STIGMATISATION OF A PATIENT CO-INFECTED WITH TB AND HIV

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DEDICATION

This study is dedicated to all those who lost their lives due to HIV and Tuberculosis, those who are living with the diseases and their loved ones who are left with the responsibility of taking care of everything. I have been fortunate to witness the blessing of their generous spirit and their grateful hearts. I thank God for their willingness to participation in this study, giving a voice to millions of those who remain silent against social ills like stigma.

It is not so much the suffering as the senselessness of it that is unendurable.

Friedrich Nietzsche

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SUMMARY

The last few years have seen an increase in the infection rate not only of HIV but also TB. The HIV/AIDS pandemic is increasing rapidly mainly in developing countries with 71% of infections in the Sub-Saharan region of Africa. South Africa, which forms part of the Sub-Saharan region, has the highest infection rate in the world with 3.2 to 3.4 million people living with HIV/AIDS. People with HIV are especially vulnerable to TB, and HIV pandemic is fuelling an explosive growth in TB cases. The increase in the infection rate of TB and HIV exert increased pressure on health service delivery thus reflecting the serious problem in the country with regard to health service delivery to people co-infected with TB and HIV/AIDS.

Health service delivery is also hindered by negative attitudes of health workers that have been reported towards people living with HIV/AIDS. They entertain a biased view of their own risk, considering risk only from occupational exposure and denying the possibility of infection in their private life. These attitudes of health workers decreases the quality of care and support delivered to patient co-infected with TB and HIV. This result in people not disclosing their illness even in cases were treatment is available like TB for the fear of stigmatisation. Hence the problem of stigmatisation escalates into a dilemma for the patient co-infected with TB and HIV. Therefore these patients tend to shy away from health services and isolate themselves due to fear of being stigmatised twice.

The need to address TB and HIV together in the light of this dimension is urgent so as to improve the utilization of the health services by people co-infected with TB and HIV. The purpose of this research was to explore and describe the experiences of patients co-infected with TB and HIV regarding stigmatisation by the health workers, to explore and describe the attitudes of health workers towards patients co-infected with TB and HIV, and to formulate guidelines for health workers that will facilitate the health service utilization by patients co-infected with TB and HIV in the Potchefstroom district.

The research was conducted in the Potchefstroom district in the North West province of South Africa. A qualitative research design was used to explore and describe the experiences of patients co-infected with TB and HIV regarding stigmatisation by the health workers, and to explore and describe the attitudes of health workers toward co-infected patients. A purposive voluntary sampling method was used to select participants who met the set criteria. Two populations were used, that is the patients co-infected with TB and HIV, and the health workers who were involved in their care. In depth unstructured interviews were conducted with the patient population and semi structured interviews with the health worker population using an interview schedule that was formulated from the background literature. Data was captured on an audiotape, and transcribed verbatim. Field notes were taken immediately after each interview. The researcher and a co-coder did data analysis after data saturation was reached and a consensus was reached on the categories that emerged.

From the findings of this research it appeared that there were general perceptions by the patients co-infected with TB and HIV that indicated stigmatisation by the health workers. This perceived stigmatisation was reported as being perpetrated by all categories of health workers. Negative behaviours such as the health workers not having time for the patients and being impatient were reported. Lack of sufficient knowledge was related to these behaviours especially amongst lower categories or non-professional health workers. In spite of the above, the researcher also observed that there was a limited number of health workers who were still being perceived as committed and caring by the patients co-infected with TB and HIV.

The researcher concluded that the relationship between the health workers and the patients co-infected with TB and HIV was characterised by conflict. The health workers seemed to perceive the patients co-infected with TB and HIV as stubborn, harsh, abuse alcohol, manipulative and not taking responsibility of their illness. These perceptions lead the health workers to have a negative attitude towards these patients and occasionally came across as unsympathetic towards them. On the other hand the researcher observed that there were other health workers who did not present with negative behaviours towards these patients and tried to understand the reasons for their sometimes-unacceptable behaviours.

Recommendations are made for the field of nursing education, community health nursing practice and nursing research with the formulation of guidelines for health workers so as to facilitate the utilization of the health services by the patients co-infected with TB and HIV.

The guidelines are discussed under three main categories, namely guidelines for the health workers to facilitate the utilization of the health services by the patients co-infected with TB and HIV, guidelines to improve the utilization of the health services more efficiently and adequately by the patients co-infected with TB and HIV, and guidelines to improve the attitudes of the health workers towards the patients co-infected with TB and HIV with the intention of improving the utilization of the health services by these patients.

Key concepts: [Stigma, Blame, Fear, Discrimination, Isolation, Attitude, Human-immunodeficiency virus, Acquired Immune Deficiency Syndrome, Tuberculosis, health workers, co-infection, and health service delivery].

OPSOMMING

Gedurende die laaste paar jaar was daar nie net in MIV nie, maar ook in TB 'n toename in die aantal infeksies. Die MIV/VIGS pandemie neem vinnig toe veral in die ontwikkelende lande met 71% van infeksies in die Sub-Sahara streek van Afrika. Suid Afrika wat deel vorm van die Sub-Sahara-streek, het die hoogste infeksie syfers met 3.2 tot 3.4 miljoen mense wat leef met MIV/VIGS. Persone met MIV is veral vatbaar vir TB en die MIV pandemie veroorsaak 'n plofbare groei in TB-gevalle. Die toename in die aantal infeksies van TB en MIV veroorsaak toenemende druk op gesondheidsdienslewering wat reflekteer word in die ernstige probleme in die land ten opsigte van dienslewering aan mense geïnfekteer met beide MIV/VIGS en TB.

Gesondheidsdienslewering word ook belemmer deur aanmeldings van negatiewe houdings van gesondheidswerkers teenoor persone wat leef met MIV/VIGS. Gesondheidswerkers het 'n bevooroordeelde indruk van hulle eie risiko, as in ag geneem word dat dit slegs 'n beroepsrisiko is en ontken die moontlikheid van infeksie in hulle privaatlewe. Hierdie houdings van gesondheidswerkers veroorsaak 'n afname in die kwaliteit van sorg en ondersteuning wat gelewer word aan pasiënte wat geïnfekteer is met beide TB en MIV. As gevolg hiervan is daar 'n neiging deur hierdie pasiënte om weg te skram van gesondheidsdienste en hulleself te isoleer as gevolg van vrees vir dubbele stigmatisering.

Die behoefte om MIV en TB saam aan te spreek in die lig van hierdie dimensie is dringend sodat die benutting van gesondheidsdienste deur hierdie persone bevorder kan word. Die doel van hierdie navorsing was om die ervarings van pasiënte geïnfekteer met beide TB en MIV, ten opsigte van stigmatisering deur gesondheidswerkers te verken en beskryf, om die houding van gesondheidswerkers teenoor hierdie pasiënte te verken en beskryf en om riglyne te formuleer vir gesondheidswerkers wat sal bydra tot die benutting van gesondheidsdienste deur hierdie pasiënte in die Potchefstroom-distrik.

Die navorsing is uitgevoer in die Potchefstroom-distrik in die Noordwes Provinsie van Suid Afrika. 'n Kwalitatiewe navorsingsontwerp is gebruik om die ervarings ten opsigte van stigmatisering deur gesondheidswerkers van pasiënte geïnfekteer met beide MIV en TB te verken en beskryf en om die houdings van gesondheidswerkers teenoor hierdie pasiënte te verken en beskryf. 'n Doelgerigte, vrywillige steekproefmetode is gebruik om deelnemers te selekteer wat voldoen het aan die kriteria. Twee populasies is gebruik naamlik pasiënte geïnfekteer met beide MIV en TB en die gesondheidswerkers wat betrokke was by hulle versorging. In-diepte , ongestruktureerde onderhoude is gevoer met die pasiëntpopulasie en semi-gestruktureerde onderhoude met die gesondheidswerker populasie deur gebruik te maak van 'n onderhoudskedule wat geformuleer is uit die literatuur. Data is opgeneem op 'n audioband en verbatim gestranskribeer. Veldnotas is dadelik gemaak na elke onderhoud. Die navorser en mede -kodeerder het die data-analise gedoen nadat data-saturasie plaasgevind het en konsensus is bereik aangaande die kategorieë wat gebruik is.

Vanuit die navorsing is bevind dat daar algemene persepsies is by pasiënte geïnfekteer met beide MIV en TB van stigmatisering deur gesondheidswerkers. Hierdie veronderstelde stigmatisering is ervaar vanaf alle kategorieë gesondheidswerkers. Negatiewe gedrag soos gesondheidswerkers wat nie tyd het vir die pasiënte nie of ongeduldig is, is gerapporteer. 'n Tekort aan kennis is verwant aan hierdie gedrag veral by laer kategorie en nie-professionele gesondheidswerkers. Ten spyte van die bogenoemde, het die navorser gemerk dat daar 'n beperkte aantal gesondheidswerkers was wat deur die pasiënte ervaar is as sou hulle toegewyd wees en omgee.

Die navorser het tot die gevolgtrekking gekom dat die verhouding tussen gesondheidswerkers en pasiënte geïnfekteer met beide MIV en TB gekenmerk word deur konflik. Die gesondheidswerkers ervaar die pasiënte geïnfekteer met beide MIV en TB as hardkoppig, grof, alkohol gebruikers, manipulerend en dat hulle nie verantwoordelikheid neem vir hulle eie toetand nie. Hierdie persepsies lei daartoe dat gesondheidswerkers negatiewe houdings het teenoor die pasiënte en met geleentheid as onsimpatiek voorkom. Aan die ander kant het die navorser opgemerk dat daar ander gesondheidswerkers is wat nie met negatiewe gedrag gepresenteer het nie en probeer het om te verstaan wat die redes is vir die pasiënte se soms, onaanvaarbare gedrag.

Aanbevelings is gemaak vir verpleegonderwys, gemeenskapsgesondheidverpleegkunde en verpleegnavorsing, met die formulering van riglyne wat die benutting van gesondheidsdienste deur pasiënte geïnfekteer met beide MIV en TB, sal fasiliteer. Hierdie riglyne is bespreek onder drie hoof kategorieë naamlik;, riglyne vir die gesondheidsdienswerkers om die benutting van gesondheidsdienste deur pasiënte geïnfekteer met beide MIV en TB te fasiliteer; riglyne om die benutting van die gesondheidsdienste meer effektief en voldoende vir die pasiënte geïnfekteer met beide MIV en TB te maak en riglyne om die houding van gesondheidswerkers teenoor pasiënte geïnfekteer met beide MIV en TB te verbeter met die doel om die gesondheidsdiens benutting deur hierdie pasiënte te verbeter.

Sleutel konsepte: [Stigma, blaam, vrees, diskriminasie, isolasie, houding, Menslike-immuniteits-gebrek virus, Menslike-immuniteits-gebrek-sindroom, Tuberkulose, gesondheidswerkers, geïnfekteer, gesondheidsdienslewering]

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CHAPTER 1

RESEARCH ORIENTATION

1.1 INTRODUCTION AND PROBLEM STATEMENT

The definition of stigma is based on Erving Goffman's classical study on stigma related to mental illness, physical deformities and what was perceived to be socially deviant behaviour (Nyblade *et al.*, 2003:8). Goffman (1963:2) notes that the ancient Greeks used the word 'stigma' to refer to bodily signs regarded to reflect something unusual and bad about the moral status of the person concerned. In his recent work Goffman (1990:12) defined stigma as referring to an attribute that is deeply discrediting which in the extreme refers to a person who is bad, dangerous or weak. A person is thus reduced in the mind from being a whole person to a tainted discounted one. According to Gallo (1991:129), stigmatisation is an age-old practice which meant that people with incurable diseases were usually isolated and held responsible for epidemics of the particular diseases they were infected with. Consequently, people who were stigmatised became social outcasts, like the lepers in Leviticus 13:45-46 (Bible, 1995), who were forced to wear torn clothes and to warn off others with the cry "unclean, unclean". Various conditions and events affecting people in the community lead to stigmatisation. The more rapid the spread of the disease and the greater the uncertainty of how the disease is transmitted, the more stigmatising the response (Nyblade *et al.*, 2003:8). In the same vein, stigma is not only attached to fast spreading diseases as noted that sixty years ago cancer was regarded as a disgrace by members of a sufferer's family and if the disease was mentioned, it was spoken about in hushed whispers (Pretorius, 1992:95). Also suicide produced stigma and the family of the person who died on account of suicide experienced negative effects on their status in society (Pretorius, 1992:96). The family was avoided and sometimes openly accused of causing the act, or gossip would be going around about the family, creating more stigma. The responses to stigma has been characterized as a social contamination reaction where negative effects such as fear emanate from various ideas associated with stigma (Pryor *et al.*, 1999:1197. Therefore stigmatisation is entirely contingent on access to social, economic and political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into categories and the full execution of disapproval, rejection, exclusion and discrimination (Link & Phelan, 200*). Furthermore, there are other concepts that are related to stigma such as prejudice, discounting, discrediting and discrimination directed at people perceived to have an infectious disease (Herek, 1999:1106).

Literature repeatedly notes that stigma builds upon and reinforces earlier prejudices. This aspect is supported in a report of the regional consultation meeting on stigma and human immune-deficiency virus/acquired immune-deficiency syndrome (HIV/AIDS) in Africa (UNAIDS, HDN & SIDA, 2001:1) stating that stigma plays into and reinforces existing social inequalities, especially those of gender, sexuality and race. This implies that the problem of stigmatisation is aggravated when a disease is sexually transmitted, as is often the case with HIV and AIDS. In addition Goldstein (as quoted by Grundlingh, 1999:57) was noted as saying that HIV and AIDS is unique in that those who were directly affected were already marginalized or minorities and victims of prejudice and discrimination either economically or politically, an example being in the United States where AIDS was labelled an African or Haitian disease. On the eve of World Aids day, UNAIDS head Peter Piot said that stigma and discrimination remains the major barriers to controlling the pandemic in Africa. He further mentioned that stigma silences individuals and communities, saps their strengths, increases their vulnerability and deprives them of care and support. According to Parley and Luhan, (2003) people infected with Tuberculosis (TB) suffer the same problem of stigmatisation as those with HIV and AIDS. This has been noted in Africa where HIV stigma has been transferred to TB. In most of the societies in Africa, it was noted that having TB is seen as synonymous to having HIV and vice versa. Clinical differences between the two are not understood by most people (Parley & Luhan, 2003). It is very difficult to reduce the stigma of TB because of the strength of the association. The association is further strengthened as HIV often has greater impacts on the poorest and most vulnerable individuals and groups in society who are already marginalized (International HIV/AIDS Alliance: 2001). Whereas with TB, the most generalised reason for the stigma is simply that traditionally it has been seen as the poor man's disease and so to admit that you have TB is to put yourself at the bottom of society (Parley & Luhan, 2003).

Data shows that in India and Bangladesh, the stigma of TB has more to do with its symbol of poverty, and in addition thereto, lack of hygiene and sanitation (Parley & Luhan, 2003). According to Dr Harun (Harun: 2002), TB carries a social stigma in the eastern and rural parts of Indonesia where an individual with TB must leave his/her village, and the house is burnt down. And also in the centre of Jakarta city, a deceased who is believed to have or have had TB may have all his personal belongings such as clothing burnt (Harun: 2002). The same pattern of stigmatisation as seen in the person with TB is experienced by persons infected with HIV and AIDS, and this was clearly demonstrated by the killing of Gugu Dlamini in South Africa. This young woman was threatened by neighbours, punched and slapped by a man who told her she should have kept quiet about her illness and finally killed by a mob who attacked her in her house (Avert Organisation: 2004).

Therefore the combination of TB and HIV, together with their intensity, makes it difficult for the patient co-infected with TB, HIV and AIDS to overcome the impact of stigma which can either be enacted or felt stigma (International HIV/AIDS Alliance, 2001). Hence individuals are fearful that they will be stigmatised and this can affect their self-esteem, their view and how they relate to others as an indication of enacted stigma. In a study conducted by Anderson and Maher (2001:14), the respondents felt that political leaders have failed to address HIV/AIDS openly and that it has perpetuated stigma amongst policy makers, and it is likely that this denial and stigma could continue to hinder TB and HIV programmes and the infected people. This case clearly explains the impact of felt stigma.

In essence, stigma is caused by the attitude of society in general resulting in the cause-effect process of stigmatisation (International HIV/AIDS Alliance, 2001). According to Goffman (1990:15), the attitudes we "normal people" have towards a stigmatised person and the action we take in this regard reduces his quality of life due to felt and enacted stigma. The terms that we use in our daily discourse such as "cripple", "bastard", and "moron" as source of metaphor and imagery is indicative of our attitudes, thus leading the person to perceive the act of stigmatisation (Goffman, 1990:15). This aspect is supported by Nyblade *et al.*, (2003:2) who noted that judgmental attitudes cause stigmatisation which impede various programmatic efforts and can result in people with HIV delaying care until absolutely necessary (Nyblade *et al.*, 2003:2). In the same breath, Keller (1994:3) stated that in the United States negative attitudes are highest towards immigrants and refugee communities affected by TB, increasing stigma in this regard.

This problem of attitudes brings another dimension that is the consequence of stigmatisation in this process, namely blame. Blame is inherent in the idea that HIV and AIDS is God's way of punishing the world and that infected people got what they deserved, that they should be held responsible for their behaviour, and are not deserving of sympathy (Beatson, as quoted by Grundlingh, 1999:60). The same issues apply to patients diagnosed with TB as reported by Dr Harun, namely that in Indonesia stigmatisation towards patients with TB is noted in educated families where dramatic divorces happen based on the blame placed on the mother that she had hidden TB from the family if the child is supposed to be suffering from TB (Harun: 2002). The process of stigmatisation moves from a facet of blame and manifest in discrimination where discrimination is seen as a result of fear of contagion that play a major role in the creation if stigma. Even when people are aware of the disease, they still act in ways that result in discrimination (Edgar *et al.*, 1992:125). Also in a national telephone survey, more than one fourth of the United States public expressed discomfort about associating with people living with AIDS in a variety of circumstances (Herek, 1999:1). Likewise, for people infected with TB, according to Dr Harun (2002), office workers with TB in Indonesia may loose their jobs at once and baby sitters are sent back to their villages.

Consequently, the effect of blame and discrimination due to stigmatisation is fear. Fear is often attributed to people's inability to deal with uncertainty (Bruhn, 1989:455). People also fear rejection and this leads to them not talking about their diseases as noted in a study on Haemophilia patients. It was reported that fear of being rejected led to patients not explaining to their partners about their positive status (Edgar *et al.*, 1992:125). This is in fact true to HIV/AIDS patients, as noted by Bruhn (1989:455), that the increasing incidence of AIDS has created a social fear that in turn has raised the level of fear and anxiety in individuals. Likewise, people fear TB as it was once difficult to cure and it still kills many people in other parts of the world (Mohammed: 2003).

Fear due to stigmatisation leads to isolation. People are being isolated by their families and communities, and they also isolate themselves because of fear of being stigmatised. It is clear that people feel that individuals who have an infectious disease should be isolated, as quoted in Connors and Heaven (1995:924): "People who have AIDS should be isolated from the rest of the community". Isolation as an effect of stigmatisation is also clearly noted in the TB patient as in the case of a 25 year old Rushdi Abdullah who was diagnosed with TB. His family moved him to a room outside the main house and forbade him to watch TV in the main house, and nobody came to his room to see him (Irin news organization, 2003). Therefore the individual with TB will fear to talk about his illness due to fear of isolation. This in turn forces the person to deny the nature of his disease to himself and others, resulting in individuals not seeking treatment (Keller, 1994:3).

Isolation as the consequence of stigmatisation is aggravated when the health workers present with negative attitudes towards the already stigmatised patients because, as Nyblade *et al.* (2003:40) stated, stigma is more intensive when perceived at home or in the health setting. Like other community members, health workers hold judgmental attitudes concerning the sexual transmission of HIV (Mbwambo *et al.,* 2003:6) leading to stigmatisation of patients. According to Bennet *et al.* and Reynold and Alonzo (as quoted by Salovey & Irwin, 2002:1) research in Australia and the United States respectively has shown that the health workers (including doctors, nurses, medical technicians and informal care givers) often presumed to have high level of knowledge concerning HIV and AIDS and minimal stigma due to their understanding and experiences, often exhibit stigma which may affect the care that the HIV patients receives. Thus negative interaction with health workers can have important implications for the health and health care of people living with HIV and AIDS (Bird, Bogart & Delahanty, 2004:19). The existence of stigma in the health care setting poses serious threats to prevention and care efforts because it prevents people from seeking early care for TB and other HIV-related opportunistic infections (France, 2004:5). Regardless of the motivation for stigma in the health care setting, one serious result is that people living with HIV and AIDS actually avoid or delay seeking care for HIV or related illnesses such as TB in order to avoid the stigma (Nyblade *et al.,* 2003:43).

TB incident rates in Africa have tripled since 1990 in countries with high prevalence and are still rising across the continent at a rate of 3%—4% annually, even in countries that have the resources (Luhan, 2005:3). According to Dr Simmoya, people with TB in Zambia are equalled with having HIV where there is a lot of stigma, therefore patients become unhappy and due to that association with HIV they refuse to accept that they have TB, making it a big problem to accept the diagnosis of TB and start on therapy (HDN moderator team: 2003). According to Illako (2005),TB in itself is very stigmatising and the link between TB and HIV is worsening the stigma leading to additional stigma on the HIV infected patient. The author further states that TB in itself is very stigmatizing. With TB and HIV co-infection at nearly 60%, this is a huge problem that needs to be dealt with urgently. The author further indicates that TB is the most frequent opportunistic infection and the leading cause of death for people living with HIV. 12 million people are reported to be co-infected with TB and HIV, two-thirds of whom live in Sub-Saharan Africa. For this reason the problem of stigmatisation escalates into a dilemma for the patient co-infected with TB and HIV, and it becomes clear when one considers the infection rate of both TB and HIV. Globally, the number of new TB cases each year is still on the increase. HIV is part of the cause and presents a massive challenge to the control of TB at all levels HDN correspondence team, 2005). The utilisation of the health services and the quality of health service provision is hindered by these problems, seeing that people are afraid to disclose their illness, even in cases where treatment is available.

The need to look at strategies that diminish stigmatisation of TB and HIV and AIDS should be emphasised. This is also the viewpoint of UNAIDS that the dual epidemic requires a dual strategy (Anderson & Maher, 2001). Acknowledging the existence of stigma is the first step towards addressing it and in the case of HIV and AIDS, this step has clearly been taken. South Africa is facing one of the worst duel epidemics of TB and HIV in the world. In Prince Cyril Zulu Communicable Diseases Clinic in Durban, South Africa, it was reported that 76% of its TB patients were HIV positive (Plus News, 2005).

Based on the above information, it is the opinion of the researcher that the increased burden of both these diseases increases pressure on health service delivery. This in turn decreases the quality of care and support delivered to patients co-infected with TB and HIV resulting in the under utilisation of the services by these patients. The utilisation of the health services and the quality of health service provision is hindered by these problems since people are afraid to disclose their illness even in cases where treatment is available. Reducing stigma will therefore empower people, especially those living with TB and HIV and AIDS< to recognize the benefit of the various services and therefore be more willing to seek care (Manet, 2003:5). If we wish to diminish the stigma of TB, there is a need to change and improve the interaction between the health workers and the patients (Torfoss, 2005). Stigma in the health care setting is of particular concern, as it has the effect on the success of programmes. Understanding the origins and issues surrounding stigma in health care settings is vital to improve access and treatment for people living with TB and HIV (Salovey & Irwin, 2002:1). We also recognize that stigma characterized by blame, discrimination, fear and isolation fuel the spread of TB and HIV, undermining prevention, care and support. For these reasons stigma must be urgently confronted within the context of co-infection of TB and HIV.

From the above problem, the following research questions arise:

1. What are the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers?
2. What are the attitudes of health workers towards patients co-infected with TB and HIV and AIDS that lead to the stigmatisation of these patients?
3. What can be done to facilitate the health service utilization by the patient co-infected with Tuberculosis and HIV?

Based on the above-mentioned questions, the researcher aimed at facilitating the health services utilization by patients co-infected with TB and HIV with research objectives as follows:

1.2 RESEARCH OBJECTIVES

The following are the research objectives:

1. To explore and describe the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers.
2. To explore and describe the attitudes of health workers towards patients co-infected with TB and HIV.
3. To formulate guidelines for health workers that will facilitate the health service utilization by patients co-infected with TB and HIV in the Potchefstroom district.

1.3 PARADIGMATIC PERSPECTIVE

The following meta-theoretical, theoretical and methodological statements define the paradigmatic perspective within which the researcher will conduct this research.

1.3.1 Meta-theoretical statement

The assumptions of The Nursing Theory for the Whole Person (Oral Roberts University: Anna Vaughn School of Nursing, 1990:136-142) form the framework of the paradigmatic perspective in this research. The theory is based on a Judeo-Christian worldview that is based on the Bible as the source of truth. These theories are adopted because they are congruent to the researcher's personal philosophy. The following meta-theoretical statements about man, health, environment and nursing are defined.

1.3.1.1 Man

For the purpose of this research man refers to both the patient co-infected with TB and HIV and the health workers who are unique human beings created by God and function in an integrated bio-psycho-social manner in their quest for wholeness. The health worker and the patient interact as a whole that is body, mind and spirit, with their external environment during the period in which the health worker takes care of a patient co-infected with TB and HIV and the patient seeking support and care from the health worker and the community in general.

1.3.1.2 Health

The continuum of health is a state of spiritual, mental and physical wholeness. It can be qualitatively described on a continuum from maximum health to minimum health. The patterns of interaction of patients co-infected with TB and HIV with their internal environment, that is their body, mind and spirit, plays an important role in establishing their continuum of health. This implies how the patients who are co-infected with TB and HIV take care of their bodies, how they cope with stress and anxiety and how they attend to their spiritual needs. Also the pattern of interaction with the external environment, meaning their interaction with the health workers in the health setting, their perceptions about the health services and their involvement with their religious denominations, determines their state of health on the health continuum. The patient's way of recognizing and acknowledging his illness and accepting the responses from the health worker and the community will determine his/her state of health, thus also improve his/her quality of life.

On the other hand, the health worker's attitude when dealing with the patient co-infected with TB and HIV will determine his/her state of health according to this theory of wholeness. This implies the way in which the health workers take precautionary measures to prevent infection with TB and/or HIV by taking care of their bodies. Furthermore, it involves the coping mechanisms that they use to deal with their frustrations while caring for the patients co-infected with TB and HIV, and how they manage their spiritual side. Their pattern of interaction with their external environment is established by their behaviour towards the patient co-infected with TB and HIV, the conduciveness of their working environment and their faith in God to sustain them while they care for the co-infected patient. Both the patient co-infected with TB and HIV and the health worker's ability to maintain balance between the above-mentioned aspects means that they strive to reach and maintain maximum health.

1.3.1.3 Environment

This concept includes the internal and external environment. The internal environment comprises of the body, mind and spirit, while the external environment consists of the physical, social, and spiritual dimensions. The focus is on the internal environment of the patient co-infected with TB and HIV which is his infected body, the psychological impact of the illness and his need for spiritual guidance and support as well as his interaction with the health worker in the health setting, the religious community and the way in which he socialises as part of his external environment. This will also involve the manner in which the health worker attends to the treatment of the patient, how he encourages social interaction and the influences he has on the spirituality of that patient (Rand Afrikaans University: Department of nursing, 1992:7-9).

1.3.1.4 Nursing

This term implies a goal directed service provided to individuals, families and the community in order to promote, maintain and restore health. Nursing will be viewed as the activities that are undertaken by the health workers to promote health in a holistic manner to the patient co-infected with TB and HIV, his family and the community. This will involve taking care of the physical, psychological and spiritual aspects of the patients co-infected with TB and HIV. Activities that will be undertaken include assisting with bathing, counselling services and ensuring that the patient is rehabilitated and well adjusted to his condition within the larger society. Giving health education to the patients will form an integral part of the nursing activities in this research (Rand Afrikaans University: Department of nursing, 1992:7-9).

1.3.2 Theoretical statements

The theoretical statements of this research include the central theoretical argument as well as conceptual definitions of core concepts applicable to this research.

1.3.2.1 Central theoretical argument

Knowledge of the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers and knowledge of the attitudes of health workers towards these patients will lead to the formulation of guidelines for health workers to facilitate the utilization of health services by people co-infected with TB and HIV in the Potchefstroom district.

1.3.2.2 Conceptual definitions

The following concepts are central in this research and are defined as follows:

Stigma

Stigma refers to an attribute that is deeply discrediting which, in the extreme, refers to a person who is bad, dangerous or weak (Goffman, 1990:13). It is also conceptualised as a psychological attitude or a fact of public opinion (Herek, 1999:1108). The responses to stigma have been characterised as a social contamination reaction where negative effects such as negative attitudes, blame, fear, discrimination and isolation emanate from various ideas associated with stigma (Pryor *et al.*, 1999:1197). Therefore stigma will refer to a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons, leading to discrimination on the basis of their co-infected status with TB and HIV, thus to an unwillingness to seek help and access resources (Siyam'kela, 2003:5)

Blame

The term blame implies causation and guilt. Usually, when we think of somebody as being to blame for an event we are judging both their behaviour and that person. We are also often involved in assigning or determining guilt (Michigan State University, 2003). The patient co-infected with TB and HIV attending the health centre in order to access health services is the point of focus. The TB patients are blamed for bringing the disease and spreading it, such as in the case of immigrants (Keller, 1994:3), while the HIV patients are blamed for immorality and promiscuity (Grundlingh, 1999:56).

Fear

Fear is an emotion that plays a major role in the creation of stigmatisation (Edgar *et al.*, 1992:125). According to Grundlingh (1999:70), the process of stigmatisation causes fear and anger amongst the stigmatised group. Fear is often attributed to people's inability to deal with uncertainty (Bruhn, 1989:455). The focus will be on the patient co-infected with TB and HIV having fear of rejection and discrimination, forcing the person to deny the nature of his disease to himself and to others (Keller, 1994:3).

Discrimination

Discrimination is a manifestation of stigma (Herek, 1999:1). It is an unfavourable treatment based on racial, sexual and other types of prejudice. Patients loosing their jobs due to being diagnosed with HIV is a sign of discrimination (McGreary, 2001:48) and in the case of TB where individuals are not allowed to watch TV with the other members of the family (Irin news organization, 2003). Hence the focus is on the unfavourable treatment by society and especially health care workers towards patients co-infected with TB and HIV.

Isolation

The term refers to the social and demographic removal of individual or group from the confines of the community (Webbs, 1997:170). This implies the isolation that the patients experiences when rejected by their families, and the isolation that they experiences due to attitudes of health workers (McGreary, 2001:50), indicating the removal and confinement of patients co-infected with TB and HIV.

Attitude

Attitude is defined as a relatively stable, primarily learned predisposition of the individual towards certain objects (Plug *et al.,* 1997:149). It is also seen as a relatively enduring organization of beliefs around an object or situation predisposing one to respond in some preferential manner (Rokeach, 1989:112). Therefore the focus is on the beliefs of the health workers regarding a patient co-infected with TB and HIV and on how those attitudes affect service delivery and the service utilisation by patients co-infected with TB and HIV.

HIV: Human immuno-deficiency virus

This is the virus that attacks the human immune system causing AIDS (Evian, 2000:261). The virus erodes the body's immune system over time, exposing the infected person to a range of lung diseases, cancers, opportunistic infections such as TB and other painful debilitating conditions. The mode of transmission is sexual intercourse, intravenous drug use, mother-to child transmission, and the use of blood or blood products that are contaminated (Manet, 2003:8).

AIDS: acquired immune deficiency syndrome

The term implies that the body's immune system is severely compromised to a point that it cannot fight against infections. It is the last stage of the HIV illness and it is identified by signs and symptoms of severe immune system dysfunction (Evian, 2000: 261). A person is said to have developed AIDS when there has been significant deterioration of the immune system and the person has been affected by one of the AIDS-defining illnesses. Eventually, AIDS-related illnesses overpower the body's ability to fight back, causing physical and sometimes mental ruin and death (Manet, 2003:8).

