

**A QUALITATIVE STUDY GENERATING AN ITEM POOL FOR A
SCALE THAT MEASURES NEGATIVITY EXPERIENCED BY
HIV/AIDS LAY COUNSELLORS**

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STATEMENT

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

Signature

Date

ABSTRACT

HIV infection rates to date have proven to be staggering both for South Africa as well as internationally. The primary victim of this deadly disease, the person living with HIV and AIDS (PLWHA) has suffered a wide range of negativity from other people, mostly as a result of less favoured associations made with the virus, namely: promiscuity, homosexuality and drug use. The PLWHA is however not the only victim of negativity such as prejudice, stigma and discrimination, as people who are closely related to him/her might be secondary targets hereof. The HIV/AIDS lay counsellor, who provides Voluntary-Counselling-and-Testing (VCT) as well as Pre-Mother-to-Child-Transmission (PMTCT) services to the community, is in regular and close contact with the PLWHA. This study has set out to investigate whether the HIV/AIDS lay counsellor, as a result of his/her continued contact with HIV, AIDS and the PLWHA, suffers negative attitudes and behaviour from others.

As the current researcher could not find an existing measuring tool for this group, the aim of the present study was to develop an item pool, which could measure experiences of negativity in HIV/AIDS lay counsellors. As point of departure in the development of this item pool a qualitative research methodology was followed, specifically utilising an Interpretative Phenomenological Analysis (IPA) process. An in-depth understanding of the realities pertaining to HIV/AIDS lay counsellors was sought, as items were constructed from their personal experiences of negativity. The finally developed item pool consisted of 30 items which related to: a) groups of people who

were negative towards HIV/AIDS lay counsellors, b) emerged themes from the collected data and c) examples of negative experiences.

The study attempted to fill the gap in existing research by focussing on a) secondary targets of negativity, in this case the HIV/AIDS lay counsellor, b) HIV/AIDS related negativity, such as prejudice, stigma and discrimination and c) the creation of a better understanding of the negativity experienced by HIV/AIDS lay counsellors. In doing so the study thus aimed at gathering information which could be used to better support, educate and select HIV/AIDS lay counsellors - also a means of combating the debilitating effects of prejudice, stigma and discrimination related to the HIV-virus.

OPSOMMING

In Suid-Afrika sowel as internasionaal het die voorkoms van HIV gevalle 'n astronomiese omvang bereik. Die primêre slagoffer van hierdie doodelike siekte, die persoon wat lewe met MIV en VIGS, ervaar 'n wye verskeidenheid van negatiwiteit vanaf andere. Dit is as gevolg van negatiewe assosiasies wat met die virus gemaak word, naamlik: promiskuiteit, homoseksualiteit en dwelmissbruik. Die persoon wat met MIV en VIGS lewe is egter nie die enigste slagoffer van negatiwiteit soos byvoorbeeld vooroordeel, stigma en diskriminasie nie, maar ook die mense wat in persoonlike kontak is met hom/haar wat as sekondêre slagoffers gereken kan word. Die MIV/VIGS berader, wat Vrywillige-Berading-en-Toetsing en Voor-Moeder-na-Kind-Transmissie dienste aanbied in die gemeenskap, is gereeld en persoonlik in kontak met die persone wat MIV en VIGS het. Hierdie studie het nagevors of die MIV/VIGS berader negatiewe houdings en gedrag van mense ervaar as gevolg van die voortdurende kontak wat hy/sy het met MIV, VIGS en persone wat MIV en VIGS onderlede het.

Aangesien die huidige navorser nie 'n bestaande meetinstrument vir hierdie groep kon vind nie, was die doelstelling van die betrokke studie om items te ontwikkel wat ervarings van negatiwiteit deur MIV/VIGS beraders kon meet. As 'n vertrekpunt is 'n kwalitatiewe navorsingsmetodologie gevolg en spesifiek die gebruik van Interpretierende Fenomenologiese Analise. 'n In-diepte begrip van die werklikhede wat verband hou met MIV/VIGS beraders was nagestreef, aangesien items vir die vraelys saamgestel is uit hulle persoonlike ervarings van negatiwiteit. Die finale 30 items hou verband met: a)

groepe mense wat negatief was teenoor beraders, b) temas wat gespruit het uit die ingewonne data en c) voorbeelde van spesifieke negatiewe ervarings.

Die studie het gepoog om die gaping in bestaande navorsing te vul deur te fokus op: a) sekondêre slagoffers van negatiewiteit, in hierdie geval die MIV/VIGS beraders, b) MIV/VIGS verwante negatiewiteit, soos vooroordeel, stigma en diskriminasie en c) die skep van 'n beter begrip van die negatiewiteit wat ervaar word deur MIV/VIGS beraders. Op hierdie wyse het die studie inligting bekom wat gebruik kan word vir die keuring en opleiding van MIV/VIGS beraders – ook om die nadelige effekte van vooroordeel, stigma en diskriminasie by hierdie groep aan te spreek.

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CHAPTER 1

Introduction

1.1 Problem Statement

From isolated cases reported in the 1980's, HIV and AIDS have shown its truly destructive potential by today infecting and affecting millions of people. Worldwide infection rates stand as evidence and additionally note the alarmingly high rates for sub-Saharan Africans ("HIV/AIDS in Sub-Saharan", 2002). Although a worldwide phenomenon, 70% of adults living with HIV and AIDS are from the sub-Saharan region and by the end of 2001, 28 million Africans were HIV infected (Rosen, 2001). During the same year an estimated 4.7 million South Africans tested positively with a growing rate of 5.3 million reported by the end of 2002 (Fredriksson & Berry, 2002). In 2003 studies estimated that 27% of pregnant South African women were HIV positive with approximately 5.6 million South Africans HIV positive by the end of that year (Noble, Berry & Fredriksson, 2005). Although current research finds HIV infection rates tapering off somewhat 10% of South African youth and one in four women aged between 20 and 24 years have tested HIV positive (Quinn, 2004). With an estimated 600 people dying daily of AIDS-related illnesses in South Africa ("Increased use of Primary", 2003), the continued relevance and importance of research related to HIV and AIDS is evident.

As the stated statistics have illuminated, HIV and AIDS have grown to epidemic proportions, effecting and affecting millions of people both in South Africa and abroad. The reality and subsequent impact of HIV and AIDS have become an undeniable force to reckon with, not only for people who are HIV infected or suffering from AIDS, but also for those who are affected by it in some way. HIV and AIDS have thus come to extend its influence on the life experiences of those who are the primary target thereof, the PLWHA (person living with HIV and AIDS), and possibly to those people closely associated with them: their families, their friends and people who act as caregivers for them (volunteers, home-based carers and counsellors).

Although the PLWHA is not alone in experiencing the effects of HIV and AIDS, he or she has as primary target been the focus of a vast body of international and local research conducted thus far. In largely focussing on the PLWHA other people affected by, related to or associated with the epidemic have generally been overlooked in past studies (France, 2002). Albeit their all-importance in an attempt to assist in the curbing of the overwhelming effects of HIV and AIDS on those primarily effected by it, HIV/AIDS caregivers (volunteers, home-based carers and counsellors) have been greatly neglected in studies related to HIV and AIDS. This study has therefore attempted to (momentarily) shift the focus from the PLWHA to a group closely associated with HIV and AIDS counselling, testing, education and support giving - the HIV/AIDS lay counsellors.

Those suffering from HIV and AIDS have for decades been the victims of a variety of negative thoughts, attitudes and behaviours directed towards them. The

PLWHA has in effect been the direct victim of prejudice, stigma and discrimination from people who have been aware of his/her positive status. Various reasons might explain this phenomenon, whether it is because of the irrevocable connection HIV and AIDS have with homosexuality, promiscuity and drug use or as a result of the deadly nature of the virus, people have acted negatively towards those infected for decades (Cree, Kay, Tisdall & Wallace, 2002). As mentioned before, it is however not only the PLWHA who experience this type of negativity, as the possibility exists that caregivers who are closely associated with the PLWHA might also be exposed to negative attitudes and behaviour directed towards them. This negativity might thus imply negative experiences, for example prejudice and stigma (negative attitudes, thoughts and perceptions) as well as discrimination (negative behaviour) in due course.

The number of volunteers, counsellors, home-based carers and caregivers is still small in comparison to the exuberant number of people suffering from HIV and AIDS who are in desperate need of their constant assistance (Brümmer, 2004). In addition, it might however be asked whether the exposure to this associated negativity (including instances like prejudice, stigma and discrimination) by caregivers, in the case of the present study HIV/AIDS lay counsellors, might not contribute to the occurrence of fallout, if not burnout, amongst those working in close proximity to the PLWHA (Maslanka, 1996; Ross, Greenfield & Bennett, 1999).

1.2 Motivation and aim

It might be asked why the present study wished to focus on HIV/AIDS lay counsellors and their possible experiences of negativity. Albeit the fact that the role of lay counsellors is of great importance, it is not simple to fulfil. Lay counsellors relieve the burden of over-loaded healthcare professionals in assisting in the delivery of VCT (Voluntary Counselling and Testing) and PMTCT (Pre-Mother-to-Child-Transmission) services (Qukula, 2003) in health care facilities in South Africa. In offering ongoing support lay counsellors build non-judgemental support systems, which potentially better the quality of life for those infected and affected by HIV and AIDS. They contribute to a national effort to educate the public on their HIV status and sexual behaviour and ultimately assist in the management of an already overbearing problem related to HIV and AIDS (as the statistics cited in the introduction clearly indicate). A shortage of 1 786 healthcare workers was reported during March 2004 - the greatest being for lay counsellors and community healthcare workers (Brümmer, 2004). The Health Systems Trust recently stated that an additional 14 000 healthcare workers, including lay counsellors specifically, are to be employed in South Africa by 2008 to ensure the success of the national prevention programme (Brümmer, 2004).

