment and he fails to come for appointment, he will complicate, if you don’t give, he might die from that, so … it’s really difficult that … and … okay, the social workers are trying in placing the children in somewhere else, but the relatives again refuse, yah, it’s really a problem. You end up not doing; you can’t do anything at all there. (…) That are the cases that I’m telling you about that you end up even crying or being emotional about, it’s … it’s … yah, you can’t do, you can’t say … it hurts, it’s painful … yah,…”

Sometimes it might be suspected that the financial support is the only end the family is aiming for – understandable in a desperate situation, but frustrating for the doctor nevertheless:

> “I am going to give the child this drug. I am just going to make sure that he gets the grant. So they just work to make sure that this child gets the grant. Once they get the grant, they pull off.”

Yet, if the support network is in place, the grandmothers might even be more reliable and more dedicated to the treatment, as the same doctor has experienced in the Western Cape, where there is a lot of support offered and available:

> "In Cape Town I found out that in some cases, where the grandmother of the children takes care of the kids, the one had about four. Now the problem with the grandmother scenario is that the grandmothers were more faithful with giving the drugs to the kids, because they practically don't have any other thing to do, e.g. they get pension. So what makes them faithful is they work with all the organisation: the social worker comes in, the NGOs, some of them supply them with things because these families are identified and they are put in some NGOs lists, so that people whom they need to supply every month may occur. So they don't really lack the basics, you know. So the grandmother has all the time to back the child, to make sure the child takes the medicine when it should."

4.3.3 "The baby needs milk to grow" – breastfeeding and MTCT

The general recommendation in South Africa is to try to avoid breastfeeding completely if the mother is HIV-positive – if this isn't possible, the baby should be exclusively breastfed instead. As many people don't have proper and reliable access to clean water or don't get a continuous supply of formula milk, it is difficult for the health care personnel to decide what to recommend. The topic of breastfeeding and mother to child transmission appeared – not surprisingly – to be of more interest to the female health carers than to the male ones; and the antenatal care is provided at another clinic anyway, so that this issue is not of everyday interest in the wellness clinic (The reason why the experiences with PMTCT, the prevention program in the antenatal clinics, were not included, as the wellness clinic staff was not involved with this program). The answer by a male doctor on the question about his experience with such problems would be:

> "I don't think any doctor would have a reason why to do that, we tell the mother not to breastfeed, so the child dies of diarrhoea. Most doctors, it's something I don't think most doctors are going to tell the patient. I haven't personally heard any doctors here that they do. Perhaps on a more personal level with other patients."

One of the female doctors (and mothers) yet has a quite strict stand on the topic of HIV-positive motherhood – she more or less enters the discussion about reproductive rights and HIV:

> "If the parent knows the status, her status and then she goes ahead and infects, I mean and falls pregnant and then six weeks later the baby tests positive. I think that person has all the information to, you know, to be cautious, but they still go ahead and infect people and sooner or later two, I mean three lives at stake. So they bring an innocent life into the act. So I think that one is really unfair and selfish, especially when somebody has knowledge."

Another doctor (and mother) approaches the topic more from the technical perspective:

> "The recommendation that is usually given is not to breastfeed at all or unless the mother has nothing else to give to the baby in which case they have to breastfeed hundred percent for some ... four months. But, what we usually try to do, because there is formula milk that is given in the clinic, that is provided at the clinic, if there is milk at the local clinic where the mother comes from, we discourage them from breastfeeding ..."

And one of the men adds the exact procedure how it is being cared for the mother-to-be:

> "Usually when they attend the clinic, the antenatal clinic and then they come to the wellness clinic, those who are pregnant. They tell them how to breastfeed. They have to register at the local clinics when they go to antenatal. So when they are registered, they supply them with some milk for the baby, so that they can feed the baby."

The whole program is sketched by this nurse:

> „If they know that the mother is HIV positive, they usually encourage them not to breastfeed. And what they do is, they encourage during pregnancy those who come for antenatal classes, they encourage them to do VCT, and when they test positive, they register them for PMTCT, so even then after delivery, they must deliver at a hospital, after giving the child Nevirapin[14] and all that, on discharge, they give the child the formula, Pellagon[15]. So they encourage the mothers not to breastfeed, to give the mothers milk formula, and they continue giving them monthly at the clinics, so I think it's easier for them."

But there are concerns that not everything is working that smoothly, like this female doctor recalls:

> "Here in Rustenburg my experience is not okay, it's not good, you know, what happens is, as you say the water supply and the milk as well and the structure of the whole program it's not, let's say, okay."

One of her female colleagues and fellow mothers is not exactly aware of the details, yet she regards it as a relevant problem and suggests a solution that might be quite unpopular with the other HIV/AIDS patients:

> "But you know, it is a very difficult problem to solve, in my own point of view. Because I know how high is the percentage of transmission from breastfeeding and at the same time, a baby needs milk. [laughing] The baby needs milk to grow. Now, it is really difficult, because most of our patients are not … are poor, they are very poor and they are telling … I don't know, I heard they were giving milk, formula, I don't know for how long the government is giving formula. But if really they can give it, me I really think it is the best, I can even suggest not to stop the little bit those are … ehm, you know that they give them

---

[14] antiretroviral drug used in the program to prevent mother to child transmission

[15] local brand of formula milk

> some money, (…) the grant, the disability grant! Some other people they are prone, maybe the CD4 count is low or they … the eligibility is based on the CD4, so some … some of them they have a low CD4 but physically they are not very bad, I would prefer then the government not to give the money to them but to give milk to mothers with babies to avoid the transmission, because I am telling you with my patient I tell them: 'Please don't breastfeed.'"

This impression that the topic of breastfeeding is not easy to be dealt with, is shared by a nurse (and fellow mother):

> "With the … with the PMTCT usually they would encourage exclusive breastfeeding for those who say: 'We don't have money to buy' or they are staying in the rural areas, you know where the water is not that clean and the … the milk … the milk that they get in the clinics, the Pellagon, sometimes is not sufficient for the child. They just give them one tin or two, they don't have enough stock to give them until they next come in the next month. So we just encourage them to do exclusive breastfeeding for three to six months and not interfering with the water and whatever. But if we stick to saying maybe they must do exclusive bottle-feeding only or cup-feeding they will be saying: 'E-e, people in their … in our community will be wondering: 'Why are you not breastfeeding?' so they'll now say: 'Maybe she is HIV positive because that's why she is not breastfeeding.' So they tend to like this thing of exclusive breastfeeding rather."