Tuberculosis: TB

It is an infectious disease caused by a micro-organism, a bacilli called *Mycobacterium tuberculosis* which usually enters the body by inhalation through the lungs. It spreads from the initial location in the lungs to other parts of the body via the blood stream, the lymphatic system, via the airway or by direct extension to other organs (Department of Health, 2000:11). Depending on the individual's immune system, the bacilli may become dormant until activated when the immune system is compromised.

Health worker

This term implies an individual employed by the health sector to render health services to the patients in the primary health care centres/clinics, hospitals and within the community. Focus is on those individuals who are employed in the public health clinics and hospitals, and render services to the patient co-infected with TB and HIV within the community and hospitals and those who present themselves at the primary health clinics. The individuals will include health workers registered with the South African Nursing Council (SANC), and those who received short training on basic health care and not registered with SANC but are working as health workers caring for the patients co-infected with TB and HIV.

Co-infection

This term refers to the simultaneous infection by two diseases. In this research the focus is on the patient infected by both TB and HIV with both the diseases having an impact on each other and hastening each other's progression.

Health Service Delivery

This term refers to the activities that are undertaken within the health services in order to promote, maintain and restore health of the individual and the community. The activities that will be undertaken by health workers in order to facilitate the health service utilization by people co-infected with TB and HIV are core issues. These activities are based on the systematic application of knowledge and skills to the resolution of the patient's health problem and the effort to promote and maintain health (Clark, 1999:69).

1.3.3 Methodological statement

The application of the Botes model (1992:36-42) in conducting the research process can increase validity and reliability of the research, since the model is specifically developed for nursing research (Botes, 1992:36). The functional reasoning approach which is the framework of this model advocates that research should lead to the development of theories which serve to improve the nursing practice (Botes, 1992:37). Research activities as presented within Botes' model (1995:36-42) are arranged in three levels in accordance with this practical aim.

The first level or order represents the practice of nursing, which forms the research domain for nursing. These research activities are aimed at the promotion, maintenance and restoration of health in the quest for wholeness. Hence the researcher focuses on the nursing practice where a health worker interacts with the patient co-infected with TB and HIV so as to facilitate the health service utilization by these patients. While nursing the patient co-infected with TB and HIV, activities take place that are not only based on scientific knowledge, but are also due to pre-scientific interpretations such as behavioural interpretation (Botes, 1992:39). This research will look at the interpretations made by the patients co-infected with TB and HIV regarding the behaviours of the health workers critically, and if they are valid, use research as a means to make them part of the knowledge content of nursing.

The first level leads to the second level in which research and theory development takes place. The researcher will focus on the exploration and description of the experiences of patients co-infected with TB and HIV concerning stigmatisation by the health workers and on exploring and describing the attitudes of health workers towards patients co-infected with TB and HIV. Knowledge acquired from this research can be applied in the nursing practice so as to facilitate health service utilization by the patient co-infected with TB and HIV through the conduct of the health worker. Ultimately, in accordance with Botes' theory (Botes, 1992:39), the practical usefulness of this research will serve as a criterion for its internal validity.

The third level represents the paradigmatic perspective within which this research is undertaken. The meta-theoretical statements will be kept within the framework of the Nursing Theory of the Whole Person (Oral Roberts University, 1990:136-142).

1.4 RESEARCH DESIGN AND METHOD

In this chapter, a summary of the research design and method is subsequently given as a detailed description of the methodology that follows in Chapter 2.

1.4.1 RESEARCH DESIGN

A qualitative research design will be used to explore and describe the experiences of patients co-infected with TB, HIV and AIDS concerning the escalating stigma created by both the diseases and to explore and describe the attitudes of the health workers towards these patients. The research will be conducted within the Potchefstroom district in the North West Province.

1.4.2 RESEARCH METHOD

A brief description of the research method is provided in the subsequent paragraphs with attention given to the sampling, data collection and data analysis.

1.4.2.1 Sampling

Sampling will be carried out as follows:

1.4.2.1.1 Population

Two populations are identified, namely:

Population one: the patients co-infected with TB and HIV who are residing in the Potchefstroom district in the North West Province.

Population two: the health workers who are involved in caring for and treating the patients co-infected with TB and HIV in the clinics and mobile health services serving in the Potchefstroom district in the North West Province.

1.4.2.1.2 Sampling method

The purposive voluntary sampling method will be used for both populations to select participants who comply with the criteria for inclusion in the research and who volunteer to participate.

1.4.2.1.3 Sample size

The sample sizes for both populations are established by data saturation (Polit & Hungler, 1993:238).

1.4.3 Data collection

1.4.3.1 Role of the researcher

Permission to conduct the research was obtained from the Director of health at the Potchefstroom City Council, and the District Manager of Health at the Potchefstroom District Office of Health in the North West Province. The purpose and the importance of the research are explained to both the authorities so as to gain their co-operation. The researcher asks for the involvement of the health workers who will act as mediators and assist in the recruitment of the patient population. The researcher then recruits the health worker population and arranges appointments to conduct the interviews with them. The detailed role of the researcher is described in Chapter 2.

1.4.3.2 Physical environment

The interviews are conducted at the homes of the patients co-infected with TB and HIV, other places of their choice and the clinics to ensure comfort, privacy and confidentiality.

1.4.3.3 Method

Unstructured interviews are conducted with patients co-infected with TB and HIV (Morse & Field, 1995:96). One open-ended question is posed to the participants in order to collect data regarding their experiences concerning stigmatisation by the health workers. To explore and describe the attitudes of the health workers towards the patients co-infected with TB and HIV, semi-structured interviews are conducted with the health workers who are involved in caring for patients co-infected with TB and HIV. The interview schedule is given to experts for content and face validity as described by Creswell (1994:151). A trial run is undertaken for both the populations so as to test and make the necessary adjustment to the questions and determine the interviewing skills of the researcher (Polit & Hungler, 1993:40). The researcher conducts the interviews, which are recorded on audiotape. Communication skills, as described by Okun (1997:70), are used. Field notes are taken after each interview, which include descriptive, reflective and demographic notes as described by Creswell (1994:152).

1.4.4 Data analysis

Data captured on the audio tapes from both the populations are transcribed verbatim and analysed, following the method of open coding as described by De Vos (De Vos *et al.*, 2002:346). A co-coder analyses the data independently in accordance with a work protocol. A consensus discussion on the categories that emerge is held between the researcher and the co-coder.

1.5 LITERATURE CONTROL

To confirm the data obtained in this research, the research results are compared with relevant literature and existing research findings. New information gained from this research is highlighted as unique findings. The literature control is conducted from the following databases: Nexus, Repertoire of South African Journal articles, inter-library loans, the North-West University, Potchefstroom Campus, library, the media (newspapers and magazines and the World Wide Web.)

1.6 GUIDELINES

From the research results and literature control, guidelines are formulated for health workers with the view to facilitate health service utilization of by people co-infected with both TB and HIV in the North West Province.

1.7 FURTHER CHAPTER OUTLINE

Chapter 2:	Literature review of the concept stigma and the stigmatisation process, and the research methodology
Chapter 3:	Discussion of research findings and literature control

Chapter 4: Conclusions, shortcomings and recommendations of the research, with specific reference to the formulation of guidelines for health workers to facilitate health service utilization by people co-infected with TB and HIV in the North West Province.

CHAPTER 2

LITERATURE REVIEW OF THE CONCEPT STIGMA AND OF THE STIGMATISATION PROCESS, AS WELL AS THE RESEARCH METHODOLOGY

2.1 INTRODUCTION

Chapter 1 gave an overview of this research which included the problem statement, the objectives, the paradigmatic perspective as well as the brief orientation in terms of the research methodology. This chapter will give a detailed description of the literature review of the concept stigma and of the stigmatisation process, as well as the research methodology with attention to the research design, research method, and ethical issues related to the quality of the research and respect for the participants, as well as trustworthiness of the research.

2.2 LITERATURE REVIEW REGARDING THE CONCEPT STIGMA AND THE STIGMATISATION PROCESS

The literature review of the concept stigma and the stigmatisation process was conducted so as to assist the researcher to develop the semi-structured interview schedule. The purpose of the interview schedule was to explore and describe the attitudes of the health workers towards the patients co-infected with TB and HIV that lead to the stigmatisation of these patients. The objectives of this research are to explore and describe the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers and to explore the attitudes of health workers towards these patients. It is therefore necessary to explore the concept stigma and the stigmatisation processes so as to understand how the health workers' attitudes contribute to the stigmatisation of the patient co-infected with TB and HIV.

2.2.1 Stigma as a concept

According to the Concise Oxford Dictionary (1992:897) the word stigma means to shame or disgrace and stigmatise refers to branding as unworthy or disgraceful. Goffman (1995:13) refers to stigma as a concept that implies an attribute that is deeply discrediting, and Herek (1999:1108) conceptualised stigma as a psychological attitude or a fact of public opinion. This view was supported where Lilley (2003) was quoted saying: "When someone appears to be different, we attach a stigma to him or her. We do not do it to be cruel; we simply do not understand his or her difference". The stigmatised are seen as a category of people who are pejoratively regarded by the broader society, and who are devalued, shunned and otherwise are lessened in their life chances and access to the humanising benefit of free social intercourse (Angelo: 1995).

Therefore stigma is not just the use of a wrong word or a wrong action; it is about disrespect, the use of negative labels to identify a person seen as portraying a deviant behaviour or living with a certain disease, and it is also a barrier that discourages individuals and families from getting the help they need due to fear of discrimination (Lilley, 2003). For stigmatisation to be realised, a certain process of events happen where negative attitudes contribute to the individuals perception of stigma (Hutchinson: 2002). These following processes are placed in perspective.

2.2.2 The process of stigmatisation

The impact of stigma can be experienced in two distinct ways: felt stigma, which relates to feelings, and enacted stigma, which relates to experiences (International HIV/AIDS Alliance, 2001). Hence, due to the feelings that the individuals experience and the life experiences that they go through or observe, they become fearful that they will be stigmatised. This can in turn affect their self-esteem, their views and how they relate to others (International HIV/AIDS Alliance, 2001). Thus stigmatisation, like other life experiences, has concepts or events that are synonymous to it and often cannot be separated from it. These concepts or events then develop into a process that precede or follow stigmatisation and are normally directed at people perceived to have deviated from societal norms or have an infectious disease (Herek, 1999:1106). These events according to Herek (1999:1106) include, among others, attitudes of prejudice and discrimination. Other concepts, such as blame, fear and isolation play an important role in the process of stigmatisation as noted in the finding of the Siyam'kela project (Siyam'kela, 2003:14). It is therefore important to study these concepts so as to understand the process of stigmatisation.

2.2.2.1 Attitude

According to the Concise Oxford Dictionary (1992:47), attitude means a behaviour reflecting an opinion or way of thinking. In essence, the negative attitude of society in general causes what is termed felt stigma, which means stigma relating to feelings (International HIV/AIDS Alliance, 2001). It is indicated that ignorance and illiteracy may play a role in people's attitudes towards issues. For instance, societies have negative attitudes towards families who have experienced suicidal death, as it is observed that when it is natural or an accident, social structure and tradition offers support to the family by means of sympathy but that in this case, it doesn't happen (Pretorius, 1992:97). Felt stigma is caused by, amongst others, the attitude of society in general, and this issue was explored in a community assessment in Mongolia where sex workers raised the complaint that these attitudes burden them with a sense of guilt and disgrace. This then results in the sex workers buying into stigma, which consequently affects their social relations (Batsukh, 2001:2). According to Patruno (2003), there were many negative attitudes in Italy towards the drug users, which resulted in the emotional indifferences, thus lack of interventions to assist them in any way. This affected the drug users who felt stigmatised, and the result was that they no longer came out openly to request help, thus making every type of therapy hard to reach. Despite its ambiguity, the concept, attitude, will remain with us always, and this concept is a relatively enduring organization of beliefs around an object or situation, predisposing one to respond in some preferential manner (Rokeach, 1989:112). This issue was observed in a study done at the Free State University among female students. The study population consisted of a selected group of intelligent young adults who should be widely read and would be expected to have enlightened view and attitudes. They were asked whether they would object to having an HIV positive roommate or an HIV positive worker in the hostel or cafeteria. Twenty-eight percent (28%) were not prepared and 39% were uncertain, even when the knowledge of the disease was satisfactory. Fifty-two percent (52%) objected to having an HIV positive worker in the kitchen (De Bruyn & Joubert, 2002:202). This view was also noted by Herek (2000) during the August-September 2000 internal survey conducted by the Research Triangle Institute to determine attitudes that cause stigmatisation towards HIV/AIDS patients. As many as 18,7% respondents stated that the infected had got what they deserved (Herek, 2000). Hence negative attitudes can be seen as what people actually believe or what they would do in a concrete situation (Plummer, 1975:105). This is true to people living with HIV where attitudes and stigma affect their loved-ones and care givers (Herek, 1999:1106). Attitude plays a major role in determining behaviour (Primer, 1996:1).

2.2.2.2 Blame

The problem of stigmatisation caused by negative attitudes results in another dimension, namely that of blame. The word blame is defined as assigning a fault or responsibility of an error to a specific individual (COD, 1992:81). Hence there is a tendency for one section of the community to blame another for the spread of diseases (Baylies & Bujra, 2000:121). Blame is also attached to the manner in which people explain misfortune and a tendency to interpret social change through a gender lens, and to regard women's behaviour as disproportionately responsible for moral decline (Baylies & Bujra, 2000:61). This, according to Douglas (1994:5), is commonly observed when a woman dies from an unknown illness and mourners ask why she died. The answers ranged from "she had offended the ancestors to she had sinned". Women have mostly been blamed for the spread of HIV in most areas of the world (Baylies & Bujra, 2000:61). This view was also identified in a study conducted in Tanzania where married woman expressed concern with regard to contracting HIV from their husbands, and men also turning their fingers to blame the woman, especially those whom they regard as promiscuous (Baylies & Bujra, 2000:121). People with HIV/AIDS are blamed for having had sex with prostitutes (in the case of men) or for having been promiscuous (in the case of women) (UNAIDS, 2000a). In a study done by the Research Triangle Institute in 2000, a significant majority of people who were misinformed about HIV transmission were found to be the ones who stigmatised, thus blamed infected people for their illness (UNAIDS, 2000b).

2.2.2.3 Discrimination

The process of stigmatisation moves from a facet of blame and manifests in discrimination where discrimination results in fear and plays a major role in the creation of stigmatisation (Edgar *et al.*, 1992:125). Discrimination can be seen in different circumstances and not only in diseases, as in countries such as India and Bangladesh, where discrimination has more to do with poverty and lack of education (Parley & Luhan, 2003:1). In South Africa before 1994, discrimination had to do with race and government policies resulting in segregation (Schlemmer & Stack, 1990:4). According to McIntyre (2004), countries such as the United States of America also have discriminating policies were they prohibit HIV positive individuals from other countries entry to the United States, and this is seen as the most blatant display of discrimination against HIV positive people. Other forms of discrimination are highly marked in the provision of health services. Consequently, the effect of discrimination due to stigmatisation is fear.

2.2.2.4 Fear

Fear is often attributed to people's inability to deal with uncertainty (Bruhn, 1989:455). This can be associated with Lilley's remark that it is human nature to fear what we do not understand and that mental illness is feared by many and still carries a stigma (Lilley, 2003:1).

2.2.2.5 Isolation

Fear can lead the person who stigmatises to isolate the stigmatised person and the stigmatised person to isolation him/herself in the process. The desire for isolation has certain parallels with the removal and confinements of people who are believed to be witches in parts of the former Northern Province (Webbs, 1997:17). President George W Bush was quoted while addressing people on 29 April 2002 during the creation of the President's new freedom commission on mental illness saying "Fear of stigma leads to isolation and discourages people from seeking the treatment they need (Lilley, 2003:1). According to Patruno (2003), to use drugs in Italy is an evil equal to self-isolation from the rest of the community; therefore the drug users automatically isolate themselves due to the fear of being judged and for instance saying that there is no use in helping them.

2.3 CONCLUSION

In this literature review the concept stigma and the related process was discussed. The indication that stigma is not only marked in diseases but in different spheres of life was outlined. The fact that the process of stigmatisation mainly originates from the negative attitudes of people and manifests itself in different dimensions such as blame, discrimination, fear and isolation was clearly outlined.

The following section is a detailed discussion of the methodology that was followed in this research in order to explore and describe the experiences of the patients co-infected with TB and HIV concerning stigmatisation by the health workers, as well as the attitudes of the health workers towards these patients.

2.4 RESEARCH DESIGN

A qualitative design was followed with the aim of exploring and describing the experiences of the patients co-infected with TB and HIV concerning stigmatisation by health workers as well as the attitudes of the health workers towards caring for these patients. Practical guidelines could then be formulated for health workers, to facilitate health service utilisation by patients co-infected with TB and HIV in the Potchefstroom district. Qualitative research, as defined by Lobiando-Woods and Haber (1990:183), implies a systematic approach that involves broadly stated questions regarding the experiences and realities of the patients co-infected with TB and HIV, studied through sustained contact with these patients in their natural environment, generating rich, descriptive data that helps the researcher to understand their experiences. The phenomenon to be described and explored was stigmatisation directed at patients co-infected with TB and HIV by health workers, as well as the attitude of the health workers towards caring for these patients, which was in line with the definition of exploration by Polit and Hungler (1993:14) and that of the description by Burns and Grove (1997:4). This research focused on the patients co-infected with TB and HIV and health workers within a particular context, which referred to the area in which they live, the time of their illness and their work respectively, culture and individual or the community's orientation with regard to the circumstances within which the research took place (Mouton & Marais,1990:90). The context that the researcher referred to was as follows:

The setting where the research took place was the health clinics and the homes of the patients co-infected with TB and HIV in the community of the Potchefstroom district. The participants chose the settings where interviews were held so that open discussion could be facilitated. Factors such as ill health, fear of being stigmatised when seen in the company of the researcher and the psychological state of the patient such as anxiety was taken into consideration when the setting was chosen. The socio-economic status and the literacy level of the patients co-infected with TB and HIV ranged from low to high, although most of the patients were from the low income group as they were unemployed and some lived on the government social grant. Patients either lived in shacks at the informal settlement or in brick houses in the townships of Ikageng, Wedela and Fochville. Sanitation and running water were available in these areas, although some used communal water system instead of single household water supply. Clinics in this district were within walking distance even though overcrowding in these institutions was a reality. This factor was due to the fact that the clinics mainly serviced a large number of people who are unemployed; thus use government facilities, since they cannot afford private clinics. Furthermore, the government moves to encourage primary health care instead of curative services and free health services at these clinics, this increases the number of people that utilize these services for other health problems.

The health workers were in the employment of the district health service, the local authority or the hospital, hence they knew the patients well and understood the psycho-social dynamics of that particular area. The health workers in these institutions were understaffed with an average of five health workers of all categories servicing an average of one hundred and fifty patients per day with different health problems in a clinic setting. Within these numbers, the registered nurses were on average two per clinic with a medical doctor visiting the clinic once a week to see only referred patients. The health workers mainly make contact with the patients when they present themselves at the clinics or by sending the non registered health workers to the patients' homes when the need arises. One public hospital situated in Potchefstroom city services all the patients within this district. Staff shortage was also reported as a problem and health workers came into contact with patients when they were admitted to hospital or referred as special cases from the clinics to the outpatient department. The implication was that patients who live in Fochville and Wedela had to travel an average distance of sixty kilometres to reach the hospital, thus increasing their financial burden. Consequently, the non governmental organisations played an important role, considering that they assisted the health workers with their work load by offering home based care services to sick patients in the district. The NGOs mainly assisted TB patients by supervising their medication through the Directly Observed Therapy Short-term (DOTS) strategy and HIV/AIDS patients who are bedridden and needed basic care and support. There were a substantial number of these organisations within this district — some formal and others informal.

2.5 RESEARCH METHOD

In this section a detailed description of the following aspects is discussed, that is the population, sampling, data collection, data analysis and literature control.

2.5.1 Population

For purposes of this research two populations were used, namely the patients co-infected with TB and HIV and the health workers who are involved in the care and treatment of patients co-infected with TB and HIV. For both populations, different cultures were involved depending on the availability and those who met the set criteria.

Following is a detailed description of the sampling methods that were used for each population and their sample size.

2.5.1.1 Sampling

- **Population one**

This population consisted of the patients who were co-infected with TB and HIV, irrespective of when they had been diagnosed and for how long they had been sick. Patients lived in the areas of Potchefstroom, Wedela and Fochville in the North West Province of South Africa.

- **Sampling method**

The purposive voluntary sampling method as described by Burns and Grove (1997:308) was used to select participants from the identified population of patients co-infected with TB and HIV, who complied with the criteria for inclusion in the research and who volunteered to participate.

The criteria for the patients co-infected with TB and HIV was set as follows:

They had to:

- be diagnosed with TB before they had tested HIV positive
  or
- be living with HIV or AIDS and subsequently became ill with TB.
- be females or males aged 16 years and older.
- be residing in either Potchefstroom, Wedela, or Fochville in the North West Province of South Africa.
- be able to share his/her experience.
- be willing to sign a consent form to participate in this research and agree on the use of an audiotape during the interview.
- be able to communicate in any language that is understood by the researcher (Zulu, Xhosa, Setswana, Sesotho, English or Afrikaans).

One health worker in each clinic who was not part of the research population of health workers acted as a mediator in the recruitment of patients as participants. This was to promote objectivity and to avoid bias when choosing the patients as participants. These mediators played an important role, since they knew the participants and had established relationships with them. Therefore the willingness of the patients to take part depended on them due to the sensitivity surrounding both these diseases, especially the fact that the HIV status of the patients would be disclosed, thus impacting on the confidentiality aspect.

The role of the mediator was to:

- identify and compile a list of potential participants,
- explain the purpose, benefits and importance of the research project to the potential participants,
- explain to the potential participants all ethical issues outlined in the consent form,
- explain to the potential participants the method of data collection and that the interview will be recorded on an audio-tape and will last more or less forty-five minutes,

- explain that the process of debriefing will be made available to the potential participants after the interview should they experience any discomfort.
- arrange appointments for the interviews on behalf of the researcher that would suit both the researcher and the participants,
- explain to the participant the importance of not being disturbed during the interview, which will include not bringing small children on the day of the interview,
- agree with the participant on behalf of the researcher on a venue where the interview will take place and that suits the participant,
- organise a private room with no or minimal disturbance at the clinic for those participants who wished to have the interview conducted there, and
- introduce the researcher to the participant before or on the day of the interview.

❖ Sample size

The sample size was determined by data saturation as described by Polit and Hungler (1993:333). This implied that the researcher did data collection by means of interviews until a sense of closure that the researcher experienced was reached when the process ceased to yield any new information. Nine participants were interviewed and saturation was achieved when a pattern of data repetition emerged.

• Population two

The different categories of health workers who had been involved in the care and treatment of patients co-infected with TB and HIV for a period not less than a year, working in the clinics and mobile health services serving in the Potchefstroom district in the North West Province.

❖ Sampling method:

A purposive voluntary sample was selected from a population of health workers who were involved in caring for the patients co-infected with TB and HIV because they had met the criteria that had been set by the researcher and had volunteered to participate (Bums & Grove, 1997:308).

The criteria for the health worker was set as follows,

They had to:

- be within any category of health workers as defined in Chapter 1
- serve in a health service within the Potchefstroom district in the North West Province
- be directly involved in caring for and treating the patients with TB and HIV in the clinics and mobile health service for at least one year, which would indicate that they understand the dynamics of that particular community
- be available and willing to be interviewed
- be of any available cultural group or gender.
- be willing to sign a consent form to participate in this research and agree on the use of an audiotape during the interview.
- be able to communicate in any one of the following languages: Zulu, Xhosa, Setswana, Sesotho, English or Afrikaans.
- have no involvement as a mediator in the recruitment of patients as participants in this research

❖ Sample size

The sample size was determined by data saturation as described by Polit and Hungler (1993:333). In this research, nine participating health workers were interviewed and saturation was achieved when a pattern of data repetition emerged. This implied that the researcher reached a point where the process ceased to yield new information, thus where the researcher experienced a sense of closure.

2.5.2 Data collection

This section will comprise of a detailed description of the role of the researcher, the physical environment and the method of data collection.

2.5.2.1 The role of the researcher.

Before data was collected, the researcher obtained permission from the authorities to carry out the research in their area of jurisdiction. This process was done by sending letters personally to the Director of Health at the Potchefstroom City Council, and the district manager of health at the Potchefstroom District Office of Health in the North West Province a month before data collection was commenced (see Appendixes A and B). The letters included the background of the study, the purpose and the inclusion criteria for participants (patients and health workers).

Having been granted the permission, the researcher identified health workers who would act as mediators in the different clinics within the Potchefstroom district and who met the set criteria as outlined earlier in this chapter. The researcher then contacted those in the Potchefstroom area personally, and those in the Wedela and Fochville area telephonically and requested their assistance in the recruitment of the patients co-infected with TB and HIV as participants in the research project. During these discussions, the researcher explained the purpose and the objectives of the research, the method of data collection, the role of the mediator as well as the ethical aspects regarding confidentiality and anonymity. Having reached agreements with the selected mediators, the researcher made the request official by sending them the letters which outlined issues that were mentioned in their earlier discussion as well as the criteria for inclusion of participants (see Appendix C). The mediators were requested to give the participants choices as to where they would like the interviews to take place and to explain to them what a setting that will be conducive to privacy should look like. The researcher informed the mediators that they were also expected to thoroughly explain the content of the consent form to the potential participants who could not read and those using any other language in the criteria other than that in the consent form. The researcher then requested the mediators to submit a name list of the recruited patients, the setting agreed upon for data collection and the dates on which the mediator was to introduce the researcher to the patients. All the patient participants opted to meet the researcher on the day of the interview without the presence of the mediator.

For the recruitment of the health workers population, the researcher personally approached different health workers who qualified according to the inclusion criteria of the research to request their involvement in the research project. In her discussion with them, the researcher explained the background, purpose and the objective of the research. The researcher also outlined the ethical issues of confidentiality and anonymity, the method of data collection as well as the expected roles of the participant as outlined in the inclusion criteria. The researcher then set appointments for data collection with those who agreed to participate and confirmed the appointment telephonically a day prior to the interview.

A specialist psychiatric nurse was approached to be available for quick referral as a support system for debriefing should the need arise as a result of the interview (see Appendix D). This service was made available to all the participants in both the populations.

Prior to each interview, the researcher labelled each audiotape and checked that the tape recorder was functioning well. In cases were the interview was held at the clinics, the researcher arrived earlier to make sure that the private room was arranged and all the equipment that would be used for the interview was in order. In cases were the interviews where held at the homes of the participants, the researcher took batteries for the tape recorder so as not to impose on the participants.

On arrival at the setting for data collection as determined by the participant, the researcher provided the participants with a consent form and explained the content in detail. These included the purpose of the research, the purpose of the audio-tape, the availability of the psychological support and reassurance concerning confidentiality and anonymity. The participants were informed that, should they wish to withdraw from the research at any stage, they may do so. The consent forms were in English and Setswana (See Appendixes E and F) but the researcher used the language that was understood by the participant as set out in the criteria. The consent form had a detachable portion attached to the letter so that the participants could sign it as a legal document indicating the agreement with the terms set by the researcher, and that they were not coerced into taking part in this research. This detachable slip was handed to the researcher prior to the interview.

After each interview the researcher wrote the field notes and placed them with the labelled tapes so that they corresponded.

2.5.2.2 The physical environment

According to Polit and Hungler (1993:305), the physical setting is a context within which human behaviour unfolds and should not be constrained, consequently facilitating capturing of in-depth information. The environment should foster psychological freedom and enhance participation. For this reason, most of the interviews with the patients took place at their homes or a place of their choice as it was agreed with the researcher so as to ensure their comfort. The settings were conducive as requested, implying that the physical environment used was quiet and private with no or minimal disturbances. For those participants who chose to be interviewed at the clinics, the physical environment was prepared like that used for the health workers as discussed below.

Interviews for the health workers were held at the clinics. A room was chosen that was private, comfortable and free from disturbances such as telephones. The room was well ventilated and clean. Chairs were arranged in such a manner that there was no barrier between the researcher and the participant during the interview, thus facilitating eye contact and rapport. The clinic staff were made aware of the interviews in process and asked not to disturb. A "no disturbance" sign was attached to the door so as to remind everybody in the clinic not to disrupt the interview process.

2.5.2.3 The duration of the interview

Although the interviews were estimated to last a maximum of forty five minutes when the appointment were arranged, the researcher informed the participants that more time could be used if they wished to talk due to the sensitivity of the subject. The average duration of the interviews was forty-five minutes to an hour. The participants were requested to make them available for a follow-up interview if the researcher saw the need.

2.5.2.4 Method of data collection

The research consisted of two populations. Unstructured in-depth interviews were conducted with the patients co-infected with TB and HIV and semi-structured interviews were conducted with the health workers (Morse & Field, 1995:90-94). The purposive voluntary sampling technique was used to identify potential participants in both the populations. The researcher undertook trial runs for both the populations so as to test and make the necessary adjustment to the questions and determine the interview skills of the researcher.

In the first population, which consisted of patients co-infected with TB and HIV, a phenomenological approach was used, as this method's purpose is to describe the experiences as they are lived and to capture the "lived experience" of study participants (Burns and Grove, 1997:70). According to Creswell (1994:12), a small number of participants are extensively studied through a process of engagement in order to develop patterns and relationships of meaning. Thus the researcher used this process of engagement to elicit information from the patients co-infected with TB and HIV in order to obtain understanding of the participant's point of view or situation. The patient's experiences were explored by asking the patient to tell a story with minimal interruption (Morse & Field, 1995:90). The question "tell me about your experiences as a patient co-infected with TB and HIV concerning stigmatisation by health workers" was asked by the researcher.

Eleven (11) participants who met the set criteria were recruited (See Appendix C) by the mediators and nine (9) availed themselves to be interviewed. The other two made it impossible for the researcher to interview them as one (1) could not be found at his place of residence as arranged and the other one changed her mind on arrival of the researcher. The interviewed group consisted of seven (7) females and two (2) males residing in the Potchefstroom district in the North West Province. Interviews were held at different settings depending on the request of the participants and these included their homes and clinics.

To explore and describe the attitudes of the health workers towards the patients co-infected with TB and HIV, semi structured interviews were conducted with the health workers who were involved in the care of patients co-infected with TB and HIV. A semi-structured interview schedule was formulated and based on literature (see Appendix G). The questions were sequenced in a psychologically meaningful order and in a manner that encouraged cooperation and candour (Polit & Hungler, 1993:203). The interview schedule was given to experts for content and face validity as described by Creswell (1994:151). Nine (9) participants were interviewed, also from the same district. Interviews were held at different clinics where the health workers were functioning as per discussed agreements. The researcher honoured the times that were agreed on by her and the individual participants resulting in all interviews proceeding according to schedule

The interviews were conducted by the researcher herself for both the populations and followed the following procedure:

- The researcher presented herself at the house, clinic or place of choice of the participants as per arrangement on the day of the appointment. She presented herself on time and dressed simply as stated by Burns and Grove (1997:335).
- The researcher waited to be ushered in and be welcomed by the participant where the place of choice was the participant's home.
- Where the place of choice was either the clinic or any other venue which was not the participant's home, the researcher presented herself earlier so that she could be able to welcome the participant.
- The researcher introduced herself and briefly re-emphasised the purpose of the visit.
- The participant was made to feel comfortable and reassured by the researcher regarding issues of confidentiality.
- The researcher let the participant read and sign a written consent form for voluntary participation (see appendixes E and F in English and Setswana).
- The researcher checked the audiotapes before the interviews started to ensure that it was in good working order, and the electric outlet and batteries were tested to ensure that they were in good condition for recording.
- The tape cassettes were clearly marked before each interview to indicate whether it was a patient or a health worker with the number of recordings done. This ensured that no information went astray or got mixed up between populations.
- When the participant was ready, the audiotapes were put on and the interview started.