People attending to the specific needs of the PLWHA are thus minimal in comparison to the exuberant demand for their services. Potential reasons for this might include: a low reward offered for the job at hand, burnout or dropout as a result of an extremely taxing service rendered, negativity experienced from others as a result of lay

counsellors' voluntary involvement with HIV and AIDS, the community's general fear and disapproval regarding HIV/AIDS and those who suffer from it and a resulting resistance from the community to get involved (as mentioned to the current researcher in anecdotal discussions with ten lay counsellors). As a great need exists for community health care workers - especially lay counsellors - the importance of focussing on their experiences of negativity (implied prejudice, stigma and discrimination) is paramount in ultimately determining factors which play a possible role in: work satisfaction, burnout and dropout determinants and the quality of support offered by lay counsellors.

The effect of this negativity on lay counsellors is important to consider as it can easily result in debilitating conditions, which can in turn result in feelings of: isolation, anger, fear, lowered self-esteem and consequently possible lowered levels of job satisfaction and effectiveness. In addressing the gap in existing research an ultimate effort is thus made by the present researcher to influence relevant role-players (for example employers and programme directorates) in making informed choices in terms of training, mentoring and support offered to HIV/AIDS lay counsellors. The possible occurrence of HIV and AIDS related negativity towards lay counsellors can be addressed and prevented more effectively in future if the experiences of those affected by it personally is studied and taken into consideration.

Many people perceive the PLWHA in a negative light as they tend to associate him/her with possible promiscuity, homosexuality or drug use (Crewe, 2002; Herek & Capitano, 1993). The present study thus wishes to investigate whether HIV/AIDS lay

counsellors, as a group who is in constant contact with the PLWHA experience similar negativity as a result of their association with HIV and AIDS. The present researcher is motivated to determine how and where these possible experiences of associated negativity occur.

In establishing the relevance of the study and to ascertain whether scales measuring negativity, such as prejudice, stigma and discrimination, experienced by HIV/AIDS lay counsellors already existed, the researcher contacted experts working in the field (telephonically or via e-mail). Experts were either:

a) professionals in the field of prejudice, stigma and discrimination in relation to mental illness (J. Arboleda – Flórez, Canada, personal communication, March 10, 2004; H. Stuart, Canada, personal communication, March 11, 2004); sexual orientation (M. Morris, Canada, personal communication, February 28, 2004) or racial inequity (A. Pedersen, Australia, personal communication, February 20, 2004),

b) experts on HIV and AIDS prejudice, stigma and discrimination (A. Clarke, South Africa, personal communication, February 24, 2004; L. Brown, United States Of America, personal communication, March 4, 2004; L. Nyblade, South Africa, personal communication, March 3, 2004; H. van Rooyen, South Africa, personal communication, March 2, 2004)

c) academics who have constructed measuring instruments in relation to the constructs in mention (M. Barrera, United States of America, personal communication, February 24, 2004; D. Fontenberry, United States of America, personal communication, February 20,

2004; E. Lukens, United States of America, personal communication, March 20, 2004; M. Ross, United States of America, personal communication, February 27, 2004).

Feedback regarding the non-existence of a scale and its relevance received from the abovementioned personal correspondence drew conclusions of a similar nature. Experts in the field of HIV/AIDS research acknowledged the great importance of the present study's focus on HIV/AIDS lay counsellors' possible experiences of negative attitudes and actions directed towards them, claiming a gap in South African and international research focussing on caregivers and their work related problems (A. Clarke, South Africa, personal communication, February 24, 2004; L. Brown, United States of America, personal communication, March 4, 2004; L. Nyblade, United States of America, personal communication, March 3, 2004; H. van Rooyen, South Africa, personal communication, March 2, 2004). Not one of the abovementioned experts was aware of an existing scale that the present researcher could utilise in the proposed study. It was additionally clear from the scales forwarded to the researcher by Barrera (United States of America, personal communication, February 24, 2004), Fontenberry (United States of America, personal communication, February 20, 2004), Lukens (United States of America, personal communication, March 20, 2004) and Ross (United States of America, personal communication, February 27, 2004) that, for example, the stigma items included in these existing scales were not suitable to be adapted and used in the proposed study. Although some of the items in scales forwarded to the current researcher were related to the measurements of experienced negativity, also for example, prejudice, stigma and discrimination, they were measuring these experiences in groups other than

lay counsellors, for example clients in clinics with STI's (Sexually Transmitted Infections), as is the instance in the work of Fontenberry (2002) in the United States of America. As the HIV/AIDS lay counsellor was not the focus of any of these studies, items could thus not merely be changed and used in the present context. It was suggested by some experts - Morris (Canada, personal communication, February 28, 2004), Pedersen (Australia, personal communication, February 20, 2004), Clarke (South, Africa, personal communication, February 24, 2004), Brown (United States of America, personal communication, March 4, 2004) and Nyblade (South Africa, personal communication, March 3, 2004) - that the present researcher should consequently construct a relevant item pool or scale to measure these constructs, as experienced by HIV/AIDS lay counsellors working in South Africa specifically. All experiences of negativity by HIV/AIDS lay counsellors will be researched in the present study, but the developed items will focus on the negative attitudes and behaviour related to lay counsellors' association with HIV and AIDS specifically.

The opinions of HIV/AIDS lay counsellors were lastly taken into account in determining whether the proposed study was relevant. Ten short, anecdotal discussions were held by the present researcher with lay counsellors from the Helderberg area, Western Cape, to ascertain whether they have in fact experienced negative attitudes or behaviour directed towards them as a result of their work with HIV and AIDS. As stigma, prejudice and discrimination are constructs that are closely related and as discussions were fairly short, it was not certain which of the constructs were experienced more dominantly. It was however clear to the present researcher that the lay counsellors were

often exposed to negativity from others (implied prejudice, stigma and discrimination) to varying degrees. Incidences differed in context and intensity, but were mostly centred around specific groups of people lay counsellors frequently interacted with, for example: clients, clients' families, medical personnel, the general public, people from their community, people known to them personally (family members or friends) and also people from their church.

The primary question posed by this study is: Do HIV/AIDS lay counsellors - who work closely with the PLWHA - experience negativity (possibly prejudice, stigma and discrimination) as a result of their work? The PLWHA has experienced these constructs as a result of the knowledge others have concerning his/her positive status (Crewe, 2002; Herek, 2002). As a result of the fear and judgment of others the PLWHA might have first hand knowledge and experience of the prejudice, stigma and discrimination others bestow on them. The problem statement however seeks to ask whether those who are not primary targets of HIV and AIDS themselves, can in deed be secondary targets of negative thoughts, attitudes and behaviour.

In conclusion, local and international experts working in the field of HIV and AIDS related negativity have clearly indicated that quantitative scales measuring secondary target's possible experiences of prejudice, stigma and discrimination in relation to HIV and AIDS need to be developed. A vast literary search by the present researcher has shown that experiences of these constructs by lay counsellors have so far been greatly ignored by past research. The primary aim of this study has thus been to

construct an item pool, which measures experienced negativity (possible experiences of prejudice, stigma and discrimination) in HIV/AIDS lay counsellors who work in public healthcare facilities (clinics and hospitals) in the Western Cape region, South Africa. In creating the items knowledge and insight have been sought in relation to the personal experiences of this group and the service they provide to the PLWHA as well as the wider public.

1.3 Clarification of Constructs

Lay Counsellor

The Department of Health, TB/HIV Directorate of the Western Cape, defines lay counsellors as caregivers who are: ... offering HIV pre- and post test counselling and ongoing support counselling to patients who attend the Provincial and Local Government health services (Qukula, 2003). Lay counsellors form an integral part of the national HIV/AIDS strategy in educating, counselling and supporting the public who accesses VCT (Voluntary Counselling and Testing) and PMTCT (Pre-mother-to-child-Transmission) programmes (Qukula, 2003). Lay counsellors are funded by the Department of Health, are normally employed by a Non-Governmental Organisation (NGO) or a local municipality and work in healthcare facilities (clinics and hospitals) across the Western Cape region. They ideally counsel between five and eight clients per day and often are expected to run support groups and give educational talks to schools, businesses, churches and other community-based groups (Qukula, 2003).

HIV/AIDS lay counsellors can either be male or female. They differ in ages, but are generally between 20 and 60 years old (South Africa, E. Smith, personal communication, 5 February 2005). They can be from diverse cultural, racial and ethnic backgrounds. All lay counsellors are expected to speak basic English and many speak more than one language - whether it is Afrikaans, English, Xhosa or Zulu (information via the current researcher's anecdotal interviews with lay counsellors). Many lay counsellors have worked as volunteers in the Public Health Sector before being employed as HIV/AIDS lay counsellors, for example as TB (Tuberculosis) voluntary workers in their local clinic or hospital or as home-based carers in the community (E. Smith, South Africa, personal communication, 5 February 2005). After being employed by a local NGO or municipality, lay counsellors are however sent on a two-week training course at ATTIC (AIDS Training, Information and Community Centre) in Cape Town where they acquire basic counselling know-how and skills development (E. Smith, South Africa, personal communication, 5 February 2005). It is not expected from lay counsellors to have a high educational level per se. Some lay counsellors have finished their secondary schooling, whilst others have relevant previous experience that count in their favour, but not a senior certificate necessarily (E. Smith, South Africa, personal communication, 5 February 2005). Lay counsellors are paid a minimal salary. They are not employed permanently, but on renewable contract basis. According to the Helderberg AIDS Centre, lay counsellors do not receive benefits from their employer besides their monthly salary and do not, for example, benefit by belonging to a medical aid or a pension fund. Lay counsellors themselves are offered counselling or mentoring on a monthly basis by a

social worker or psychologist assigned by the NGO or municipality in their area of employment. Sessions are either in a group or individual context with the aim of assisting counsellors in coping with the job they have at hand.