Independent of the availability of formula milk, the stigma and the local traditions seem to limit the possibilities to avoid breastfeeding anyway, as another nurse (and mother) confirms, who has made the same experience of young mothers who 'need' to breastfeed for social reasons:

> "But anyway, they do this thing they call … what was it, what feeding … exclusive breastfeeding, yah, so let's hope it works. … BUT I THINK with this problem of stigma to others it's difficult, because they know that most people think that if you are not breastfeeding that means that you are HIV positive. So those who are still hiding their status from others, they still insist on breastfeeding to hide it from others." (a nurse)

So these narratives suggest that despite the fact that the use of formula milk and the avoidance of breastfeeding is generally recommended and formula milk should be supplied through the local 'clinics' (primary care centres), at least in this area many HIV-positive women still breastfeed, mainly because there is a social pressure to do so. The potentially unreliable supply of formula milk and fresh water contributes as an additional factor. Unfortunately, the social pressure to breastfeed not to disclose once HIV-status results in the fact that exclusive breastfeeding usually isn't possible either, since the refusal of the usual addition of porridge to the baby's diet would demand an explanation as well – exactly the step the mother is shy to do.

4.3.4 Winning the battle? – prevention and care

As last topic in this chapter, a number of statements shall be honoured that the interviewees gave with regard to the goal of fighting the pandemic, how the society and politics are doing in this regard, what factors might influence the general situation and what they personally do to contribute.

A nurse is concerned about the fact that HIV/AIDS patients are only taken into the program when they have reached a certain clinical stage:

> “We have a lot of people, we have mines, a lot of community members that needs to be seen and still we have to see people with a CD4 count of less than 200, and you feel it’s unfair sometimes if a patient tells you: ‘Now that my CD4 is 300 they say I must go back to that clinic so that means I have to come back when I am about to die.’ So maybe they should have just said: ‘People who are HIV positive should come to wellness clinic and then there is something you can do though you know that if you give ARVs to somebody with a CD4 count of more than 200 it won’t be helping that much.”

But this is after all a political decision; health politics shapes the framework for the delivery of medical services. On the performance of politics and politicians a number of comments were given, a doctor in general agrees with the government but points at public health tasks:

> “By giving treatment, I think the government is doing something right, but of course we need to step up our primary prevention strategy.”

Particularly from an extra-South-African point of view, this assessment is shared by another doctor (who grew up in Western Africa):

> “South Africa is doing quite a lot if you compare it to all the other African countries.”

But his view allows him as well to recognise the political role HIV/AIDS is playing at the moment:

> “HIV medicine in South Africa at the moment is highly politicised in the sense they make shift where they want to use you, but they don’t really give you anything.”

Another doctor shares this ‘foreign’ background and his general appreciation for what the government does:

> “So as, eh, government, I don’t think they are doing badly at all, I honestly don’t. It’s just that the people have a way of resisting change in their behaviour, you know: ‘Why should we change our behaviour’, it’s a very difficult thing about human beings changing behaviour, the most difficult thing about human behaviour from biblical times.”

- politics (and medicine) could be so nice and easy if just the people would do what they are supposed to do (a problem Marxism encountered as well)!

Another doctor suspects the deficits on the side of the politicians:

> “The problem, I think, is more political, you know, because with us here who are sitting with the problem and then there is somebody, a politician, who doesn’t understand anything about medicine or anything, doesn’t understand the necessary need and the urgency for them to deliver, open more sites. You know, they are always concentrating on the money and then always are, you know … I don’t know, forever they are just not in their office to do their work.”

But there are more obstacles in South Africa to reckon with, like the well known objections against the use of condoms, as one nurse knows:

> “You tell the husband that … or the couple that day that they will have to use a condom so that you don’t reinfect yourself and then they’ll be telling you that: ‘No, I have to take it meat to meat’ and ‘You can not eat a sweetie with the paper’, ‘How do you expect me to get that sweet’ and you try to explain and to convince and it’s that … that … that cultural person that cannot change anything, but still he is HIV positive and she expects you to give medication and still there is more and more of the … the STIs and reinfections, so …”

Some of the local problems though might be founded in the political history, as one doctor with foreign background suspects, due to own experiences:

> “For South Africa, I just think that even the pandemic is so bad because family structure was just destroyed because of apartheid. In my country, the family structure is very very strong, so if a girl … a girl can’t even think having a child before getting married. If she has one, she has to get rid of it. The girl back home, before she has her first boyfriend, before she has sex, it’s some internal conflict.”

But as a health care worker, one has to live and deal with all these human mistakes to ultimately achieve the goal of health improvement for the patient (this might be true on the level of individual health care as well as on the public health level):

> “Oh personally, personally I am a Christian. I always recommend … if for a Christian, I always recommend people not to go into trouble, sexually. It means: get married … (…) but: If I look at the patient, if I look at the level of understanding, education, whatever, I realise that there are not many who are going to listen to me, not many [laughing]! I can say it, but there are not many, they are not going to listen. Then somehow I might fail with my way of talking [laughing], that’s why I told them to use condoms. I tell … I tell the patients to use condoms, because I … I know them [laughing].“

5 Discussion

One of the well known problems of writing a scientific paper is that the complexity and multidimensionality of ‘real life’ has to be transformed into a linear sequence of chapters and topics. This encounters the risk of losing much of the information that is relevant for the issue under investigation, information that probably had been contained in the original ‘data’. Especially using qualitative research, what per definitionem is not merely looking at the statistical analysis of numeral data but at human behaviour as documented in recordings of interactions, transcriptions of the spoken word and the same. Discussing the psychology of communication, Schulze von Thun[16] has identified four different levels or aspects of communication that are all contained in the ‘spoken message’: the aspect of the matter itself (Sachinhalt), the aspect of the self-expression (Selbstkundgabe), the aspect of relation (Beziehung) and the aspect of appeal (Appell).

Using this sketch for a view on the interviewer/ interviewee relationship, potential confounders will be discussed which might have an effect on the results.

5.1 Possible confounders – the effects on ‘validity’ and ‘reliability’

Two expressions that are commonly used in the assessment of the quality of scientific work shall guide the following discussion: ‘reliability’ and ‘validity’. ‘Reliability’ is describing the fact whether or not the used ‘technical instruments’ measure the item that they are focussed at well and with results that will be found similarly if the research is repeated by other researchers (‘interpersonal r.’) or at another time (‘intrapersonal r.’). To use an example from clinical medicine: If I use a test in the laboratory, e.g. an HIV-antibody test, this test would be reliable if it gives the same results when repeated by another technician or on another day.