To facilitate the interview and to encourage the participant to feel free to talk, the following communication techniques as described by Okun (1997: 70-71) were used.

- *Minimal verbal response:* A verbal response that is occasionally accompanied by nodding of the headed, such as "hmm", "yes"' or "I see," which indicates that the researcher is listening.
- *Probing:* an attempt to persuade the interviewee to give more information about an aspect under discussion. Statements are made, such as "can you tell me more about ..."
- *Paraphrasing:* It is a verbal response in which the researcher enhances meaning by stating the participant's word in another form with the same meaning.

- *Reflecting:* Reflecting back something important that the person just said in order to get him/her to expand on that idea, e.g. "so you believe that stigma is present"
- *Clarification:* It is to get clarity on unclear statements, such as "You seem to be saying"
- *Encouragement:* Encouraging a participant to pursue a line of thought. "I find that fascinating. Tell me more".
- *Summarising:* An attempt to synthesize the interviewee's ideas, thought and feelings are verbalized to test whether you understood what was said.

The researcher also used non-verbal communication so as to show that she was actively listening and that she was interested. The non-verbal techniques that were used included eye contact, maintaining an open posture, sitting up with no physical barriers between the interviewer and the interviewee, occasional nodding, occasional smiling and showing an involved facial expression. The duration of the interviews lasted between 45 to 60 minutes and field notes were written immediately after each interview. The field notes were attached to the corresponding audiotapes for all the interviews. There were no incidences of severe emotional trauma experienced during or after the interviews, therefore the researcher did not refer any person for further counselling or for psychological support.

2.5.2.5 Field notes

The field notes regarding each interview were recorded before the next interview commenced (see Appendix H). This assisted the researcher not to forget important aspects of the interview. The following were some critical points that the researcher followed, as pointed out by Creswell (1994:152).

- Descriptive notes: These are the reports on the portraits or descriptions of the participants, the physical setting, the interviewer's account of particular events that occurred and activities that took place during the interview.
- Reflective notes: These are a record of personal thoughts such as speculation of incidents, feelings, problems encountered during an interview, ideas generated during the process, hunches, impressions and prejudices.

- Demographic notes: These are information pertaining to the time, place and date to describe the physical setting where the interview had taken place.

Field notes were typed, clearly marked and attached to each transcription of each interview.

2.5.3 Data analysis

The audiotapes for all the interviews were transcribed verbatim and analysed, following the method of open coding as described by De Vos (*in* De Vos *et al.*, 2002:346). The interviews with the co-infected patients formed a set of data and the interviews with the health workers formed another set of data. The following method for data analysis was followed:

- All the transcripts were read to get an overall idea.
- One transcript was chosen and read again.
- Using words and sentences as units of analysis, the transcript was read again, and the spoken word and sentences were underlined.
- The underlined words and sentences were transferred to the left hand column of the transcript together with concepts that were detected.
- Personal perceptions of the researcher were written on the right hand column of the transcript.
- The categories that were transferred to the right were read so as to identify the main categories, the sub categories as well as the redundant categories.
- The underlined words (still in the respondent's own words) were then transferred to a table indicating the main categories, the subcategories and further categories.
- These categories were subsequently finalized by going through the table again.
- The spoken words were translated into scientific language and the possibility that the categorization can be refined was kept in mind.
- The same steps were followed to analyse the rest of the transcripts.

An independent co-coder who is experienced in qualitative research was appointed. A work protocol (see Appendix I) together with the transcripts and field notes was sent to the co-coder. A consensus discussion had taken place between the researcher and the co-coder after the independent coding took place. The purpose was to compare and identify similarities and differences of the emerging themes. A consensus was reached regarding the categories and sub-categories and these were subsequently finalised.

2.5.4 Literature control

A literature control was used to verify the findings of this research regarding the stigmatisation of patients co-infected with TB and HIV. The following data bases were used for this purpose: Nexus, Repertoire of South African Journal articles, inter-library loans, the North-West University library, the media (newspapers and magazines) and the World Wide Web. The purpose of literature control, as stated by Polit and Hungler (1993:66), was to provide a scientific basis and highlight new insight gained from it.

2.6 TRUSTWORTHINESS

The criteria for trustworthiness as formulated by Guba (*in* Krefting, 1991:215) were observed as follows:

2.6.1 TRUTH-VALUE

Truth-value asks whether the researcher has established confidence in the truth of the findings for the participants and the context in which the research was conducted. In this research it was obtained from the discovery of the experiences of the patient co-infected with TB and HIV and the attitudes of the health workers towards these patients. The purpose of the researcher in this regard was to improve and evaluate the *credibility* of the data and conclusion, which indicated confidence in the truth of the data. This is emphasised by Sandelowski (as quoted by Krefting, 1991: 215) when he suggests that the findings present an accurate description of patient's experiences in such a way that participants immediately recognize their experiences in them. Within this research, the following strategies were adopted by the researcher to enhance the truth of the data.

- A relationship of trust was established with patients co-infected with TB and HIV, and with the health worker involved in the care of these patients. The purpose was to minimise suspicions and to ensure that they were relaxed during the interview so as to maintain free flow of the discussion.

- Field notes were recorded immediately after the interview and it formed part of the data analysis.
- Cross validation was done by independent data analysis and a consensus discussion was held between the researcher and the co-coder after completion of data analysis.
- A literature control was executed, as previously explained in this research.

There are a variety of techniques for improving the credibility of a qualitative research as suggested by Lincoln and Guba (*in* Krefting, 1991:216).

Prolonged engagement was used which means the researcher should spend an extended period of time with the participants, allowing him/her to check perspectives and allowing the participants to become accustomed to the him/her (Krefting, 1991:220). During this research, the researcher was engaged in the research field for a considerable amount of time as she was involved in different community project, and came into contact with different participants on continuous bases. This allowed her to reframe, repeat and expand questions thereby increasing credibility.

The other technique used was member checking (Krefting, 191:219), which is used to continuously check whether the researcher had accurately translated the participant's views. This was achieved by continually testing with the participants, the researcher's interpretations and conclusions. Furthermore, the participants were informed during the interview that they should make themselves available for a follow-up interview if need be. Peer examination was also used to strengthen credibility where concurrent data analysis was done with an independent co-coder who is experienced with qualitative research. The transcripts together with the field notes were given to the co-coder who independently analysed the data to maximize the comprehension of the concepts. A discussion followed to check on developed categories from the data by both the researcher and the co-coder before consensus was reached regarding these categories to ensure that the data was interpreted correctly. Reflexive analysis was achieved by the use of the field notes to ensure that all the observations as well as ideas in the researcher's mind were noted. This allowed the researcher to reflect on her own bias, pre-conceived ideas, behaviour and experiences as the interviewer and separated it from the findings.

2.6.2 Applicability

Applicability refers to the degree to which the findings can be applied to other contexts and settings (Krefting, 1991:215). In qualitative research, this does not necessarily mean that the findings that are generated from the Potchefstroom district can be generalised to a larger population, according to Sandelowski (*in* Krefting, 1991:216). This is due to the fact that research settings differ and the purpose of qualitative research is to describe specific experiences and not to generalize.

To ensure applicability, the researcher provided a dense descriptive of methods and context in the research report so that consumers and other researchers can evaluate the applicability of data to other contexts.

2.6.3 Consistency

The emphasis was on whether the findings would be consistent if the interviews were replicated with the same participants or in a similar context (Krefting, 1991:216). Qualitative research emphasises the uniqueness of human situations, so that variation in experience rather than identical repetition is sought (Morse & Field, 1995: 144). In this research consistency was reached when dependability was established (Krefting, 1991: 221). Lincoln and Guba (*in* Polit and Hungler, 1993: 255) view dependability of data as the stability of data over time and over conditions. The inquiry audit approach was used, as explained by Polit and Hungler (1993:255). This approach consists of scrutiny of the data and relevant supporting documents by an external reviewer as well as a research expert. The co-coder was that individual. The replication technique was incorporated in the research design in order to ensure dependability. The researcher also provided sufficient descriptive data so that consumers and other researchers can evaluate the consistency of data to other contexts.

2.6.4 Neutrality

Sandelowski defines neutrality as the freedom from bias in the research procedures and results. This would be ensured by the use of conformability as a criterion and is achieved when truth value and applicability is established (Krefting, 1991:216). Neutrality also refers to the degree to which the findings are a function solely of the informants and the condition of the research and not other biases, motivations and perspectives Guba (*in* Krefting, 1991:216). To ensure the neutrality of this research, the raw data, field notes, and the interview schedules were made available to the co-coder (Krefting, 1991:221).

2.7 ETHICAL ASPECTS

Nursing research tends to focus consistently on people, their health attitudes, experiences associated with illness, values and support systems (LoBiando & Haber, 1993:244). The researcher has to be very much aware of the right of human subjects and other ethical issues when planning a research project. Brink (1996:38) emphasizes that to conduct research in an ethical manner means that the nurse researcher must carry out the research competently and most importantly consider the consequences of the research for society. The following are the ethical procedures that were adhered to:

2.7.1 Review by ethical committee

The researcher submitted the research plan to the ethical committee of the North-West University, Potchefstroom campus, for review and for permission to undertake the research (Brink, 1996:38). A full proposal was submitted clearly indicating the purpose of the research, the research design and the ethical considerations that the researcher will adhere to. The researcher was subsequently granted permission to undertake the research.

2.7.2 Fundamental ethical principles

There are fundamental ethical principles that are concerned with the protection of the right of human subjects. The researcher adhered to these principles in the following manner:

2.7.2.1 The right not to be harmed

Harm to a research participant is described as exposure to the possibility of injury going beyond everyday situations (Wilson, 1993:249). These include physical, emotional, legal, financial and social harm. Burns and Grove asserts this (1997:206) by stating the principal of beneficence that states that one should do good and above all, do no harm. In this research, the researcher explained the risk-benefit ratio to the participants extensively before they agreed to take part in the study. The participants were within the age category that is stated in the selection criteria and able to give consent. The researcher advised the participants with regard to the availability of a psychiatric nurse who had agreed to assist with counselling services should the participant experience serious emotional trauma. In this case there were no participants who requested the use of such a service.

2.7.2.2 The right to full disclosure

Full disclosure involved informing the participants about the following aspects (Wilson, 1993:250) which the researcher adhered to

- The nature, duration and purpose of the study
- The methods, procedures and processes by which data was collected. This was expressed in straightforward lay terminology.
- Any inconveniences or discomfort that could result
- Any result or side effects that followed from participating in the research
- The right to refuse to participate or to withdraw at any stage
- The identities of the researcher and how to contact her

The researcher included all the above-mentioned criteria in the consent form as explained earlier in this chapter. The researcher and the mediator explained to the participants in extensively in the language that they fully understood.

2.7.2.3 The right to self-determination

The right to self-determination is noted by lack of constraints from the participants, no coercion or undue influence of any kind. This is confirmed by Burns and Grove, (1997:200) in the set ethical principle of respect for persons that states that "humans are capable of self-determination or controlling their own destiny". To allow the participant self-determination, the researcher avoided coercion and used plain simple language when communicating with the participants. The participants were given the latitude to ask the researcher questions for the purpose of clarity and decision-making on whether or not to participate. In addition, the participants were informed that they have the right to withdraw from the research at any stage, and that there will not be any risk of penalty or prejudicial treatment against them should they decide to withdraw (Brink, 1996:40). All this information was included in the consent form. (Appendix E and F).

2.7.2.4 The right to Privacy, Anonymity and Confidentiality

The participants in this research had the right to determine the time, the extent to as well as the circumstances under which private information would be disclosed or withheld (Burns and Grove, 1997:203). The interviews were conducted at the venues chosen by the participants. This afforded the participant freedom to choose a place where privacy was maintained with no interruptions. Anonymity refers to the fact that no links can be made between the participant and the information reported. Only the researcher and the mediator knew the identity of the participants but this was treated with the utmost confidentiality and no other person could make a link between the information that was given and the participants. During the interviews, the participants' names did not appear in any documentation, and codes were used to refer to participants. The data on the audio-tapes were destroyed after being transcribed; therefore if names were mentioned during the interview, no one had access to them. No names were mentioned while reporting data and participants were reassured regarding this matter.

2.7.3 Scientific honesty

The researcher had the responsibility to share the results with the scientific community in a respectful manner and in an accredited journal. The research adhered to this aspect by ensuring that all the information that was reported was accurate and that no data was falsified. The other authors, whose literatures were used to enrich this research, were acknowledged to ensure that no plagiarism was committed. Furthermore, the intention of the researcher was to share the results with the relevant health departments so as to serve the purpose of this research as highlighted in Chapter 1.

2.8 CONCLUSION

In this chapter, a detailed description of the research design, data collection and analysis was given. The trustworthiness and ethical issues were also discussed. The thorough planning of this research and factors that could have had an influence on this research were discussed, thus forming a framework of how the researcher implemented the research.

CHAPTER 3

DISCUSSION OF RESEARCH FINDINGS AND LITERATURE CONTROL

3.1 INTRODUCTION

In the previous chapter, the literature review regarding the concept stigma and the stigmatisation process was discussed, and a detailed description of the research methodology was given. The data collection and data analysis realised as discussed and the research findings pertaining to the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers (Table 3.2.1), and the attitudes of health workers towards patient co-infected with TB and HIV (Table 3.2.2) follow in this chapter. The findings are enriched by the examples of direct quotations from the interviews. The researcher compares and confirms these findings with existing literature pertaining to stigmatisation by health workers and indicates those findings that are unique to this research.

3.2 RESEARCH FINDINGS AND LITERATURE CONTROL

The consensus between the researcher and the co-coder resulted in four main categories for the patients co-infected with TB and HIV. For the health workers involved in the care of the patient co-infected with TB and HIV, three main categories were identified. These categories were further divided into sub-categories and further categories as displayed in Tables 3.2.1 and 3.2.2. Following, will be a detailed discussion of both sets of data that are dealt with separately, quotations and literature control.

Discussions of the findings regarding the experiences of patients co-infected with TB and HIV in relation to stigmatisation by health workers.

Four main categories were identified, as summarised in Table 3.2.1:

- experiences of stigmatisation due to the behaviour of health workers
- experiences of stigmatisation due to the perceived attitudes of health workers
- experiences of discrimination due to labelling by health workers
- patients' responses to stigmatisation by health workers

3.2.1.1 Experiences of stigmatisation due to the behaviours of health workers

This main category, as indicated in Table 3.2.1, Column A was further divided into two sub-categories, which are highlighted under the same column, namely firstly, that health workers do not treat the patients well and secondly, that health workers do not communicate well with the patients.

- **Health workers do not treat the patients well**

From the findings of this research it was clearly indicated by the patients that the behaviour of the health workers contributed a great deal to their feeling of being stigmatised. This was due to the treatment that was not acceptable from the health workers as experienced by the patients co-infected with TB and HIV. Further categories are indicated in Table 3.2.1.1 with regard to the treatment that the patients receive from health workers.

3.2. TABLE 3.2.1 Experiences of patients co-infected with TB and HIV regarding stigmatization by health workers

COLUMN A	COLUMN B	COLUMN C	COLUMN D
Experiences of stigmatization due to the behaviour of health workers	**Experiences of stigmatization due to the perceived attitudes of health workers**	**Experiences of stigmatization due to labelling by health workers**	**Patients responses to stigmatization by health workers**
Health workers do not treat the patients well They do not have time and respect for the patients They do not want to assist the patient with basic needs such as washing They are impatient with the patient They avoid physical contact with the patient Health workers do not communicate well with the patients They shout at and scold the patients They do not explain procedure to the patients They threaten patients and coerce them into taking blood samples	**They do not care about patients** **and do not take them seriously** **Health workers are disgusted with patients** **They are ignorant and lack knowledge** **They are not dedicated and committed** **They do not show warmth**	Labelling of patients based on their appearance Thin people have TB or HIV Labelling based on their environment Make association of infection with specific ward in hospital Dedicated room in the clinic for patient specifically with TB or HIV	Patients emotional response They become stressed They feel sad They feel worthless and hopeless Patients response to the health service They lack trust as the health workers divulge their status They lose hope in the health service They feel as if they only need to collect their treatment and not communicate with them They change clinics and do not go to the nearest clinic, thus bring about an increase in financial pressure They do not go back to the clinic at all, which impacts on their adherence to treatment

Table 3.2.1.1: Health workers do not treat the patients well

They do not have time and respect for the patients
They do not want to assist the patient with basic needs such as washing
They are impatient with the patient
They avoid physical contact with the patient

The experiences of the patients concerning the fact that health workers do not treat the patients well will subsequently be discussed.

- **Health workers do not have time or respect for patients**

The patients expressed their discontent with the way the health workers treated them in the health services. It was evident from the patients' responses that the health workers did not take time when they dealt with the patients who are co-infected with TB and HIV. It was repeatedly expressed that the health workers were not respectful towards these patients. This was clear from the disrespectful and hasty response that they showed when the patients asked them to interpret what the doctors said to them, especially when the language that was used was foreign. An example is the use of English by doctors, and some patients do not understand but they are left there without any clarification in their home language, even when the health worker knows the patient's home language. The patient perceived this type of behaviour to be a sign of stigmatisation towards them. A sense of being ignored and not assisted because of their illness being reported though the participant felt that the health workers used language issues as an excuse not to treat them well.

"They pretend like they are OK, but sometimes when someone is not treating you well with respect you can see"

"When you ask them to explain what the doctor said they scold you, saying that they do not have time and say you should ask them yourself, sometimes you do not know these foreign languages, well they just ignore you ..."

"at the clinic I come to the TB side and quickly go home, they do not give you much time, coming here is for collecting tablets only...so even before you deal with them you will like to go back home".

Similar findings were reported where it was mentioned that the health workers do not have time to attend to the patients hence counselling is rushed and ineffective (Manet, 2003:20). Baum (2005) reported that TB patients are looked upon as less than worthwhile human beings with no respect expressed towards them. No literature was available to confirm this issue in relation to the patients co-infected with TB and HIV.

- **They do not want to assist the patient with basic needs such as washing**

Further experiences of being stigmatised by the health workers' behaviour was demonstrated by the unwillingness of the health workers to assist clients when in need. Some participants in this research articulated this aspect clearly and one even mentioned that the health workers go to the extent of refusing the patient food to avoid assisting them. Patients saw these acts as severe stigmatisation behaviour.

"There was a TB patient who was very ill, and asked that they should bring him water to wash. They refused and said that he should wake up and go to the bathroom. He died in the bathroom"

"They hit her, she wasn't given food so that she won't defecate"

Similar incidents have been reported in a study done by the Pan American Health Organization (2003) where discriminatory acts towards patients co-infected with TB and HIV such as delayed treatment and basic care to refusal of providing hygiene to patients have been noted. In another incident, a health worker left an HIV positive boy to bleed after his blood accidentally spilled onto his head during the blood taking procedure without caring about the welfare of the boy and the consequences of him bleeding too (Jariyavilas *et al.,* 2003:16). These behaviours were confirmed in a research done amongst Zambian health workers who acknowledged that HIV/AIDS patients were often not given the same services because doctors knew that they were going to die, and therefore spent less time on them (PAHO, 2003:26).

- **They are impatient with the patient**

Other experiences reported by the patients were that the health workers are very impatient and the result is that they do not get proper care at the end. One participant indicated that she often wonders whether health workers were aware of the situation that they were up against when they joined the profession. But due to the impatient behaviours that they show to people, it makes it difficult for the patients co-infected with TB and HIV to report other ailments that they experience. One participant emphasised that when one has TB and HIV one actually is at risk of dying due to this impatient behaviour, as other fatal conditions such as Pneumocystis carinii pneumonia (PCP) will not be investigated until it is too late. This behaviour also leads to the patients lying or exaggerating their illness so that further examinations can be done on them. The following are the quotations from the interviews.

"I explained to him that I was sick, he impatiently just gave me tablets and said I must go ... that was that"

"They are impatient when you complain ... she said (sarcastically) Hey all the ointment didn't help you so you have to go to the private doctor.

"... there is one specific health worker who is very impatient with people ..."

"I was breathing with difficulty, I had short breath. I couldn't walk to the clinic. When I arrived at the clinic the doctor said impatiently, Hey, you have TB you have to cough, go away ... later I was admitted for two weeks and found that I have PCP."

"... I was once admitted at hospital, and yes I lied to him and said ... one doctor said that if I cough again I should come to the hospital, that is when he wrote me a referral letter".

Most literature acknowledges that health workers do not treat the patient well but none confirms the aspect of impatience while caring for the patient as in this research. It therefore means that this aspect is a unique finding, thus needs further research.

❖ **They avoid physical contact with the patient**

Patients expressed that when health workers avoid physical contact with them they feel stigmatised, as this behaviour only applies to them as patients co-infected with TB and HIV. Other participants indicated that the fear of contagion might be due to lack of knowledge about spread of infection. Contrary to this, participants indicate that most of the said behaviour is noticed more amongst health workers in lower positions than in professionals. A unique finding in this research in relation to this behaviour was that the fear might be was due to health workers fearing that they also might be HIV positive. One participant explained this notion by saying that the possibility was that the particular health worker who did not want her to touch her things, knew that she was HIV positive, thus looked at the patient and identified herself as what she was going to look like in future. This type of fear made the health worker to avoid contact with the patient so that she could protect her already affected immune system, since according to the participant, it was later discovered that the health worker was infected. Following, are the patients' experiences as quoted from the interviews:

"They have an attitude, you can see when they are scared of you … cared to touch you"

"Assistant nurses especially have a problem of negative attitudes and do not want to come in contact with us…those with epaulettes not so much".

"When you drink with her things … she will comment … no, no, no, don't touch this, it is not for people, I brought it for myself, let me put it away"

"I asked myself what is happening with her, why is she so scared of me … she came to me crying, she also has tested HIV positive. She was asking herself that maybe one day she will be like that because at that stage I was very sick".

Patients living with HIV in Tanzania confirmed that health workers do not attend them and will not touch them (France, 2003:6). In New Delhi, doctors often refused to touch TB patients, even going as far as forcing them to stand on the other side of the room during examination (HDN key correspondence team, 2005:2). Health workers used latex gloves even when taking vital signs, which is unnecessary and inappropriate (Engenderhealth, 2004).

❖ Health workers do not communicate well with patients

Another sub-category that emerged from the data was that the health workers do not communicate well with patients (see Column A, Table 3.2.1). Communication as a form of respect is understood in all societies.

Table 3.2.1.2 Health workers do not communicate well with patients

They shout and scold the patients
They do not explain procedures to the patients
They threaten patients and coerce them into taking blood samples

❖ Health workers shout at and scold patients

It was clear that a common stigmatising behaviour by health workers was the way in which they spoke to patients. It was also evident that the patients felt abused verbally and could not do anything about it as they saw the health worker in a position of power. One participant reiterated this fact by saying that if you answer them back, they see you as silly. They explained that the way the health workers shouted at them was belittling. Thus the communication aspect increases stigmatisation and it was seen as the worst behaviour that the health workers displayed to stigmatise the patients co-infected with TB and HIV. The patients explained the following as their experiences

> "He gets disgusted with patients ... He will scorn you and say that the first thing that a woman does on waking up is to wash first ... can't you see how you look, you are ill because you don't wash, it is because of being dirty"
>
> "Sometimes you end up asking the sister and he will shouts at you and says ... I don't

know, why don't you ask the doctor, what should I do ..."

"She screams at you and says you should not cough in front of her ... Go outside, they don't talk nicely with you.

"They shout at you and when you need to do something, they want you to do it for yourself, even if you are weak ..."

"They scold you in front of the other patients ..."

"If they see that you are down to earth when they shout, they see you as a fool, and again if you talk back to them the way that you want, they say you are silly"

These behaviours were confirmed in an incident where the matron in charge humiliated and verbally abused a patient in the presence of the other patients, insisting that they did not provide care for patients living with HIV/AIDS (Siyam'kela, 2003:18). Contrary to this aspect, one patient in this research felt that the patients themselves provoke the health workers resulting in the negative reaction from the health workers. Though he accepted that the reaction is not proper for a professional person, he believed that health workers are also human and can react negatively when coerced to do so.

- **They do not explain procedures to them**

Patients co-infected with TB and HIV also felt that the health workers did not explain procedures to them and expected them to know what do to. When they do not act as expected, the health workers spoke to them in a harsh manner. Patients reported that health workers expect them to understand the procedures even though they were never clarified to them and they expected cooperation. These are some of the direct quotations from the transcription:

"... Like they used to give us this bottles written danger for the sputum, and they say you should take it somewhere ... they scream at you and we don't know ... they didn't tell us"

"They never came back and gave me feedback after they took my blood ... "

"I don't even know what PCP is. They didn't explain it to me ..."

"If they can educate us, we don't have a problem of co-operating with them"

Zulu (2001:1) supports the above-mentioned experiences in saying that failure of health workers to break the news when a person is tested and found to be HIV positive is in itself another manifestation of stigma in the health care sector.

- **They threaten patients and coerce them into taking blood samples**

Another form of stigmatisation by means of disrespectful communication was threatening of patients. It was obvious in this research that most patients where firstly diagnosed with TB and then coerced to take blood test for HIV. Patients reported that they were threatened that they will not be given health care if they did not test for HIV or divulge their HIV status to the health workers. Participants were quoted saying:

"... they insisted that if I refused that they should take my blood, they will leave me just like that. Then I will have to see how I go about with my illness"

"They told me that the doctors won't check me if I don't take blood test, they insisted that I take the blood and at the end I did."

In a research conducted by Worthington and Myers (2003:650), most of the participants felt that they were not given a choice of whether or not to be tested for HIV. They were tested because of illness, their personal circumstance or without their knowledge and it was demanded that they be tested. In Engenderhealth (2004:1), a health worker admitted to once coercing a patient to take tests for HIV after he accidentally pricked himself with a needle.

3.2.1.2 Experiences of stigmatisation due to the perceived attitudes of health workers

The second main theme that was identified in this research was experiences of the patients co-infected with TB and HIV due to their perception concerning the attitudes of health workers. This was summarised in Table 3.2.1, Column B, and further categories were identified. The following is a detailed discussion of the further categories as reported by patients:

Table 3.2.1.3 Experiences of stigmatisation due to the perceived attitudes of health workers

They do not care about patients and do not take them seriously
Health workers are disgusted with patients
They are ignorant and lack knowledge
They are not dedicated and committed
They do not show warmth

❖ **They do not care about patients and do not take them seriously**

Participants reported that the health workers do not care about them. One participant felt that the health workers did not care for their well-being, although they are in the health care services to do just that. She explained that they went to the extent of forgetting to give the patients treatment, thus endangering them further. The participants reported that they were not taken seriously. Another participant said that it was even worse when you have TB and they didn't give them the same treatment as those who did not have TB. The following are remarks that were made by participants:

They don't care for people "niks" ... they don't care for people ... especially those with TB ... They don't give them the same treatment like people who don't have TB and HIV"

"When you have TB they don't care for you at the clinic ... It is like as long as they have given you the TB treatment for the week, they don't care".

"It is like they don't care for people who have TB so they don't take them seriously".

"They don't take you seriously ... and when you have TB and HIV ... Hmmm ... sometimes they show you that you are going to die anyway"

Other research confirmed that there is poor quality of care in the health setting towards those who are infected or suspected of being infected with TB and HIV (Engenderhealth, 2004). Similar findings were reported where patients were deliberately denied proper medication and care when the health workers felt that the life of the patient was not recoverable (Manet, 2003:12).

- **Health workers are disgusted with patients**

Patients co-infected with TB and HIV reiterated this aspect in their experiences that health workers stigmatised them because they were disgusted with them. Patients explained their perception in this regard:

"... She is disgusted but she knows that in nursing, when you go to nursing you are going to handle blood, faeces, rotten things and so on ..."

"For TB and HIV people, they get disgusted ... they feel disgusted really"

"... she says to people she gets disgusted, they should go and cough their sputum where and so on ..."

According to Herek *et al.* (2002:4), in a study of university students' attitudes towards people infected with HIV, one in four adults expressed feelings of disgust when dealing with people living with HIV. They also emphasised that feelings of disgust are a form of stigmatisation as it mostly occurs when the diseases are those that are seen as discrediting. These feelings of disgust displayed by the health workers were also perceived by parents of children who were HIV positive when they took them to the health facilities (Jariyavilas, 2003:64).

- **They are ignorant and lack knowledge**

Patients reported that the health workers stigmatised them as patients co-infected with TB and HIV due to lack of knowledge. They emphasised the importance of this aspect by suggesting that the health workers needed to be trained so that they can improve their understanding and better their behaviour. The following are the feelings reported by the participants:

"I think they don't have knowledge ... I know just like HIV it is being considered that when you have HIV it is the sickness of loose people ..."

"...I was asking last time that do they ever go to workshops ... for DOTS or something ..."

"... I feel that they need to be trained ..."

Most of the literature confirmed that lack of knowledge increased the possibility of stigmatisation. This observation also applies to health workers as confirmed by a study of clinicians in Nigeria regarding stigma and discrimination (Engenderhealth, 2004) that their fears were often rooted in their lack of knowledge. Jariyavilas *et al.* (2003:15) supported these findings where a medical student asked a mother "Aren't you worried from getting AIDS from your child?" and the mother asked him whether he was ever taught how AIDS is transmitted . In many private and public hospitals in India, stigma was said to be very severe, and this was aggravated by insufficient training of the health workers (Hutchinson, 2002).

- **They are not dedicated and committed**

Patients also expressed that health workers were not committed to their work. One participant mentioned that the way they were going on indicated that they were not there for the patients but for the money. To the knowledge of the researcher, many health workers fall under the category of nurses in South Africa, and this is one of the few professions in which students get salaries while in training. Most of the students from low-income families join this profession due to a lack of funds that would have been necessary for other professions. And this was the argument that the participants advanced, namely that these health workers did not come to the profession due to a calling. Owing to this aspect, the health workers then tend to assume a negative attitude towards the patients resulting in the increase in stigma. Participants explained this aspect using the following phrases:

"... to be honest they are not dedicated."

"You will get them sitting and having their own conversation ... and not caring about their patients.

"Some take the profession of nursing only because they do not have a job."

"You see it must be a call ... you must do it from the heart, you must be dedicated"

Although literature could not confirm lack of dedication and commitment in a health profession as a cause of stigmatisation, there have been reports that emphasise that having staff that are dedicated and care about their patients can help resolve problems before it adversely impacts on their treatment and care (Watts, 2005:1).

- **They do not show warmth**

Participants reported that, for a health worker to be able to work with patients co-infected with TB and HIV, they should show warmth. They expressed that most of the health worker lacked this attribute and therefore stigmatised the patients co-infected with TB and HIV. The participants reported the following statements to support the lack of warmth among health workers:

"The worst part about nurses is that they don't have that warmth ... It is only one in a million"

"When they feel that they have done whatever, they work based on time then they are through ... no follow ups coming from them ... from deep inside their hearts"

Literature confirmed this aspect as indicated in the following quotation, "No one in the hospital staff took my hand, rubbed my back, gave me support, or did any of the comforts and care measure showing warmth that the nurses pride themselves on" (Bunting, 1996:66).

3.2.1.3 Experiences of discrimination due to labelling by health workers

The third main theme identified by patients co-infected with TB and HIV as summarised in Table 3.2.1, Column C deals with the patients' experience of discrimination by health workers due to labelling patterns. Out of the nine patients interviewed, there seemed to be a general feeling of discriminatory behaviour manifested through the use of labels by health workers towards patients co-infected with TB and HIV. Literature mentions that discrimination by health workers was rife, and this view was supported in the report by the Pan American Health Organization (2003) that, despite some "ground for optimism", HIV/AIDS-related stigma and discrimination persists among health workers of many countries, including those in America. From the finding of this research, it is apparent that the patients felt that discrimination plays a major role in stigmatisation. It was evident that discrimination was more due to the labels that the health workers attached to appearances and/or a place.