The person living with HIV and AIDS has, as illustrated by previous studies (Herek, 2002; Herek & Capitano, 1993), been the victim of negativity directed towards them by other people. The negative experiences of the PLWHA include instances of prejudice, stigma and discrimination (Herek & Glunt, 1991; Miller & Kaiser, 2001). As lay counsellors have constant contact with the PLWHA as well as HIV and AIDS in clinics and hospitals in which they work, the current researcher is of opinion that they might, as is the case with the PLWHA, also have negative experiences as a result. The negative experiences of the lay counsellor can possibly be seen as in accordance with the negativity experienced by people who are HIV positive or who have AIDS. In this same manner it is thus proposed that that lay counsellors might experience prejudice, stigma and discrimination as secondary targets thereof.

Negativity

As mentioned in the passage above, the negativity experienced by HIV/AIDS lay counsellors might possibly include prejudice, stigma and discrimination. This perceived negativity might be experienced as attitudes or behaviour, which are either directly and observably (overtly) or in a slightly more demure manner (covertly) displayed. Prejudice, stigma and discrimination are social constructs, which occur to variant degrees and in

different settings and contexts and often seem to overlap and might appear to be interwoven (Arboleda-Flórez, 2003). Independent definitions are however applicable as essential differences between these constructs do exist.

Prejudice

A classic definition of prejudice is put forth by Gordon Allport who aptly defined it as, “ ... an antipathy based on faulty and inflexible generalization. It may be felt or expressed. It may be directed toward a group or an individual of that group” (James, 2004, p. 1). In this definition the word antipathy refers to a negative attitude towards a person belonging to a specific group. Allport describes prejudice as faulty and inflexible as it is unable to change and normally develops prior to any real contact with the person or group (James, 2004). Prejudice is thus a generalisation and includes a “negative and hostile attitude towards another social group” (James, 2004, p. 1).

Prejudice primarily relates to attitudes (mostly negative), evaluative judgements and thoughts directed toward individuals or groups of people with specific characteristics (Jones, 1997). A person harbouring negative attitudes and feelings will possibly experience elements of disgust, fear, hatred, embarrassment, blame, anger or resentment towards a person or group of people he or she is prejudiced against. Negative evaluations are thus made based solely on membership to a certain social group. Individual traits or characteristics of the person experiencing prejudice is thus largely ignored or overseen by those harbouring negative feelings towards them (Baron & Byrne, 2003). Prejudiced

attitudes and feelings have been shown towards other people of opposing race, gender, religion, physical appearance, sexuality and even nationality.

In understanding why many people harbour negative prejudiced attitudes, feelings or thoughts two possibilities exist. In the first instance, people who are prejudiced naturally and automatically create two opposing groups, the so-called in-group and out-group. The in-group can be defined as, “ The social group to which an individual perceives herself or himself as belonging to (us)”. The out-group can be defined as, “ Any group other than the one to which individuals perceive themselves belonging (them)” (Baron & Byrne, 2003, p 222). When someone is being prejudiced he sees himself as a member of the in-group. The person he is prejudiced against can be seen as a member of the out-group, as he or she does not belong to the in-group. A social divide is thus created - some being “us” and yet others “them” (Baron & Byrne, 2003). The in-group has the perception that: a) they are superior to the out-group, b) the out-group is different and alien to them, c) they have the right to power, and prestige and d) they should fear the out-group as they are constantly trying to gain access to in-group benefits and status (James, 2004).

The in-group has the perception that all the members belonging to the opposing or out-group, in this case HIV/AIDS lay counsellors, have similar characteristics or traits. Members of the out-group are thus perceived as less variable than members of the in-group (Baron & Byrne, 2003). The authors call this phenomenon an illusion of out-group homogeneity. At the same time it is believed that members of one’s own group, the so-

called in-group, are all diverse, that many differences between individual members exist. The in-group members are thus perceived as a far more heterogeneous group and greater in-group differentiation is believed to exist (Baron & Byrne, 2003). People who are prejudiced against the PLWHA might, for example, believe that every PLWHA is essentially similar as a member of the out-group. They might think that every PLWHA is without moral standing, is promiscuous or possibly homosexual, which results in negative prejudiced attitudes and stereotypes.

In the second instance, people are prejudiced as it enhances their perceptions of self-worth or their own self-image (Baron & Byrne, 2003). Simply put, by looking down on another group or members of that group, one's own feelings of superiority and value are affirmed. Prejudice thus plays a role in protecting and bettering our sense of self-concept. People are prejudiced as it saves cognitive effort (Baron & Byrne, 2003). If we generalise the attributes of the group we are prejudiced about, we do not have to take time to carefully think about and process information about them or our social world.

HIV/AIDS lay counsellors might thus experience prejudice as people have certain negative perceptions of them, simply as they belong to the group labelled "HIV/AIDS lay counsellor". The community might, for example, believe lay counsellors are only interested in doing such a job as they are HIV positive themselves (as discussed in anecdotal interviews with lay counsellors). In reality few, if any, lay counsellors might have a positive status, but their individual differences are ignored to fit in with the overriding negative perception of the PLWHA created within the community - a

community that might think no person would want to work with the dangers and shame associated with HIV/AIDS unless they are themselves implicated in some way.

Stigma

The word stigma has a Greek origin and literally means sign (Davids, 2004). A person was believed to bear a certain sign or label which referred to a set of shameful personal characteristics (Davids, 2004). A stigma is thus a personal characteristic that other people view negatively. Stigma can be seen as something, which brands someone with a mark of disgrace or disapproval. It is described by de Bruyn (1999) as "... a powerful and discrediting social label which radically changes the way individuals view themselves and are viewed as persons" (p. 2). Negative ideas, perceptions and beliefs are thus connected to such a branded person and the person might be met with fear, rejection and discrimination as a result of this mark or sign he or she bears. Throughout time people who have been the victims of stigma have been the targets of bias, stereotyping, embarrassment, avoidance and anger (Davids, 2004). It is thus clear that the person who is stigmatised is labelled in a negative manner and might experience feelings of isolation and low self-esteem in due process (Davids, 2004).

Modern definitions of stigma can be traced to the influential writings of Goffman during the 1960's. Goffman (1963) defined stigma as a "less valued, deeply discrediting and somewhat spoiled identity, which subsequently results in the stigmatised person being set apart from society as being different" (p. 3). Individuals or groups of people

thus devalue or negatively perceive someone on the grounds of a specific characteristic, for example, having a certain religion, being of a certain race, having a certain gender, suffering from a specific illness or disease, having a specific disability or maybe doing a specific job.

Other definitions on stigma echo this perception and focus on the role of societal structures and interactions in the process of stigmatisation (Arboleda-Flórez, 2003). Herek (2002) defines stigma as: "... an enduring condition, status, or attribute that is negatively valued by a society and whose possession consequently discredits and disadvantages an individual" (p. 595). Stigma is thus accepted and is in agreement with a society's norms and values. Additionally important is Goffman's (1963) definition of secondary or courtesy stigma, as it may be relevant to the present study's focus on the experiences of HIV/AIDS lay counsellors. According to Goffman (1963) people who are not primary targets of stigma, but who are devaluated as they are closely associated with primary targets might experience secondary or courtesy stigma. In the case of HIV and AIDS this implies personal connections or associations of the PLWHA (family, partners and friends) and professionals working closely with them (caregivers, home-based carers, volunteers and lay counsellors). HIV/AIDS lay counsellors might thus be negatively perceived and ultimately stigmatised as a result of their close and regular contact with people who are HIV positive or suffering from AIDS – a deadly illness which is strongly connected with a low or questionable moral standing. The lay counsellor's identity is thus "spoiled" as a result of regular contact with the PLWHA and he or she is treated differently, specifically less valued, because of this.

In forming an understanding of the working of stigma a short overview of schemas or sets of schemas will be given in the following passage. Schemas can be defined as cognitive frameworks, which are used to organise, to interpret and to recall large amounts of social information (Baron & Byrne, 2003). This seems to happen in an almost automatic manner. A person thinks about people and situations and it seems information is naturally, effortlessly or unintentionally organised in this manner (Baron & Byrne, 2003). Schemas also assist a person in making mental shortcuts when large amounts of information are to be processed cognitively. Of great importance is that these schemas, or sets of cognitive frameworks can thus influence the way we think and in effect feel about the things and people around us – our social world (Baron & Byrne, 2003).

When people stigmatise they go about processing information about the group they feel negatively about in a different manner than other groups (Baron & Byrne, 2003). Their schemas or cognitive frameworks interpret and organise information regarding these groups in a negative manner, or with negative connotations and undertones. Their cognitive framework or schemas for lay counsellors have been processing information regarding lay counsellors or HIV and AIDS in such a manner that they automatically and effortlessly have a set of information and possibly a set of assumptions at hand when thinking of the group. If the schemas for lay counsellors are negative frameworks, the way in which they think and eventually react towards lay counsellors will reflect this negativity. When thinking of HIV and AIDS, for example, people might have organised information in a negative manner, conjuring up images of

drug users, homosexuals and sexual promiscuity. As stated by Crandall and Glor (1997), HIV and AIDS have acquired a status of "moral disease". People who stigmatise have thus created cognitive frameworks, which are based on their symbolic associations with the virus, in this case a symbolic value that reflects a low moral standing. People who stigmatise might use cognitive shortcuts, possibly stereotypes, to process information about a certain person or group he or she belongs to. Stereotypes can be defined as a set of beliefs that all the members of a certain group have the same traits, regardless of their individual characteristics (Baron & Byrne, 2003). It is thus clear when people stigmatise they might also have a set way of thinking about members of a specific group, for example HIV/AIDS lay counsellors.

Discrimination

Discrimination, on the other hand, differs from prejudice and stigma as it is defined in terms of behaviour, actions (Herek, 2002), outcomes or treatments (James, 2004). It implies the lived-out or outward manifestation, the acting out of negative attributions, feelings or perceptions towards an individual or group who is the target of prejudice. It can thus be defined as, "negative behaviour directed towards members of social groups who are the object of prejudice" (Baron & Byrne, 2003, p. 211).