‘Validity’ in contrast to that stands as the parameter whether the measured and reported values really represent what they claim to tell us – to stay with the example of the HIV test: Even if the test is extremely reliable, e.g. always giving a positive result for a certain patient, independent of when or by whom the test is performed, it could still happen that this test is ‘false positive’, meaning that it actually does not

---

[16] Schulz von Thun F, Ruppel J, Stratmann R (1981). Miteinander Reden: Kommunikationspsychologie für Führungskräfte. Cited from: Schlein U (2006). Wirksames „Miteinander Reden“ im beruflichen Alltag. Der Chirurg BDC (1):23f

represent an HIV infection but maybe some ‘cross-reactive’ antibodies as well – in the end we will have a technically perfect test (high ‘reliability’) but unfortunately it doesn’t answer our question: ‘Is the patient infected with the HI-virus?’

In a similar way, the two terms might be utilised in the field of qualitative research: ‘Reliability’ would mean that we will reach the same research results (e.g. “the health carers in HIV medicine are not having any problems”) with the method applied, independent of when and by whom this method is used to answer the research question. But to get a wrong answer to the question obviously isn’t the ideal outcome of a research (e.g. if we suppose that actually there are problems for the health care worker), Even if we get this result time and time again, thus with a high reliability, a false result is not a good one for research. Therefore ‘validity’ is needed in qualitative, social research, too, since we want to be sure that we really have found the ‘true’ answer to our question. In other words, the results of the research efforts should be independent of the researcher and dependent (and representative) of the research subjects. A further distinction had been introduced between ‘internal’ and ‘external’ validity, the former to describe the validity of the results for the group (or sample) they were found at and the latter to express whether they could be generalised to the larger population the sample was taken from, thus meaning whether the results are true (or relevant or significant) not only for the sample but for the entire population that the research aims at. This aspect of ‘external validity’ will be discussed under the headline ‘generalisability’ in section 5.3.

5.1.1 Interviewee, Interviewer and their communication

Using the above outlined model of communication by Schulz von Thun, in the following some potential confounders shall be discussed.

1. The ‘matter itself’ (Sachinhalt): This is usually the first and foremost thing when discussing topics - what is stated about the topics, what facts are being named? In the interview, the medical personnel were asked about their experiences, their difficulties and dilemmas, and they spoke about clinical facts and cases, about emotions, wishes and worries they have. All these things were expressed verbally as answers to the interview questions. Analysing the transcripts of such interviews, it is soon to be realised that not only it is important what has been said, but it might be similarly important what has *not* been said. Such silence about certain topics can

have a number of reasons, the interview situation and the relation between the researcher and the ‘subject’, social desirability or shame, fear and denial etc. Since these factors can obviously act as ‘confounders’ and change the result of the research, some of them shall be discussed by looking at the other ‘dimensions’ of communication.

2. The aspect of self-expression (Selbstkundgabe): Every person is a person through other people; this sociological principle is quite popular in African philosophy[17] and arts. One of the consequences is that every person represents a wild composition of social roles and expectations loaded onto him or her, with the ‘self’ – hardly independent – lurking out of these ‘onion-like’ layers of social expectations (which shall be further discussed under the next topic). By expressing themselves during the interview, those interviewed sometimes do not just answer the question but tell something more specific about themselves. One example for this phenomenon has been addressed sometimes in the chapter (4) presenting the results: Medical doctors would be more reluctant to talk about personal feelings and emotions and show a certain tendency to turn the discussed topic to a more abstract level, away from ‘my life, my experiences and how I *feel* about it’ towards ‘the patients, the virus and the requirements of the treatment’. The nurses, in opposition to that, seem to be more of ‘specialists for communicating emotions’, since they seem more willing and prepared to talk about what they feel. This finding most likely should not be interpreted in the way that doctors ‘just have less emotions’ (what might or might not be the case), but rather as a sign that by socialisation the doctors have ‘learned’ to deny their feelings whilst nurses probably are expected to be competent in communicating emotions in order to fulfil their ‘nursing tasks’. So this possibly socially learned difference might obviously act as a confounder if one tries to learn more about the emotional impact certain dilemmas have on the health carers.

Another example for such ‘self-expression’ is a phenomenon that could be called ‘genderisation of examples’. Using examples to visualise e.g. HIV related behavioural problems, particularly in connection with sexual intercourse, the interviewees would usually chose the ‘sympathetic example’ (or the victim) from their own sex and the ‘offender’ from the opposite. Though only two of the interviewees were male and seven were female (this might not be statistically significant in the strictest of senses), it was quite striking: The men used ‘vaginal thrush’ as an example under what

---

[17] ‘Motho ke motho ka batho ba bang’ – Setswana proverb: A person is a person through other people

circumstances the patient should abstain from intercourse or tell the partner to use a condom because of the risk of HIV transmission, they suggested that “far more men sleep with their HIV infected wives not knowing about their status than vice versa” (because of the economical dependency) and an example on the dilemma of disclosure used “an old school mate of yours” and “his HIV-positive wife who is your patient”. In opposition to this, the women would speak of the “men’s refusal to use condoms”, of guys “sleeping around and spreading the virus”, using an example of a patient’s husband who is unwilling to get tested himself and they would declare their sympathy to women who are discriminated against as “bitch who sleeps around” because of her HIV status. Thus the individuals’ gender and his or her own experiences with and concerns about sexuality obviously affect the way they look at certain sex related topics – another potential confounder.

A further sign of (non verbal) self-expression is the ‘use’ of laughter in certain situations like:

> “… in fact you just have to become rude [laughing]”

or:

> “… we are always in danger somehow [laughing]”

At these occasions the laughter is not spontaneous because what has been said was so funny. Rather is the laughing after or during some very serious statement a means to take away a little of the brutality of the truth told – the laughing does not imply it is ridiculous what is being said but rather is meant to prevent too much of a tense situation in the communication during the interview and is thus a contribution to the level of relation.

3. The aspect of relation (Beziehung): As has been mentioned above, everybody of us is embedded into a multidimensional network of social relations, resulting in a multitude of role-expectations. Definitely these social expectations are powerfully influencing our behaviour – and the way we interact with each other (even in the ‘cosy’ situation of a semi-structured interview). The specific effect of these expectations has been called the social desirability error and one might gain an idea of its impact listening to how two health care professionals, one doctor and one nurse, describe their commitment to role-expectations during the interaction with the patients. Asked about how they deal with the fear of infection, one doctor answered:

> “I have no idea, it’s so scary, I really don’t know, it’s just scary, you know. But then I think, you know, at the end of the day I mean we as health givers, one of us must be strong for

> the patient. If we seam, you know, to be scared as well, we don't give them any hope. So it is like pull a strong face just for the patient to really believe what you are saying."