Two sub-categories were identified in this theme with further categories. Following, is a detailed discussion of these sub-categories and further categories:

- **Labelling of patients based on their appearance**

Society at large seems to classify the patients' illness based on their appearance. Health workers also form part of society and they also align themselves with the same perceptions that the communities hold. From the findings of this research, the patients clearly indicated that the behaviour of the health workers contributed a great deal to them being discriminated against as patients co-infected with TB and HIV. This was due to the reactions and labelling comments that were made towards them as patients co-infected with TB and HIV. Further categories are indicated in Table 3.2.1.4 with regard to the treatment and labels that the patients experienced from health workers.

Table 3.2.1.4.1: Labelling of patients based on their appearance

- Thin people have TB and HIV

❖ Thin people have TB and HIV

Participants indicated that the health workers often concluded that they had HIV just by looking at them. What was obvious was that when a patient was thin, she was automatically categorized as having TB or HIV by different categories of health workers, since weight loss is one of the symptoms of TB and/or HIV. This then lead to the patients being discriminated against and stigmatised in the health services. The following are direct quotations from the participants relating to weight loss and their "assumed" TB/ HIV status:

"I went to the doctor ... I was so sick, I had lost weight ... they already concluded that I have HIV ..."

"They talk the way they want with people especially when you look thin and sick. It is like they already judge you ..."

" even when he suspect and is not sure about you based on the results, he just looked at your body and say ... this one has HIV ... or TB"

"The nurses have a tendency of speaking these fanny languages ... they look at you and use terms like ... is that ... the three words".

The Siyam'kela (2003:17) has also identified this aspect while dealing with stigma that, as a result of the silence surrounding HIV/AIDS, a culture of suspicion has developed in which people tried to identify possible infected people through association. One participant in that research was quoted saying "If we see that you are loosing weight, whether you are exercising or whatever, we just assume that you have AIDS.

- **Labelling based on their environment**

Another category that emerged was the perceptions that were made about the patients' health status in association with the environment where they received their treatment. The researcher observed that patients became anxious or sad when they spoke about the environment in which they received care. The environment that was referred to was either a ward in the hospital or a room in a clinic. The following is a detailed description of the further categories as outlined in Table 3.2.1.5

Table 3.2.1.4.2: Labelling of patients based on their environment

Making association of infection with a specific ward in the hospital
Making association with a allotted room in the clinic for patients specifically with TB and HIV

❖ Making association of infection with a specific ward in the hospital

The patients clearly stated that, due to segregation of wards in the hospital allocated for a certain condition, the community and the health workers associated these wards with particular conditions. It therefore means that even if the patient didn't have that particular condition, the fact that he/she was seen in that ward frequently, the supposition is made that you have the disease. In the South African context where hospital wards are divided into medical, surgical, paediatric etc, patients with medical conditions are placed in the same ward. But with the high incidence of TB and HIV it therefore means that these wards mainly have patients diagnosed with these particular diseases. The following are the responses from the participants:

> "They will make you feel that you have TB and HIV ... more especially I don't like this idea of ward 8 ... as then everybody will know exactly what is happening to you. The nurses also have a tendency of speaking about it saying ... did you see that and that person ... it is what ... it is that three words. They conclude that you have HIV, as I wasn't tested when I was admitted there"
>
> "Actually me ... I wasn't tested for HIV before ... so they had already concluded that I am HIV positive even though I was ... hadn't tested. They were already saying that I am HIV

positive because I was in that ward"

"Everybody knows that it (refer to ward in hospital) is for HIV and AIDS ... therefore they know exactly what is happening to you ..."

Literature confirmed this aspect as noted in a hospital in Ibadan, Nigeria, where patients were isolated and placed in different wards based on the suspicion that they have HIV and AIDS. Even though patients were not yet tested, health workers placed them in that specific ward associated with HIV and AIDS (Engenderhealth, 2004:1). Nyblade (2003:39) had similar reports of participants being afraid of being seen at the VCT centre due to fear of being stigmatised, seeing that people assumed that being in that place means you are HIV positive.

The following further category that was highlighted is almost similar to the above-mentioned one but this is more specific to a primary health care setting. The researcher therefore saw the need to make a synopsis of the two.

- **Making association with an allotted room in the clinic for patients specifically with TB and HIV**

The participants reported that this issue of allotting a room to infectious diseases contributes to stigmatisation, thus to an increase in the defaulter rate. The participant reported that this measure encourages stigmatisation, seeing that other community members who came to the clinic concluded that they were infected because the nurses gossip when they come from those rooms. Also the health workers spoke loudly about the people's status when they came from those rooms, making the patients in the waiting room aware of what was going on in these rooms. The following are other quotations from the interviews that support the foregoing discussion:

"You see those nurse shows everybody that comes in that you have HIV ... It is like the person who just entered will see that this one has just been taken blood ... you will see them gossiping and giggling and you ask yourself if you should enter ... they have done that to that other person ... how are you going to enter".

"You see when I come I have a card that I bring to that specific room ... The room for TB patients"

"You see in the clinic I come at the side which is for TB people, and when I come I don't ask them anything, coming here is for collecting the tablets".

Participants in another research confirmed this aspect when they reported that they experienced stigma when people labelled them HIV positive due to associating their presence at a room known for VCT with HIV positive status (Manet, 2003:4). On the other hand, Housler (2000:32) reported that isolation of TB patients from other patients by the allocation of rooms and TB wards is essential as an environmental control measure to protect health workers and other patients from TB infection; therefore this measure is not seen as discriminatory.

3.2.1.4 Patients' responses to stigmatisation by health workers

The research goal was to explore the experiences of patients regarding stigma, but during the interviews, a common theme immerged that had a strong bearing on the study. This category is summarised in Table 3.2.1, Column D. The main theme that was highlighted by the participants was the manner in which they responded to this issue of stigmatisation. Three sub-categories and further categories were identified and these follow in the next discussion.

- **Patients' emotional responses**

The issue of stigmatisation created certain emotional responses amongst participants, which impacted on how they viewed the health system. However, their reaction was either directed at an individual or the whole system and their view also impacted on either the person or the health system. This aspect was not part of the research but emerged automatically and the researcher saw the need to highlight it as it has a bearing on the service utilisation by the patients. The significance of these responses were found to be the influence they had on the willingness of the patients co-infected with TB and HIV to utilise the available services. The following is a detailed discussion on the sub-categories and further categories.

Table 3.2.1.5.1 Patients' emotional responses

They become stressed
They feel sad
They feel worthless and hopeless

- **They become stressed**

Most of the participants reported that they become stressed after having been informed about their status. This emotion was made worse by the reactions of the community and especially by those of the health workers. Some of the participants reported that knowing that they were going to die was very stressful and actually made them sicker and they did not go to seek help at the health services until they came to terms with the illness.

> I became stressed and mixed up when I was diagnosed, I started getting sick. My heart was broken but I accepted. There is nothing I can do. I just accepted. I then went to my church where they helped me and did not return to the clinic"
>
> "... you become stressed because the nurses giggle, this diseases is been looked down on, you become irritated ... they make us scared to talk about our disease".
>
> "Yes I was stressed. I did not want myself ... I told them that I didn't want to take blood ..."

According to Auerbach and Gramling (2004), stress is defined as an unpleasant state of emotional and physiological arousal that people experience in situations that they perceive as dangerous or threatening to their well-being. The word *stress* means different things to different people. It can be defined as events or situations that cause feelings of tension, pressure or negative emotions such as anxiety and anger. Others view stress as the response to these situations. However, most psychologists regard stress as a process involving a person's interpretation and response to a threatening event. In this research it is clear that the participants find their situation to be threatening and creates the above-mentioned feelings, since they all associate their illnesses with death. Most of the participants stopped utilizing the health services and opted to go for alternative services for help.

- **They feel sad**

Most participants expressed that they felt sad about having these diseases and being treated differently by others, especially by the health workers. Some of the participants did not express their sadness in words but the researcher acknowledged it during her observation. The following are comments made by some participants:

It is sad ... (raising the voice)because you know that these people you are looking for help from ... can help you but sometimes it is ... Even they say that we should not take people with TB and HIV bad ..., so they also take part in that"

"It hurts ... they concluded that I have AIDS ... so I am dying"

"...Every time somebody with TB comes from those clinics, they have a complaint. You see you feel bad really bad, this thing stays with you deep in your heart ... your heart inside is broken".

The researcher experienced difficulty finding words of sadness expressed by the victims themselves in literature. But most of the publications used the word "sad" when describing events or stories in the lives of people living with TB and/or HIV. This is a unique finding, considering that this feeling of sadness contributes to the non-utilisation of services by the patients co-infected with TB and HIV.

- **They feel worthless and hopeless**

The participants also clearly expressed that the health workers didn't treat them well and looked down upon them. In the previous discussions it was clearly reported that the health workers scolded them and didn't treat them with respect. Therefore the participants reported that all these actions made them feel worthless as human beings. The feeling of worthlessness then results in the participants feeling hopeless and looked at the disease as a death sentence and therefore stigmatised themselves. One participant mentioned that she was hopeless and knew that she was going to die; therefore she sat there every day, waiting for judgement day. This statement made it clear to the researcher how significantly high the state of hopelessness amongst the participants was leading to self stigmatisation and the non-utilisation of the health services. The following are quotations from the interviews

> "... You start thinking less of yourself ... that is what is making a lot of people not to talk of their problems and you continually worry ..."
>
> "When you have them that is TB and HIV it is like ... you are not a person anymore ... you are scorned really"
>
> "When a health worker look down on you or scorn you in the presence of others ... do you know how it feels, and you can't answer back ... you feel worthless"
>
> "The way they told me I just accepted ... I have it there is nothing I can do ... there is no cure ... I am hopeless, I am just waiting for the judgement day".

Literature has outlined that feelings of worthlessness and hopelessness was common, especially amongst people who have debilitating illnesses. People with HIV and AIDS may feel an immense sense of anguish and hopelessness and often feel that they have nothing to offer to society (Nyblade *et al.*, 2003:34). In a study by Ngamwittayaphong (2004:23) a patient who was co-infected with TB and HIV was reported to have been hopeless and just wanted to die, thus was not motivated to take his TB treatment due to lack of support from health workers. Manet (2003:13) outlined that one consequence of lack of proper care is that the patients lose hope, thereby potentially accelerating their death.

- **Patients' responses to the health service**

The following is the further categories that emerged during the interviews indicating what happened when the patients experienced stigmatisation from the health workers. The researcher saw these aspects as very important because of the impact of these responses on the spread of both TB and HIV and on the utilisation of the services by the patients.

Table 3.2.1.5.2 Patients' responses to the health service

They lack trust, as the health workers divulge their status
They lose hope in the health service
They feel as if they only need to collect their treatment and not communicate with them
They change clinics and do not go to the nearest clinic, thus bringing about an increase in financial pressure
They do not go back to the clinic at all, which impacts on their adherence to treatment

❖ **They lack trust, as the health workers divulge their status**

In this research, most participants reported that they did not trust the health workers with their confidential information in the beginning. This was mainly because they feared that the health workers would divulge their health status to others without their consent. The following is how the participants responded:

> "... They will only be announcing that you have HIV to everybody, and they don't do anything about you ..."
>
> "He didn't say anything after and before taking blood, only one man came who said he is a pastor, and I asked him who said I have HIV ..."
>
> "The sister who attended me told my sister my status ..."

Literature confirmed the breach of confidentiality issue as a problem amongst health workers. According to Manet (2003:4), it is not uncommon in Malawi for those with access to information regarding others' sero-status to disclose this information, failing to respect people's right to privacy and confidentiality. Similar incidents were identified where health workers disclosed the clients' status to their relatives but not to their clients and also gossiped with their colleagues about their clients' status (Mbwambo *et al.*, 2003:10). No specific literature was found in relation to TB.

- **They lose hope in the health service**

Some participants indicated that they had lost hope in the health system. This was due to the double message given by the health workers to the community at large. To them as participants the situation seemed hopeless. Other issues contributing to feelings of hopelessness included referrals of patients from one place to another without actually receiving any help. These are some of the comments taken verbatim from the interviews

"health workers encourages people not to stigmatise but they are the one's doing it, thus who should we trust ... it is hopeless".

"He is supposed to help me, that is why I opened my heart to him ... but no (sarcastically) ... he just wrote it there ... it is hopeless."

"The nurse has referred me from this one to the other one, so I ended up not knowing where I was going and so now here I am now (looking hopeless) dying and I am not getting help ..."

This pattern of loss of hope in the heath system is not only seen in the patients co-infected with TB and HIV but also amongst patients with mental disorders. In her presentation at the sixth annual mental health services conference of Australia and New Zealand, Deegan (1996:3) said that the entire programmes, service delivery systems and treatment models could get caught up in this despair and anguish as well. These systems begin to behave just like the person with a psychiatric disability who has given up hope in the system. In such mental health systems we have "gatekeepers" whose job it is to "screen" and "divert" service users. In fact, we actually use the language of war in our work. For instance, we talk about sending "front-line staff" into the "field" to develop treatment "strategies" for "target populations". The above-mentioned analogy indicates that when people are faced with an illness that is stigmatised, and most often perceive stigmatisation from the health workers, they lose hope in the health system and do not see the need to utilize it.

- **They feel like they only need to collect their treatment and not communicate with them**

Although the participants indicated their loss of hope in the health system, some participants still felt obligated to go and collect their medication. In most cases, this was due to the fact that participants felt the need to take responsibility for their own health and some indicated that it is just a routine in their lives. It was also apparent that they did not even report other problems that they had encountered when they get to the clinic — they simply collect their routine treatment. Some participants indicated that asking questions or talking to health workers might create problems for them. The following are supporting quotations from the interviews:

"... I just take my tablets and go ... I don't want to make problems ..."

"... coming here is for collecting the tablets ... yes ..."

"When you start going to the clinic and they know that you have ... they start treating you just ... and that make people not to talk about their problems ... so you tell yourself let me get out of their sight ..."

According to Strydom (1998:67), health workers tend to play the parent role and the patients play the child role. It therefore means that patients feel intimidated by the health workers and decide to rather keep quiet so as not to make them angry. In this research it was clear that some participants played the child role so intensely that they would never ask anything from the health worker. They felt that their responsibility was only to collect their treatment, causing and the health workers to feel satisfied with them.

- **They change clinics and do not go to the nearest clinic thus increase in financial pressure**

The other patients opted to change clinics even if it meant that it would have an impact on their finances and would result in other inconveniences. One participant indicated that she changed the clinic even though she risked coming to the chosen clinic on rainy days without transport as she felt comfortable in that clinic. The other participant mentioned that changing clinics is also a way of avoiding confrontation with the health workers due to their behaviour.

They said:

"... My heart pains ... That is why I live them and come to this clinic ... even when I struggle with transport ..."

"Sometimes we don't have money. We struggle, just like this morning. It was raining. We have to travel in the rain. But it if fine here, I don't want to go there".

"I even left that clinic because of her ..."

"The other clinic next to me doesn't treat people well, and here there is better co-operation. There they are nasty, they talk to people as they want ... you feel better after you have answered back ... so you tell yourself let me get out of their sight".

Literature indicated that when individuals were not satisfied with the care they received, they either became passive or withdrew from those services. Patients changed health provider when they felt that the relationship was not satisfactory, as one HIV patient indicated that the relationship was forceful (Worthington & Myers, 2003:648). Patients preferred to go to places where they thought they would be treated well, which means they travel further and incur greater costs (Mbwambo, 2003:10).

- **They do not go back to the clinic at all, impacting on adherence to treatment**

While it was established that other participants changed their clinics, it was also clear that there are those who stopped or would like to stop attending the clinic completely, thus impacting on their adherence to treatment. The following is a supporting quotation from the interviews:

> "... Hey when they do that, I feel so angry, I feel that I don't want to go there to see them ... I don't go completely ..."

In a study by Watson (2002:72) mothers withdrew from childcare services where they felt that they were not treated with care and respect.

3.2.2 Discussions of the findings regarding the attitudes of health workers towards patients co-infected with TB and HIV

The health worker's analysis of their attitudes resulted in three main categories being identified, as summarised in Table 3.2.2. These categories were further divided into sub-categories and further categories. The following is a detailed discussion of the categories, sub-categories and further categories with relevant quotations from the transcripts to enrich the data and literature control.

The main categories are as follows:

- Perceptions of health workers concerning patients co-infected with TB and HIV
- Health workers' behaviour towards patients co-infected with TB and HIV
- Health workers' feelings towards patients co-infected with TB and HIV

COLUMN A	COLUMN B	COLUMN C
Perceptions of health workers concerning patients co-infected with TB and HIV	Health workers behaviour towards patients co-infected with TB and HIV	Health workers feelings towards patients co-infected with TB and HIV
Perceptions concerning patients behaviour during consultation They are harsh and stubborn They are resistant and manipulative They are difficult to work with They do not talk easily They take alcohol while on treatment	Negative behaviours They are impatient when helping the patients They are harsh when addressing the patients They assist the patients out of obligation	Health workers feeling towards the patients They feel sorry for the patients They feel anger towards the patients who do not want to take responsibility for their health They empathise with the patient
Perceptions concerning patients adherence to treatment **Factors that do not enhance adherence** They behave like children and do not take responsibility for their treatment They deny their condition thus they are afraid of coming to the clinic They are oblivious of their condition They are impatient and want to be helped quickly	Positive behaviours They persuade the patients to take their treatment They make follow up on the condition of the patient They advocate for the patients They involve the family in caring for the patient They communicate with the patient at his/her own level They refer the patient to the older health workers for the purpose of trust and rapport They are dedicated to patients	Health workers feeling towards the health system They feel helpless due to being limited in doing their job They feel angry when they cannot assist patients with the necessary treatment

COLUMN A Perceptions of health workers concerning patients co-infected with TB and HIV	COLUMN B Health workers behaviour towards patients co-infected with TB and HIV	COLUMN C Health workers feelings towards patients co-infected with TB and HIV
They are distrustful towards the clinic and thus want the health workers to scold them so that they can adhere Lack of continuity during consultation influences adherence **Factors that enhance adherence** Health workers should have good listening skills They should spend more time with the patient They should give full explanation to the patient especially about why they are handled by more than one person They should refer the patient when necessary		

3.2.2.1 Perceptions of health workers concerning patients co-infected with TB and HIV

This main category is indicated in Table 3.2.2, and Column A was further divided into two sub-categories that are highlighted under the same column.

- **Perceptions concerning patients' behaviour during consultation**

From the findings of this research it was clearly indicated by the health workers that the patients that are co-infected with TB and HIV displayed certain behaviours that were not acceptable. These behaviours often resulted in conflict between the health workers and the patients. They then feel victimised or stigmatised. Health workers also reported that some patients behaved in manners that indicated that they are not taking responsibility for their own health and expected the health workers to accept such behaviour without reprimanding them. Table 3.2.1.1 indicates the further categories that were identified in this sub-category. These sub-categories will subsequently be discussed.

Table 3.2.2.1.1: Perceptions concerning patients' behaviour during consultation

They are harsh and stubborn

They are resistant and manipulative

They are difficult to work with

They do not talk easily

They take alcohol while on treatment

❖ **They are harsh and stubborn**

The health workers expressed a common view that most of the patients co-infected with TB and HIV are harsh when spoken to and stubborn. Though there was much agreement on this aspect, some health workers reported that they did not agree with this fact and believed that the reaction that was perceived as stubborn actually was due to fear. One health worker mentioned that *"it is not fair to expect that the patient will be spontaneous to every health worker when having diseases that are stigmatised"*. Following, are the comments taken from the transcripts of the health workers:

"… They are often harsh … if you are impatient, you will say they don't want any help …"

"They are stubborn … when you say this, they overreact and get angry with you …"

"Those patients co-infected with TB and HIV are very stubborn …

"Some of them are rude, they are silly. Especially women …"

"If I have to describe them in one word it is STUBBORN …"

Literature confirmed that patients with HIV directly challenged decisions and action statements and withhold information from the health workers as a way to increase a sense of control. One patient described herself as aggressive towards the health workers (Worthington & Myers, 2003:649). It was reported that health workers in Jamaica indicated that some patients with HIV/AIDS are very stubborn. "I don't know why some of them even when they are orientated and able to walk to the bathroom, like to go around the ward dropping faeces on the floor" (PAHO, 2003:35.) Contrary to that, no literature could be found that confirms these findings about the patients co-infected with TB and HIV.

- **They are resistant and manipulative**

Some health workers perceived patients co-infected with TB and HIV as resistant and acted as if they were not sick or did not need help. One health worker mentioned that this response was aggravated when the health worker was notified by someone else regarding the patient's illness. The health workers also articulated that, together with their resistance, the patients are also very manipulative. Some mentioned that patients lie and will try to make you appear stupid if you are not firm with them. The following are quotations from the interviews, as transcribed:

"Most of the times I see them as resistant people ... they are resistant to talk about what they have to somebody else ... the person will answer you rudely and say there is nothing wrong with him ..."

"It is even worse when someone told you that the patient is sick, and you do a home visit, the patients refused to cooperate and play down their illness as if it is not worse".

"They are manipulative ... if you speak softly to them they take you for granted and say "Ag"... they take advantage ..."

"Most of the patients who come in for TB testing already knows their HIV status and act as if they are not aware or lie about it, they are manipulative".

This finding seems to be unique to this research, since no literature was found that confirms that patients co-infected with TB and HIV are resistant and manipulative as articulated by the health workers in this research.

- **They are difficult to work with**

Due to the above-mentioned behaviours, the health workers came to the conclusion that it is very difficult to work with the patient co-infected with TB and HIV. The researcher observed that most health workers who mentioned this aspect appeared hopeless. The following are supporting statements made by the participants:

"... They are very difficult to work with ... you still need to be firm so that they understand you ..."

"What I mean when I say that they are difficult ... they take you as stupid, they fool around with your head, even when they lie to you they take it that it is fine ..."

"... but to work with them ... it is difficult ... .it is very difficult. They are silly ... most of the time they don't do what they are told ..."

Literature confirmed that there were other instances where health workers shared the same sentiments as found in this research. In a study by Panos/UNICEF 2001 (as quoted by PAHO, 2003:26) it was reported that some Zambian health workers claimed that patients with HIV/AIDS are more difficult because of their multiple infections, their hysteria and their attention-seeking, therefore they responded negatively to these patients.

- **They do not talk easily**

Some health workers reported that the patients did not easily talk to them. According to them, the fact that the patients are dealt with by different health workers was a contributory factor to the patients' silence. Some health workers confirmed the aspect the patients raised in their interviews that they do not talk about their problems; they just collect their treatment and go. The patients felt that if they had spoken to one health worker and he/she is not available when they arrived at the clinic, they would not tell the others. They would just collect their tablets and not discuss any other problem or they would walk away. The following are supporting quotations from the transcripts:

"… They are very quiet and don't talk easy, their don't talk about their problems concerning the medication and that is where I see many of them default"

"… They just don't want to talk easily … because they think that when they come to the clinic they are going to be handled by so many people … They don't become open …"

"They are short tempered, they do not want to be asked a lot of questions …"

Literature could not be found that clearly outlines the sentiments raised by the health workers in this regard.

- **They take alcohol while on treatment**

One of the problems that were highlighted was that of alcohol intake. The health workers reported that patients continue to consume alcohol during their treatment duration even if they were advised not to. What was not clearly outlined by the health workers was whether the patients came to the clinic drunk or whether they consumed alcohol only while they were in the community. But the emphasis of the matter was raised by the health workers as an issue of concern, as they felt that the patient should not take alcohol while on treatment. They also highlighted the negative response they always received when they mentioned this issue to the patients, and the fact that it resulted in conflict. The following are comments made by the health workers during the interviews:

"Even when you tell a person that you are not supposed to drink alcohol because you are on treatment, they ask you why …"

"… When I have seen him drunk at the township, … I will talk to him and show him the way …"

"… when you say don't drink alcohol … they become rude"

Madru (2003:41) confirmed by the 19th century reformers that Tuberculosis as a disease of the poor was connected to alcoholism. She further explained that responses to illnesses associated with the poor invariably recommended the adaptation of middle class values to which drunkenness was thought to be the impediment.

- **Perceptions concerning patients' adherence to treatment**

The second sub-category as indicated in Table 3.2.2, and Column A was then divided into two further categories. These further categories will be discussed in detail as the researcher tries to clarify the relationship between the perceptions formed by health workers concerning the behavioural patterns of the patients co-infected with TB and HIV and the perceived stigmatisation of these patients by the health workers.

The findings of this research indicated that the health workers have certain perceptions about the adherence patterns of the patients co-infected with TB and HIV. Although the health workers did not confirm that these perceptions might have an influence on their behaviour towards the patients, the researcher identified this fact during her observation (see field notes: Appendix H). Most health workers appeared positive and enthusiastic when they spoke about the positive adherence pattern. And when they mentioned the negative adherence patterns, they tended to show signs of anger towards or hopelessness in the patients.

Table 3.2.2.1.2 Perceptions concerning patients' adherence to treatment

• **Factors that do not enhance adherence**
They behave like children and do not take responsibility for their treatment
They deny their condition, thus they are scared to come to the clinic
They are oblivious of their condition
They are impatient and want to be helped quickly
They are distrustful towards the clinic and thus want the health worker to scold them so that they can adhere
Lack of continuity during consultation influences adherence
• **Factors that enhance adherence**

Health workers should have good listening skills

They should spend more time with the patient

They should give full explanation to the patient, especially about why they are dealt with by more than one person

They should refer the patient when necessary

- **Factors that do not enhance adherence**

  - **They behave like children and do not take responsibility for their treatment.**

In the findings of this research, the health workers felt that the patients do not take responsibility for their own health. Most of the health workers felt strong about this fact although some of them gave reasons for why they think the patients behaved that way. A participant mentioned that *"most of the patients co-infected with TB and HIV feels hopeless, thus they do not see the need to act responsibly".* Even though some health workers felt that way and did not take offence to the situation, some reported that this particular behaviour made them angry. Some health workers reported that when the patients do not take responsibility for their treatment, they (health workers) feel hopeless and become strict or firm when dealing with these patients. Though the health workers felt this way, some disagreed with this behaviour of being harsh, strict or rude to the patients and felt that the health workers should be empathetic towards the patients co-infected with TB and HIV. They reported that this behaviour from the health workers exacerbate the situation as patients then decide to abscond and no longer take treatment. The following statements were made by participants during the interviews:

"I become hopeless when I am dealing with somebody who is not willing to do anything for himself. I want him to take responsibility that he drinks his medication everyday"

"... immediately if you talk to them for not complying, they will abscond and not take TB treatment or whatever treatment they get for HIV ... they will start to criticise the clinic"

"... they behave like kids, especially when they feel healthy, then they abstains. They don't come regularly ... so if you explain to them especially with TB treatment and say "YOU MUST" complete it ..."

One health worker said "these patients needed to be treated harshly as it is the only way to make them take responsibility and adhere to their treatment".

Although literature does not confirm the aspect that they behave like children, it confirms the irresponsible behaviours that the health workers mentioned. The patients might not see these behaviours as irresponsible, as they may be using them as a defence mechanism. Madru (2003:42) indicated that the patients with HIV may fabricate reasons for medical appointment as a way to avoid being labelled or stigmatised and not taking full responsibility. She further mentioned that some hide their medication.

- **They deny their condition thus they are afraid of coming to the clinic**

The other aspect that was reported in this research as a negative behavioural pattern from the patients was the fact that they deny their illnesses. The health workers reported that some patients preferred to be identified as TB patients only and the HIV side of their condition be kept a secret or not be mentioned. At the same time, some health workers reported that some patients do not want to be identified as TB patients as they fear that once you are known to have TB, everybody assume that you have HIV. Therefore even though health workers reported that TB is less stigmatised, but that there are myths that people who have TB have HIV and that if one is HIV positive, one will have TB, it results in the co-infected patients denying having one or both of these illnesses. The following are supporting quotations from the transcripts:

> "They feel embarrassed about their HIV status, because before TB alone they thought it wasn't de-stigmatised, but since HIV they don't come forward because they feel ... they don't want people to know about it"
>
> "Some of them accept, some of them don't ... if they didn't improve on TB treatment you find that they are HIV positive, they come back and ask us how come, they say that they are not sure that they have the disease because "I don't sleep around ..."
>
> "... they say that in the clinics we are crazy, the results are not right ... they will rather be associated with TB only ..."
>
> "They feel scared ... they feel it is a scandal to have these diseases ... the fact that TB and HIV goes together, so they fear ... as they are both sensitive ..."

Literature confirms that most patients with HIV/AIDS deny their illness. Data in Zambia shows that people with HIV claim to have different afflictions so as to mask their true illness, and people may even delay seeking care for TB as it is seen as synonymous with HIV and AIDS (Nyblade, 2003:43). The author went on to indicate that fear of being associated with HIV is so great that patients with HIV sometimes claim to have a different condition and even refuse proper treatment in an effort to mask their true illness. There is denial of HIV status, individually, socially and nationally, leading to delayed treatment, care and support.

- **They are oblivious of their condition**

Even though the findings of this research identified denial as a problem that the patient co-infected with TB and HIV has, it was noted that some patients were not in denial but unaware of the facts regarding both the illnesses. Some health workers reported that there are patients who heard about HIV and the fact that they are positive but are not aware of the patho-physiology thereof. Thus, when the patients go on TB treatment, they think that they will be cured of HIV. When this does not happen or it is clearly explained to them, the patients feel hopeless and do not see the need to continue their prophylaxis treatment for HIV. One health worker indicated that some patients do not believe that any person can be infected by either TB or HIV. She mentioned that patients still believe that these conditions affect a certain type of people or a certain age group. The following statements are quoted directly from the transcriptions of the interviews:

> "We are still having people that when they are co-infected they don't come forward for their TB treatment ... because they still feels that people will look at you and will gossip about you and are not aware of the dangers involved"
>
> "One patient who have just finished his TB treatment and know that he is HIV positive ...when he arrived for prophylaxis, he asked me when he will be cured for HIV, after I explained to him, he appeared hopeless and reluctant to continue but I encouraged him ..."
>
> "They associate the illness with some witchcraft rather than accept the illness ... one patient didn't use TB or HIV medication just herbs and she came to test again to see if she is not positive ..."

"... she said I am still young, I am not yet married, I still stay with my mother, so this TB is pestering me ..."

According to McIntyre (2004), many people know nothing about HIV or simply believe that being infected with HIV is an automatic death sentence. They are oblivious of the fact that HIV positive people can and are living. The moderation team (2004) indicated that an inadequate understanding of the way transmission takes place could increase the aspect of being oblivious to an illness.

- **They are impatient and want to be helped quickly**

The health workers perceived that one of the behaviours that results in non adherence is the fact that the patients co-infected with TB and HIV are impatient and want to be helped quickly. Some health workers seemed to acknowledge that the patients' impatience might be due to fear of being identified in the clinics by the community members as a patient co-infected with TB and HIV and thus become stigmatised. Some health workers do not share the same sentiments and feel that these patients need to behave like every other patient and wait to be helped. The following are the direct quotations from the transcripts indicating how the health workers perceive the patients' lack of patience:

"They are irritable people ... they are impatient and shout now and then and they don't want to queue the line when they get to the clinic ... they just want to be quickly helped and go ..."

"some of these patients are impatient ... they will turn and go away if they feel that they are not helped quickly irrespective of whether you are busy or not at that point in time".

"... they are impatient and like special attention ... if they feel that they are not taken seriously ... they stay home and never come back because they feel neglected"

"They are impatient as they are afraid to be seen in the clinic frequently as people suspect that they are infected and become stigmatised".

During the interviews conducted with them the patients themselves reiterated this aspect. According to them it was not a way to seek attention, but to avoid being seen and thus stigmatised. It therefore stands true what the health workers reported about patients' inability to wait for their turn to be helped. It was noted in Manet (2003:13) that some health workers were quoted asking the patient with HIV: "Who are you to deserve preferential treatment?" This supports the health workers' feeling in this research that the co-infected patients want special attention. No scientific proof in the literature could be found that confirms the impatience of the patients co-infected with TB and HIV and their need to be assisted quickly, as outlined by the health workers within the same context.