Discriminatory behaviour additionally implies an unjustifiably different treatment towards those who are targets thereof (Insideout Research, 2003). Targets of discrimination are thus treated differently than non-targets – normally negatively. People

who discriminate can do so verbally or physically, whether they do so blatantly or more subtly. An example of subtle discrimination may include, for example, modern racism (Baron & Byrne, 2003). When the person who is discriminating is in public he or she is not noticeably racist, but behind closed doors he or she displays negative feelings and attitudes towards someone from an opposing race (Baron & Byrne, 2003).

People who discriminate show their disgust, fear, hatred or avoidance of the person or group they feel prejudiced about or think ill of in a way noticeable to other people (Baron & Byrne, 2003). Examples of discriminatory behaviour are easy to recall: racism (Apartheid in the South African history), sexism (violence against homosexuals), more simply, glaring or shouting at someone from the out-group, clearly ignoring a person, blaming or accusing someone of wrongdoings as he or she belongs to an opposing group, physically attacking someone, being hostile, or, for example, not appointing someone in a position he or she has earned on the bases of membership to a less liked group (Baron & Byrne, 2003). An example of discrimination that is pertinent to the present study is the hatred and fear towards the PLWHA, which have been evident in many instances in the past. People whose status has been made known to others have experienced a vast range of negative behaviour, including: avoidance, public embarrassment - even threats to their lives, in many countries of the world (Crew, 2002).

From the anecdotal discussion the present researcher conducted with lay counsellors before the onset of the research, it was clear that they experienced

discrimination from different groups of people they have regular contact with. This served as motivation for the continuation of the present study.

CHAPTER 2

Theoretical Approaches

Underlying the possible negative experiences of prejudice, stigma and discrimination by HIV/AIDS lay counsellors is a network of theories, which might stand to describe the reasons for the occurrence thereof. Although there is a legion theories explaining the occurrence of prejudice, stigma and discrimination, the current researcher has chosen these theories as they support the information supplied by the ten anecdotal interviews held with lay counsellors from the Helderberg AIDS Centre. Theories that define the occurrence of negativity towards the PLWHA have in addition guided the current researcher in making a possible selection. The theories stated in the following passages include: Spoilt Identity Theory, Terror Management Theory, Downward Comparison Theory, Social Identity Theory, Sociocultural Approach Theory and the Social Dominance Theory.

2.1 Spoilt Identity Theory

When evaluating theories possibly underlying the occurrence of HIV and AIDS related prejudice, stigma and discrimination in general, Goffman's (1963) Spoilt Identity Theory can be used as a departure point. The Spoilt Identity Theory simply states that a person is devalued as a result of a characteristic, some "mark" or "blemish", which sets the person apart from the rest of a group as being different. A subsequent "different", less

favoured, behaviour towards the target person can subsequently be expected. Lay counsellors might not experience devaluation as a result of a personal blemish per se, in this case a HIV positive status for example, but rather as a result of their association or connection with HIV and AIDS patients. They might acquire a “secondary blemished identity”, second only to the primary victim, as they are in regular and close contact with the PLWHA. It might be argued that the threat, fear and moral judgement associated with HIV and AIDS transcend boundaries, eventually spilling over to secondary or associated targets – the HIV/AIDS lay counsellor him or herself.

2.2 Terror Management Theory

Terror Management Theory (Greenberg, Solomon & Pyszczynski, 1997) closely relates to the ideas set forth by Goffman’s Spoilt Identity Theory by illuminating human beings’ fear of disease and dying and their subsequent attempts to protect themselves from it. According to this theory people create barriers to avoid, diminish or push away potential threats. Terror Management Theory argues that people become more aggressive, avoidant and rejecting as the threat to their personal safety increases. Taking into account that masses of people are HIV infected, that the infection normally results in severe illness and possibly death and that, until recently, there has been very little available treatment, if not a cure, it is understandable how this fear has been upheld by the general public as well as the PLWHA. In retrospect it has been suggested that the response to HIV and AIDS is not much different to earlier examples of equally feared illnesses and diseases: leprosy, cholera and syphilis (Valdiserri, 2002). The HIV/AIDS lay counsellor

might thus experience negative, avoidant behaviour towards him or herself, as people fear their association with a deadly disease, with people who are infected by it and ultimately death itself.

2.3 Downward Comparison Theory

In understanding the possible negative attitudes and behaviour directed towards lay counsellors by their clients, clients' family and medical staff the Downward Comparison Theory (Wills, 1981) can be utilized. According to this theory people might diminish the status of the opposing group (the out-group) in an ultimate effort to reinstate or boost their own self-worth or self-image. Being informed of a positive status might have extremely negative connotations, as society often rejects those who are HIV positive and as it implies a death sentence to many others. As lay counsellors convey a client's status to him or her and is often the only person who has access to confidential information, clients may devalue lay counsellors in an effort to reinstate their own feelings of low self-worth. According to the Downward Comparison Theory (Wills, 1981) clients and their families who share feelings of low self-esteem, shame or guilt as a result of a positive status, might attempt to create an environment in which they can discriminate and disadvantage lay counsellors who have in fact been the bearers of a positive test result or to some even a death sentence. In doing so they thus attempt to make themselves appear less poorly, lifting their own low self-esteems. Anecdotal interviews with lay counsellors by the present researcher additionally revealed the possibility that medical personnel - specifically nursing staff - feel threatened by lay

counsellors. Medical staff may subsequently minimise lay counsellors' worth in an attempt to enhance their own self-esteem and personal sense of well-being, as suggested by the principles of the Downward Comparison Theory.

2.4 Social Identity Theory

Social Identity Theory, often referred to as SIT (Tajfel & Turner, 1979), is related to the Downward Comparison Theory, but rather focuses on the self-esteem and image of the group and not so much the individual. By creating an in- and out-group identity the in-group enhances the group self-esteem and distinctive group characteristics. Clients (whether they have tested positively or not) might place lay counsellors in an out-group. As lay counsellors have access to clients' personal information, as they often advise on alternative sexual behaviour and as they are often the bearers of bad news, clients might devalue lay counsellors as "one of them", as a member of the so-called "out-group". If clients feel guilt, anger or humiliation during the counselling and testing process, it might be of even greater necessity to lift the self-esteem of the group he or she belongs to (in this case clients), by means of devaluating the established out-group (lay counsellors). As a result lay counsellors might experience negative attitudes and behaviour directed towards them by clients.

2.5 Sociocultural Approach Theory

Vygotsky's (1986) Sociocultural Approach Theory is additionally related to the negative attitudes and behaviour of, for example, medical personnel towards HIV/AIDS lay counsellors. According to the theory people might discriminate or look down on those who they perceive to be of a lower socio-cultural standing in their surrounding society than themselves. Anecdotal interviews by the present researcher have shown that the communities in which nursing staff works perceive them as educated and professional people. They are normally placed in high regard and are respected by others from the community. Lay counsellors are of opinion that medical personnel are aware of this perception and that they subsequently treat staff members (for example the lay counsellors) with a lower level of educational progress with little if any dignity. As lay counsellors are not perceived to be educated or well-learned people (they mostly do not have tertiary qualifications) and as a result of their constant contact with the less approved of PLWHA, they may thus suffer the negative attitudes and behaviour of medical and nursing staff in clinics and hospitals. According to the Sociocultural Approach Theory (Vygotsky, 1986) nursing staff might thus act in a discriminating manner, as they perceive lay counsellors to be at the lowest rank of the clinic or hospital's socio-cultural hierarchy – partly as a result of a lower educational level. The anecdotal discussions with lay counsellors additionally revealed their constant contact with the PLWHA and HIV/AIDS might additionally influence medical staff to place them at a lower level than others working in the clinic or hospital, which granted them leeway to discriminate against them.

2.6 Social Dominance Theory

Social Dominance Theory (Sidanius & Pratto, 1999) supports the opinion stated in the Sociocultural Approach Theory by stating that any society will ultimately consist of a hierarchy of at least two groups. One group will set out to be more advanced, whether it be financially, socially or developmentally (for example nursing personnel) than the second group (HIV/AIDS lay counsellors). Groups within this society are consequently in constant competition for scarce resources (for example salaries or work benefits) and social standing, resulting in the dominant group to devalue the out-group in due process. Medical staff (specifically nursing staff) is thus possibly competing with and subsequently devaluating HIV/AIDS lay counsellors (a group they may find less sophisticated and less developed than their own group as they work with HIV and AIDS) for social standing within the community, clinic or hospital.

These theories can be utilised to create an understanding of the possible occurrences of negativity, for example prejudice, stigma and discrimination, as experienced by HIV/AIDS lay counsellors. In following chapters the researcher will attempt to incorporate these theories into the analysis of the collected data, as to understand the occurrence of negative attitudes and behaviours towards HIV/AIDS lay counsellors more effectively.

CHAPTER 3

Literature Overview

As illustrated by previous studies (Brown, Macintyre & Trujillo, 2003; Herek, 2002; Herek & Capitanio, 1993, 1997; Herek & Glunt, 1991; Miller & Kaiser, 2001), a vast body of research exists in relation to negative attitudes and behaviour directed towards the PLWHA (Person Living with HIV and AIDS). A magnitude of research on the negativity of individuals or a society towards an HIV infected minority (the PLWHA) can thus be found (Crewe, 2002). Notably less, if any, attention has however been given to the negativity as it is experienced or directed towards HIV/AIDS caregivers or service providers, including the all important HIV/AIDS lay counsellor. Reasons for this might include a long tradition of focussing on a primary target (Oyserman & Swim (2001), in this instance the PLWHA, versus a secondary target. Lay counsellors, as secondary targets of negativity like prejudice, stigma and discrimination related to HIV and AIDS, have thus been overlooked in past studies as they might not be deemed as severely influenced by these issues as primary targets thereof.

As stated the PLWHA has been the target of extreme negativity in the past from, for example, the broad society or community they live in, churches, co-workers and even family and friends. Past research has found a traditionally strong association between HIV/AIDS and drug use, homosexuality and promiscuity (Insideout Research, 2003). The association with these issues are still not morally acceptable in many parts of the world

today. It is thus important to note that those who have close contact with the PLWHA (HIV/AIDS lay counsellors in this case) might be viewed negatively as they are associated with an implied low moral standing as well.