And after having expressed the emotional burdens caused by the patients' suffering, a nurse states as well:

> "… it makes you depressed sometimes, when you look at their emotional suffering, you end up saying: 'You become strong for the patient.'"

Though both these examples are taken from the health carer/patient relation, they may give an idea of how social desirability affects the interviewer/interviewee relation and the results of the research – with one possible example, the extend of verbalisation of own emotions, addressed above.

Another potential confounding factor in the interviewer/interviewee relation is given by the fact that all doctors and nurses who were interviewed were black (and/or African[18]) and the author is white (and/or European) – a fact that was referred to twice by interviewed doctors:

> "You know, the traditional things. I know them, you know, I am a black person, it is our culture."
>
> "You know that in Africa the percentage of people who are illiterate is … is a bit high."

Both expressions – the first more openly, the second implicitly point to the fact that one of the partners in that conversation is African and the other isn't, it is a fact – the first dimension of communication. Yet all the other dimensions can be found in these spoken words as well: "I feel myself as African and I am willing to express that" could be the meaning in the dimension of 'self-expression' and "I know you are different – in terms of skin colour, cultural background and life experience" could be the 'aspect of relation' in these phrases. Even the 'aspect of appeal' would be present with ideas like: "I expect that you respect our culture" (for the first sentence) or "Africa needs support to open more schools" (for the second one). Thus the quoted examples shall prove that such aspects are prevalent in the interview situation and that especially the 'aspect of relation' between the different skin colours and cultures in other cases might not have resulted in an open addressing of the fact but rather in misunderstandings or even silence about the topics, something that would clearly affect the reliability.

Besides skin colour and cultural background, another possible confounder with influence on reliability and grounded in the relation between interviewer and

---

[18] some confusion is caused by the fact that the 'social desirability' in some countries demands to call 'black' people 'Africans' and 'white' ones 'Europeans' – leaving no homestead for 'black Europeans' or 'white Africans'), but in this case the blacks are Africans and the white is European

interviewee might be found in the professional background. Since the author is a medical doctor, a fact known to all the interviewees, doctors and nurses alike, this certainly has influenced the way of communication. The simplest sign for this is the ease with which the interviewees referred to medical details or abbreviations without explanation – the common medical background was assumed and used. The doctors though regarded the interview as a conversation between colleagues, proven by phrases like:

> “No doctor is happy to loose a patient. You should know.”

Thus the doctors would more easily criticise other professional groups whilst talking to ‘one of them’ – as has been shown above (4.1.2). In difference to that, nurses would be quite unlikely to criticise doctors whilst speaking to one, and they actually abstained from doing so during the interviews – a strong indicator that the professional background had an effect on what was said during the interviews by this way on the results.

An additional factor might have been the ‘social closeness’ of the researcher to the personnel due to the fact that his wife is working as a medical doctor at the Rustenburg Provincial Hospital.

All these factors may influence the reliability of the result, as probably a nurse researcher might have heard a number of things somewhat different and the results therefore are not entirely independent of the researcher – yet a complete independence is impossible to achieve in this kind of research that depends to a large part on interpersonal skills.

Despite of this caveat it should be acknowledged that all the interviewees have been quite frank in their comments and critics of most of the people and institutions they are confronted with due to their work at wellness clinic. And similarly, most of them have shown a great openness in talking about emotions, sexuality (with the interviewer’s gender seemingly being of only little influence) and other sensitive topics, giving hope that the communication between interviewer and interviewees was successful and that the presented results enjoy a good degree of reliability.

Further more the fact that some of the topics (workload, patients and adherence) were continuously and with strong emphasise mentioned nourishes the confidence that the results should be quite valid (at least for this group) as well.

As an additional proof for the successful interaction the last dimension of communication according to Schulze von Thun may serve:

4. The aspect of appeal (Appell): The fact that many complaints as well as suggestions have been expressed or implied during the interviews indicates that the health carers perceived the interview situation as an opportunity to show their needs and concerns.

5.1.2 ‘Grounded theory’ or ‘verification of assumptions’

It might be argued that the prior definition of certain clusters and topics in the field of the research by using the available literature might affect the validity of the findings: If the ‘field of discussion’ is structured by the researcher prior to the interview and the list of topics is prepared to be ticked during this interview, this might lead to ‘finding’ exactly these topics as results when the interviews are analysed afterwards, either because the specific way of questioning provokes these answers or because the researcher ‘analyses’ these results ‘into’ the interviews during the process of data interpretation.

This objection is true in as far as there is a risk of being preoccupied by this procedure. Yet there are at least two possible objections to this criticism, a theoretical and a practical one. From a theoretical point of view, it is merely impossible to conduct any research without being ‘preoccupied’ in the one way or the other. Each and every of us has enjoyed various experiences during his or her life that shaped our ideas about the world and how it is turning around. Since we cannot entirely get rid of these personal experiences, all our research efforts are influenced by our prior knowledge and experience – thus the theoretical approach of ‘grounded theory’, i.e. to develop theories entirely as deductions from the data might be a nice but unrealistic ideal. The epistemological discussions about how to invent theories or hypotheses fill great libraries and certainly cannot be reviewed here. The practical objection to the above criticism would be that the research within a given frame would be completely impossible, since the technique of semi-structured interviews has been introduced to enable a more comprehensive investigation of a topic, highlighting different aspects, within a certain timeframe. A completely narrative interview, in contrast, would certainly produce exciting stories, but it would be difficult to decide whether all potentially relevant topics have been touched. And it might be doubted that highly stressed medical personnel would allow the researcher to extend the interview until this goal has been reached – most likely it is appreciated if the interviewer shows some degree of familiarity with the research issue during the interview instead of complete naivety towards the field.

Nevertheless it should be borne in mind that this methodology could affect the results of the research. The researcher might tend to focus more on certain topics than the others, causing a ‘bias’ in the results which then might rather represent the researchers idea about what is going on and not the true e.g. concerns of the health care workers. Many factors, personal to the researcher or grounded in the society, could affect the outcome in this way, as e.g. very popular discussions or current topics in the society, personal experience or even personal fears of the researcher may cause one topics to be recognised and others to be forgotten[19].

In an attempt to avoid such unintentional influence on the results, a lot of effort was spent to keep the process open: The introductory question during the interview was completely open, allowing for a free description of the felt main difficulties. The further questions were asked in a manner of keywords, giving the interviewee the opportunity either to reject the topic or to comment on it from own experiences. Similarly the concluding questions of the interview, asking the interviewee to point out which of the topics touched he or she regards as the most important and finally allowing to mention other topics in his or her mind that had not been considered aimed at the same end. During the process of analysis again effort was given to the ‘open’ interpretation of the data. Though certainly this process was not ‘unconditional’ (as was laid out above) the coding of the interview was dependent on the content rather than on preformed clusters and allowed for the appearance of new topics and clusters independent from the literature review.