- **They are distrustful towards the clinic and thus want the health worker to scold them so that they adhere**

The health workers that were interviewed for this research agreed that the patients who are co-infected with TB and HIV do not trust the clinics. Some health workers believed that, to solve this problem, the health worker needs to be harsh so that the patients can understand that they can receive assistance from anybody and they need to come for their treatment regularly. The following are the comments that were made by the health workers to clarify the lack of trust in the clinics:

> "... they don't trust the clinic as such ... they trust the individual ... I am firm and very strict, and even think I am harsh ... but I explain to them ... and they love me for that"
>
> "... you still need to be firm so that they can understand you ..."
>
> "if someone doesn't turn up for treatment ... it hurts because it is his life ... If you speak a little bit soft they take it for granted ... then I use harsh words to make him aware that it is wrong ... and that person will come regularly to the clinic that is for sure ..."

No literature could be found that confirms the need of the patients co-infected with TB and HIV to be scolded as a means to get them to adhere to treatment. Also literature can not confirm the fact that the patients do not trust the clinics as indicated by the health workers in this research.

- **Lack of continuity during consultation influences adherence**

The findings in this research indicated that the health workers had concerns regarding the continuity of treatment for the patients co-infected with TB and HIV. They reported that the patients are seen by different people towing to scope of practice and shortage of staff, among others. Some health workers indicated that this lack of continuity of care is the actual cause of the mistrust that the patients have in the clinic. They reported that, to the patient, it appears as a breach of confidentiality concerning their illnesses as they become referred from one person to the other. In addition, the fact that the health workers do not explain to the patients in detail the reason why they should be seen by different people creates the feeling among the patients that health workers have different opinions and knowledge levels. The following are the statements that were made by the health workers during the interviews:

> "... somebody come to the clinic and didn't get explanation about the channels that he is going to go through, the next time that he comes he find that the person that attended to him initially is not there ... so they turn and go ..."
>
> "They are scared to go to the clinic ... they think that when they come to the clinic they are going to be dealt with by many people as one do this part and there is the other doing that part maybe somebody trained in counselling ..."
>
> "They don't understand that it is not possible for one person constantly ... they still have an issue of confidentiality ..."

The health worker seemed to confirm what the patient reported about issues of confidentiality. Therefore this confirms that the patient prefers to speak to one health worker about her condition, thus needs continuity. No literature could be found that confirms whether this fact is true to patients co-infected with TB and HIV regarding the need for continuity as a means of adherence.

- **Factors that enhance adherence**

Although the findings of this research indicated that the health workers had perceptions concerning the factors that influenced the patients not to adhere to their treatment, they reported that they identified factors that could enhance adherence among patients co-infected with TB and HIV.

- **Health workers should have good listening skills**

Health workers reported that for the patients co-infected with TB and HIV to adhere to their treatment, health workers should play a role in facilitating this. Most health workers reported that when you listen to the patients while they explain their problems to you, the patients appreciate it and come to the clinic regularly. They report that this behaviour makes the patients to feel wanted and at home. The following are the direct comments from the transcriptions of the health workers interviews

"... You need to sit down with them and listen, they don't want impatient people ..."

"... I think they need support ... to be heard ... they need thorough counselling because it is difficult to carry co-infection ..."

Health workers acknowledged the fact that they will have to possess good listening skills to make the patients co-infected with TB and HIV feel wanted and cared for, as outlined by the patients earlier in this chapter. They acknowledged the importance of counselling and listening skills as the main focus. Literature confirms this view regarding the importance of listening, as noted by Housler (2000:4), that health workers should listen to the patient and monitor, encourage and provide feedback on progress to ensure patient-centred care of a TB patient.

- **They should spend more time with the patients**

The health workers reported that when you spend time with the patient during consultation, it enhances adherence. They reported that the patients that are co-infected with TB and HIV have many other health problems, and if a health worker does not spend time with the patient they will not identify them. And also the patients will not report them as they will perceive the health workers as impatient and not willing to help. Contrary to this mentioned aspect, some health workers reported that spending more time with the patients that are co-infected with TB and HIV can result in stigmatisation. This is due to the fact that other patients are not given much time and once the patient co-infected with TB and HIV is given much, the other patients start suspecting the illnesses of the patients.

The following are the comments that were made by the health workers during the interviews:

"... the health workers need to be open and talk about these things with the patients, they need to spend time with them"

"... so they need a person who have time for them, especially when they are complaining about their health ..."

"... if they have a problem about accepting, you sit down, create time and educate them about these conditions ..."

"... when they come in you start softening up ... the patient end up with you for a long time in the consulting room and the other patients start to wonder why you took so long with that patient and become suspicious"

According to Zulu (2001:2), health workers working with the Tanga Aids Working Group in Tanzania confirm the finding of this research that health workers need to spend time and have scope to provide quality service. Similarly Housler (2000:4) reported that health workers should spend time with the patient to address each patient's need, discussing the patient's feelings, expectations and potential barriers that will prevent success from the outset.

- **They should give full explanation to the patients, especially about why they are dealt with by more than one person**

The health workers acknowledged that most of the time they do not give enough explanation to the patients, especially about the clinic routine. Some health workers reported that they have had good response from the patients that are co-infected with TB and HIV after they had explained how they are going to be dealt with in the clinics and why. Most health workers reported that this aspect is important. They still maintained that the confidentiality should not be breached unnecessarily and if it has to be, the patients should be informed as to the reasons for it. The other explanation that the health workers reported as important is giving the patients the bare facts about their illnesses. That will include the fact that when you are co-infected with TB and HIV you can still lead a normal life, providing you are on treatment. The following statements are direct quotations from the transcriptions of the interviews conducted with the health workers.

"Firstly, you need to explain the clinic procedures to them ... so whatever happens to you is between you and the staff that is in the clinic that work with those issues only ..."

"We need to make people aware that we can still lead a normal life, you could still have good health in your life ..."

The researcher observed during the interviews that most health workers shared the same belief in terms of giving explanation to the patients co-infected with TB and HIV. Literature confirms that explanation is important, like explaining the importance of completing treatment to a TB patient (Housler, 2000:4). No literature could be found to confirm the importance to explain why they are dealt with by more than one person as a need for the patients co-infected with TB and HIV.

- **They should refer the patient when necessary**

The health workers reported that it is important to explain to the patients the scope of practice and the need for further referral. The health workers reported that when the patients understand the importance of preventing treatment delay, they will appreciate the health system and that will improve adherence. In this research it was clear that health workers felt that it is necessary for the patients co-infected with TB and HIV to be referred for specialised treatment when necessary. The following is a comment made by a health worker indicating the importance of referral.

"... I explain to them that I can only do up to here, don't expect more than this ... I will refer you to the relevant person to deal with more specific issues.

The patients also highlighted this opinion during the interviews that were held with them. According to (PAHO, 2004:46), a multi-sectorial approach is very important. Interventions are more likely to be successful when they are part of a broader action taken in the community. The author indicated that referral could include local and government structures, NGOs and the religious structures.

3.2.2.2 Health workers' behaviour towards patients co-infected with TB and HIV

This research clearly identified behaviour that the health workers acknowledged as having towards the patient co-infected with TB and HIV. Some of the behaviours were good and actually attracted the patient to attend the health services and made them feel at home, but some behaviours, as acknowledged by the health workers themselves, depicted lack of respect towards these patients. Even though most health workers reported that the patients themselves caused these behaviours, some health workers indicated that these were not acceptable to human beings irrespective of what they have done. Some health workers defended their behaviour by saying that they where done in order to make the patients take responsibility for their health because they cared for them. A detailed discussion of further categories will follow as outlined in Table 3.2.2, Column B.

Negative behaviours

Table 3.2.2.2.1 Negative behaviours

They are impatient when helping the patients
They are harsh when addressing the patients
They assist the patients out of obligation

- **They are impatient when helping the patients**

The health workers reported that patients co-infected with TB and HIV often behave in a disrespectful manner, which makes them become impatient while dealing with them. Some health workers acknowledged their impatience and attribute it to the patients' lack of cooperation. The following are supporting statements that were made by the health workers during the interviews confirming the patients' view:

"... well I am impatient person to be honest ..."

"I loose my temper when they do things like that ... and I live them ..."

This lack of patience was also noted where Zambian health workers admitted that HIV/ AIDS patients were often not given the same service because doctors where impatient as they know that they are going to die, therefore spend less time on them (PAHO, 2004:26). No literature was found in relation to TB patients in this regard.

- **They are harsh when addressing the patients**

The findings of the research identified that the health workers often reacted harshly to the patient co-infected with TB and HIV. The health workers acknowledged this fact and said that the patients expect it from them. Some health workers reported that there are individual health workers who are harsh, irrespective of the situation, and those are the people who normally do not address the patients with respect. The following statements are direct quotations from the interview transcripts:

"It depends on how she approaches me ... look at that approach and scold her ..."

"There are people who are harsh when they speak, we are not the same ..."

"Some health workers come frustrated from home and they become angry at everybody, they take out their frustrations on the patients "don't annoy me I said you should come here early"(shouting) you see things like that ..."

"... then I use harsh words to make him aware that it is wrong what you are doing ..."

The researcher found that it was clear from a study conducted in Tanzania that patients with HIV were scolded and spoken to harshly by health workers (Nyblade, 2003:41).

- **They assist the patients out of obligation**

The health workers reported that they feel obligated to help the patients even if they do not want to. They reported that they sometimes feel hopeless, especially when the patient is difficult, that they just do it because they are hired to do a job. The following are comments made by health workers:

"... she is a patient and she has come to the clinic, I have to help her so I help her. I am obligated"

"There are some health workers who do not agree with the policies regarding management of TB or HIV patients, that is that the patient who have TB should be counselled for HIV, and those with HIV should be tested for TB. Therefore those health workers will not go an extra mile for patient but only do what they are obligated to do".

Although literature confirms that health workers present with negative behaviours towards patients infected with HIV, the link of that behaviour of obligation could not be found towards patients co-infected with TB and HIV.

Positive behaviours

Although there were negative behaviours that were identified by the health workers in this research contributing to stigmatisation of patients co-infected with TB and HIV, there are positive behaviours that the health workers display in order to try and reduce stigmatisation.

Table 3.2.2.2.2 Positive behaviours

They persuade the patients to take their treatment
They follow up on the condition of the patient
They advocate for the patients
They involve the family in the care of the patient
They communicate with the patient at his/her own level
They refer the patient to the older health workers for the purpose of trust and rapport
They are dedicated to patients

- **Persuade the patients to take their treatment**

This research identified that there are health workers who realised the importance of positive behaviour towards the patients co-infected wit TB and HIV. Some health workers reported that they understood that it was not easy to be on treatment for a long time without defaulting, thus patients need to be persuaded to take their treatment regularly". The following are direct quotations from the interviews with the health workers:

"I explain to the patient to go for the test, but I tell them that it is if they want to go ... but it is better to go to the clinic and test for TB and HIV ..."

"You have to sit with them and persuade them that you want to help ... that is why I am here I want to help you ..."

"If a patient seems to lose hope and refuse my help, I would persuade them until they are willing to be helped"

"I had a patient who was TB and found out that he is HIV positive … he felt that it was useless to drink the TB medication as he wasn't going to be cured … he decided that he is never coming back to the clinic and I said ... NO you have to continue, you can't give up now … you will be fine … until now he is fine"

No literature could be found that indicated that health workers persuade the patients co-infected with TB and HIV to take their medication.

- **Follow up on the condition of the patient**

Most health workers reported that following up the patients co-infected with TB and HIV is very important. Some reported that as a health worker one needs to understand the reasons why the patient does not come for treatment. Therefore health workers follow up with the intention to trace patients who were lost to the system due to not accepting their conditions and not taking responsibility for their health, among other reasons. The following are supporting statements from the interviews:

"… mostly they don't accept their status easily but you don't leave it there ... you are supposed to follow them up to show them that we are there for them … they are not the only one with the problem …"

"Those who don't take responsibility … I do trace them and I will talk to him about his problem"

"… but if a person has TB and I have to make a follow up, I won't have a problem. I will follow up the person even to where they stay everyday

The researcher could find no literature supporting this aspect.

- **They advocate for the patients**

The health workers reported that the health system sometimes frustrates them. They mentioned that most patients who are on treatment do not have food at home and they are supposed to get nutritional supplements from the clinics. But sometimes these supplements are not made available on time and the patients suffer. Therefore, as health workers, they sometimes feel that they need to fight the system on behalf of the patients. The following are the statements made by the health workers during the interviews:

> "... that is why I get angry and fight when there is no food supplements in the clinic ... each and every patient whether she affords it or not should get it to be healthy ..."

Literature indicates that health workers, especially nurses, act as advocates for their patients. This was confirmed in a research where a health worker was quoted saying: "I am concerned about my HIV-positive patients and I will fight for them with who ever" Deetlefs (1998:81). This aspect, according to the author, indicated that the health workers were willing to be the advocates for the HIV positive patients even if it meant conflict with their colleagues.

- **They involve the family in the care of the patient**

The health workers acknowledged that they see the family structure as important to assist in caring for the patient co-infected with TB and HIV. They reported that they often try to get the family involved, especially if there are problems with getting the treatment regularly or when the patient is uncooperative. The following are direct quotations from the transcripts of the interviews with the health workers:

> "... I will try my best to include his family if maybe he has a problem of collecting medication ..."
>
> "... I followed him up for a long time and he still refused to come to the clinic ... I met his brother who doesn't live with them and told him though not his status. The brother collected him and brought him to the clinic ..."

The researcher found no supporting literature regarding the involvement of family by the health workers concerning the care of a patients co-infected with TB and HIV, therefore this is a unique finding and needs to be further researched.

- **They communicate with the patient at his/her own level**

The health workers identified the fact that communicating at the level of the patient improves relations between them and the patients co-infected with TB and HIV. They reported that when they use the language that is used by the patients and their street names, they become comfortable to come to the clinic regularly as they feel at home. The following are direct quotations from the transcripts of the interviews indicating the communication level.

"... mostly when a person comes in I use these street names ..."

"... when they come I will talk to them in Tsotsi language and ask them how they feel, especially males ... .so I am sure they miss me when they are at home and decide that in that clinic it is fine so let me go ..."

This finding is unique, as most literature only explains using the patients' language for the purpose of understanding each other.

- **They refer the patient to the older health workers for the purpose of trust and rapport**

The health workers identified that age often plays a role when working with the patient co-infected with TB and HIV. This might be due to the taboos surrounding the illnesses in some cultures, especially HIV, therefore older people do not feel comfortable discussing their sexuality with a younger health worker. The health workers thus indicate that they do not become resistant to this aspect. The following statement is a direct quotation from the interviews.

"Older women have a problem with me ... but if they don't cooperate I call the elder nurse and we sit and she informs them. She reemphasis what I have said"

The researcher could find no literature regarding referral to the older health worker of showing positive behaviour to enhance utilization of the health services by the patient co-infected with TB and HIV, therefore this is a unique finding and needs to be further researched.

- **They are dedicated to patients**

Health workers reported that they are also dedicated to their patients so as to help them to become healthy. They report that they show their dedication by being there for the patients in whatever ways possible. Health workers seamed to realise that being dedicated to their patient increases the trust relationships and consequently reduces stigma. The following quotations were taken directly from the transcripts of the interviews of the health workers:

> "I will be patient with this patient and continuously teach and educate this person ... as a health worker you need to be there for whatever questions, whatever problems that the patient have ..."
>
> "I give them care, attention and I try by all means that they do understand how I feel for them"
>
> "... one specific nurse who worked with TB patients, was very dedicated to her patients, always have a positive attitude, so the patients enjoy coming to the clinic ..."

No literature was found in which the health workers confirmed their dedication to patients co-infected with TB and HIV.

3.2.2.3 Health workers' feelings towards patients co-infected with TB and HIV

This third main category is indicated in Table 3.2.2, and Column C was further divided into two sub-categories which are highlighted in the same column.

- **Health workers' feelings towards the patients**

The finding of this research indicated that the health workers had feelings towards the patients that might be perceived as stigmatisation by the patient co-infected with TB and HIV. The health workers indicated that most of the time they try not to show these feelings as it may lead to stigmatisation. But some health workers argue that they sometimes need to show their own feelings towards the patients whether negative or positive so that the patient can cooperate.

- **Table 3.2.2.3 Health workers' feelings towards the patients co-infected with TB and HIV**

They feel sorry for the patients
They feel anger towards the patients who do not want to take responsibility for their health
They empathise with the patient

- **They feel sorry for the patients**

The health workers indicated that most of the time they feel sorry for the patient for having both these illnesses. The health workers reported that this feeling sometimes does not benefit the patients as they then interpret it differently. The health workers clarified that the patients co-infected with TB and HIV then feel discriminated against when they are given special treatment and feel that they need to be treated normally — in the same way that other patients are treated. The following quotations are from the interviews with the health workers:

> "... they immediately feels pity for the patient ... they start to feel sorry for them, and the patients don't want that ..."
>
> "Most of the time you will find most of us feeling sorry for them and they are given this special attention more than the others ..."
>
> "I feel sorry because it shows that the counselling was not enough ..."
>
> "... it is not right, I feel sorry for them ..."

Deetlefs (1998:69) confirms that the health workers feel sorry for the patient infected with HIV and it is emotionally difficult when the patient dies. No literature was found that indicated this aspect regarding TB patients.

- **They feel anger towards the patients who do not want to take responsibility for their health**

Most of the health workers reported the feeling of anger towards the patients co-infected with TB and HIV. But this was clarified that it is not because of their conditions but because of not taking care of themselves. The health workers then feel that the patient is taking advantage of their help and that of the health system by not being cooperative. The health workers reported that when they had felt that way and showed it to the patients, they would apologise for that behaviour later on. The following are comments that were made by the health workers during the interviews:

"... but honestly speaking, if someone doesn't turn up for his treatment and I had explained to him, I become a little bit rude"

"I apologise after being harsh and explain to them that I am angry because they don't come for treatment for no reason ..."

Feelings of anger experienced by the health worker as a way to persuade a patient co-infected with TB and HIV are not recorded in literature. According to Deetlefs (1998:71), health workers expressed anger towards patients infected with HIV who do not believe that they are infected and infect others in the process. The author further explained that it was also because they feared that they will get infected.

- **They empathise with the patient**

The health workers reported that they do empathise with the patients as they also form part of the community. They indicated that most of them are affected by the conditions and some are even infected. Some health workers mentioned that they even applied their experiences when counselling the patients. Some health workers mentioned that they put themselves into the patients' shoes as it can happen to anybody. The following statements were made by the health workers during their interviews.

"I try and show them that they are not alone in their situation. I am there to sacrifice my help to see that this problem is ours.. we need to work together"

"... you put yourself in that person's shoes and see that NO this person doesn't deserve this ..."

"... I empathises ... well it hurts ... it is a painful disease ... even me I don't accept..."

"In the clinic we are affected and some are infected. So it is difficult to have a negative attitude towards those people as we must support each other and work toward a goal ..."

"I feel sad for them, I had TB before and I know how it feels, and I know its problems ..."

In a study done by Dr Ian Hodgson at the University of Brandford (HDN Key correspondence, 2004) where health workers were interviewed, it was discovered that, unlike stigmatisation seeming to be rampant in the mainstream social culture, it was not so in the case of health workers. It was identified that the health workers where not afraid of catching HIV from their clients and identified with them to some extent. This confirm the empathy that the health workers reported in this research as the author further mentioned that they projected an accepting attitude about the universality of HIV, seeing that everyone is potentially at risk.

- **Health workers' feelings towards the health system**

The other further category that was identified was the feeling that the health workers have towards the health system. Although it was not the intention of the researcher to obtain this information, the relevance of it compelled the researcher to add it as part of the findings. Since one of the objectives of this research is to develop guidelines for health workers, it is valid that the identified feelings of the health workers towards the health system be discussed.

Table 3.2.2.4 Health workers' feelings towards the health system

They feel helpless due to being limited in doing their job
They feel angry when they cannot assist patients with the necessary treatment

- **They feel helpless due to being limited in doing their job**

The health workers reported that they felt helpless most of the time, as they realised that they were not doing enough for the patients co-infected with TB and HIV. Some health workers explained that, due to staff shortage, the senior categories cannot deal with the workload and they feel helpless when the patients look to then for assistance. Due to this feeling of helplessness, they sometimes feel that they are not competent enough to assist the patient, thus feel hopeless that both the conditions will never be controlled. This feeling of helplessness becomes more intense when they realise that the patients loose hope of ever being helped and thus their hope to live. The following is the a direct quotation from the transcriptions of the interviews:

> "I feel that I could do more for them since they have put their trust in me (junior staff) ... but I can't do more ... I am helpless

According to Dr Sangiwa (as quoted by Zulu, 2001:1), helplessness resulting from failure to cure the disease and the undue prominence of HIV/AIDS over other diseases were some of the manifestations of stigma in the health settings. Most literature does not clearly explain the sense of helplessness that the health workers report, but it is clear that in many cases they have a sense of being overwhelmed and powerless. They may feel powerless due to being forced to deal with situations beyond their means (PAHO, 2004:27). In this research the health workers who reported this feeling of helplessness were those in junior positions, which is an indication that they are faced with tasks that are beyond their means.

- **They feel angry when they cannot assist patients with the necessary treatment**

The health workers also reported anger towards the health system as they feel that structures that will help the patient are taking a long time to be put in place. They also reported that the government policies in dealing with this problem might actually be the one that is fuelling the epidemic. One health worker indicated that the confidentiality issue surrounding HIV especially is one of the things that increases the spread of the disease and stigmatisation, because the more people become open, the more will communities become aware and stigma reduced. The following are comments made by the health workers during the interviews:

"For now seeing that we don't have the ARV's roll out yet ... I feel like I am closed inside a tin ... meaning ... you are limited here"

"they say if I tell this person or test this person for HIV ... and what then, what is it that I am going to do with this particular patient ... I don't have anything to offer this patient, what is the use of counselling this person for testing for HIV ..."

According to PAHO (2004:26), failure in health systems may lead to discrimination and stigma where no stigmatisation is intended. The author explains these failures as lack of cure and/or lack of available treatment for HIV/AIDS among others resulting in the health workers feeling angry. Mbwambo *et al.*, (2003:6) confirms that health workers reported feeling helpless and depressed because the system does not support them and the patients. Health workers complained about issues of budgetary constraints and limited resources that resulted in their frustrations concerning the health system (Siyam'kela, 2003:26).

3.3 CONCLUSION

The findings of the research and the literature control regarding the experiences of the patients co-infected with TB and HIV in relation to stigmatisation by health workers and the attitudes of health workers regarding these patients were discussed in this chapter. Findings were discussed according to their different categories, sub-categories and further categories with the unique findings highlighted. In the next chapter the limitations of the research and the conclusion according to the researcher will be discussed. The researcher will also focus on the guidelines formulation for the health workers so as to facilitate utilisation of the health system by the patient co-infected with TB and HIV.

CHAPTER 4

CONCLUSIONS, SHORTCOMINGS AND RECOMMENDATIONS FOR NURSING EDUCATION, NURSING RESEARCH AND COMMUNITY HEALTH PRACTICE

4.1 INTRODUCTION

In the previous chapter the research findings were discussed. The findings were supported by direct quotations from the interview with the participants, and confirmation was also made through reference to relevant literature. In this chapter the conclusions and shortcomings will be discussed, recommendations will be made for nursing education, nursing research and community health practice with special reference to the formulation of guidelines for health workers to facilitate the utilization of health services by patients co-infected with TB and HIV.

4.2 CONCLUSIONS

Conclusions from the data of this research, confirming literature as well as the field notes will be discussed in this chapter. Data analysis resulted in four major categories with regard to the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers as well as three major categories with regard to the attitudes of health workers towards patients co-infected with TB and HIV. Conclusions pertaining to these two sets of data will be discussed separately.

4.2.1 Conclusions pertaining to the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers

Conclusions pertaining to the experiences of the patients co-infected with TB and HIV concerning stigmatisation by the health workers will be discussed according to the four major categories as reflected in Table 3.2.1.

- **Behaviours of health workers**

A conclusion that can be made from the findings is that the patients co-infected with TB and HIV are indeed stigmatised by the health workers. Although there are individual health workers who are committed to their work and treat the patients fairly, it is clear that there are still substantial numbers of health workers who do not treat the patients well.

One major aspect regarding the behaviour of the health workers, as reported by the patients is that there is stigmatisation across all categories of health workers. Although this was not clearly outlined in the different categories that emerged, the researcher identified that different patients co-infected with TB and HIV experienced stigmatisation from different categories of health workers. This aspect then leads the researcher to the conclusion that different categories of health workers stigmatise patients at some stage or another. Negative behaviours such as the health workers not having time for the patients and being impatient was observed amongst the more professional health workers such as doctors and professional nurses. The other non-professional or lower categories were reported to display behaviours such as avoiding physical contact and refusing to assist the patients with the basic needs such as washing. This aspect can be related to lack of sufficient knowledge in relation to the spread of these two diseases as these categories of health workers have minimal training in this regard.

Although there might be a rationale to the above-mentioned aspects, it was clear that the health workers do not have basic human compassion and respect for the patient co-infected with TB and HIV. Their lack of compassion was identified by behaviours such as refusing to assist the patients with basic needs. This pattern of stigmatisation also breaches the patients' right to health and proper care and consequently the patients do not receive the care that they deserve. Their communication pattern with these patients strikes one as very demeaning. The researcher noted the above-mentioned aspect through the emotions that were shown by the patients when communicating how the health workers addressed them. These negative behaviours of the health workers not only affect the patients' self-esteem but contribute to their feeling of being isolated by society as a whole. Patients tend to isolate themselves due to fear of being ridiculed in the presence of the others by the health workers in the health services. It is therefore concluded that stigmatisation is present in the health services, as isolation and discrimination forms part of the process of stigmatisation.

Poor explanation of expectations and procedures seemed to be a major cause of conflict between the patients and the health workers. This aspect was observed when the patients expressed that health workers place certain expectations on them without educating them from the onset. According to the researcher, this behaviour is not professional, since part of the health worker's duties is education, and this includes explaining procedures to patients. This aspect will minimise the perception that the patients reported that health workers made them to feel like fools when they do the wrong things even though what was expected of them was not clarified.

The other notable negative behaviour of health workers is that of being impatient when dealing with the patients co-infected with TB and HIV, making it difficult for them to report the other ailments that they experience. As a result, patients ignore other symptoms because they perceive that nothing is going to be done for them anyway. This behaviour of impatience also led to the patients lying or exaggerating their illness so that further examination could be done on them. It is apparent that for patients to receive proper care, they should employ measures so as to receive assistance promptly. This can either be lying, as mentioned above, or they have to agree to investigations suggested by the health workers, even if it is against their will. The researcher concluded that the coercion that the health workers use such as taking blood samples from the patient is stigmatising and has a negative impact on the perceptions of the patients towards the health workers. This leads to patients concluding that the health workers infringe on their rights and that they as patient cannot do anything about it as they are at their mercy. Therefore it can be concluded that the health workers' behaviours have a significant influence on the perceptions of stigmatisation of patients co-infected with TB and HIV in the health services, resulting in the said patients avoiding the health services so as to avoid the health workers, which leads to non-adherence to treatment.

- **Perceived attitudes of health workers towards them.**

A conclusion that can be made is that the patients co-infected with TB and HIV perceive the health workers as having a negative attitude towards them. Most of the patient co-infected with TB and HIV reported attitudes such as lack of care and warmth from the health workers, which led to an assumption that the health workers blame them for getting the diseases. Attitudes of disgust were marked and it resulted in the patients co-infected with TB and HIV fearing to disclose their diseases or any other health problem that they might have encountered. The attitudes of disgust led to a conclusion that the health workers are not dedicated and committed, thus are not sympathetic towards these patients. The patient co-infected with TB and HIV then identifies this attitude as stigmatisation. It seems that these attitudes led to the patients not utilizing the health services accordingly, as they fear discriminatory attitudes of the health workers.

This discrimination results from the perceived ignorance and lack of knowledge among the health workers, thus the patients see these attitudes as a defence mechanism used by the health workers. These attitudes were mostly observed from the non-professional or lower categories of health workers although other professionals also presented with these attitudes to a certain point.

There were a few instances were health workers were exonerated from having negative attitudes. The common factor with these exonerated health workers was that they were mostly from the primary health care services, as noted in the field notes (Annexure 1). The researcher, in her contact with health workers in the community clinics, noted this change of attitude and saw it as a move in the right direction.

- **Discrimination due to labelling by the health workers towards them.**

The conclusion made from the findings is that once the patients have TB and are loosing weight, health workers conclude that they are HIV positive. On this account the patients co-infected with TB and HIV feel bad when they start loosing weight. Thus it becomes difficult for them to go to the health services for any other reasons due to fear of being identified by their appearance. It is also apparent that the health workers make a distinct link between weight and TB and/or HIV, and as a result, tend to focus only on those two diagnoses. The consequences of this attitude can be very detrimental, seeing that other important conditions might be missed in the process.

In addition to this, health workers specify the environment in which the patients co-infected with TB and HIV have to use. This on its own is a form of discrimination, which makes the patients uncomfortable and identifiable to the rest of the community.

The fact that most patients are not ready to disclose their diseases yet, especially the HIV status, compounds the issue of specific ward or rooms, because patients then feel they cannot hide their status. The patient co-infected with TB and HIV thus feels intimidated by these places and consequently they do not go to the health services. South African government has supported the Primary Health Care approach with clear evidence made by the adoption of the Kopanong Declaration on Primary Health Care in August 2003. The adoption was to emphasize the government commitment since it came to power in 1994 and adopted the Alma-Ata Declaration of 1978 (Van Rensburg *et al.,* 2004:422). This whole approach emphasized the package of care, meaning that patients should receive all the care that they need on the same day in the same room (supermarket system). One of the intensions of the package was to eliminate fragmentation of services and reduce delay in the waiting time as patients need not come at certain times or go to certain rooms (Van Rensburg *et al.,* 2004:422). According to this research, it seems as if most of the clinics in the researched district are not yet using the strategy, thus still having different rooms for different services. This, however, results in what the patients perceived as labelling that leads to stigmatisation.

- **Response of patients co-infected with TB and HIV to stigmatisation.**

In conclusion, although the researcher intended to explore the experiences of the patients co-infected with TB and HIV, strong responses were observed from the patients co-infected with TB and HIV concerning stigmatisation by the health workers. Due to the significant impact of the diseases on the patients' health, they experience many emotional responses. Patients felt stressed as they were afraid of what might happen to them and when. The stress was also the result of fear of being judged as one participant alluded that one is being seen as being a prostitute and thus stigmatised. This impacts on their physical health and they become sicker. The fact that the health workers concluded that they are going to die and did not want to waste time on them resulted in sadness. Patients felt disillusioned and hurt, as they believed that the health system was supposed to protect them from stigma and not to stigmatise them.

Hence the patients felt worthless and hopeless about their lives and were also hopeless that the health system will not protect them from stigmatisation. Patients seem to be anxiously waiting for the day that they will die. Some patients clearly stated this fact by saying that they had accepted their condition and there is nothing they can do about it except wait for their death. Fear of death was high, although they sometimes believed that a solution would present itself and that they would also be treated with dignity. They believed that it would only realise when health workers were trained and have become empathetic towards their plight.

Patients also responded to the health system by loosing hope in it. They felt that the health system was not doing enough for them as patients co-infected with TB and HIV. They felt that the health system either focuses on one condition but never on both TB and HIV simultaneously, which is detrimental to their well-being. In addition they lacked trust towards the health workers who they feel divulge their status. This resulted in the patients changing health services frequently or stopping attending the health services entirely. According to the researcher this aspect creates a large barrier between the patients and the health systems in general. Patients opted to go to a health service further away from were they lived so that they could not be recognised, which has an implication for adherence and financial burdens. People who still have their self-respect and self-esteem and want to maintain it will go to great lengths to make sure that they protect themselves. These are the people who still want to continue with their treatment but do not want to be treated badly by others who are in a position of power.