As a result of the fact that a vast number of people are infected with the virus (as stated in the introduction) the focus of all attention is on the PLWHA. People who attend to the needs of and who care for the PLWHA, including HIV/AIDS lay counsellors, are thus ignored in studies related to experienced negativity - regardless of the exuberant need for their assistance in coping with the problems posed by HIV and AIDS. Grinstead and van der Straten (2000) are based in the United States of America, but aptly state the following regarding their work in developing countries (including Africa):” Demand for HIV counselling services is increasing in developing countries, but there have been few previous studies that describe counsellors’ roles and experiences providing HIV-related counselling in developing countries” (p. 625).

In addition, research focussing on personal experiences of negativity by caregivers like HIV/AIDS lay counsellors has not been conducted, as is the opinion of Oyserman and Swim (2001). In 1998 Swim and Stangor stated the imperative need for continued research on the perspectives and experiences of the target, but also expressed the importance of research on the secondary target’s viewpoints. If lay counsellors’ viewpoints (as secondary targets) are also taken into account various benefits might come to the fore. The inclusion of lay counsellors’ viewpoints can potentially result in a wide and in-depth understanding of the dynamics of any perceived negativity towards the

target (the HIV/AIDS lay counsellor) and his or her environment – illuminating possible experiences of prejudice, stigma and discrimination. By having an insiders' view more helpful ways of reducing related problems can subsequently be devised, ultimately resulting in ways to assist HIV/AIDS lay counsellors in combating the negativity they experience from other people. Plous (2003) condones these suggested benefits and contributes with the opinion of Swim and Stangor (2003) “... (it) gives a voice to target groups, validates their experiences, helps pinpoint their unique strengths and weaknesses, and can ultimately increase empathy for the targets of prejudice...” (p. 36).

Regardless of previous studies on prejudice, stigma and discrimination, researchers still believe a more comprehensive understanding in relation to HIV and AIDS does not exist and needs further investigation (Herek & Mitnick, 1996; Piot in Parker, Aggleton, Attawell, Pulerwitz & Brown, 2002). Others believe that omitting secondary targets (for example care-givers) as focus is not only short-sighted, but that effective prevention and care interventions will be limited as a result thereof (Bharat, 2003; Monico, Tanga, Nuwagaba, Aggleton & Tyrer, 2001). Internationally it has thus been recommended that this neglected group should be the focus of future research and it has been suggested that secondary stigma has been a less visible phenomenon in the past, resulting in researchers focussing their work on the PLWHA solely (Herek & Mitnick, 1996). This suggestion also holds true for South Africa, as suggested by South Africa's Health and Development Networks (France, 2002) on the need for: “ Questionnaire items that address stigma directed towards people who are not necessarily HIV positive, but

who are associated with HIV/AIDS or with PLWHA, such as health care workers, sex workers, injecting drug users, providers of home-based care, and family..." (p. 12).

In measuring prejudice, stigma and discrimination towards the PLWHA studies have made use of both qualitative and quantitative measures in doing so. Quantitative scales and surveys (telephone and in-person) have mainly been used to, once again, measure the majority group's negative attitudes (prejudice and stigma) and behaviour (discrimination) toward minority groups. Herek and Capitano (1997) have for example focussed on the general public, Prasad (2001) on medical personnel and the South African Population Council on co-workers' attitudes and behaviour towards HIV and AIDS (Stewart, Pulerwitz & Esu-Williams, 2002). Qualitative studies have also gained valuable information on the manifestations of prejudice, stigma and discrimination towards the PLWHA its determinants and its consequences. In South Africa in-depth interviews and focus group discussions with key informants (Insideout Research, 2003), the affected, co-workers, community leaders (Hutchinson, Pulerwitz, Esu-Williams & Stewart, 2003), religious leaders, counsellors and professionals (Monico et al., 2001) have been conducted in obtaining information on majority group attitudes and behaviour towards a HIV-related minority group in South Africa – once again notably less so on the personal experiences hereof by targets themselves.

Focussing on the occurrence of prejudice, stigma and discrimination towards HIV/AIDS lay counsellors specifically, relevant literature is not to be found. Past studies have however mentioned issues centred on work satisfaction of HIV/AIDS caregivers

and volunteers (Bennett, Ross & Sunderland, 1996; Maslanka, 1996; Ross, Greenfield & Bennett, 1999). The focus has been on general experiences of: a) stressors, for example over-involvement, coping with the terminal nature of the virus and lack of support, and b) rewards, for example intellectual stimulation and friendship (Bennett, Ross & Sunderland, 1996). Most studies have additionally placed these factors in specific relation to burnout and dropout rates (Maslanka, 1996; Ross et al., 1999). The HIV Volunteer Inventory has been used in various studies to measure experiences of stressors and rewards (Bennett, Kelaher & Ross in Bennett et al., 1996) and the Maslach Burnout Inventory (MBI) has additionally been utilised in most studies to measure burnout in HIV/AIDS volunteers and caregivers (Ross et al., 1999).

In addition, qualitative measures have been utilised in past studies to measure the impact of HIV and AIDS on people caring for or supporting a PLWHA. Flaskerud (1998), conducted personal interviews with HIV/AIDS caregivers and recorded their experiences of loneliness, anger and isolation. Results of this specific study showed that care-givers suffered from severe mental (depression and anxiety) and physical problems (high blood pressure, sleeplessness etc.) as a result of their experiences of the loneliness, anger and isolation related to their work. More recently Grinstead and van der Straten (2000) recorded the stressful as well as rewarding experiences of HIV counsellors working in Africa. The researchers interviewed counsellors and their supervisors working in Kenya and Tanzania. Results showed that counsellors experienced pressure to constantly inform the community, that they had trouble being role models for the community, that they had economic and political hardships and that they found their

counselling setting problematic. Closer to home, Rohleder (2003) conducted a qualitative study of a similar nature, focussing on the experiences of HIV/AIDS counsellors working near Cape Town, South Africa. The results mentioned difficulties experienced by lay counsellors: problems related to clients, counsellor difficulties and culturally-bound obstacles. Largely omitted however are studies specifically focussed on HIV/AIDS counsellors and their experiences of negativity, such as prejudice, stigma and discrimination specifically.

Literature on prejudice, stigma and discrimination has traditionally focussed on issues concerning amongst others: age, gender, sexuality, weight and race. Diverse fields thus share an interest in these constructs such as: Applied Social Psychology, Sociology, Anthropology, Feminism and Political Science (Swim & Stangor, 1998). Studies on mental illnesses, for example schizophrenia, have been instrumental in understanding negative attitudes and behaviour toward patients, their families and caregivers (Gaebel & Baumann, 2003; Link, Strucening, Neese-Todd, Amussen & Phelan, 2001). A focus on illnesses or diseases, for example gonorrhoea (Fontenberry et al., 2002), severe acute respiratory syndrome (Person, Sy, Holton, Govert & Liang, 2004), cancer (Berpenberg, Finlay, Stephan & Stephan, 2002) and HIV /AIDS (Lew-Ting & Hsu, 2002) has supported possibilities that people suffering as well as those associated with them might experience the negativity associated with prejudice, stigma and discrimination. Existing literature thus acknowledges the possibility that secondary targets might experience the constructs in mention and supports the focus of this study in determining whether it

possibly occurs in HIV/AIDS lay counsellors who are in constant contact with the PLWHA.

In conclusion, a variety of shortcomings in existing research on experiences of negativity, prejudice, stigma and discrimination per se, in relation to HIV/AIDS lay counsellors have been identified in this literary overview. The first point relates to past research's ignorance towards the secondary target's viewpoint or perspective of the problem at hand – in this case the opinion of the HIV/AIDS lay counsellor working in clinics and hospitals in the Western Cape, South Africa. Secondly, the focus of conventional, existing HIV/AIDS research has to be moved from the traditional focus on the PLWHA to the paramount important care-givers of those who are infected – in this study the HIV/AIDS lay counsellor. Thirdly, a need exists for the development of quantitative scales, which measure a secondary target's viewpoints of experienced prejudice, stigma and discrimination – in this case a focus on the experiences of the HIV/AIDS lay counsellor.

CHAPTER 4

Methodology

The current researcher will discuss the research methodology utilised in the present study in the following passages. The reasoning behind the chosen qualitative research design, in particular the Phenomenological approach, will be set out. Attention will be given to the importance of interviews as research instruments, to the participants of the study and the researcher's role in the study. In addition, the procedure of data collection, analyses and the construction of the item pool in mention will be the focus of the following chapter.

The aim of the current study is to construct an item pool, which measures the experiences of negativity, like prejudice, stigma and discrimination, by HIV/AIDS lay counsellors. As none such an instrument could be found by the current researcher this explorative study thus sets out to generate the items mention. In reaching this aim the researcher had to employ a research methodology, which allowed her to gain access to the lived experiences, the ideas and opinions of HIV/AIDS lay counsellors related to this type of negativity. It was decided to utilise a qualitative research method with an Interpretive Phenomenological Analysis approach as a means of gaining an understanding and in-depth knowledge of the HIV/AIDS lay counsellor's thoughts on the experiences of negativity.

4.1 Qualitative Method

In understanding why a qualitative method was decided on by the current researcher, a short overview on the nature of qualitative research will be presented. In essence qualitative research is a description of the characteristics and properties of an entity (Smith & Osborn, 2003). It aims to provide a vivid and rich description of a phenomenon, a happening, a person or situation. Qualitative research seeks to find the meaning in verbal texts and transcripts and it gathers data by means of, for example, interviews or written accounts. According to Smith and Osborn (2003) it aims at understanding the fullness of human communication by interpreting and analysing participants' language and verbal expressions in detail and with earnest. Qualitative research is thus concerned with the exploration of the personal life experience and description of the social worlds of its participants.