To conclude this discussion on possible confounders, a last problem should be mentioned that might contribute to some loss or misinterpretation of information: None of the people involved in this research, neither the health carer nor the researcher, enjoyed the privilege to speak English as mother tongue. Therefore the ‘language barrier’ might have had some negative impact – during the interviews or during the process of transcription.

---

[19] the classical example for such bias in the media is ‚sex sells’ – if a story is ‚sexy’ (or sex related), it enjoys a far greater likelihood to be published, regardless of whether it is more relevant or not than others

5.2 Needs and worries – does the clinic fit into the literature?

When discussing the problem of health carer burn out in HIV care, Wilson et al. (2002:452) give a list of the ‘causes of burnout’:

- overwhelming workload;
- lack of reward – both financial and emotional;
- unfairness and poor handled evaluations, promotions, or grievances;
- compromised values, owing to high workloads;
- loss of control and inability to finish projects;
- rigid or chaotic health care settings and
- the loss of a sense of community because of tensions with one’s employer or colleagues.

This row reads – unfortunately – almost like the list of complaints of the Rustenburg wellness clinic’s personnel about the situation at their workplace. Luckily, the symptoms of burnout, e.g. loss of interest, sarcasm, social withdrawal etc. haven’t been extensively present. The entire staff at wellness clinic expressed homonymous concern about the workload and the effect this situation has on the work-satisfaction. The tensions between the staff members due to this burden were easily detectable. But despite of these undeniable problems the mood in general seemed far better than what had been described in the literature e.g. for the Eastern African region (Raviola et al. 2002), with a high percentage of depressive disorders amongst the health care workers in Kenya. Of course it has to be admitted that this research did not use psychological tools to evaluate such disorders specifically and the perception from the interviews and interactions might be erroneous. Nevertheless, the multiple comments on ‘hope’, ‘happiness’ and ‘motivation’ and the ‘clinical impression’ indicate that this team is not (yet?) in a stage of ‘collective burnout’. The main difference to the Kenyan experience might be that the ‘sample’ of this investigation was not only extensively involved with the HIV/AIDS pandemic, but was armed with a powerful tool to help the patients – the HAART – whilst the doctors in the Kenyan study merely had to ‘watch the patients dying’. This thesis is supported by the statements where interviewees compared their own experiences from the ‘pre-HAART’ era with the current situation.

The second major topic besides workload and -satisfaction were the HIV patients' special features and the difficulties to achieve adherence. These are specific wellness clinic problems since (a) the wellness clinic is the place where exactly these supposedly special HIV/AIDS patients come to and (b) adherence is the one fundamental condition without which the whole concept of HAART is not going to succeed, neither on the individual nor on the community level. Two additional factors make this field of HIV medicine, the interaction with the patients and the achieving of adherence, more difficult: the still strongly prevalent stigma and the interference of local traditional healers and churches. Both these factors are deeply rooted in the society and in the minds of the individuals, but they need to be further analysed and countered with comprehensive and integrative strategies. Another factor with negative impact is the social and economical situation of the patients. Here it appears that the recently invented grant may give the wrong incentives due to the way it is administrated – 'rewarding' a patient for bad health when he is on treatment with a regimen difficult to adhere to might result in a public health blunder, especially when the patient starts to understand the link between drug intake and haematological result.

Some of the topics suggest by the literature did not seem to play an important role in the local setting, e.g. has the general recommendation of condoms (which was advocated by the interviewees) not been perceived to constitute any 'turmoil of conscience' despite of a high number of members of the roman catholic church amongst those interviewed - unfortunately independent of this the general willingness to 'condomise' in South Africa is very low. Other topics were confirmed in their relevance by the health care workers, so has been e.g. the problem of breastfeeding, where there could be shown that local traditions contradict the recommendation to abstain from breastfeeding. Similarly confirmed has been the problem of disclosure (and unwillingness to disclose), resultant in a request to supply the health carers with more detailed and legally proof recommendations in case of severe ethical dilemmas.

A last problem that was not mentioned yet under the results has only been addressed by one person during the interviews – the language problem:

> "But then another problem there is that the other doctors who are giving treatment, they only speak English and are not fluent with that and not perfect and you find them from time to time, you know, they even don't have an interpreter, that's very difficult – very, very difficult not to have an interpreter and then sometimes the patients comes to me: 'But the doctor said this.' 'No, I didn't … I didn't understand' or 'He didn't tell me', but the doctor wrote, you know, that's what they do, that can also be hard …"

Though all four nurses spoke the local language, Setswana, as mother tongue, only one of the doctors did so (and one other speaking a closely related one), whilst the three other doctors (and others at wellness clinic) had entirely different mother tongues. As South Africa still seems to motivate the local intelligentsia to exercise ‘brain drain’ (the emigration of skilled personnel to other countries), there is an aim to recruit doctors from other countries to fill in the gaps – a tendency that does not necessarily ease the Babylonian language situation in wellness clinic.

5.3 Limits of generalisability

One might as well argue that the very narrow local base of the sample of interviewed people will reduce the result’s ability to be generalised for the ‘general population’ of all the health care workers (nurses and doctors) involved in the rollout program in South Africa. This generalisability is sometimes referred to as ‘external validity’, expressing the idea whether the results derived from the sample would be transferable to the larger group the sample was taken from and would be similarly true for this whole group. To discuss this topic, it will be useful to consider how much local settings and conditions would influence some of the results.

Obviously, the factor of locality has a strong influence on the situation at the workplace. This influence is at least caused by two factors, the number of patients to be served and the local (infra-) structure. First the workload for the clinic is determined very much by the local situation, i.e. the area and population that has to be covered and the prevalence of the infection (HIV rate) in this population. The North West province and the Rustenburg area have certain attributes influencing these factors – the province has been combined of areas of the former Transvaal province of South Africa and of Homelands (Bantustans) of the Apartheid-era (Bophuthatswana). Therefore the province still faces the task to harmonise and combine the formerly separated administrative structures, and it includes quite rural areas with comparatively low population density and far distances, facing greater problems in this regard than e.g. the mainly urban Gauteng province with Pretoria and Johannesburg. On the other hand, especially the Rustenburg area is economically quite prosperous, particularly due to the large amount of mining industries in the region, and therefore better of than e.g. the mainly rural Limpopo (or Northern) province. Unfortunately, this beneficial economical advantage comes at a price, as the mines usually employ a high number of migrant workers - a population group that is known to exercise serious risk behaviour and thus has an extremely high rate of HIV infections.