The researcher, being part of the community herself, often hears people expressing their mistrust in the health system. Most participants reported that they did not trust the health workers with their confidential information in the beginning. This is mainly because they fear that the health workers divulge their health status to others without their consent. This aspect was highlighted in Chapter 3 where a patient explained that the health workers go to the extent of discussing their status with the patients' relatives without their permission which often leads to conflict in the family and to stigmatisation.

Although the patients co-infected with TB and HIV mostly responded negatively to the health system, they still felt that there is room for improvement within the health service. It seems that recognition for lack of sufficient knowledge and ignorance was highly noted. Patients suggested that all the categories of health workers should be trained in issues of communicable diseases and interpersonal relationships.

4.2.2 Conclusions pertaining to the attitudes of the health workers towards the patients co-infected with TB and HIV

Conclusions pertaining to the attitudes of the health workers towards the patients co-infected with TB and HIV will be discussed according to the three major categories as outlined in Table 3.2.2.

- **Perceptions of health workers about patients co-infected with TB and HIV**

A conclusion can be made that the relationship between the health workers and the patients co-infected with TB and HIV is often characterised by conflict. The health workers seem to perceive the patients co-infected with TB and HIV with negative behaviours such as stubbornness, harshness and manipulation. In addition, the health workers believe that the patients co-infected with TB and HIV are impatient and do not wish to talk about their conditions. It was a general perception that these patients do not want to take responsibility for their own health and expect to be treated differently from other patients. Irrespective of the above-mentioned issues, it is obvious that not all the patients are seen in that light by the health workers. During the interviews with the health workers the researcher observed that the patients that were labelled as cooperative are those who are submissive and do not question anything that is said to them by the health workers. The patients that do not follow the status quo and challenge the behaviour of the health workers are seen as stubborn.

Hence the health workers classify these patients as resistant and difficult to work with. Consequently, the health workers' perceptions of these patients resulted in each party being defensive and hostile towards each other. The health workers do not seem to be very sympathetic towards the personal crisis that the patients might be experiencing and they only focus on the verbal expressions. Although this assumption might be true, there are health workers who do not characterise these patients as mentioned above and try to understand the reasons for their behaviour. This fact was observed when the other health workers mentioned that nobody will talk about their diseases to each and every person and that it does not mean that that person is stubborn.

In addition to these perceptions, it seems that the health workers believed that the patients co-infected with TB and HIV abuse alcohol while on treatment. Although there was no proof of this aspect from the health workers, they assumed that it was one of the reasons that caused the patient not to co-operate. This aspect further complicated the relationship between the health workers and the patients. The researcher observed it as belittling towards the patients.

From the findings of this research it also appeared that adherence to treatment was an important issue to the health workers. It seems that there are factors that influence the patient co-infected with TB and HIV to either adhere or not adhere to treatment. Health workers seem to believe that the patients behave like children and do not take responsibility for their treatment, which is one behaviour that influences the patients negatively. It was also noted that the health workers find that the patients are either oblivious of the illnesses or deny the presence of the illness. Both these result in the patients not seeking help on time or not adhering to their treatment. In addition, the health workers believed that lack of continuity where different individuals are attending to a patient during a consultation influences adherence, seeing that the patient believes that confidentiality is being breached.

In spite of the negative aspects concerning adherence to treatment, it appeared that the health workers acknowledged where the gaps occurred and that they therefore realised how the situation relating to adherence could be improved. There was total agreement that the health workers need to spend more time with the patients co-infected with TB and HIV. The health workers need to listen to the patients' problems, give full explanation to the patients regarding their illnesses and the procedures that are followed in the clinics. Also, health workers need to explain to the patients the reasons for poor continuity or lack thereof in the clinic situation. These aspects will then improve patients' adherence and improve the utilisation of the health services. Therefore the researcher concluded that there is no trust relationship between the health workers and the patients co-infected with TB and HIV. This aspect confirms the conclusion made in the patients' experiences where this observation was made.

- **The health workers' behaviour towards the patients co-infected with TB and HIV**

A conclusion was made that although the health workers seemed to believe that their behaviour towards the patient co-infected with TB and HIV was fair and non-stigmatising, some agreed during the interviews that they as health workers behaved in a manner that was disrespectful and not acceptable to the patients. Furthermore, it appeared that most health workers acknowledge the fact that they are not always treating the patients well. Although they notice that they are impatient and harsh when dealing with these patients, they were defensive about this and explained it as being a way of getting the patients to co-operate and take responsibility for their own health. It appeared that some of them were dealing with these patients out of obligation and that this led to a lack of commitment. It was observed that, while the health workers were aware of the stigmatisation towards these patients within the health services, some of them ignored it and made as if it was non-existent or not important.

In spite of these negative behaviours, it seemed that there are positive behaviours that the health workers portrait which could be emphasised, thus improving the utilisation of the health services by the patients co-infected with TB and HIV. The positive behaviours included persuading the clients to take their treatment, advocating for the patients and involving the family in the care of the patients, amongst others. The health workers agreed that if all the members of the health teams behaved as such, more patients would come forward for treatment and perceptions of stigmatisation would be lessened within the health services.

- **The health workers' feelings towards the patients co-infected with TB and HIV**

The findings of this research indicated that the health workers presented with different feeling towards the patients co-infected with TB and HIV. It was observed that the health workers, especially non-professional or lower categories, felt helpless about not being able to assist the patients as they would have liked. This aspect is seen as an obstacle by the above-mentioned categories of health workers, although it is a legal aspect based on the different scope of practice which prevents certain categories from performing certain duties. It can be concluded that, in spite of the negative attitudes and behaviours that were mentioned in this research, the health workers felt sorry for the patients co-infected with TB and HIV. This feeling was expressed, mostly privately, as the health workers feared that if they openly showed that they felt sorry for the patients, the patients might feel discriminated against, thus would perceive stigmatisation.

In addition, it appeared that some of the health workers empathised with the patient co-infected with TB and HIV. Most of the health workers that felt this way had either been infected with TB or was affected by either one of the diseases in some way or another. Hence it seemed that they felt the pains of the patients and understood their position. Although the health workers felt that way, they still felt anger towards those patients who were not co-operative. It appeared that the anger was mostly due to the health workers' feeling of hopelessness, which they then transferred to the patients. The health workers' hopelessness was also observed to be directed at the health system, especially when they acknowledged that the health system is not doing enough to assist the patient to have a better quality of life. It seemed that the health workers believed that if issues such as treatment for HIV can be made available in all the health services, the patient would utilize the health systems much easier and tensions between them and the patients co-infected with TB and HIV would be reduced.

4.2.3 Conclusions pertaining to the stigmatisation of the patients co-infected with TB and HIV

The conclusion that can be made in this regard is that the patients that are co-infected with TB and HIV have a very strong perception about stigmatisation by the health workers. It was plain that the patients experience stigmatisation due to the behaviours and the attitude of the health workers within the health system. The health workers, on the other hand, acknowledge the fact that they sometimes behave negatively towards the patients co-infected with TB and HIV, but do not see this aspect as stigmatisation. Most of the health workers defend these behaviours and say that they do it in order to force the patients to take responsibility for their own diseases. It was also clear that the patients appreciated some health workers and felt that they were supportive although it depended on the facility that these workers were working at. The patient participants identified lack of knowledge about the spread of TB and HIV as a contributory factor towards poor interpersonal relations between the patients and the heath workers. In this case, it seemed as if the lower categories of the health workers were more prone to display negative attitudes due to ignorance. At the same time it was clear that the higher categories displayed negative behaviours and attitudes owing to either blaming the patients for not taking responsibility for their diseases or as a result of a feeling of inadequacy and helplessness. The feeling of helplessness was due to the fact that they could not do much for the patient on account of a lack of adequate resources from the health system and legal issues such as the scope of practice.

In addition, it was clear that the patients co-infected with TB and HIV experienced stigmatisation by the health workers because of feelings of being disrespected and dehumanised. This was caused by the health workers not explaining procedures and what was expected of them as patients in the health services and poor communication skills. Hence, the patients co-infected with TB and HIV felt the need that the health workers should be properly trained in this regard. The health workers acknowledged the fact that communication with these patients in the health services was not sufficient, as they did not devote enough time to the patients in order to explain issues to them. They also acknowledged that they needed to listen more to the patients and become sympathetic in order to win the patients' trust and to improve their utilisation of the health system.

It is apparent to the researcher that both the patients and the health workers were frustrated by the health system's lack of support. The patients were bitter about the inability of the health system to provide for complete treatment especially for HIV, while the health workers were frustrated by the lack of food supplements and the availability of a proper referral system for further management of the patients co-infected with TB and HIV when they present with complications. It seemed that the health workers also saw the red tape caused by the legal acts and procedures within the health system as a stumbling block for rendering quality care to the patient co-infected with TB and HIV. This aspect results in the patients losing trust in the health workers and perceiving stigmatisation. In conclusion, one can assume that stigmatisation of the patients co-infected with TB and HIV by the health workers is rife, although there are health workers that recognise this and are willing to deal with it in order to assist in the reduction of stigma in the health system. It is obvious that having both the diseases put the patient in more risk of being stigmatised, since a common assumption was observed that patients who have TB already have HIV based on the association with a ward in the hospital, a room in a clinic or their physical appearance.

4.3 SHORTCOMINGS OF THE RESEARCH

The following is the shortcomings of the research as experienced and observed by the researcher.

The research had two populations: one comprising of patients co-infected with TB and HIV, and the other of the health workers. In the first population, the researcher discovered that the mediators did not give the participants full explanations regarding the purpose of the research. This resulted in the participants not being prepared for the researcher, seeing that they saw her as a stranger while the topic also was sensitive, causing them to be reluctant. Therefore it took the researcher more time to explain the purpose of the research so as to gain the participant's trust and confidence and to obtain their written consent. Two of the recruited participants refused to continue with the interviews when the researcher arrived and once they understood the purpose of the research. They explained that they would not have been involved if full explanation had been given in advance. In spite of this aspect, the participants who eventually did take part were cooperative. Consequently this shortcoming did not have a negative influence on the results.

Another shortcoming was that the mediators recruited most of the participants based on their contact with them personally in the clinics and the conclusion these mediators made was that they were cooperative patients. This interfered with full disclosure regarding the health workers' attitudes, as the participants seemed to be reluctant to talk about this and closed up. The researcher observed the above-mentioned aspect in the responses she received from the patients that were recruited from the clinics, as some of them seemed intimidated and uncomfortable to discuss stigmatisation by the health workers due to fear of being victimized, thus giving minimal information. When probing, the researcher had to continuously reassure the participants that the interview was confidential, resulting in the participants then opening up. These findings contrasted with the spontaneous responses from the participants that the researcher identified — participants who had already completed treatment and were members of different non-governmental organisations.

The researcher identified language as a shortcoming in this research. This is because in the spoken African language there is no much difference between the concepts "stigmatisation" and "discrimination". It therefore became difficult for the researcher to clarify the concept stigma to the illiterate participants without bringing the concept of discrimination into play. The researcher had to use examples that, in some cases, became leading in the participants' response. The researcher also found the issue of co-infection as a shortcoming, because she observed that most participants had accepted one condition and not the other, thus identified with one illness more than the other. This resulted in the responses mostly focusing on the acceptable condition and the co-infection being down-played. The researcher had to probe further and this resulted in some participants agreeing with what she was explaining and giving brief answers of YES and NO.

With the second population, which was supposed to comprise of different levels of health workers, the main shortcoming was that all the participants were recruited from the clinic settings; therefore the hospital setting was not represented. This aspect was caused by the authorization that the researcher received which did not include the hospitals within its boundaries. The impact to this research is that the views of the health workers in the hospitals are not represented although the patients referred to them during their interviews. The other shortcoming in this population was the fact that most of the health workers who were interviewed were nurses and the other lower categories such as partially trained community health workers and clerks. Due to the sampling technique used in this research, the other members from different disciplines such as medical doctors, dentists etc. could not be accessed by the researcher. Consequently their views are not represented in this research.

4.4 Recommendations for nursing education, nursing research and community health nursing practice

In this section, recommendations for nursing education, nursing research and community health nursing practice will be discussed. Reference will be made to the data of this research, and to the conclusions that were made.

4.4.1 Recommendations for nursing education

The finding of this research could bring much value to nursing education if it could be included in the curriculum of all basic nursing programmes that are offered in the colleges and universities. Counselling should be developed as an obligatory module with emphasis on the communication skills, as the learner will be taught the skills to effectively deal with patients co-infected with TB and HIV. Learners will also learn to recognize defence mechanisms that are applied by the patients co-infected with TB and HIV, thus acquire the necessary skills to deal with them effectively. The learners will also be able to understand different cultural issues and responses to life threatening illnesses and diseases.

This aspect should also be implemented in the post basic programmes so as to update the learners who were not exposed to it in the basic programmes. It will also assist them with the latest trends within the TB and HIV/AIDS programmes in South Africa and around the world.

4.4.2 Recommendations for nursing research

Based on the research findings, literature and conclusions made from this research, it is evident that there is potential for further research in the field of co-infection of TB and HIV as research on stigmatisation recommends the following possible areas:

4.4.2.1 The attitudes of the members of the other health disciplines towards the patient co-infected with TB and HIV.

4.4.2.2 The knowledge level of the non-professional health workers regarding TB and HIV co-infection.

4.4.2.3 The perceptions of the health workers regarding the available support system in the work place while dealing with patients co-infected with TB and HIV.

4.4.2.4 An exploration of the level of commitment amongst health workers continuously dealing continuously with patients co-infected with TB and HIV

4.4.2.5 An exploration of coping mechanisms that are applied by the patients co-infected with TB and HIV

4.4.2.6 An exploration of stigmatisation by environmental association amongst patients with stigmatised illnesses.

4.4.2.7 An evaluation of the designation of wards or rooms for HIV/TB treatment system in health care services and the impact thereof.

4.4.3 Recommendations for community health nursing practice

Recommendations for community health nursing practice bear reference to the specific guidelines as set under the objectives of this research with the view to formulate guidelines for health workers to facilitate the utilization of health services by people co-infected with TB and HIV, to formulate guidelines for the health workers to assist in improving the understanding of the patients co-infected with TB and HIV of the health system so that they can utilise the health services efficiently and adequately and finally to improve their attitudes towards these patients with the above-mentioned overall goal in mind.

Firstly, guidelines for health workers in their role of facilitating the utilization of the health services by patients co-infected with TB and HIV will be discussed.

4.4.3.1 Guidelines for the health workers to facilitate the utilization of the health services by the patients co-infected with TB and HIV

From the findings and the conclusions of this research, it seems that there is a need for the health services to review the allocation of wards in the hospital or rooms in the clinics to specific diseases. This is necessitated by the fact that patients co-infected with TB and HIV interpreted the use of this system as discriminatory towards them, thus increasing stigmatisation by both the community and the health workers. This aspect was noted in instances where the patients assumed that a specific room for TB or counselling identified them as co-infected, therefore avoided to be seen there. It therefore implies that this system hinders the utilisation of the health services by the patients co-infected with TB and HIV and impact negatively on these patients' adherence to treatment.

In addition to this, it will also be meaningful for the patients co-infected with TB and HIV to understand the procedures that are followed in the health services, for instance who is responsible for prescribing medication, since this aspect influences their perceptions of being stigmatised when a particular health worker cannot assist them. This is seen in the instances were the patient is referred from one health worker to another with the intension that it is the second level of assistance. An example is where a non-professional health worker sees patients with TB for follow-up with treatment compliance, then refers them to a counsellor for HIV pre-counselling and finally to a professional health worker for HIV testing. The purpose of this action is not to increase stigmatisation by the health workers. Protocols are set by the health system, which need to be adhered to. If the patients co-infected with TB and HIV are equipped with this knowledge, they will understand the bureaucracy of the system and feel less stigmatised. Therefore it is the duty of the health workers to explain and educate the patients co-infected with TB and HIV about what is happening in the health system and what is expected from them as patients.

On the other hand, it is important for the health workers to understand the conflict that the patients might be experiencing due to their diseases. It therefore means that they need to be more empathetic towards these patients and treat them with sensitivity. The health workers also need to understand the legal issues concerning TB and HIV, such as the patient's right to confidentiality, and the need to handle the patients with respect. By being made aware of the implication of stigmatising the patients co-infected with TB and HIV, the health workers will realise the importance of good communication skills and the need to acknowledge these patients' right to proper health care. It will be meaningful if all the health workers across different categories could be given intense training on people skills so that they can acquire proper communication techniques. It will be proper for the lower categories of health workers to understand issues concerning the spread of TB and HIV so as to improve their attitude, which was not intentional, but mainly seen as a result of ignorance.

When the patients co-infected with TB and HIV understand the above-mentioned aspects, it will assist in their understanding of the health system. And when the health workers acknowledge the need to act humane towards these patients, it will improve their interpersonal relationship with these patients and reduce stigmatisation. The following guidelines will assist in facilitating the utilisation of the health system by the patients co-infected with TB and HIV.

Secondly, to achieve this above-mentioned objective, guidelines will subsequently be discussed that are recommended to improve the understanding of the patients co-infected with TB and HIV of the health system so that they can utilise the health services efficiently and adequately.

4.4.3.2 Guidelines to improve the more efficient and adequate utilisation of the health services by the patients co-infected with TB and HIV .

- The health workers need to educate the patients co-infected with TB and HIV regarding the relationship between TB and HIV and empower them with regard to their conditions concerning the spread thereof, complications and the fact that TB can be cured but HIV not.
- The health worker should explain the pathology and reactions of treatment to the patients co-infected with TB and HIV, using the language that they understand at their level.
- Until changes are made regarding this system, the health workers need to continually explain the reasons to the patients co-infected with TB and HIV for different wards in the hospital and rooms in the clinic. An example would be to

explain that TB and HIV are medical conditions and that this is the reason why they are in a medical ward and not a "TB/HIV ward".

- The health workers should continually clarify the role and responsibilities of patients co-infected with TB and HIV regarding their conditions to them as well as what is expected of them during their period of care, and should emphasize the importance of adherence to treatment.

All these mentioned aspects should already take place during the first visit of the patient co-infected with TB and HIV to the health services and throughout. Having made the patient aware of the above-mentioned factors that often create perceptions of stigmatisation when not understood the health workers can develop strategies that will facilitate utilization of the health services, such as those noted below:

- The health workers need to ensure an environment that is conducive to the patients co-infected with TB and HIV talking about their fears regarding their diseases. This can be done by forming support groups within the health services where the patients can become be alerted to the fact that they are not alone in their battle.

- The health worker should educate the patients co-infected with TB and HIV about their human right in relation to health matters and legal issues surrounding confidentiality.

- The health workers should make the patients aware of the other resources that are available in the community close to them and work with the government, like the non governmental organisations, so as to access them easily in times of need, without sacrificing their responsibility with regard to the patient.

- The health workers should co-ordinate workshops at regular intervals, for example bimonthly, and invite experts and/or a person who has been co-infected before to address the patients and health workers.

- The health workers should co-ordinate health awareness events around both TB and HIV with themes that clarify the causes of co-infection and management thereof so as to improve the understanding of co-infection, and demystify stigma.

- It will be useful to involve the patients co-infected with TB and HIV in the development, planning and implementation of programmes such as self–help schemes to make them feel worthwhile and hopeful that they can survive. This will reduce their perception of being stigmatised, as it will improve their self-esteem.

Finally, guidelines for health workers with the view to improve their attitudes towards the patients co-infected with TB and HIV will be discussed.

4.4.3.3 Guidelines to improve the attitudes of health workers towards the patients co-infected with TB and HIV with the intention of improving the utilisation of the health services by these patients.

- All the health workers should develop their communication skills, which includes their listening skills so that they will be able to communicate with the patients in a respectful manner.

- All the categories of health workers should go on training for counselling so that they can be able to intervene effectively if the patient seeks help. This will reduce the cases of patients being sent from one person to another for counselling and thus improve trust relationships.

- All the categories should be retrained and kept posted regarding the latest developments in relation to the management of both these diseases management so that continuity and uniformity can be maintained, thus clearing the myth that some health workers do not know enough about these diseases.

- Workshops should be held for all the categories of health workers to teach them about the legal issues and its impact on the health system, as knowledge of this can reduce their negative behaviours that lead to stigmatisation towards the patients.

- The health system should have resources in place where structured debriefing sessions can be held for all the health workers who deal with these patients. This can assist them in expressing their emotional burdens to the experts who can help by teaching them different skills in term of handling the situation and dealing with it.

- The health workers should have forums were they can form support groups for health workers of different categories and disciplines. This can enable them to talk about their fears and discomfort amongst their peers and learn coping mechanisms that can assist in improving their attitudes towards these patients.

- Forums for the health workers and the patients should be facilitated where they can all raise their problems. This can clarify issues that were not understood by both parties and reduce the conflict that is often caused by misunderstandings. It will also reduce stigmatisation, since every individual will be communicating at the same level as members of the forum.

- The findings and the guidelines should be included in the in-service training programmes of the public health sector, the private sectors and the non-governmental organizations to empower all the levels of health workers that deal with the patients co-infected with TB and HIV. These in-service programmes should also be presented to volunteers, partially trained community health workers other non-professional categories such as clerks, seeing that often come into contact with the patients co-infected with TB and HIV. This will enable them to facilitate the utilization of health services by people co-infected with TB and HIV.

4.5 Concluding remarks

The objectives of this research was achieved which mainly were to explore and describe the experiences of patients co-infected with TB and HIV concerning stigmatisation by community health workers, to explore and describe the attitudes of community health workers towards patients co-infected with both TB and HIV as well as to formulate guidelines that will improve the utilisation of the health services by these patients.

An open-ended question and a semi-structured schedule was formulated from and based on the background literature of this research. The researcher did data collection, and analysis was conducted with the assistance of an independent co-coder. The findings of this research explicitly described the experiences of the patients co-infected with TB and HIV concerning stigmatisation by the health workers and the attitudes of the health workers towards these patients. Literature from the electronic database was used to confirm these findings. Unique findings in this research were highlighted and unexpected exposés by the patients were reported in the form of recommendations.

The conclusion that can be made is that the patients that are co-infected with TB and HIV experience stigmatisation by the health workers and by the health system. This results in the patient co-infected with TB and HIV not utilising the health services, even when there is a great need to do so. It was also evident that the health workers acknowledge the presence of this stigmatisation but are defensive, seeing that they feel that the patients' behaviour towards them and non-adherence to treatment cause those reactions.

Recommendations in this research are made for nursing research, nursing education and nursing practice. Specific guidelines were formulated for the health workers with the intension to facilitate the utilisation of the health services by these patients. To achieve this objective, guidelines were formulated to improve the understanding of the patients co-infected with TB and HIV of the health system so that they can utilise the health services efficiently and adequately. In addition, guidelines were formulated to improve the attitudes of health workers towards the patient co-infected with TB and HIV with the intention of improving the utilisation of the health services by these patients.

Having the above-mentioned guidelines in place could reduce the stigmatisation of patient co-infected with TB and HIV and improve their utilisation of the health services, consequently proper adherence to treatment. This could also be used to support and achieve the commitment of the government to proper health care for all, which includes the patient co-infected with TB and HIV. This research highlighted the fact that TB and HIV are stigmatised diseases, therefore a patient that is co-infected with both these disease carries a much heavier burden of stigmatisation, especially when the act is being perceived to come from the health workers. Hence, the implications are more detrimental, since they impact on the adherence to treatment by the patients co-infected with TB and HIV and can thus result in mortality that could have been prevented. It is therefore the obligation of the health system to reduce stigmatisation towards these patients by facilitating change in the attitudes of the health workers towards these patients.

BIBLIOGRAPHY

ANDERSON, S.R. & MAHER, D. 2001. An analysis of interaction between TB and HIV/AIDS programmes in Sub-Saharan Africa. Geneva : World Health Organisation. 35 p.

ANGELO, A.A. 1995. Illness and social behaviour. [Web:] http://www.sociology. ohio-state.edu.html [Date of access: 17 February 2002].

ATTAWELL, K. 1995. Tackling TB and HIV. [Web:] http://www.aidsaction.info/aa/aa31.html [Date of access: 30 June 2005].

AUERBACH, S. & GRAMLING, E. 2004. Stress management workbook: techniques and self assessment. [Web:] http://www.amazon.com [Date of access: 25 July 2005].

AVERT ORGANISATION. 2004. HIV/AIDS in South Africa. [Web:] http://www. avert.org.aidssouthafrica.htm [Date of access: 22 August 2005].

BAUM, J. (jbaum@post.tau.ac.il) 2005. Tel Aviv recommends DOTS-S for TB treatment. [Discussion group.] stop-tb@eforum.healthdev.org March 29.

BAYLIES, C. & BUJRA, J. 2000. AIDS, sexuality and gender in Africa: collective strategies and struggles in Tanzania and Zambia. London : Routledge. 222 p.

BEYOND AWARENESS CAMPAIGN. Department of Health. 2000. Living openly: HIV positive South Africans tell their stories. Pretoria : HIV/AIDS and STD Directorate. 64 p.

BIBLE. 1995. The Holy Bible: new international version. Cape Town : Bible Society of South Africa.

BIRD, S.T., BOGART, L.M. & DELAHANTY, D.L. 2004. Health-related correlations of perceived discrimination in HIV care. *Journal of AIDS patient care and STDs,* 18(1):26.

BOTES, A.C. 1992. A model for research in nursing. Johannesburg : Rand Afrikaans University.

BRINK, H. 1996. Fundamentals of research methodology for health care professionals. Kenwyn : Juta. 220 p.

BRUHN, J. 1989. Counselling persons with a fear of AIDS. *Journal of counselling and development*, 67:455-457, April.

BUNTING, S.M. 1996. Sources of stigma associated with women with HIV. *Journal of advances in nursing science*, 19(2):64-73, December.

BURNS, N. & GROVE, S.K. 1997. The practice of nursing research: conduct, critique, and utilization. 3rd ed. Philadelphia, Pa. : Saunders. 828 p.

CAMPBELL-WELLINGTON, C. (ccnicholas@yahoo.com) 2003. Stigma, HIV and drug users-29. [Discussion group:] stigma-aids@healthdev.net August 13.

CLARK, M.J. 1999. Nursing in the community: dimensions of community health nursing. 3rd ed. Stamford, Conn. : Appleton & Lange. 1103 p.

COD **see** CONCISE OXFORD DICTIONARY

CONCISE OXFORD DICTIONARY (COD). 1992. Stigma. Oxford : Clarendon Press.

CONNORS, J. & HEAVEN, P. 1995. Health beliefs and attitudes towards people living with HIV/AIDS. *Journal of applied social psychology*, 16(25):922-931, May.

CRESWELL, J.W. 1994. Research design: qualitative and quantitative approaches. Thousand Oaks, Calif. : Sage. 228 p.

DAYNE, G. 1993. The stigma of mental illness. *South African medical journal*, 83(7):534, July.

DE BRUYN, L. & JOUBERT, G. 2002. The perceptions of female university students regarding STDs and HIV: research on campus. *South African medical journal*, 93(3):202-203, March.

DEEGAN, P. 1996. Recovery and conspiracy of hope. [Web:] htpp://www.namisc.org/newsletter/February02/PatDeegan.htm [Date of access: 29 July 2005].

DEETLEFS, E. 1998. Die houding van verpleegkundiges teenoor die MIV-positiewe pasient. Potchefstroom : PU vir CHO. (Dissertation - BCur.) 79 p.

DE VOS, A.S. 2002. Qualitative data analysis and interpretation. (*In* De Vos, A.S. *ed.*, Strydom, H, Fouché, H.B. & Delport, C.S.L. Research at grass roots for the social sciences and human service profession. 2nd ed. Pretoria : Van Schaik. p. 339-355.)

DOUGLAS, M. 1994. Risk and blame: essay in cultural theory. London : Routledge. 323 p.

EDGAR, T., FRITZPATRICK, M.A. & FREIMUTH, V.S. 1992. AIDS: a communication perspective. Hillside, N.J. : Erlbaum. 231 p.

ENGENDERHEALTH. 2004. Reducing Stigma and discrimination related HIV and AIDS: training for health care workers. (Participant's handbook.) ENGENDER= HEALTH.

EVIAN, C. 2000. Primary Aids care: a practical guide for primary health care personnel in the clinical and supportive care of people living with HIV/AIDS. 3rd ed. Houghton : Jacana Education. 332 p.

FOREMEN, M., LYRA, P. & BREINBAUER, C. 2003. Understanding and responding to HIV/AIDS-related stigma and discrimination in the health sector. Washington, D.C. : Pan American Health Organization. 56 p.

FRANCE, N. s.a. Stigma and HIV/AIDS in Africa. Review of issues and responses based on literature review, focus group discussions and Stigma-AIDS email discussion forum. [Web:] http://www.heart-intl.net/HEpatitis/Stigma%20 and%20HIVAIDS%20in%20Africa.ht [Date of access: 19 February 2005].

GALLO, M. 1991. Communication and stigma. Pacific Grove, Calif. : Brooks/Cole. 129 p.

GERHARDT, E. & WADSWORTH, E.J. 1985. Stress and stigma: explanation and evidence in the sociology of crime and illness. New York : St Martin's press. 206 p.

GOFFMAN, E. 1963. Stigma: notes on the management of spoiled identity. London : Penguin Books.

GOFFMAN, E. 1990. Stigma. London : Penguin Books. 174 p.

GRUNDLINGH, L. 1999. HIV/AIDS in South Africa: a case of failed responses because of stigmatization, discrimination and morality, 1983-1994. *New contree,* 46:55-81, November

GUBA, E.G. & LINCOLN, Y.S. 1989. Fourth generation evaluation. London : Sage. 294 p.

HARUN, M. (mhjkt@attglobal.net) 2002. TB stigma: a response. [Discussion group:] stop-tb@forums.healthdev.org May 17.

HDN KEY CORRESPONDENT. (correspondents@hdnet.org) 2004. Freedom from fear. [Discussion group:] stigma-aids@eforums.healthdev.org July 14.

HDN KEY CORRESPONDENT. (correspondents@hdnet.org) 2005. Sportlight: stigma-lurking on the edge of TB response. [Discussion group:] stop-tb@forums. healthdev.org April 13.

HDN MODERATOR TEAM. (moderators@hdnet.org) 2003. HIV/AIDS in Africa. [Discussion group:] stop-tb@forums.healthdev.org

HEREK, G. 1999. Stigma (social psychology); AIDS (disease) patients social conditions. *American behavioural scientist*, 42(7):1106-1111, April.

HEREK, G. 2000. Morbidity and mortality weekly report. [Web:] http://www.psychology.ucdavis.edu/rainbow/html/auds.html [Date of access: 11 February 2002].

HOLLINGSWORTH, R.W. & TURNER, M.R. 2000. HIV/AIDS journey. [Web:] http://www.aidschannel.com/signed richard/article2.htm [Date of access: 22 August 2004].

HOUSLER, H. 2000. Tuberculosis and HIV/AIDS: clinical guidelines. [Web:] http://www.doh.gov.za/aids/docs/tuberculosis.html [Date of access: 30 June 2005].

HUTCHINSON, S. 2002. Study fosters patient-friendly hospital environment. [Web:] http//www.popcouncil.org/horizons/newsletter/horizon(5)_6.html [Date of access: 30 June 2005].

ILLAKO, F. (festusl@amrefug.org) 2005. Vertical TB programming is a challenge. [Discussion group:] stop-tb@eforum.healthdev.org March 3.

INTERNATIONAL HIV/AIDS ALLIENCE. 2001. Time to tackle stigma. Brighton : International HIV/AIDS Alliance. 4 p.

IRIN NEWS ORGANIZATION. 2003. Stigma fuels the spread of tuberculosis. [Web:] http://www.irinnews.org/print.asp?ReportID=34769 [Date of access: 17 February 2004].

IRIN PLUS NEWS. 2004. Africa: the challenge of stigma. [Web:] http://www.plusnews.org/pnprint.asp?ReportID=3379 [Date of access: 14 August 2004].