Taking the breadth and depth of investigation that qualitative research offers the researcher into account the current researcher decided to use a qualitative research method as it presented many benefits to the study. In the first instance it allowed the researcher an insider's view of the thoughts, perceptions and experiences of the participants of the study - the HIV/AIDS lay counsellor. Via in-depth interviews the researcher could thus directly gain access to the lived world of the lay counsellor on a first hand basis – via the thoughts and words of the lay counsellors themselves. By gaining access to the lived experiences of the lay counsellors the researcher envisioned that she would be able to create an in-depth understanding and insight as well as gain

knowledge of the negativity experienced by HIV/AIDS lay counsellors. As the current researcher could find no existing scale measuring negativity in lay counsellors and as very little past research has been conducted in relating to HIV/AIDS lay counsellors per se, she was convinced that she would generate new information and ultimately a new sense of understanding about a subject matter which has not been investigated in-depth before. By employing a qualitative research method, the researcher predicted that she would be able to make sense of the complex phenomenon (experienced negativity by HIV/AIDS lay counsellors) as the design allowed a detailed description thereof. A qualitative research methodology offered the current researcher an opportunity to analyse and interpret the lived experiences of the lay counsellor and to eventually gain a broad understanding of the meaning of their experiences of negativity. As an ultimate benefit, a qualitative enquiry allowed the researcher to write items for a questionnaire, which would represent the realities, which are the lived experiences of the lay counsellors themselves.

Explorative Research

As no existing research (both overseas and in South Africa) on the experiences of negativity by HIV/AIDS lay counsellors could be found, the current researcher perceived this as an explorative study. The explorative nature of the current study is due to the fact that the researcher needs to investigate whether the constructs under investigation (negativity, such as prejudice, stigma and discrimination) do in fact present themselves in the lived experiences of the HIV/AIDS lay counsellors. The chosen qualitative research method thus enables the current researcher to investigate this new subject matter in a

flexible and analytical manner. Via a qualitative method the possible experiences of negativity by lay counsellors and the knowledge gained from focussing on this subject can also be related to a broader South African context.

Interpretative Phenomenological Analysis

Within the methodology of qualitative research, different, sometimes overlapping, approaches exist, including, for example: Phenomenology and Interpretative Phenomenological Analysis, Ethnography and Grounded Theory (Smith & Osborn, 2003). After an investigation of each of these approaches was undertaken the researcher chose to use an Interpretive Phenomenological Analysis (IPA) approach in the current study.

The Interpretive Phenomenological Analysis approach is a fairly new qualitative research tool, which was developed in the mid 1990's by Jonathan Smith and it has its origin in the philosophical stance of Husserl's phenomenology (Aubeeluck, 2004). This philosophy is concerned with a person's personal experience or perception of an event, happening, state or situation (Nissan, 2005). Smith and Osborn (2003) aptly states, "The approach is phenomenological in that it involves detailed examination of the participant's lifeworld; it attempts to explore personal experience and is concerned with an individual's personal perception or account of an object or event..." (p. 51). Interpretive Phenomenological Analysis (IPA) is thus focussed on the individual's viewpoint and the meaning he or she attaches to the lived world surrounding him or her. More so this type

of process is not only interested in the manner in which the individual experiences his or her world, but also how he or she makes sense of it or attaches meaning to it (Smith & Osborn, 2003). Smith and Osborn (2004) support that this statement is of importance, “... the main currency for an IPA study is the meanings particular experiences, events, states hold for participants” (p. 51).

The researcher conducting an Interpretive Phenomenological Analysis (IPA) must go about it by initially selecting a research sample and by gathering data from participants, typically via semi-structured interviews, but possible via other means, for example diary accounts (Smith & Osborn, 2004). Sample groups are normally small, construing between six to fifteen participants, which enables the researcher to get an in-depth and close-up view of the personal experiences of the participants (Smith & Osborn, 2004). Smith and Osborn (2004) state that the researcher can only move on to make general statements about the group as a whole (in this case HIV/AIDS lay counsellors) when a detailed analyses has been made of the individual case-studies. The Interpretive Phenomenological Analysis process pays special attention to the complex interconnection between the participant’s cognitive, linguistic, physical and affective dimensions that are at play during an interview (Smith & Osborn, 2003).

The current researcher expected Interpretive Phenomenological Analysis to be a flexible, explorative, non-experimental tool. She hoped it would enable her to gain a full and detailed insight into the lived experiences of lay counsellors regarding negativity, like prejudice, stigma and discrimination. As she would collect data via semi-structured

interviews an added benefit would be that she receive information on a first-hand basis from participants – listening to the personal renditions of lay counsellors themselves. By keeping a close distance to the rich and full text supply by semi-structured interviews and by analysing the data in detail, the researcher hoped to ultimately benefit from Interpretive Phenomenological Analysis by constructing relevant and meaningful items for the scale in question.

4.2 Participants

Although it could be expected that possible negativity, such as prejudice, stigma and discrimination, experienced by HIV/AIDS lay counsellors might be similar within the whole of South Africa, if not also internationally, the researcher utilised a sample from within the Western Cape region (South Africa), as it was a convenient and accessible sample to her.

The researcher initially gathered information via ten anecdotal interviews with HIV/AIDS lay counsellors working for the Helderberg AIDS Centre in Somerset-West. Four of the lay counsellors were male and the remaining six were female. They were between the ages of 25 and 48, with a mean age of 32 years. Five of the lay counsellors were coloured and five were black. All of the lay counsellors were fluent in English although they had other home languages. Three of the coloured lay counsellors preferred English as home language and the remaining two spoke Afrikaans. The black lay counsellors were all Xhosa speaking.

Thereafter in-depth, semi-structured interviews with 25 HIV/AIDS lay counsellors, who worked in public healthcare facilities (clinics and hospitals) within the Western Cape, South Africa, were conducted. Although Smith and Osborn (2004) suggest a sample of between six and fifteen participants the current researcher chose to involve a larger group (N = 25) as the HIV/AIDS lay counsellors construe a vastly diverse group (of different ages, genders and cultures) and as they work in both rural and urban areas. The aim was thus to involve a truly representative group of participants and to ensure a reliable database by doing so.

The area (in which the interviews were conducted) is represented in four regions, namely: Metro, Westcoast/ Winelands, South Cape/ Karoo and Boland/ Overberg. Twelve of the interviewed participants lived in an urban region (Metro) and the remaining thirteen were from rural areas within the Western Cape region (Westcoast/ Winelands, South Cape/ Karoo and Boland/ Overberg). Participants' ages varied between 22 and 60 years, with a mean age of 35 years. Nine participants were male and sixteen were female with three participants being white, twelve coloured and ten black. Afrikaans was the home language of thirteen participants while four spoke English. Seven preferred Xhosa and one participant preferred Zulu as home language. All of the participants were however fluent in English and interviews were subsequently conducted in either Afrikaans or English. Twelve of the interviewed participants were married and the remaining thirteen were single. The lay counsellors differed in terms of their period of employment by the NGO (Non-Governmental Organisation) or municipality they worked for. Twelve of the participants worked for at least three years, ten worked for two years

and three of them had worked for a period of a year. Thirteen of the participants had previous experience working in the field of HIV and AIDS and twelve had no prior experience.

4.3 The Researcher

The current researcher's choice of Interpretative Phenomenological Analysis as research method emphasises the importance of the researcher as a dynamic and active role-player in the research process (Smith & Osborn, 2003). According to this methodology the researcher is constantly attempting to enter the emotional and cognitive world of the participant to, as stated by Smith & Osborn (2003), get an "insider's view" of the experiences and realities of the study participant (p. 51). The researcher is in essence trying to understand the participant, who is in his or her turn attempting to understand his/her own situation (Smith & Osborn, 2003) by telling personal stories during an interview. Smith and Osborn (2004) sum up the process by stating,

"...IPA is committed to the value of attempting to understand the world from the perspective of one's participants, it also recognises that this cannot be done without interpretive work by the researcher who is trying to make sense of what the participant is saying. This explains the interpretive part in the name of the methodology" (p. 230).

It is thus clear that the process as a whole is not simple or uncomplicated, but rather a complex interaction of dialogue between researcher and participant. The researcher attempts to decipher what the participant is feeling and thinking by means of listening to his or her life stories. The researcher's own personal history and background might thus influence the way in which he/she is interacting with the data he/she is presented with during the interview (Smith & Osborn, 2004). It is therefore important to take the personal background of the researcher into consideration when describing the process of data collection.

In relation to the current study the present researcher is a white South African female of 30 years. She is from a middle class, Afrikaans speaking family and is married with one child. The researcher's interest in HIV and AIDS related issues developed as she was studying Psychology as an undergraduate at the University of Stellenbosch, South Africa, during the 1990's. After completing her undergraduate studies her work as centre manager for a Non-governmental Organisation (NGO), the Helderberg AIDS Centre in Somerset West, gave her the opportunity to get a closer view of the realities of HIV and AIDS in the South African context at that time. As centre manager the researcher oversaw the general service (VCT, Voluntary Counselling and Testing, and PMTCT, Pre-mother-to-child-transmission) provided by the centre in its totality, specifically the rendering of a counselling service provided to the wider Helderberg community at clinics and hospitals in the area. The NGO employed thirteen lay counsellors and the current researcher met with them formally on a monthly basis (group sessions) as well as weekly at their place of work or the centre office (where she was

based). As a result of the researcher's regular contact with these HIV/AIDS lay counsellors she developed a sense of the troubles and joys they experienced in their work, for example the hardships of telling someone he or she is positive, the troubles associated with earning a very minimal salary, the sadness of testing children and so forth. As the current researcher commenced postgraduate studies in Psychology her interest in HIV and AIDS as well as her focus on HIV/AIDS lay counsellors persisted and eventually contributed to the development of the research topic of the current study.