As a second factor the staffing, organisation and management at the local clinic can have a strong impact on the degree to which the work setting is perceived as a burden. A (relative to the patient numbers) shortness of staff, lack of remuneration and immaterial awards and tensions between the staff members can be prevalent at one site and yet be unknown at another.

Examples that have been mentioned during the interviews indicate such differences, though such comparisons might be sometimes misleading as ‘the neighbour’s lawn always seems to be a bit greener than the own one’. But nevertheless, it was described by a number of interviewees, either from own working experience or from contacts during training courses or meetings, that some of the critical topics mentioned above seem to be organised somewhat better at other locations. These examples included the supply with formula milk as a method of PMTCT being more reliable in Gauteng, the workload per doctor at large medical centres’ (Johannesburg Hospital, Chris Hani Baragwanath Hospital) HIV clinics being far less and the support structures (NGOs, self help and economical empowerment by small businesses) for the HIV patients and care takers of orphans as well as the delivery of paediatric HIV care being far more developed in the Western Cape.

For these reasons, it would be desirable to extend the investigation about the problems, burdens and dilemmas experienced by the health carers in HIV medicine to such sites as well. In comparing the results, it should be possible to find out whether the older and more established centres e.g. in the Western Cape enjoy certain advantages in terms of workload and -satisfaction, management and support of patients etc. For the same reason, it should be aimed to include centres from a (even) more rural area into the future researches to be able to assess whether the abovementioned problems of e.g. transportation and interference of traditional concepts may result in even bigger problems there. At the end, a comprehensive picture should occur by this way that gives a proper and realistic idea of the problems for the HIV carers in South Africa. This will hopefully lead to the necessary steps to adjust the shortfalls and counter the risk of burnout being done.

6 Conclusions

The dramatic experiences described for an Eastern African setting with a high level of desperation and hopelessness luckily have not been found in the current local situation under examination. A feeling of hope and the motivation to change the situation for the affected population seems to govern the health carers' activities in Rustenburg's wellness clinic. Nevertheless, a number of relevant stressors have been named, resulting both from structural shortfalls and from problems 'imminent' to the care of HIV and the local situation. The two major ones amongst these problems are firstly the excessive workload that is to be faced at the clinic and secondly the difficulties that are related to the interaction with the patients, due to the 'being-different' of the HIV/AIDS patients as well as to the special demands of the therapy. Additionally there are distinct problems caused by the 'competing ideas' of traditional medicine, ethical dilemmas linked to the patient's failure to disclose his or her HIV status to the spouse and an unsatisfying situation in regard of the care for children and the prevention of mother to child transmission. It will be essential for the successful future of the program that these problems will be recognised by those overseeing the program and influencing the framework, since otherwise an over-exhaustion of the involved personal might occur, with detrimental effect for the program and of course for the patients who depend on it.

Assessing the issue from a public health point of view, it should be tried to differentiate the many problems according to their potential to be solved:

- Whether they are within the range of responsibility of the administration (e.g. organisational or managerial deficiencies, style of leadership, shortness of staff, building, remuneration, etc.),
- Whether they are potentially changeable but beyond the reasonable reach of those responsible for the treatment program (e.g. cultural and social problems, stigmas, superstitions, legal regulations and grant policy) or
- Whether they are imminent to the HIV medicine and can at best be handled optimal but not be solved (e.g. need for adherence, risk of transmission).

The first group should result in immediate action by those responsible, the second group should be brought to the attention of those who implement health or educational policies and it should be aimed to eliminate these problems in the longer range whilst the last group of problems will have to be recognised and taken into account by everybody involved to achieve the best possible outcome.

A lot of such solutions and even policies have been suggested by the health care workers who are day-to-day involved with the practical problems. To benefit from this treasure of potential, they just have to be listened to when expressed.

With regard to the development of further research strategies, the interaction of traditional medicine (and its concoctions) with the antiretroviral drugs (both pharmaceutically and in terms of adherence) appears as an exciting and important question in local HIV medicine.

With more relevance to the protection of the health care workers involved in this field of medicine and to gain a better understanding of the burdens these individuals have to face, the research on 'dilemmas for HIV health carer' should be extended regionally. Additional investigations at other locations throughout the country will be needed to decide whether the observed phenomena can be generalised for the whole country. It will be necessary to go to the other provinces, to look into other cultural settings and to include both more urban and more rural areas. Once the foundation work by qualitative research has been done by identifying the most relevant topics, a more quantitative approach should be added. This could include a questionnaire to ask the health care workers to assign levels of importance (very relevant – not relevant at all) to suggested problems and dilemmas. Such a questionnaire would be distributed to a much higher number of both individuals and centres and could serve as a method to monitor overall satisfaction as well as increasingly developing problems in the program (if the distribution of the questionnaire is repeated after a while). In a similar way as it was described for the study in Kenya (Raviola et al. 2002), such a questionnaire could contain approved psychological tools from questionnaires used to identify depression to learn more about the actual degree of burnout and resulting depressive disorders amongst the health care workers in South African HIV medicine.

As Wilson et al. (2002:452) state in their "Handbook of HIV medicine" after discussing the problem of 'burnout':

> "Losing any health care giver to burnout comes at an unacceptable cost to the individual, the health care system, and the society at large."

All people in the position to influence this health care system should aim at making the health carers' situation less exhausting. If the health carers are to face a dilemma, a difficult choice between two equal options, it should not be an aversion-

aversion-conflict (the choice what is less bad), e.g. the damaging effects of the work setting on once personal life and health versus the loss of the salaried employment – but let it be an appentence-appentence-conflict: The job so fulfilling and the work-satisfaction so high that it will become a difficult choice for the health carer whether to leave such work at wellness clinic even for a much better paid employment elsewhere.

Certainly still a long way has to be gone to reach this goal and many stakeholders will have to contribute, but as one doctor said with an almost Sartrean appeal to everybody's responsibility:

> "We are not dead, we can still change things!"

Acknowledgement

Prof. Wehkamp as supervisor and Prof. Setswe as second examiner accompanied and guided me through this thrilling and challenging encounter with the social science part of medicine, providing invaluable support and advice.

My wife Prudence nourished my interest in Public Health and helped me to organise and perform the interviews.

Mrs M. Phahla read over a large part of the manuscript and helped me to improve the English this thesis is written in.