JARIYAVILAS, A., NGAMKASEM, H., MATNANGKOON, L., SIRIPONG, A., PANCHAROEN, C. & THISYAKORN, U. 2004. I will survive: the story of three HIV-infected children, their families and the stigmatisation they faced. Bangkok : Parbpim. 156 p.

KELLER, S. 1994. A legacy of fear. *Buffalo news. Medical research: an electronic journal*:3. [Web:] http.//ethnomed.org/pearl/p_tbstigma.html [Date of access: 15 September 2002].

KREFTING, L. 1991. Rigor in qualitative research: the assessment of trustworthiness. *American Journal of occupational therapy,* 45(3):215-221, April.

LILLEY, L. 2004. MENTAL HEALTH PROBLEMS: THE STIGMA AND ISOLATION IN REMOTE AND RURAL COMMUNITIES. [WEB:] HTTP://WWW.ESRC.AC.UK/ERSCINFOCENTRE/MENTALHEALTH. ASPX [DATE OF ACCESS: 27 AUGUST 2004].

LINK, B.G. & PHELAN, J.C. 1995. On stigma and its public health implications. [Web:] http//:www.stigmaconference.nih.gov/FinalLinkPaper.html [Date of access: 30 June. 2005].

LOBIONDO-WOOD, G. & HABER, H. 1990. Nursing research: critical appraisal, and utilization. 2nd ed. St Louis : Mosby. 470 p.

LUHAN, M. (luhanm@who.int) 2005. TB cases and death linked to HIV, now at alarming levels in Africa. [Discussion group:] stop-tb@forums.healthdev.org March 29.

MADRU, N. 2003. Stigma and HIV: does the social response affect the natural course of the epidemic? *Journal of the Association of nurses in AIDS care,* 14(5):39-48, Sept. / Oct.

MALAWI NETWORK OF PEOPLE LIVING WITH HIV/AIDS. 2003. Voices for equality and dignity: qualitative research on stigma and discrimination issues as they affect PLWHA in Malawi. Lilongwe. 46 p.

MBWAMBO, J., MacQUARIE, K., KILONZO, G., KOPOKA, P. & NYBLADE, L. 2003. Stigma and care givers in health care setting in Tanzania. Washington, D.C. : International Center for Research on Women. 11 p.

McGREARY, J. 2001. Death stalks a continent. *Time*, February 12.

McINTYRE, B. 2004. (bradmcin@telus.net) Village boycott women with HIV (2). [Discussion group:] stigma-aids@eforums.healthdev.org February 17.

MOHAMED, O. (onmohamed@dhr.state.ga.us) 2003. Freedom from fear. [Discussion group:] stop-tb@forums.healthdev.org July 19.

MOHAMED, O. (onmohamed@dhr.state.ga.us) 2005. Stigma-lurking on the edge of TB response (3). [Discussion group:] stop-tb@forums.healthdev.org April 04.

MORSE, J.M. & FIELD, P.A. 1995. Qualitative research methods for health professionals. 2nd ed. London : Sage. 254 p.

MOUTON, J. & MARAIS, H.C. 1990. Basic concepts in the methodology of the social sciences. Pretoria : Human Sciences Research Council. 169 p.

NGAMWITTAYAPHONG, A. 2004. Knowledge, hope, strength for curing TB. s.l. : 21 Century Co. 32 p.

NYBLADE, L., PANDE, R., MATHUR, S., MacQUARIE, K., KIDD, R., BANTEYERGA, H., KIDANU, A., KILONZO, G., MBWAMBO, J. & BOND, V. 2003. Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia. Washington, D.C. : International Center for Research on Women. 53 p.

OKUN, B.F. 1997. Effective helping: interviewing and counselling techniques. 5th ed. Pacific Grove, Calif. : Brooks/Cole. 309 p.

ORAL ROBERTS UNIVERSITY. Anna Vaughn School of Nursing. 1990. Self study report, submitted to the Council of Baccalaureate and higher degree programs, National League for Nursing, v. 1. Narrative by criteria. Tulsa, Okla. : Oral Roberts University. p. 136-142.

PAN AMERICAN HEALTH ORGANIZATION. 2003. Understanding and responding to HIV/AIDS-related stigma and discrimination in the health sector. [Web:] http://www.paho.org/English/AD/FCH/AI/stigma.htm [Date of access: 14 August 2004].

PARLEY, Y. & LUHAN, M. 2003. Boosting detection is goal of 2003 world TB day. [Web:] http://www.alertnet.org/thefacts/reliefresources/604487.html [Date of access: 15 May 2004].

PATRUNO, F. (fondazione@villamaraini.it) 2003. Stigma, HIV and drug users. [Discussion group:] stigma-aids@healthdev.net August 8.

PLUMMER, K. 1975. Sexual Stigma: an integrationist's account. London: Routledge & Kegan Paul. 258 p.

PLUS NEWS (stop-tb@forums.healthdev.org) 2005. Clinic tackles urgent need for AIDS/TB treatment. [Discussion group:] stop-tb@forums.healthdev.org May 05.

POLIT, D.F. & HUNGLER, B.P. 1993. Essentials of nursing research: methods, appraisal and utilization. 4th ed. Philadelphia, Pa. : Lippincott. 479 p.

PRETORIUS, R. 1992. Parents of children who commit suicide as victims of stigma attached to the suicide of the child in the family. *Social work*, 28(1):93-97, March.

PRIMER, S. 1996. Attitudes drive behavior. [Web:] http://www.as.wvu.edu/~sbb/comm221/chapters/abc.htm [Date of access: 20 July2005].

PRYOR, J., REEDER, G.D. & LANDAU, S. 1999. A social-psychological analysis of HIV-related stigma. *American behavioral scientist*, 42(7):1193-1211, April.

RANDSE AFRIKAANSE UNIVERSITEIT. 1992. Nursing theory for the whole person. Johannesburg : RAU. 41 p. (Unpublished.)

ROKEACH, M. 1989. Beliefs, attitudes, and values: a theory of organisation and change. San Francisco, Calif. : Jossey-Bass. 214 p.

SALOVEY, P. & IRWIN, K. 2002. Understanding HIV-relevant stigma in India. [Web:] http//www.cira.med.yale.edu/research/indiastigma.html [Date of access: 19 February 2005].

SIYAM'KELA. 2003. Measuring HIV/AIDS related stigma. A report on the fieldwork leading to the development of HIV/AIDS stigma indicators and guidelines. 34 p.

SMEADLY, L.N. 1978. The Chinese community in South Africa, phase 2: a sociological study. Pretoria : HSRC. 109 p.

SOUTH AFRICA. Department of Health. 2000. Tuberculosis control programme: practical guidelines. Cape Town : CTP Book. 46 p.

STANNARD, L. 2001. Estimates of national prevalence for the year 1990-1998. [Web:] http://www.aids.org.za/aids_in_southafrica.htm [Date of access: 28 February 2002].

STRYDOM, M. 1995. Die belewing van die pasiënt en die verpleegkundige tydens Tuberkulose-onderrig. Potchefstroom : PU vir CHO. (Dissertation - BA Nursing.) 60 p.

TORFOSS, T. (Torfoss T@who.int) 2005. Fighting stigma and promoting community involvement. [Discussion group:] stop-tb@forums.healthdev.org April 28.

UNAIDS. 2000a. HIV epidemic update. [Web:] http://www.unaids/epidemic-update/report/EPI_report.pdf [Date of access: 28 February 2002].

UNAIDS. 2000b. HIV-related knowledge and stigma, United States, 2000. [Web:] http://www.cdc.gov/mmwr/preview/mmwrhtml/mm4947a2.htm [Date of access: 23 June 2002].

UNAIDS. 2001. Advocacy for action on stigma and HIV/AIDS in Africa. (Regional consultation meeting on stigma and HIV/AIDS in Africa, 4-6 June, Dar-es-Salaam.) UNAIDS, Health and Development Network (HDN) and the Swedish International Development (SIDA).

VAN RENSBURG, H.C.J., BENATAR, J.E., HEUNIS, J.C., McINTYRE, D.E., NGWENA, C.G., PELSER, A.J., PRETORIUS, E., REDELINGHUYS, N. & SUMMERTON, J.V. 2004. Health and health care in South Africa. Pretoria : Van Schaik. 626 p.

WATSON, M. J. 2002. Kultuurkongruente beraming van die moeder en haar baba binne 'n kultuurdiverse gemeenskap. Potchefstroom : PU vir CHO. (Dissertation - MCur.) 240 p.

WATTS, T. (tw@twwales.freeserve.co.uk) 2005. TB diagnosis and treatment compliance-a challenge. [Discussion group:] stop-tb@forums.healthdev.org March 15.

WEBBS, D. 1997. HIV and AIDS in Africa. London : Pluto. 258 p.

WHO see WORLD HEALTH ORGANIZATION (WHO)

WORLD HEALTH ORGANIZATION (WHO). 1998. Facts about world TB. [Web:] http.//www.stoptb.org/workinggroups/ TBHIV/factsecttb_hiv/TBDOL.htm [Date of access: 10 March 2002].

WORLD HEALTH ORGANIZATION (WHO). 2001. A human right approach to TB. [Web:] http://www.stoptb.org/world.tb.day/WTBD_2001/HumanRightReport. htm [Date of access: 23 June 2002].

WILSON, H.S. 1989. Nursing research. Redwood City, Calif. : Addison-Wesley Nursing. 434 p.

WILSON, H.S. 1993. Introducing research in nursing. 2nd ed. Redwood City, Calif. : Addison-Wesley Nursing. 352 p.

WORTHINGTON, C. & MYERS, T. 2003. Factors underlying anxiety in HIV Testing: risk perceptions, stigma, and patient-provider power dynamic. *Qualitative health research,* 13(5):636-655, May.

ZULU, D. 2001. Stigma and HIV/AIDS in Africa: setting the operational research agenda. [Web:] http://www.hdnet.org [Date of access: 14 August 2004].

APPENDIX

APPENDIX A

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN THE POTCHEFSTROOM HEALTH DISTRICT

Mr M Roopa

Director health services

Potchefstroom City Council

Sir

PARTICIPATION IN RESEARCH: INFORMATION AND REQUEST FOR PERMISSION

I am currently registered as a student for a MCur (Community Nursing Science) degree at the Potchefstroom campus of the North-West University and as part of the degree I plan to do a research about the stigmatisation of a patient co-infected with TB and HIV.

The purpose of this research is to:

- To explore and describe the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers.
- To explore and describe the attitudes of health workers towards patients co-infected with TB and HIV.
- To formulate guidelines for health workers that will facilitate the health service utilization by patients co-infected with TB and HIV in the Potchefstroom district.

In order to achieve these objectives, unstructured interviews with the patients co-infected with TB and HIV, and semi-structured interviews with the health workers will be conducted. Both these groups should be living in the areas of Potchefstroom, Wedela and Fochville in the North-West Province.

The criteria for inclusion are as follows:

In case of the patients co-infected with TB and HIV, they must

- be diagnosed with TB before they had tested HIV positive
  or
- be living with HIV or AIDS and subsequently became ill with TB.
- be females or males aged 16 years and older.
- be willing to sign a consent form to participate in this research and agree on the use of an audiotape during the interview.
- be able to communicate in any language that is understood by the researcher (Zulu, Xhosa, Setswana, Sesotho, English or Afrikaans).

Health workers must

- be within any category of health workers
- serve in a health services within the Potchefstroom district in the North West Province
- be directly involved in caring for and treating the patients with TB and HIV in the clinics and mobile health service for at least one year, which would indicate that they understand the dynamics of that particular community
- be willing to sign a consent form to participate in this research and agree on the use of an audiotape during the interview.
- be able to communicate in any one of the following languages: Zulu, Xhosa, Setswana, Sesotho, English or Afrikaans.

The interviews for those who agree to participate will be conducted during August and September 2004. Interviews will be preferably conducted at the place of choice of the participant, be it their homes or the clinic and will last forty-five minutes to an hour per

person. All the names of the participants and the research proceedings will be treated confidentially.

It will be appreciated if one health worker in each clinic who is not part of the research population of health workers will be identified and act as a mediator in the recruitment of patients as participants. Your timeous response will be of great help as I will be able to make further arrangements.

If more information is needed with regards to this research, please call me at the above mentioned telephone numbers.

Thanking you in anticipation

Yours sincerely

____

D R PHETLHU (Researcher)

____

Mrs E DU PLESSIS (Study Leader)

____

Mrs M J WATSON (Co-Study leader)

GESONDHEIDSDIENSTE/HEALTH SERVICES
DITIRELO TSA PHOLO

STADSRAAD/CITY COUNCIL
MOTSESETOROPO

POTCHEFSTROOM

PRIMêRE GESONDHEIDSORG
PRIMARY HEALTH CARE SERVICES

Riana: 082 851 2979
rianak@potch.co.za
Faks. 018 - 299 5258

AAN: Rene Phetlhu
TO:

VERW./REF: Riana Kolbé
DATUM/DATE:
18/02/2004

Madam,

<u>REQUEST FOR CONDUCTING RESEARCH IN GREATER POTCH AREA</u>

Your application to do research in the greater Potchefstroom area has been approved by this Directorate

If help is needed we would gladly do so if possible.

Best wishes accompany you with your research.

Yours truly,

RKolbé (CPN)

M ROOPA
DIRECTOR: HEALTH AND ENVIRONMENT SERVICES

APPENDIX B

REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN THE POTCHEFSTROOM HEALTH DISTRICT

Mrs A Mohutsioa

Sub-District manager

Potchefstroon Health Services

Madam

PARTICIPATION IN RESEARCH: INFORMATION AND REQUEST FOR PERMISSION

I am currently registered as a student for a MCur (Community Nursing Science) degree at the Potchefstroom campus of the North-West University and as part of the degree I plan to do a research about the stigmatisation of a patient co-infected with TB and HIV.

The purpose of this research is to:

- ❖ To explore and describe the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers.
- ❖ To explore and describe the attitudes of health workers towards patients co-infected with TB and HIV.
- ❖ To formulate guidelines for health workers that will facilitate the health service utilization by patients co-infected with TB and HIV in the Potchefstroom district.

In order to achieve these objectives, unstructured interviews with the patients co-infected with TB and HIV, and semi-structured interviews with the health workers will be conducted.

Both these groups should be living in the areas of Potchefstroom, Wedela and Fochville in the North-West Province.

The criteria for inclusion are as follows:

In case of the patients co-infected with TB and HIV, they must

- be diagnosed with TB before they had tested HIV positive
  or
- be living with HIV or AIDS and subsequently became ill with TB.
- be females or males aged 16 years and older.
- be willing to sign a consent form to participate in this research and agree on the use of an audiotape during the interview.
- be able to communicate in any language that is understood by the researcher (Zulu, Xhosa, Setswana, Sesotho, English or Afrikaans).

Health workers must

- be within any category of health workers
- serve in a health services within the Potchefstroom district in the North West Province
- be directly involved in caring for and treating the patients with TB and HIV in the clinics and mobile health service for at least one year, which would indicate that they understand the dynamics of that particular community
- be willing to sign a consent form to participate in this research and agree on the use of an audiotape during the interview.
- be able to communicate in any one of the following languages: Zulu, Xhosa, Setswana, Sesotho, English or Afrikaans.

The interviews for those who agree to participate will be conducted during August and September 2004. Interviews will be preferably conducted at the place of choice of the participant, be it their homes or the clinic and will last forty-five minutes to an hour per

person. All the names of the participants and the research proceedings will be treated confidentially.

It will be appreciated if one health worker in each clinic who is not part of the research population of health workers will be identified and act as a mediator in the recruitment of patients as participants. Your timeous response will be of great help as I will be able to make further arrangements.

If more information is needed with regards to this research, please call me at the above mentioned telephone numbers.

Thanking you in anticipation

Yours sincerely

____

D R PHETLHU (Researcher)

____

Mrs E DU PLESSIS (Study Leader)

____

Mrs M J WATSON (Co-Study leader)

DEPARTMENT OF HEALTH
North West Province
POTCHEFSTROOM SUB-DISTRICT

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Enq: Mrs M Mohutsioa

Reference:

"Celebrating Ten Years of Democracy and Accelerated Health Service Delivery"

"Celebrating Ten Years of Democracy and Accelerated Health Service Delivery"

To: Mrs D.R. Phetlhu
PUCHE
Potchefstroom

The Management team of the Potchefstroom sub-district of health would like to acknowledge receipt of your letter, requesting permission to conduct research on Stigmatization of patients co-infected with TB and HIV and AIDS.

As management we appreciate your interest in conducting research within our sub-district and heartily grant you permission to continue with your research.

We will appreciate it fully if you can share the result of your research studies with us so that we are able to correct the relationship between health workers and the patients, and thus improve on the entire service delivery.

Wishing you the best of success in your studies.

Thank you

(Mrs.) MA Mohutsioa
Acting District Manager
02.06.2004

Join the Partnership Against AIDS – Our Action Counts

APPENDIX C

REQUEST TO ACT AS A MEDIATOR IN RESEARCH IN THE POTCHEFSTROOM HEALTH DISTRICT

Sir/Madam

PARTICIPATION AS MEDIATOR IN RESEARCH: INFORMATION AND REQUEST FOR PERMISSION

I am currently registered as a student for a MCur (Community Nursing Science) degree at the Potchefstroom campus of the North-West University and as part of the degree I plan to do a research about the stigmatisation of a patient co-infected with TB and HIV.

The purpose of this research is to:

- To explore and describe the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers.
- To explore and describe the attitudes of health workers towards patients co-infected with TB and HIV.
- To formulate guidelines for health workers that will facilitate the health service utilization by patients co-infected with TB and HIV in the Potchefstroom district.

In order to achieve these objectives, unstructured interviews with the patients co-infected with TB and HIV, and semi-structured interviews with the health workers will be conducted. Both these groups should be living in the areas of Potchefstroom, Wedela and Fochville in the North-West Province.

The role of the mediator was to:

- identify and compile a list of potential participants,
- explain the purpose, benefits and importance of the research project to the potential participants,
- explain to the potential participants all ethical issues outlined in the consent form,

- explain to the potential participants the method of data collection and that the interview will be recorded on an audio-tape and will last more or less forty-five minutes,
- explain that the process of debriefing will be made available to the potential participants after the interview should they experience any discomfort.
- arrange appointments for the interviews on behalf of the researcher that would suit both the researcher and the participants,
- explain to the participant the importance of not being disturbed during the interview, which will include not bringing small children on the day of the interview,
- agree with the participant on behalf of the researcher on a venue where the interview will take place and that suits the participant,
- organise a private room with no or minimal disturbance at the clinic for those participants who wished to have the interview conducted there, and
- introduce the researcher to the participant before or on the day of the interview.

The criteria for inclusion of patients as participants are as follows:

they must

- be diagnosed with TB before they had tested HIV positive
  or

- be living with HIV or AIDS and subsequently became ill with TB.
- be females or males aged 16 years and older.
- be willing to sign a consent form to participate in this research and agree on the use of an audiotape during the interview.
- be able to communicate in any language that is understood by the researcher (Zulu, Xhosa, Setswana, Sesotho, English or Afrikaans).

The interviews for those who agree to participate will be conducted during August and September 2004. Interviews will be preferably conducted at the place of choice of the participant, be it their homes or the clinic and will last forty-five minutes to an hour per

person. All the names of the participants and the research proceedings will be treated confidentially.

It will be appreciated if you submit the list of participants that have agreed to be involved and the arrangements that you made with them on my behalf. Your timeous response will be of great help as I will be able to make further arrangements.

If more information is needed with regards to this research, please call me at the above mentioned telephone numbers.

Thanking you in anticipation

Yours sincerely

____

D R PHETLHU (Researcher)

____

Mrs E DU PLESSIS (Study Leader)

____

Mrs M J WATSON (Co-Study leader)

APPENDIX D

REQUEST TO REFER THE PATIENTS FOR COUNSELLING

Sir

I am currently registered as a student for a MCur (Community Nursing Science) degree at the Potchefstroom campus of the North-West University and as part of the degree I plan to do a research about the stigmatisation of a patient co-infected with TB and HIV.

The purpose of this research is to:

- To explore and describe the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers.
- To explore and describe the attitudes of health workers towards patients co-infected with TB and HIV.
- To formulate guidelines for health workers that will facilitate the health service utilization by patients co-infected with TB and HIV in the Potchefstroom district.

In order to achieve these objectives, unstructured interviews with the patients co-infected with TB and HIV, and semi-structured interviews with the health workers will be conducted. Both these groups should be living in the areas of Potchefstroom, Wedela and Fochville in the North-West Province.

The interviews for those who agree to participate will be conducted during August and September 2004. Interviews will preferably be conducted at the place of choice of the participant, be it their homes or the clinic and will last forty-five minutes to an hour per person. These interviews might cause the participants to experience feelings of distress due to their explanation of their lived experiences.

I therefore request your availability for counseling and debriefing for these participants as an expert in this regard. All the names of the participants and the research proceedings will be treated confidentially.

If more information is needed with regards to this research, please call me at the above mentioned telephone numbers.

Thank you

Yours sincerely

____

D R PHETLHU (Researcher)

____

Mrs E DU PLESSIS (Study Leader)

____

Mrs M J WATSON (Co-Study leader)

APPENDIX E

CONSENT TO BE A PARTICIPANT IN RESEARCH: STIGMATISATION OF A PATIENT CO-INFECTED WITH TB AND HIV

A. PURPOSE AND BACKGROUND

Mrs Phetlhu is conducting research to try and understand stigma towards the patients co-infected with TB and HIV. The researcher has developed a question/ questionnaire to explore your experience regarding this issue.

The objectives of the research are

1. To explore and describe the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers.
2. To explore and describe the attitudes of health workers towards patients co-infected with TB and HIV.
3. To formulate guidelines for health workers that will facilitate the health service utilization by patients co-infected with TB and HIV in the Potchefstroom district.

You are being asked to participate in this research because your responses will help in reaching these objectives

B. PROCEDURE

If you agree to be in this research the following will occur:

1. You will respond to a questionnaire/ questions that will be asked by the researcher.
2. A tape recorder will be used so as to make sure that the researcher has the whole information, and it will be destroyed after it has been transcribed.
3. Your participation will take no longer than about forty-five minute to an hour.
4. The setting will either be health service, work, home or community.

C. RISKS/DISCOMFORTS

1. Some of the questions may remind you of unpleasant feelings but you may decline to answer any questions you do not wish to answer.
2. You may become tired while answering the questions.
3. You will be referred to a psychiatric nurse for counseling on your request/ if necessary.

D. CONFIDENTIALITY

Participation in this research may involve a loss of privacy; however your records will be handled as confidentially as possible. Only Mrs Phetlhu will have access to your research records. No individual identifiers will be used in any reports or publications resulting from the survey.

E. BENEFITS

There will be no direct benefit to you from participating in this study. Your participation will help the researchers to formulate guidelines for health workers that will facilitate the health service utilization by patients co-infected with TB and HIV.

F. COSTS

There will be no cost to you as a result of participating in the research.

G. PAYMENT

You will receive no payment for your participation. Transportation costs will be reimbursed.

H. QUESTIONS

You have talked to Mrs Phetlhu or the health worker who signed below about this research and have had your questions concerning the consent answered. If you still have further questions, feel free to ask Mrs Phetlhu or call her at 018 299 2398

I. CONSENT

You will be given a copy of this consent to keep

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. You are free to decline to be in this research, or to withdraw from it at any point. Your decision as to whether or not to participate in this research will have no influence on your present or future use of the health services.

_______________ ____

DATE **SIGNATURE OF THE STUDY PARTICIPANT**

_______________ ____

DATE SIGNATURE OF THE PERSON OBTAINING CONSENT

APPENDIX F

TUMELELO YA GO NNA MOTSAYA KAROLO MO DIPATLISISONG:

SETIKIMA SA MOLWETSI YO O TSHELANG KA MALWETSI A TB LE HIV KA GONGWE

A. MAIKAELELO LE LEMORAGO

Moh Phetlhu o dira dipatlisiso go tlhaloganya ka setikima se se lebisitsweng kwa molwetsing yo o tshwaeditsweng ke malwetsi a TB le HIV ka gangwe. Mmatlisisi o dirile potso/dipotsolotso mabapi le go tlhaloganya maitemogelo a gago ka kgang e.

Maikaelelo a patlisiso e ke go:

1. batlisisa le go tlhalosa maitemogelo a balwetsi ba ba tshwaeditsweng ke malwetsi a TB le HIV ka gongwe ka ga setikima gotswa go badiri ba pholo
2. batlisisa le go tlhalosa maitsholo/maikutlo a badiri ba pholo go ya kwa balwetsing ba ba tshwaeditsweng ke malwetsi a TB le HIV ka gongwe
3. dira melawana e e ka thusang badiri ba pholo go rotloetsa balwetsi ba ba tshwaeditsweng ke malwetsi a TB le HIV ka gangwe go dirisa di tirelo tsa pholo mo tikologong ya Potchefstroom

O kopiwa go tsaya karolo mo thutong e, kantlha ya gore tsibogo ya gago go tla thusa go fitlhelela maikaelelo a.

B. TSAMAISO

Fa o dumela go tsaya karolo mo thutong e, go tla diragala tse di latelang:

1. O tla tshwanela ke go tsibogela potso/dipotsolotso tseo di botsiwang ke mmatlisisi.
2. Go tla dirisiwa setsaya mantswe go gatisa puisano eo go kgontsha mmatlisisi go ka nna le dintlha tsotlhe, mme e tla phumulwa morago ga go kwalololwa.
3. Go tsaya karolo ga gago go ka se fete palogotlhe ya metsotso e somenne tlhano go ya go ura

4. Se se ka dirwa mo lefelong la boitekanelo (tliliniki, bookelo) kwa tirong kwa gae kgotsa mo baaging.

C. MATSAPA/GO SE IKETLE

1. Dingwe tsa dipotso di ka go kgobera mme o ka gana go araba dipotso tseo o sa batleng go di araba.
2. O ka ikutlwa o lapile fa o araba dipotso.
3. Go tla nna le mooki wa moitsanape mo mererong ya maikutlo mme o tla romelwa kwa go ena fa o mo tlhoka

D. BOKHUPAMARAMA

Go tsaya karolo mo dipatlisisong tse go ka akaretsa go latlhegelwa ke sephiri, le fa gontse jalo direkoto tsa gago di tla tsholwa mo sephiring ka moo go kgonagalang. Ke Moh Phetlhu fela yoo tla nnang le phitlhelelo ya direkoto tsa gago tsa thuto. Ga go boitshupo ba batho boo bo tla diriswang mo dipegelong kgotsa mo diphasalatsong tsa dipatlisiso.

E. DIPOELO

Ga go dipoelo ka tlhamalalo tseo o tla di bonang ka go tsaya karolo mo thutong e. Mme mmatlisisi o tla kgona go dira melawana e e ka thusang gore balwetsi ba ba tshwaeditsweng ke bolwetsi jwa TB le HIV ka gangwe ga kgontswe go dirisa di tirelo tsa pholo.

F. DITSHENEYEGELO

Ga go ditsheneyegelo tse o tla itemogelang tsona fa o tsaya karolo mo dithutong tse.

G. DITUELO

Ga nkitla o amogela dituelo tsa go tsaya karolo. O tla busediwa ditsheneyego mabapi le dipalangwa

H. DIPOTSO

O buile le Moh Phetlhu kgotsa modiredi pholo yo o saenileng fa tlase mabapi le thuto e mme dipotso tsa gago tsa arajwa mabapi le tumelelo. Fa o santse o na le dipotso, gololosega go botsa mmatlisisi kgotsa o leletse Moh Phetlhu mo go 018 299 1829.

I. TUMELELO

O tla fiwa khophi ya tumelelo e go e tshola.

GO TSAYA KAROLO MO THUTONG E GO DIRWA KA BIOTHAOPO. O gololosegile go gana go tsaya karolo mo thutong e, kgotsa go ikgolola mo go yona nako nngwe le nngwe. Tshwetso ya gago ya go tsaya karolo mo thutong e, gankitla e nna le khuetso epe mo boemong jwa gago jwa ga jaana kgotsa jwa isagwe jwa tiriso ya mafelo a pholo.

____________ ____________________________________

LETLHA **TSHAENO YA MOTSAAKAROLO MO THUTONG**

____________ ____________________________________

LETLHA **TSHAENO YA MMATLISISI**

APPENDIX G

SEMI-STRUCTURED INTERVIEW SCHEDULE FOR HEALTH WORKERS ON THEIR ATTITUDE TOWARDS THE PATIENTS CO-INFECTED WITH TB AND HIV

1. What is your opinion about patients co infected with TB and HIV
2. What feeling do you experience towards these patients as the person working closely with them
3. How do you as a health worker behave towards patient co-infected with TB and HIV when working with them
4. How will you describe your attitude towards patient co-infected with TB and HIV

APPENDIX H

FIELD NOTES FOR PATIENTS AND HEALTH WORKERS

1. FIELD NOTES FOR PATIENTS

PATIENT 1

Descriptive notes

A middle aged woman, who have been diagnosed with HIV three (3) years ago and have been on TB treatment for the past four (4) months. The patient looked sick though she tried her best not to show it. She was willing to talk even though she was not keen to talk about her HIV status. The interviewer struggled to get the patient to talk as the patient kept silence most of the time. She preferred to give short answer and even when probing was done she responded very shortly. That aspect made it difficult for the interviewer as the patient close off and answered mostly with Yes or No. The interview was held in a private room in the clinic. No interruptions were experienced.

Reflective notes

A very withdrawn person. The patient appear sad but doesn't want to talk about it. She says she is fine but mentioned the death of her sister and that of her partner with tears in her eyes. Doesn't like to ask questions even in the clinic area thus the patient is not keen on counseling. She looked relaxed but very calculating in what she was saying. She seemed to be avoiding some probes about her experiences especially when the clinic is mentioned.

Demographic notes

The interview took place on the 16th August 2004 at 09:30 at the clinic. The researcher found the patient at her sister's house as arranged and they drove together in the researcher's car to the clinic. A private room was used and the interview lasted for about twenty-five minutes.

PATIENT 2

Descriptive notes

The patient is a young adult who is very involved in issues of TB and HIV and is part of a support group. She has been living with HIV for five (5) years and had been infected with TB twice. She appeared healthy though she expressed that she had lost weight. The patient was willing to talk about her experiences and she appeared very relaxed and come though as passionate when discussing things that get her down. The interview was held at the clinic in a private room and no interruptions were experienced. Probes were used to encourage the patient to talk as well as the non verbal communication. Most of the time the patient volunteered information and enjoyed to express her views.

Reflective notes

She came across as well informed with regards to both these diseases. She seems to be very open about her condition. The patient says whatever she feels and whatever comes to her mind and is not intimidated by the researcher. Although very strong willed, she often shows non verbal signs of loss of hope by sighing when answering some questions. She often shows signs of anger by increasing her tone of voice when she wants to emphasize a point. One tends to notice some level of sadness as she blinks away tears and not allowing herself to be emotional. Patient seems to be using the interview as a platform for debriefing and venting her frustrations. She actually commended that she had wanted to talk to someone about this issue of stigma. She seemed to have no trust at all towards the health workers and expressed their lack of confidentiality quiet frequent. She appeared to have anger towards those who does not treat the patients' right. She was also very critical about the health service and appears to think that much more can be done to save lives. She also seemed to be very critical about the knowledge level of some health workers which she expressed as fuelling stigma.

Demographic notes

The interview was held at about 11:00 on the 16th August 2004 at the clinic. It lasted for one hour thirty minutes as the patient wanted to express herself and the researcher allowed her to do so without putting any restrain on time.

PATIENT 3

Descriptive notes

A middle aged woman living with her husband and daughter in a very modern home. The interview was held at the patient's house. On the researcher's arrival, the patient's husband was present but left on arrival of the researcher. The husband was apparently prepared for the visit and was aware about the reasons thereof. The patient appeared relaxed regarding the interview and showed no signs of discomfort. She was willing to talk openly about her condition and did not appear to feel embarrassed. Her non verbal responses showed that she was calm. Her support system at home was visible as her partner acknowledged our meeting and gave us privacy. The discussion went smoothly with the researcher trying to probe as much as she can on the subject.