It can be assumed that the researcher brings with him or her a whole set of personal ideas, beliefs, frameworks and attitudes, possibly biases and assumptions (Smith & Osborn, 2004) which can in turn influence the manner in which the researcher listens to and analyses the collected data. As the current researcher worked closely with HIV/AIDS lay counsellors at a previous time, she was aware that she might make some assumptions about their work situations and experiences prior to interviewing them. She might, for example, expect to find many instances of negative attitudes and behaviour directed towards lay counsellors as she has personally witnessed many accounts thereof during her time employed as manager of the centre. She therefore specifically set out to be self-aware and to keep an open mind, devoid of her own perceptions and assumptions, when interviewing and analysing the collected data. The researcher was thus cautious of not imposing her own personal ideas, which were derived from prior contact with HIV/AIDS lay counsellors, on the research process.

4.4 Ethical Considerations

The researcher perceived her role as being that of guide or facilitator of the research process. Taking this responsibility to heart, she was concerned with the ethical implications of the study on researcher participants (Smith & Osborn, 2004). The researcher set out to describe the study and its objectives clearly to potential participants when she first met with them at group mentoring sessions and also the monthly meetings held by the NGO or municipality. During these meeting times she took care to inform lay counsellors that they would partake in the study as volunteers and that no lay counsellor would be forced to do so. In addition, they were informed of their rights as potential participants of the study, if they wished to partake in it. Participants were informed of their right to: a) privacy, b) confidentiality, c) anonymity, d) withdraw from interviews at any time or to skip any questions asked and e) follow-up counselling, if so needed. The ethical guidelines presented by Smith and Osborn (2004) support the ethical focus of the current researcher, as they state the participant: a) has the right to stop an interview, b) has the right to confidentiality and c) could possibly suffer distress as a result of the interview and therefore need follow-up counselling. The current researcher drafted letters of consent, which were signed by both researcher and participant before interviews commenced (see addendum B). In this letter the current researcher attempted to, once again, inform participants of their rights in relation to the present study.

4.5 Interviews as Research Instrument

The current researcher chose to collect data via semi-structured interviews, although Interpretative Phenomenological Analysis (IPA) suggests that either structured or semi-structured interviews can be used (Smith & Osborn, 2003). IPA presents semi-structured interviews as an apt method for data collection as it has many advantages that structured interviews do not necessarily share, for example: a) questions can be modified as the researcher progresses with the interview, b) interesting areas which occur may be probed and investigated during the interview, c) the researcher is allowed more freedom within the interview, d) a greater sense of empathy can be established by the researcher and e) a richer set of data can be collected in this manner (Smith & Osborn, 2003). As the current researcher's aim was to gather a rich and descriptive rendition of HIV/AIDS lay counsellor's lived experiences of negativity, this method of data collection seemed most appropriate. Semi-structured interviews have thus served to give the researcher a closer view of the meanings behind the constructed realities of lay counsellors, as is said of semi-structured interviews as tools of Interpretive Phenomenological Analysis by Smith and Osborn (2004), "... (it) is committed to the value of attempting to understand the world from the perspective of one's participants" (p. 203). As semi-structured interviews are commonly used by IPA as data selection method the researcher acknowledges the importance of the connection between what is said and what the participant is thinking and feeling at the specific moment of the interview.

Semi-structured Interviews

As is set out by Smith and Osborn (2004), the researcher conducting a semi-structured interview is guided by a set of questions from the interview schedule, but is not dictated by it in totality. The semi-structured interview thus allows for a rapport to be established between researcher and participant, with the researcher (or interviewer) free to explore interesting related topics, which might arise in due process (Smith & Osborn, 2004). The researcher's choice of this data collection tool reflected her aim to become a part of the world of the participant (the HIV/AIDS lay counsellor), as he or she experienced it. As is said by Smith and Osborn (2003), "... there is a wish to enter, as far as possible, the psychological and social world of the respondent" (p. 57).

The current researcher perceived the semi-structured interview to be a form of communication or dialogue between her and the interviewee or participant, therefore an interview schedule was set-up before hand to guide the discussion during the interview. Smith and Osborn (2003) state that the interview schedule assists the researcher in concentrating on what is being said during the interview, as thought and attention have been given to the possible proceeding of the interview prior to its onset (via the set interview schedule). By setting an interview schedule in advance and learning the contents beforehand, the researcher envisioned that her full attention would be on the participant and his or her verbal and non-verbal expressions. The researcher used the guidelines presented by Smith and Osborn (2004) in setting an interview schedule, incorporating the four pointers provided: a) start by thinking of the wide range of issues

you want to cover in the interview, b) place the topics in a logical order – sensitive topics to be addressed later on during the interview, c) find suitable questions for each area of interest and d) think of probes and prompts you can use for some of the generated questions. The present researcher decided to precede the generated questions on the schedule by asking the participants to respond to some basic demographic indicators. By answering a set of easy and logical questions before the onset of the open-ended questions on the interview schedule the researcher attempted to ease the participants into the interview in a relaxed manner. At the same time the demographic information could be used to describe the sample group more comprehensively. The researcher set open-ended questions in the interview schedule, which would potentially allow participants or interviewees to tell her their own stories freely, to fill the gaps left by the questions asked so to speak (see the interview schedule in Table 1).

Table 1

Interview Schedule

Categories	Questions asked
a) Demographics	<ul style="list-style-type: none">- Could you tell me how old you are currently?- Are you married or single?- What is your home language?- How long have you been employed as lay counsellor?- Have you worked with HIV and AIDS before this job?

- b) Being a lay counsellor - Please describe your work to me in your own words.
Prompt: What does a lay counsellor do?
- Could you describe the people you have contact with at work?
Prompt: Who do you counsel? Who do you work with?
- c) Experiencing negativity - Could you tell me how you feel about your job?
Prompt: Do you enjoy or dislike it? Does it make you happy or sad? Do you feel fulfilled?
- Could you tell me about the difficulties you experience at work?
Prompt: What situations? Which people? What happened?
- Could you tell me about the times when people acted negatively towards you?
Prompt: What situations? Which people? What happened?
How does this make you feel?
-

The current researcher needed to gain insight and know-how in conducting semi-structured interviews successfully. Besides taking the guidelines into consideration, which were offered by the researcher's study supervisor (W. H. Theron, personal communication, 28 June 2004), the researcher referred to the general guidelines presented by Aubeeluck (2004), which include some of the following: a) try to stay neutral in the interview (interpreted by the current researcher as not being bias or

opinionated), b) ask open-ended questions (interpreted by the current researcher as giving participants the chance to tell their stories freely), c) avoid jargon (interpreted by the current researcher as speaking a language easily understood and accessible to the participant), d) use prompts when participants struggle to answer questions or do not answer them (interpreted by the current researcher as a means to guide the participant into telling his or her story without interfering with the telling thereof), e) allow participants to talk about things which might not be in the interview schedule (the researcher interpreted this as a way of gaining access to interesting related topics or issues not covered by the schedule per se, getting to the real meanings lay counsellors attach to experiences and situations) and f) do not force a participant to answer every question. In addition to these suggestions, the current researcher also used the guidelines presented by Smith and Osborn (2003) in conducting interviews which included: a) do not rush into the interview too quickly (the current researcher appreciated the fact that participants might need time to think and answer especially sensitive questions), b) do not use too many probes (the current researcher realised that small encouragement was sometimes all that was needed for a participant to continue an interesting story, many distractions might cut a story short) and c) ask only one question at a time (the current researcher interpreted this as a cue not to overwhelm or confuse the participant with complexly constructed questions).

With the abovementioned guidelines in mind, the current researcher could not forget the importance of herself as facilitator or guide in the successful conducting of the semi-structured interviews with HIV/AIDS lay counsellors. As facilitator of the

interviews she tried to remember that the participants needed to form some bases of trust between them in answering her questions truthfully. She therefore tried to put participants at ease when talking to them about the study, answering all questions and addressing fears about being interviewed. The researcher also concentrated on personal qualities which she envisaged as being of important use when interviewing participants, for example: a) keeping a calm and relaxed tempo when asking questions, b) listening attentively to what participants were saying and what meanings might be hidden in what was said, c) paying attention to non-verbal cues, for example body language and facial expression as means of reading the meaning of what participants were trying to convey, d) giving participants a chance to answer questions in their own time and e) showing interest and having empathy for what the participant was saying.

4.6 Procedure of Data Collection

Phase 1:

Phase one of the study entailed the writing of an introduction letter to a NGO in the Helderberg area (Somerset West, South Africa), as to be granted permission to contact and have short, anecdotal discussions with ten lay counsellors employed by them. Introduction letters were simultaneously drafted and sent to other NGO's, municipalities and Department of Health representatives within the Western Cape area, as to inform them of the proposed study and to ask permission to conduct interviews with lay counsellors in their employment (please see Appendix A).

Phase one was completed by gaining access to ten lay counsellors of the Helderberg AIDS Centre (based in Somerset-West) and by having short (\pm 20 to 30 minute), voluntary, discussions with them regarding their personal experiences of their work. Counsellors were asked to talk about any possible problems they encountered with people in regards to their work. The anecdotal discussions were evaluated on face value and notes were made on relevant points raised during the correspondence. The information gathered from these ten discussions motivated the researcher to continue the study as lay counsellors recalled certain problematic situations and experiences, from which the researcher could deduct instances and categories of experienced prejudice, stigma and discrimination related to their work.

Phase 2:

Phase two of the proposed study proceeded with 25 semi-structured, in-depth interviews conducted with lay counsellors from both urban and rural areas within the four Western Cape regions: Metro, Westcoast/ Winelands, South Cape/ Karoo and Boland/ Overberg area. The researcher made contact with potential participants by attending a monthly group mentoring session held in the towns of: Somerset-West, Paarl, Hermanus and Villiersdorp. The researcher briefly introduced the study to the lay counsellors and set out the study objectives to them. Interested lay counsellors were contacted thereafter telephonically as to set up an interview date and time suitable to them. Interviews were conducted in the towns of: Somerset West, Gordon's Bay, Strand, Macassar, Lwandle, Sir Lowrie's Pass, Grabouw, Hermanus, Paarl, Wellington, Darling, Veldrif and

Laaiplek. As mentioned before, a letter of consent was drafted and was signed by both researcher and participant before interviews commenced (please see Addendum B). Interviews were preceded with participants relating demographic details to the researcher. Demographic categories included: age, gender, marital status, home language, period of time employed as lay counsellor and previous experience working with HIV and AIDS.