My fellow student Amena Ahmad continuously and reliably provided me with scarce information from Germany and helped to get this thesis into its final printed shape.

The following institutions supplied me with the relevant literature and their staff was helpful in locating the sources: The University of South Africa in Pretoria, the Universiteit van Pretoria, the Medical University of Southern Africa in Ga-Rankuwa, 'Popline' at the John Hopkins Bloomberg School of Public Health in Baltimore, USA and the Stanford Law School, USA.

The German Armed Forces' service for professional development (Berufsförderungsdienst) funded my degree course in Public Health.

And last but not least the nurses and doctors at Rustenburg Provincial Hospital's wellness clinic gave their time for the interviews and allowed me to gain an insight into their experiences.

All of them enjoy my deep and honest gratitude.

7 References

7.1 HIV/ AIDS and their burdens

Abdool Karim S S, Abdool Karim Q (2005). *HIV/ AIDS in South Africa.* Cape Town

Adams W (1994). "But do you have to tell my parents?" The dilemma for minors seeking HIV-testing and treatment. *John Marshall Law Rev* 27(2):493-512

Arruda R (1994). A moral dilemma. *WorldAIDS* 35:11

Baumgartner, G H (1986). *AIDS, psychosocial factors in the acquired immune deficiency syndrome.* Springfield

Benatar S R. Ethical challenges for health care in South Africa (2004). In: Van Rensburg H C J, ed. *Health and Health Care in South Africa*. Pretoria:561-601

Bernstein B (1995). Solving the physician's dilemma: an HIV partner-notification plan. *Stanford Law Pol Rev* 6(2):127-36.

Betancourt J R, Green A R, Carrillo J E (2000). The Challenges of Cross-Cultural Healthcare – Diversity, Ethics, and the Medical Encounter. *Bioethics Forum* 16(3): 27-32

Black B P, Miles M S (2002). Calculating the risks and benefits of disclosure in African American women who have HIV. *J Obstet Gynecol Neonatal Nurs* 31(6):688-97

Carney L, Hopper M J (2003). A clinician's dilemma: diminished capacity in HIV/AIDS patients. *HIV Clin* 15(2):1, 5-8

Colvin M (2005). Impact of AIDS – the health care burden. In: Abdool Karim S S, Abdool Karim Q (Eds). *HIV/ AIDS in South Africa.* Cape Town:336-350

Coutsoudis A (2005). Infant feeding dilemmas created by HIV: South African experiences. *J Nutr* 135(4):956-9

Deane N (2005). The political history of AIDS treatment. In: Abdool Karim S S, Abdool Karim Q. *HIV/ AIDS in South Africa.* Cape Town:538-547

Dohrn J (2005). Breastfeeding in the HIV epidemic: A midwife’s dilemma in international work. *Online Journal of Health ethics* (the University of Mississippi Medical Center), accessed at
ethicsjournal.umc.edu/ojs/include/ getdoc.php?id=118&article=17&mode=pdf
on 06.02.2006

Edwards S D (1986). Traditional and modern medicine in South Africa: A research study. *Soc Sci Med* 22(11):1273-6

Evian C (2000). Primary AIDS care. A practical guide for primary health care personnel in the clinical and supportive care of people with HIV/ AIDS. 3rd ed. Houghton

Flagler E, Baylis S, Rodgers S (1997). Ethical dilemmas that arise in the care of pregnant women: rethinking "maternal–fetal conflicts". *Can Med Assoc J* 156:1729-32

Frohlich J (2005). The impact of AIDS on the community. In: Abdool Karim S S, Abdool Karim Q. *HIV/ AIDS in South Africa.* Cape Town:351-370

Garcia JG, Froehlich RJ, Cartwright B et al (1999). Ethical dilemmas related to counseling clients living with HIV/AIDS. *Rehabil Couns Bull* 43(1):41-50

Geis S, Fuller R (1986). Hospice Staff Response to Fear of AIDS. In: Feldman D A, Johnson, T M. *The social dimensions of AIDS.* New York: 235-241

Harries A D, Nyangulu D S, Hargreaves N J et al (2001). Preventing antiretroviral anarchy in sub-Saharan Africa. *Lancet* 358:410-4

Heywood M (2005). The achilles heel? The impact of HIV/ AIDS on democracy in South Africa. In: Abdool Karim S S, Abdool Karim Q, eds. *HIV/ AIDS in South Africa.* Cape Town:371-383

HPCSA – Health Professions Council of South Africa (2002). Guidelines for the management of patients with HIV infection or AIDS. In: HPCSA. *Handbook – Guidelines for good and ethical practise in medicine, dentistry and the medical science.* Pretoria:88-97

Isaacs D, Jooste K (2004). The managerial duties of the nurse in charge of a unit in combating the spreading of HIV/AIDS. *Curationis* 27(3):49-61

Jolys O. Der Fluch einer Krankheit (2005). AIDS, Hexerei und Demokratie in Südafrika. [AIDS, witchcraft and democracy in South Africa] *Der Überblick* 2:29-30

Karstaedt A S, Pantanowitz L (2001). Occupational exposure of interns to blood in an area of high HIV seroprevalence. *S Afr Med J* 91:57-61

Kell P, Sadeghi-Nejad H, Price D (2002). An ethical dilemma: erectile dysfunction in the HIV-positive patient: to treat or not to treat. *Int J STD AIDS* 13(6):355-7

Manganyi N C (1987). Ethics and the social responsibility of health workers. *SA J Contin Med Educ* 5(4):35-9

Mbaye I, Mbaye N, Becker C, et al (2004). Problèmes éthiques rencontrés par les médecins dans la gestion de l'infection VIH en milieu de travail [Ethical problems faced by physicians in managing HIV in workplace] *Dakar Med* 49(1):1-4.