Reflective notes

The patient did not appear to be hiding anything. There were no emotions such as anger detected or bitterness. She seems to have come to terms with her condition. She seemed sincere about the treatment that she receives from the clinics. She also appeared to be in control of her situation and not afraid to express her discomfort about the health services.

Demographic notes

The interviews were held at 10:00 on the 17th August 2004. The interview was held at the patient's house. It was very private and it was only the two of us at home after the partner left on commencement of the interview. The ventilation was good as it was slightly cold that morning. The interview lasted for about forty-five minutes.

PATIENT 4

Descriptive notes

A young adult of approximately 34 years of age. Patient started being hesitant and not sure that she wanted to participate in the discussion. After thorough discussions and explanation by the researcher, she started to relax. After a while she became very comfortable with talking about her condition and explaining her experiences. She was calm though sometimes became emotional and cried during the interview. She expressed herself enthusiastically with the use of signs to show what she meant. The interview was held at the clinic. Once interrupted by a health worker even when indication was made that there are interviews in process. The researcher encouraged the patient to vent her feeling and occasionally touched her when she became emotional. The interview went smoothly.

Reflective notes

Patient appeared angry when telling her story about the treatment that the patients received at the other clinics. But she showed real enthusiasm when she referred to the health worker that treat her with respect. There was a lot of sadness detected from the patient as expressed through her crying and the tone of her voice.

Demographic notes

The interview was held at the clinic on the 17th August 2004 at about 11:30 and lasted for one (1) hour. A private room was used and a sign that indicated that there were interviews in process was placed on the door. It was raining and slightly cold but the ventilation was satisfactory.

PATIENT 5

Descriptive notes

The patient was a young adult approximately 30 years of age and has been living with HIV for three (3) years and currently on TB treatment. The patient was not relaxed in the beginning but calmed down as the discussion continued. She was willing to discuss her status and very honest about how she felt about the clinics and the health workers. The interview was held in a private room at the clinic. No interruptions occurred.

Reflective notes

The patient seemed to have insight into her condition and is in touch with the latest developments regarding HIV. She seemed to be very defensive about the health workers in one particular clinic. She appears to have a very good trust relationship with the health workers there. She sometimes expressed her anger towards the health workers at the other clinic by raising her tone of voice when she explained some aspects. She seemed to be very cynical about the behaviours of some health workers and portrayed a sense of lack of trust. She seemed to have accepted her condition though she believed that she is going to die and was hopeless that nothing could be done.

Demographic noted

The interview was held on the 17th August 2004 in the afternoon. It was raining on that day and slightly cold. The interview lasted for about forty-five minutes.

PATIENT 6

Descriptive notes

The patient was young adult woman of approximately 26 years of age. She was very tense in the beginning of the interview and concentrated more on her TB status than the HIV. After a while she become relaxed and stared to talk calmly. She was willing to talk and share experiences although she was not very open about other issues as she felt that it might create conflict. Patient verbalised that she is sometimes depressed even though she appeared anxious as she would talk continuously for sometimes without getting to a point. The interview was held at the clinic, and one interruption occurred as the room use for the interview was also used for other TB patients.

Reflective notes

Patient appeared to be defensive about her condition and blamed other family relatives for her conflicting relationships with other. But she appears to trust the health workers and showed a willingness to discuss anything with them or strangers. At times she seemed to manipulate information as she would then correct herself when she realize that she had contradicted herself. She seemed not to have accepted both her TB and HIV status. She had a strong believe on traditional and spiritual healing and trusted alternative methods of healing. She seemed sad at appoint and cried but when the researcher offered to refer her for counseling, she refused and said she will be fine.

Demographic notes

The interview was held on the 17th August 2004 at 16:00 in a clinic at Potchefstroom. The room was private and no interruptions were encountered. The interview lasted for about one hour.

PATIENT 7

Descriptive notes

A young adult aged 30 years who have disclosed her HIV status openly in the community, is part of a support group and is doing voluntary counseling in the clinics. The patient is very involved with the issues of TB and HIV in and outside the community She was very relaxed and keen to take part on the discussion. She was very informed about her conditions and the implication thereof. The patient portrayed a very positive self image and had a positive attitude toward life. She was willing to talk to anybody about these conditions. Very strong willed and is enthusiastic about helping other people in the same situation. The interview was held at a clinic. The room was private though other patients were sitting outside and their noise could be heard.

Reflective notes

She is very passionate about the topic. The patient sometimes talked about issues that were not related to the topic but the researcher managed to bring her back. She seems to be willing to do anything to be heard. She sometimes showed anger towards those who treat people unfairly by raining her voice when expressing a point. The patient seems to be frustrated by the way things are done at the health services and feels that more could be done for the patients. She does not get intimidated by the health workers and say exactly what she thinks of the situation without hiding anything. She appears to use the discussion as a platform to pass her frustrations with hope that she might get quick solutions. Often a quick sign of sadness is notices especially when she talks about people close to her and how she observes other people being treated unfairly. She also appears to be using the interview as a sort of therapeutic counseling session for herself.

Demographic notes

The interviews were held at the clinic in Potchefstroom on the 18th August 2004. The session was done at about 10:30 and lasted for approximately two hours.

PATIENT 8

Descriptive notes

Middle aged male of about forty six years who appear ill though still up and about. The patient was originally from the rural area of the Eastern Cape and has moved to Wedela a year ago. The patient looked relaxed though did not co-operate information freely. He appears to be shy and not sure about himself. The researcher tried to probe but the patient remained aloof. The interview was held in a private room at the clinic and no interruptions were experienced.

Reflective notes

The patient appears to be denying his illness and does not want of talk about it. On the other hand since the patient is from the rural area, his inability to talk about his experiences maybe the results of culture. He also seemed to lack trust and fears that what he might say would be revealed thus closely calculate what he says.

Demographic notes

The interview was held at the clinic in on the 19th August at about 10:00 and lasted approximately fifteen minutes.

PATIENT 9

Descriptive notes

A young male approximately 25 years of age who have been diagnosed with TB four months ago and then tested HIV positive two months later. In the beginning of the interview the patient appeared to be anxious and kept fidgeting with his hands. As the interview progressed he became more relaxed and started to express his views openly. The interview was held in a private room at a clinic. There were initially a lot of disturbances as the health workers kept coming in the interview room although the "interviews in progress" sign was displayed. The researcher had to stop for a few minutes and address the health workers about the importance of not entering the room while the interviews were done. The other patients were also sitting outside the room and noise was a problem though the patient was not bothered with the setting.

Reflective notes

In the beginning the patient seemed to be afraid to say something about the health workers' behaviour and came across as very defensive about that. However he seemed to be expressing what he thought about the patients, the health workers and the health services truthfully. Sadness was often observed when he spoke about how the others have treated him when he was very ill.

Demographic notes

The interview was held at a clinic in Wedela on the 19th August 2005 at about 10:30. The interview lasted for forty minutes.

2. FIELD NOTES FOR HEALTH WORKERS

HEALTH WORKER 1

Descriptive notes

The health worker was a thirty six year old woman who has been working in the community for approximately ten (10) years. She was very relaxed and eager to share. She was very passionate about the subject and showed that she goes an extra mile for the patients. Her non verbal communication indicated that she took great responsibility for what she does and feels a sense of responsibility towards her patients. The interview was held in a private room and no interruptions experienced. The interview went smoothly and the researcher allowed the participant to vent out her feeling

Reflective notes

The participant vented some anger about being helpless. She appeared to be willing to do anything to assist the patient. A sense of desperation to assist her patient as far as she could and frustration when her objectives were not reached was observed. She became emotional when she expresses how she feels towards these patients. She appeared to be firm and believed in her convictions. Though she mentioned that she is strict, she comes across as very compassionate. She also seemed to be very dedicated to her patients.

Demographic notes

The interview was held at the clinic on the 24th August 2004 at about 11:00. The weather was slightly cold but the room was very comfortable.

HEALTH WORKER 2

Descriptive notes

The participant was a very soft spoken woman of about twenty eight years of age who liked to laughs a lot. She was very relaxed during the interview. She shared her enthusiasm in working with patients co-infected with TB and HIV. The interview was well organised in a private room and no interruptions were experienced.

Reflective notes

She seemed to be a very reliable person and very honest. She appeared to be open minded thus could have trust relationship with the patients very easy. She seemed to be willing to help the patients and was attached to them. This was indicated when she gave them food from her own home. She also acted as an advocate for the patients. Anger towards the health system was noted in her tone when she spoke about the in ability to assist the patient with basic needs such as when there are no food supplements for the patient.

Demographic notes

The interview was held at a clinic on the 24th August 2004 at about 15:30 and lasted for an hour. The room was well ventilated even though it was clod outside.

HEALTH WORKER 3

Descriptive notes

The participant was a middle aged woman of about thirty nine years. She was very relaxed and willing to share information with the researcher. She showed enthusiasm in working with these patients and mostly referred to the as "my friends". She indicated that she respected them and that was noted in the way she addressed them. Her general attitude about the diseases was open and she talked freely without looking embarrassed. The room was very private even though it was in the clinic. The room did not have any disruptions including telephones. The discussion was free flowing and the participant was not coerced into answering questions. The researcher was very encouraging and reassured the people about the purpose of the study.

Reflective notes

The participant seemed to have a trust relationship with the patients even though she doesn't show them any sympathy what so ever. She believed that doing so would create a feeling of discrimination towards them. She appeared passionate about her work and willing to do anything to make the co-infected patients feel like everybody else and welcomed.

Demographic notes

The interview was held on the 24th August 2004 at 16:55 and lasted for forty-five minutes. The room in which they were held was comfortable and well ventilated.

HEALTH WORKER 4

Descriptive notes

The participant was very nervous in the beginning but relaxed. She was very open about the topic. She was not keeping eye contact and sometimes hesitant when answering the question. The place where the interview was held was not very private. It was one of the rooms in the clinic and it was very busy with other health workers coming in to collect medication. We were interrupted twice and the researcher had to explain to the other health workers in the clinic the importance of not interrupting the process.

Reflective notes

The participant was not defensive and seemed to be very honest about how she felt. Very empathetic towards her patient but scared about testing herself for the virus. She did not appear confident with her counseling skills or handling of patients. At times she appeared to be intimidated by the questions and pause for a long time as if calculating what is right or wrong. She was at times evasive of the direct questions and became very abstract in her answering.

Demographic notes

The interview was held at a clinic in Fochville on the 25th August 2004 at about 11:00. It was cold and raining on that particular day.

HEALTH WORKER 5

Descriptive notes

The participant was a middle aged woman of approximately forty-five years. She has been working in the community for more than ten (10) years. In the beginning of the interview she was tense and not keeping eye contact. She became relaxed and started to be herself and talked freely. She was a loud speaking person and likes to laugh while expressing her thoughts. She was very knowledgeable especially about these two conditions. The interviews were held at the clinics and there were no interruptions.

Reflective notes

She comes across as a very strict person. That was noted in her facial expression when she explained aspects about the patients. She was a little defensive about the attitudes of the health workers as she tried and justified why some things are done the way they were done. She seemed to care about the patients but didn't like to be emotionally tide to them. She was very evasive in the beginning and tried to avoid giving her own opinion by laughing but decided to be honest. She seemed to be impatient when dealing with the patients and get angry when they do not do as she instructed. This was noted in her tone of voice and was shown by her facial expression when she responded.

Demographic notes

The interview was held on the 26th August 2004 at the clinic in Potchefstroom. It started at 09:15 lasted for approximately forty five minutes.

HEALTH WORKER 6

Descriptive notes

The participant was an elderly woman of approximately fifty years and has been working in the community for over ten (10) years. She was very keen about her patients and knows most of them by name. She was very enthusiastic about the discussion and passionate about what she does for the patient. She was very calm and relaxed during the interview. Her non verbal response indicated that she had confidence in herself and her colleagues. She has a good trust relationship with her patients. Interview went uninterrupted in a private room in the clinic.

Reflective notes

She appeared emotionally attached to her patient and willing to do anything to help them. She was very open minded about the conditions and was not judgmental. She was very empathetic as she mentioned that everybody can be infected and that they are affected in that clinic. Some frustration was noticed especially where she expressed a sense of helplessness.

Demographic notes

The interview was conducted on the 26th August 2004 at 11:00 and lasted one hour. The condition in the room where the interview was held was comfortable.

HEALTH WORKER 7

Descriptive notes

Middle aged woman of about forty six years who has been working in the community for more than ten years. In the beginning the participant seemed nervous but started to relax and was able to share a lot of thing. She was fidgeting with a pen but later put it away. The interviews were interrupted twice by other health personnel. The room was comfortable but the clinic was small and that made it difficult for us to get a very private room but the interruptions stopped as soon as they realised that we were busy with the interview.

Reflective notes

The participant appeared to be hesitant and not spontaneous on answering questions. It seems that she wanted to say the right things and not what was in her mind. She sometimes came across as defensive and denied to express her real feeling especially how she felt towards patient. That was observed when she mentioned that it hurts her but won't show in front of the patient, she become emotional. She appears to be nonjudgmental about the people and tried to work with them well.

Demographic notes

The interview was held on the 26th August 2004 at 16: 00 in a clinic in Potchefstroom. It lasted for approximately forty minutes. The weather was getting cold but the ventilation was good in the room where the interview was held.

HEALTH WORKER 8

Descriptive notes

The participant was a middle aged woman who has been working in the community for twelve years. In the beginning the participant was tense but she relaxed as soon as she realised the line of questioning. The researcher made the participant as comfortable as possible by reassuring her regarding confidentiality. She became very open and shared information that was personal. She loved talking about the topic and showed enthusiasm by the tone of voice that changed every time she became passionate. The interview went uninterrupted.

Reflective notes

In the beginning it appeared that the participant was scared and was hiding something. She appears to be a person who speaks loudly and may come across as rude. At times she sounded defensive especially when talking about her own attitude towards patients. But generally she seemed like a person who is willing to help others. She did not appear to be afraid about what she was mentioning in the discussion

Demographic notes

The interview was held on the 27th August 2004 at a clinic in Potchefstroom. It started at 09:30 and lasted for an hour.

HEALTH WORKER 9

Descriptive notes

The participant was a young adult of about 26 years of age. She has been working in the community for approximately three years. The health worker was calm and willing to share her experiences with the researcher. She was well informed about what is going on in the clinics. The interview was held in the privacy of the health workers home. No interruptions experienced during the interview.

Reflective notes

She appeared to be very emotionally involved in her work. She gave her opinions without being protective of the health system or defensive of her collogues. She seems to be very respectful towards the patient though she handles them with extreme care. She appeared to be very sensitive when talking about these patients. She showed emotions of sadness especially when expressing how she felt about them and seemed to have a trust relationship with these patients

Demographic notes

The interview was held on Friday the 27th August 2004 in Potchefstroom. The weather was good and the interview lasted for one hour.

APPENDIX I

WORK PROTOCOL FOR DATA ANALYSIS

Dear Mrs Emmerencia Du Plessis

Thank you for agreeing to be my co-coder for this research. The objectives of this research is as follows

1. To explore and describe the experiences of patients co-infected with TB and HIV concerning stigmatisation by health workers.
2. To explore and describe the attitudes of health workers towards patients co-infected with TB and HIV.
3. To formulate guidelines for health workers that will facilitate the health service utilization by patients co-infected with TB and HIV in the Potchefstroom district.

Two populations were used namely the patients co-infected with TB and HIV, and the health workers who were involved in the care of these patients.

For the patient population unstructured in-depth interviews were conducted and the question **"Tell me about your experiences as a patient co-infected with TB and HIV concerning stigmatization by health workers"** was asked by the researcher.

For the health worker population semi structured interview schedule was used. The following four (4) questions were asked

5. What is your opinion about patients co infected with TB and HIV
6. What feeling do you experience towards these patients as the person working closely with them
7. How do you as a health worker behave towards patient co-infected with TB and HIV when working with them
8. How will you describe your attitude towards patient co-infected with TB and HIV

As per our agreement, nine (9) transcripts of interviews conducted with the patients co-infected with TB and HIV, and nine (9) of the health workers together with their individual field notes are enclosed. The method of open coding as described by De Vos (*in* De Vos *et al.*, 2002:346) is used to analyze data. The following steps are followed

- Read all the transcripts to get an overall idea.
- Choose one transcript and read it again.
- Using words and sentences as units of analysis, read the transcript again, and underline the spoken word and sentences.
- Transfer the underlined words and sentences to the left hand column of the transcript together with concepts that are detected as categories.
- Write down your personal perceptions on the right hand column of the transcript.
- Then read the categories that were transferred to the right hand column so as to identify the main categories, the sub categories as well as the redundant categories.
- Transfer the underlined words (still in the respondent's own words) to a table indicating the main categories, the subcategories and further categories.
- Finalise these categories by going through the table again.
- Translated the spoken words into scientific language with the possibility that the categorization can be refined kept in mind.

As per our prior discussions, the consensus meeting will take place on 04 October 2004 at 14:00 in your office.

Thank you

____

Mrs D R Phetlhu

(Researcher)

APPENDIX J

PART OF A TRANSCRIPTION OF AN INTERVIEW WITH A PATIENT CO-INFECTED WITH TB AND HIV

PATIENT 7

(R: Researcher, P: Participants)

Patient 7

Researcher	I need the experience regarding the stigma in this case. Do you feel that there is stigma attached to you having TB and HIV at the same time, especially in the health system. What was the reaction from everybody from the word go?	
Researcher	In hospital...............it is like.......yes stigma is there at hospital. It means that they will make you feel that you have HIV and you have TB, more especially to be obvious.... I don't like this idea of ward 8. You see more over everybody knows that ward 8 is for HIV and AIDS, you understand. And everybody goes to ward 8. And even me, I was one of the people, that when I was sick, I go to ward 8, every time when I am sick, it is ward 8 you see. And then ....and....they.......know exactly what is happening to you. The nurses also.... they......they have a tendency	

	of speaking this funny languages.......so you have to be strong.	
Researcher	Funny languages, What are they saying?	
Patient	They will be saying........you see they use terms like....did you see that and that person, what what.....did you see him also, it is what...it is that... the three words(using small voice) what... you see those thing and then they will.........they invite some other nurses......to say who is here........I didn't know that they did it only with me or on everybody, but the way I saw it, ward 8 is not a nice ward.	
Researcher:	Seeing that you were admitted with TB, what was your experience and what was the reaction from other towards this issue of TB.	
Researcher:	Actually me, because I wasn't tested for HIV before, so they had already concluded that I am HIV+ even though I was......hadn't tested.......they were already saying that I am positive. and I.....I had just.................	
Researcher	Who was saying that?	
Researcher	Nurses, and they were saying" I am	

	just changing it. I want to say I have TB but it is not TB ...and if you are HIV and have TB they......do HIV....they don't consider TB anymore. They concentrate on HIV and still I don't see them doing anything you see. They will only be announcing that you have HIV but they don't do anything you see.......And worse part about nurses, they don't have that warmth (showing with hand to chest) did you see that? If they can, I feel that they need to be trained to have that....it is those... maybe 1 in a million that they have the warm feeling that they give to patients.......do you understand......that in other situations you end up being confused.......it is this and that....when you are sick you end up loosing memories and you do that....you say this and that.....you need professional help.....you need to........meaning that people shouldn't drive you to do other things. they should help you to.....to... in truth ....what should we do..........sometimes you end up asking the sister and she says(raising voice)" What should I do....I must do that." She should have a way to ask or answer you. She should be tactful you see. she	

	shouldn't say "now what should I do it is like that." Sometimes you ask her.....the doctor was there, and you were scared to ask him and you ask her," sister now that I have developed this, what is this and why? She will say (shouting) " I don't know, why didn't you ask the doctor" you see....that kid of language.	
Researcher	Mm	
Patient	They have that type of problem in ward 8. You see if they can't change it!!!!! more especially the boys....it is the boys and girls in ward 8.......ant they put everybody there, the psych...and so on. There is no rest in ward 8.	
R	Ok	
P	And people are not.......that is why people inward 8 are not getting healed.........there are no.....you get that one has diarrhoea, I end up going to the toilets and get that infection of somebody with diarrhoea...... It becomes routine.....It is not like in other ward where it is clean. This one is always dirty to be honest. it is not a clean ward.	
R	Ok	

P	Mmm (nodding)	
R	Now I want us to go back to that issue you said when you have TB and HIV they focus on HIV. What do you think lacks so that they don't focus on TB? Can you elaborate on that.	
P	I think they don't have knowledge. I know just like HIV......it is......being considered that when you have HIV it is the sickness of loose people just like that...do you understand......so that is why they announce it. That is why they do that. It is lacking knowledge that HIV is only.... it doesn't only mean that HIV, when you are infected, you were loose, you were sleeping around.	
R	Mmm and then	
P	It is like that, that is the way it is now. Most of the people......when it began HIV, it came with the concept that if you are HIV you were sleeping around. You see it didn't come brought like now at least they know......but you understand when we were diagnosed "us" with HIV+,........It was when you were HIV+, especially when you were beautiful and clever, and people knew you were involved in beauty	

	competitions and so on, people said yes, she had a lot of affairs. so so. she got HIV she was silly. Mmm	
R	You mentioned that nurses lacked empathy, they lacked care, Do you as a person who has experience....do they lack care? why do you say they lack care, was it on you personally or on everybody?	
P	It is a broad thing, It is a broad thing they are........if I should be honest, they are not dedicated. Some take this profession of nursing only because they don't have a job. You see it must be a call....you understand, it must be a call... You must know exactly.. you must do it from the heart, you must be dedicated. So the just going... they earn and they go off.....that is they go there letting the ticket go They are going to work, working for their children and as ....they go to work and they come back. they don't go...going to work becoming attached doing something because sometimes......like most of the cases, I used to end up not having treatment....the other one had forgotten that I am supposed to drink. They are able to forget. even	

	when you didn't drink (raising voice). It means you will get them sitting sometimes having their own conversation, not checking, not doing........you know they have such plenty of time to rounds and check that...that person has really taken their tablets, do follow ups........small once only........coming from them, from deap inside their hearts. But when they feel they have done whatever, they work based on time, they are through, they are through, you understand.	
R	Mmm	
P	It is few who will make sure that they see that patients has eaten, if it is the one that need a nappy.... Hmmm....There was a patient who I slept with, she used to defecated on herself and so on. She wasn't coping that patient, she wasn't doing it deliberately.....They hit her, she was not given food so that she won't defecate, but she needed to eat at the end of the day because on the other hand she was a TB patient. Do you understand. So she wasn't given food so that she wont defecate because they don't want top change her nappy. They don't want to.....So what is that? It shows that a person	

	came only there, She is disgusted but she knows that in nursing, when you go to nursing, you are going to handle blood, faeces, rotten things and so on. You must be ready for those things but when they are there, they get surprised.	
R	You mentioned something that I need us to explore, You said you sometimes ask the nurses about something and she said why didn't you ask the doctor. If I may ask that question, why as a patient didn't you ask the doctor?	
P	Sometimes you get that you are not free to the doctor. It will be a white doctor.....maybe you couldn't explain what you want to say.....you see.....and you feel that the nurse is Tswana like you, and then you can be able to talk to her. you see.	
R	Ok, what is your experience regarding the doctors?	
P	Me to be honest, I used to talk for myself, I used to talk a lot, asking them questions and every time complaining to them that this and that, that this happened and with that I never had a problem. Because even my doctor was there for me, they were all there for me to be	

	honest. I was fighting.	
R	Mmmm	
P	If I wasn't happy about something I just told them, and if I feel that I have a complain I, called them immediately........you see, My problem that I had was the sisters who were not dedicated because most of the time they used to forget my treatment.	
R	What treatment?	
P	Like the time I was allergic, when they were supposed to give me the pill that I was supposed to get before I took the other tablets, to prevent me from reacting or so, they will give me after. That time when I was vomiting blood they were supposed to give me..... there are other tablets that they had to sign for. the forgot,.......I asked myself but don't they see the danger that I was in......And you get that sometimes something big happens at the end. You get that the doctor is called. I get injected on my belly button because of small faults by the sister......she didn't go and get ....something. On weekends, the forgot to go the chemist, the other one needed to tell the next that you	

	have to book for this person for the weekend	
R	Mmmm! Is this a general thing that they forget or is it on specific cases	
P	I think it is general, not specifically to me.	
R	Ok........Can I say that the stigma is not only on TB and HIV patients but on all the sick people or would you say there is specific for TB and HIV patients?	
P	*There is for tb and hiv people and also for sick people*	
R	Can you explain that a bit, how do you differentiate it?	
P	For TB and HIV people, they get disgusted...... they feel disgusted really, you get that when you cough and you want containers for the sputum, they shout at you, like when you need to do something, they want you to do it for yourself........And sometimes you are weak Neh......Like they used to give us this containers written danger for putting sputum there. They say, they say you should take it somewhere, they scream at you and we don't know you see. If they educated us,	

	we don't have a problem of cooperating with them. I used to be strong enough to avoid a lot of things. I will stand up, go and throw it away, wash it and so on you see	
R	Ok. *Will you say the same stigma is* rife in the clinics?	
P	Not knowing........ but the clinics that I have gone to, No........not knowing about other *clinics to* be honest.......But this clinic No. They are very good, they pick up a lot of things, they can quickly check what. Even when clients are sitting there,, the nurse can pick up that this one need help and so on. They take efforts, they really take efforts, that is why clients...even me I ended up *willing to help. Other clients* we volunteer. Even for food, when we have extra food we give this clients........not knowing in other clinics.........(hesitant) Like I have seen in one clinic to be honest, they don't treat people well. The people there screams at patients (raising voice)"cough and take out your sputum there" *and* so on. But here not.	
R	At that clinic who actually do the screaming?	

P	Like especially the clerk,.....she is not treating people well	
R	Is it the clerk?	
	P Yes, she is not treating people well, she says to people she gets disgusted, they should go and cough their sputum where and so on. Of which here people don't complain. And patients who come here are bad	
R	What about the nurses?	
P	Yes they are also impatient. I didn't know.......there is one specific sister who is very impatient. I don't know of is it because she is young or if it is her first year being exposed to TB patients or what.	
R	Ok ......thanks for the information that I got, it is good enough. I am hoping to look at this results quick and if I need to have further discussion with you regarding this issue, I hope that will be welcomed again. I really need to say thank you but before I close is there anything that you want to talk about regarding this topic of stigma in TB and HIV that we did not touch?	

PART OF A TRANSCRIPTION OF AN INTERVIEW WITH A HEALTH WORKER INVOLVED IN THE CARE OF A PATIENTS CO-INFECTED WITH TB AND HIV

HEALTH WORKER

Interview for health worker 7

R	What is you opinion about the patient co-infected with TB ad HIV	
P	:....................Usually you find that the patient who are having TB or HIV,...... mostly they start by having TB and don't know that they are HIV+ or visa versa. So my opinion is that when you get a patient with HIV you must test for TB. If you get the TB's also test for HIV so that you can treat the patient on the TB side and also on the opportunistic infections such as PCP.	
R	But can you give me your opinion about the people, how are they ,how will you describe them?	
P	Eh.............In my skills and knowledge they are just ordinary people. Some are just becoming sick without being aware that they are HIV or TB. They will becoming here complaining and on examination maybe suggest that they should do test for TB or HIV.	
R	Their behaviour	
P	They differ with behaviour. Some will feel ashamed of having TB and HIV. And that	

	type of patient will never comply to the treatment. He can rather associate that illness with some witch craft other they accept the condition, they attend treatment for TB and HIV. So it is 50 -50.	
R	You said that they don't comply, can you explain it a little	
P	They don't comply, you find that she doesn't care for maybe TB treatment or HIV treatment. She will go to the traditional healer for treatment. Like this morning, I had two client who were diagnosed with HIV, they were never treated with Bactrim as prophylaxis... They were using herbs.....and then she wanted to be tested again to see if she is no negative. Unfortunately she was still positive.... so I had to counsel her.. tell her again about HIV that it is incurable. the only thing were have is prophylaxis for opportunistic diseases....	
R	Just to clarify what you said, would you say they are uncooperative?	
P	They are ....not to say they are uncooperative. It is because they are having stigma, they don't want to accept that they are HIV+. they want to associate it with something that is curable.	
R	You mentioned stigma, from who?	
P	From them, they have stigma from the	

	disease.........They don't want to be associated with that HIV or TB.	
R	Ok How do you feel about the patient co-infected with TB and HIV?	
P	I feel sorry because it shows that the counselling was not enough that is why the patients still feels that she can be cured by herbs. Maybe she was given only ehh..one counselling. So I think continuous post counselling to the patient is needed to encourage them to be on treatment. To tell them more about HIV and TB, to know more about HIV........ In my experience, you get different opinions from clients or what I have discovered when I am busy with them is that this one, she will comply and accept that she is HIV+, this one will still believe that the traditional healers will heal her.	
R	How do you behave towards the patient co-infected with TB and HIV?	
P	Well I behave normally as if ....eh eh.....so that they must accept HIV like any other disease, they must accept it. They mustn't feel that if they are HIV+ positive they are dying. So.....my behaviour I am just telling them to take care of themselves, it correctly, use condoms and look after their health s than they can live for a longer period. Because it doesn't mean that when you are HIV positive you are dying. It is just that you	

	are infected with this virus.	
R	Why do you think you should behave normal to this patient?	
P	I feel I behave normally because I don't sympathise with her that she must feel that people are sorry about what. I want her to accept that disease. Because once she sees that I am sorry for her, Feeling shame with her, she will be stigmatised.	
R	Ok...........Somebody mentioned that with these patients one need to be firm......what do you think about that statement?	
P	I don't think that is the case, you don't have to be strict on that patient. You have to do proper counselling , the patient must understand what is happening, give her time to ask you questions.........talk to her and then give a chance to say something to you.	
R	oK......Lastly.......What is you attitude towardsR the patient co-infected with TB and HIV.	
P	My attitude.... I am normal because I don't want to.........it is hurting to be HIV positive but I won't show the patient that it is hurting.........because even if I have to tell her that you are now positive you know.......I will take a breath, then look at her...I will look at her facial expression how doe she accept the disease.....so I am not going to cry with her to	

	show that it is hurting me......I am going to comfort her. but I am going to cry because if I do the patient will be demoralised but once I show that I am strong, I am accepting the disease, she will also accept that condition.	
R	Your personal attitude is positive as you say but is it all health workers have that attitude	
P	Well ehh.... some do have a negative attitude. One patient told me that one doctor told her that she is going to die. That you cannot tell the patient because you are not ...ehh GOD to decide when is the person going to die. That one you cannot say. And I still feel that there are some health workers who don't talk well with HIV clients. But since we are having counsellors people are now well counselled. And you will find that most of the counsellors are also affected so they are able to share with that client. And usually you find that the clients who are counselled by an infected person who is ehh.....looks well....they stood up, even if they are dying, they become strong. I cannot mention names but we had one counsellor who was very beautiful and she told the patients that I am HIV positive, and all those patients that she counselled they are up....they are up.	
R	Is there anything that you will like to add to this discussion that we haven't touched?	
P	There are still clients that are having stigma towards HIV, like right now I am having a	

	case where a patient has claimed R15 000.00 from me because she is HIV infected, she was coming to fill in the grand forms, so she was sited with the other people and I said give me those forms, Now she took that statement" give me your forms", that I was exposing her HIV status. mean while those forms any body can fill them not only the HIV + people. Children are filling them, BP AND DIABETICS are filling them.......so that patient took me to the lawyer	
R	And what happened?	
P	She wrote to the nursing council and they wrote my mangers for investigation?	
R	Does this mean that the patients stigmatised themselves	
P	Yes because I didn't say HIV forms, why should she react like that........those forms doesn't mean you are HIV +. So she doesn't accept the disease she has stigmatised herself.	
R	: oK...Thank you for you time and I really appreciate you giving me this chance. Thanks very much.	