Mbeki T (1998). South Africa : Two nations. Statement of Deputy President Thabo Mbeki at the opening of the National Assembly, on reconciliation and nation building, Cape Town, 29 May 1998. In: Hadland A, Rantao J: The life and times of Thabo Mbeki. Rivonia 1999

Moodley K (2003). HIV and AIDS--the ethical dilemma central to many issues in HIV/AIDS revolves around individual good versus societal good. *SADJ* 58(8):320-1

Myer L, Morroni C (2005). Supporting the sexual and reproductive rights of HIV-infected individuals. *SAMJ* 95(11):852-3

Niehaus I, Jonsson G (2005). Dr. Wouter Basson, Americans, and Wild Beasts: Men's Conspiracy Theories of HIV/AIDS in the South African Lowveld. *Medical Anthropology* 24:179-208

van Niekerk A A (2004). Mother-to-Child-Transmission of HIV/AIDS in Africa: Ethical Problems and Perspectives. *Jahrbuch für Wissenschaft und Ethik* 8:149-171

Ojascastro A (2000). Upholding standards of care for difficult patients. *Bioethics Forum* 16(3):17-21

Pelser A J (2004). Health, environment and development in South Africa. *Jahrbuch für Wissenschaft und Ethik* 8:171-214

Pelser A J, Ngwena C G, Summerton J V (2004). The HIV/AIDS epidemic in South Africa: trends, impacts and policy responses. In: Van Rensburg H C J, ed. *Health and Health Care in South Africa*. Pretoria:276-314

Preston-Whyte E. (1999). Reproductive health and the condom dilemma in South Africa. In: Cadwell J C, Cadwell P, Anarfi J et al (eds). *Resistances to behavioural changes to reduce HIV/AIDS infection in predominantly heterosexual epidemics in third world countries*. Canberra:139-55

Raviola G, Machoki M, Mwaikambo E, Delvecchio Good M J (2002). HIV, Disease plague, Demoralization and "burnout": Resident experience of the Medical Profession in Nairobi, Kenya. *Cult Med Psychiatry* 26:55-86

Redelinghuys N, van Rensburg H C J (2004). Health, morbidity and mortality: The health status of the South African population. In: van Rensburg H C J, ed. *Health and Health Care in South Africa*. Pretoria, 2004:215-274

van Rensburg H C J (2004). The health professions and human resources for health – status, trends and core issues. In: van Rensburg H C J, ed. *Health and Health Care in South Africa*. Pretoria, 2004:316-374

Rutecki GW, Geib J D (1991). A time to be silent and a time to speak (Ec 3:7): the dilemma of confidentiality and the Christian health care worker. *J Biblic Ethics Med* 5(4):9-15

Shisana O, Simbayi L (2002): *Nelson Mandela/ HRSC Study of HIV/AIDS. South African National HIV Prevalence, Behavioural Risks and Mass Media. Household Survey 2002. Executive Summary*. Cape Town

Singh J (2005). The impact on ethics. In: Abdool Karim S S, Abdool Karim Q. *HIV/ AIDS in South Africa.* Cape Town:384-404

South African Department of Health (2004). *National Antiretroviral Treatment Guidelines.* Pretoria

Toomey K E (1990). HIV infection: the dilemma of patient confidentiality. *Am Fam Physician*:955-959

Varga C A (1999). South African young people's sexual dynamics: implications for behavioural responses to HIV/AIDS. In: Cadwell J C, Cadwell P, Anarfi J et al (eds). *Resistances to behavioural changes to reduce HIV/AIDS infection in predominantly heterosexual epidemics in third world countries*. Canberra:13-34

Wilson D, Naidoo S, Bekker L-G, Cotton M, Maartens G (2002). *Handbook of HIV medicine*. Cape Town

World Health Organization - Regional Office for Europe (WHO – Europe) (1998). *HEALTH21: an introduction to the health for all policy framework for the WHO European Region*. (European Health for All Series; No. 5). Copenhagen

Whyte S R, Whyte M A, Kyaddondo (2005). Diskretion: Gesundheitspersonal in der Zwickmühle. [Discreation: Health care personnel on the horns of a dilemma] *Der Überblick* (2):37-40

7.2 Methodology

Böhm A (2004). Theoretisches Codieren: Textanalyse in der Grounded Theory. In: Flick U, von Kardorff E, Steinke I (2004) eds: *Qualitative Forschung. Ein Handbuch*, 3rd ed. Reinbek:475-485

Henning E, van Rendsburg W, Smit B (2004). *Finding your way in qualitative research.* Pretoria

Hopf C (2004). Qualitive Interviews – ein Überblick. In: Flick U, von Kardorff E, Steinke I (2004) eds: *Qualitative Forschung. Ein Handbuch*, 3rd ed. Reinbek:349-60

Kowal S, O'Connel D C (2004). Zur Transkription von Gesprächen. In: Flick U, von Kardorff E, Steinke I (2004) eds: *Qualitative Forschung. Ein Handbuch*, 3rd ed. Reinbek:437-47

Lambert H, McKevitt C (2002). Anthropology in health research: from qualitative methods to multidisciplinarity. *BMJ* 325:210 - 213

Mayring P (2004). Qualitative Inhaltsanalyse. In: Flick U, von Kardorff E, Steinke I (2004) eds: *Qualitative Forschung. Ein Handbuch*, 3rd ed. Reinbek:468-475

Mays N, Pope C (1995a). Qualitative Research: Rigour and qualitative research. *BMJ* 311:109 - 112

Mays N, Pope C (1995b). Qualitative Research: Observational methods in health care settings. *BMJ* 311:182-184

Mays N, Pope C (2000). Quality Research in Health Care. Assessing Quality in Qualitative Research. *BMJ* 320:50-52

Meinefeld W (2004). Hypothesen und Vorwissen in der qualitativen Sozialforschung. In: Flick U, von Kardorff E, Steinke I (2004) eds: *Qualitative Forschung. Ein Handbuch*, 3rd ed. Reinbek:265-75

Merkens H (2004). Auswahlverfahren, Sampling, Fallkonstruktion. In: Flick U, von Kardorff E, Steinke I (2004) eds: *Qualitative Forschung. Ein Handbuch*, 3rd ed. Reinbek:286-99

Meyer J. Qualitative Research in Health Care (2000). Using Qualitative Methods in Health Related Action Research. *BMJ* 320:178-181

Pope C, Mays N (1995). Qualitative Research: Reaching the Parts other Methods cannot reach: An Introduction to Qualitative Methods in Health and Health Services Research. *BMJ* 311:42-45

Pope C, Ziebald S, Mays N (2000). Qualitative Research in Health Care. Analysing Qualitative Data. *BMJ* 320:114-116

Eidesstattliche Erklärung

Ich versichere, dass ich die vorliegende Arbeit ohne fremde Hilfe selbstständig verfasst und nur die angegebenen Quellen und Hilfsmittel benutzt habe. Wörtlich oder dem Sinn nach aus anderen Werken entnommene Stellen sind unter Angabe der Quelle kenntlich gemacht. Die Arbeit hat in dieser oder in ähnlicher Form noch keiner Prüfungsbehörde vorgelegen.

Statutory declaration

This is to declare that I have prepared this thesis entirely by myself using only the sources and aids mentioned. Quotations or borrowings from other works have been indicated as such. This thesis – or any variation thereof - has never been submitted to any examination authority.

Dr. Dirk Hagemeister Rustenburg, South Africa