Interviews were conducted with the voluntary participants regarding their work and their personal experiences of negative attitudes and behaviour they have encountered towards them as a result of their work. The current researcher was able to conduct interviews in either English or Afrikaans and interviews were tape-recorded. Interviews took 45 minutes to an hour to complete and were held after working hours in a private and comfortable venue (for example a municipal library hall). Follow-up counselling was offered to lay counsellors who experience difficulties as a result of the interview. One lay counsellor made use of the offer in due process and was put in contact with a Psychology intern from the University of Stellenbosch who was working at a hospital in her area.

During phase two all interviews were transcribed and entered into the Atlas ti. electronic analysis programme. The researcher proceeded with line-by-line coding which assisted her in organising the qualitative data (gathered via the 25 semi-structured interviews) into seven categories and ten themes that emerged in due process. The categories related to people who were negative towards the HIV/AIDS lay counsellor, namely: clients, medical staff, the community, Department of Health, families and friends, NGO/ municipality employing lay counsellors and colleagues. Thirty-five codes

were used to label or code instances of negativity, also examples of possible prejudice, stigma and discrimination, found in the transcribed interviews. Examples of codes which emerged and were used are: medical staff's overt negativity, medical staff's disrespect, community's ignorance, community's connotations and associations of lay counsellor's work and client's unease regarding race issues. Ten themes subsequently emerged from the coded data related to the overt and covert negative experiences of lay counsellors, namely: mistrust, blame, avoidance, gossiping, provocation, assumptions, demanding attitudes, fear, dishonesty and ignorance. The researcher utilised an Interpretive Phenomenological Analyses (IPA) process in coding and categorising the collected data as well as organising the gathered information in themes, which emerged from the interviews, as set out by Smith and Osborn (2003). The transcription of interviews, line-by-line open-coding, the generation and listing of themes and the eventual writing-up of themes comprised some of the steps taken in analysing the collected data according to an Interpretive Phenomenological Analyses design (Smith & Osborn, 2004).

Phase 3:

Phase three of the study entailed the construction of an item pool from the information gathered via the semi-structured interviews with lay counsellors, which was used to eventually construct the final scale. The initial item pool reflected the range of presented themes representing the constructs embedded in these themes (negativity, like prejudice, stigma and discrimination). A wide variety of scale items were written and the initial item pool was quite large, as is set out in the guidelines provided by de Vellis

(1991), “The first step is to generate a large pool of items that are candidates for eventual inclusion in the scale” (p. 54). Items from the initial item pool were evaluated for inclusion in the scale by using the guidelines, which were again, supplied by de Vellis (1991). Items, which did not reflect the underlying purpose of the scale (to measure negativity as experienced by HIV/AIDS lay counsellors), were omitted.

Following this the reduced item pool was presented to a panel of judges who were familiar with the research within the specified fields of interest (in terms of scale construction as well as the constructs prejudice, stigma and discrimination) as to evaluate each of the items. The panel evaluated the items from the item pool, similarly doing away with some items in an effort to enhance the content validity of the scale. The panel could thus evaluate each item according to or in relation to the constructs in mention, as specified by de Vellis (1991). In addition, the panel of judges assisted the current researcher by evaluating items on the basis of conciseness and clarity (de Vellis, 1991). Unclear or ambiguous items were once again eliminated from the item pool by the panel in due process. The researcher then asked a small test sample (four lay counsellors) to evaluate the constructed scale, as to ensure the final pool of items was relevant and easy to read and understand. As a result of the first run with the smaller test sample problematic items were analysed and re-worded with the help of the panel of experts.

4.7 Analysis

Transcription of Semi-structured Interviews

The first step in analysing the collected data was the transcription of the 25 semi-structured interviews. The researcher proceeded by listening to the audio taped interviews and then typing the interviews line-by-line. Both the spoken words of the participant and the researcher were typed into a Microsoft Word document (please see Table 2). A verbatim written record was thus created in this manner (Smith & Osborn, 2004). In addition, information and personal details, which could identify the participant, were omitted as is suggested by Smith and Osborn (2004). This was done as an effort by the present researcher to ensure anonymity and confidentiality were kept in check.

Table 2

Example of Transcribed Interview

Speaker	Transcription
R:	Do you want to tell me about it?
N:	That is a problem. Because those people, they come to the clinic, they have been tested, and then they are from the community. Then when they see me there in the community, they sometimes don't even want to see me. They run away some times. I used to greet them some times, before they come for the test. But now that they know their status, they don't want to see me now. I mean, I don't know when they see me now, I don't know whether they feel threatened. Or maybe I will tell somebody of their

status or what. I feel sometimes, uhm, there is no trust between, there is no trust between me and the clients. They do not trust me. Maybe they think I will tell the people, you see that man there, that guy there, he is HIV positive. But they are avoiding me sometimes, most of them avoid me.

R: Most of them?

N: Most of them. And the others are coming to my place, just to need some advice. What do I do now? Where do I go now? What would happen if this and this? And I say, no, if you need to talk about things like that, go to the clinic. I am not here in the community for that now, ja {laughs}.

R: So either they ignore you, they do not want to see you, or they come to your house at any time, you must be available?

N: Ja, they do that. I must be available. That is a problem for us when working in the community. We sometimes say it is not good working in the community, because if they see you in the community, you are not at work, they see someone who is going to help us now. They need you, like now. And it is impossible.

Note. R is an abbreviation for the researcher, N is an abbreviation for the participant.

Open-coding

The present researcher loaded the 25 transcribed semi-structured interviews into the electronic analysis programme Atlas ti. The programme enabled the researcher to, after reading the interview as a whole, highlight and code certain areas of text, which

were of importance or relevance to the study. A line-by-line analysis was thus conducted in which certain parts of the text were highlighted and marked with a corresponding code or comment. A list of codes was generated during this process and codes started to repeat or reoccur between different interviews, as experiences and situations seemed to overlap in the different stories told by all of the lay counsellors. The researcher constantly attempted to focus on the (hidden) meanings of the interview contents as to determine what the participant was thinking and feeling at the time, as is suggested by Smith and Osborn (2003), "... meaning is central, and its aim is to try and understand that content and complexity of those meanings rather than measure their frequency" (p. 64). The Atlas.ti. analysis programme additionally allowed the researcher to make comments or to record ideas related to certain areas of text by means of an electronic memo pad. This enabled the researcher to keep track of her own feelings and ideas as she was engaging in the open-coding stage of the data analysis. Table 3 shows the first stage of the analysis, or open-coding, as an example.

Table 3

Example of Open-coding

Code	Transcription
Client's public reaction	N: That is a problem. Because those people, they come to the clinic, they have been tested, and then they are from the community. Then when they see me there in the community, they sometimes don't even want to see me.

Client's public reaction	They run away sometimes. I used to greet them some times, before they come for the test. But now that they know their status, they don't want to see me now. I mean, I don't know when they see me now, I don't know whether
Client confidentiality	they feel threatened. Or maybe I will tell somebody of their status or what. I feel sometimes, uhm, there is no trust
Clients trust issues	between, there is no trust between me and the clients. They
Clients trust issues	do not trust me. Maybe they think I will tell the people,
Client confidentiality	you see that man there, that guy there, he is HIV positive.
Client's public reaction	But they are avoiding me sometimes, most of them avoid me.
	R: Most of them?
	N: Most of them. And the others are coming to my place, just to need some advice. What do I do now? Where do I go now? What would happen if this and this? And I say, no,
Clients misuse	if you need to talk about things like that, go to the clinic. I
Clients demand help	am not here in the community for that now, ja {laughs}.
Clients privacy issues	

Note. R is an abbreviation for the researcher, N is an abbreviation for the participant.

Generating Categories

As the researcher was coding the transcribed interviews, categories of people who were negative towards the HIV/AIDS lay counsellor came to the fore. Lay counsellors indicated that these were the groups of people who were prejudice, who stigmatised and who discriminated against them the most in their experience, which included: clients, medical staff, the community, the Department of Health, the family and friends of lay counsellors, the NGO/ municipality employing the lay counsellor and colleagues.

Generating Themes

After reading the transcribed interviews yet again as to familiarise herself with the contents and meanings thereof, the current researcher moved from open-coding and the generating of categories to the next step in the process of analysing - the generation of themes. According to Smith and Osborn (2003) the researcher was now to evolve the initial negativity (using the initial codes) into more concise psychological concepts, which were to “ ... capture the essential quality of what was found in the text” (p. 68). The whole of the transcript is thus worked on to construct themes, which emerge in due course of the analysis (Smith & Osborn, 2003). Themes overlapped and reoccurred between the different transcripts, supporting the current researcher’s suspicions that participants were experiencing similar negative attitudes and behaviour directed towards them, although stories and situations might be different for each participant (see Table 4 for an example of emerged themes from the text).

Table 4

Example of Emerged Themes

Transcription	Theme
<p>N: That is a problem. Because those people, they come to the clinic, they have been tested, and then they are from the community. Then when they see me there in the community, they sometimes don't even want to see me. They run away sometimes. I used to greet them sometimes, before they come for the test. But now that they know their status, they don't want to see me now. I mean, I don't know when they see me now, I don't know whether they feel threatened. Or maybe I will tell somebody of their status or what. I feel sometimes, uhm, there is no trust between, there is no trust between me and the clients. They do not trust me. Maybe they think I will tell the people, you see that man there, that guy there, he is HIV positive. But they are avoiding me sometimes, most of them avoid me.</p>	<p>Avoidance</p> <p>Avoidance</p> <p>Fear</p> <p>Fear</p> <p>Mistrust</p> <p>Mistrust</p> <p>Fear</p> <p>Avoidance</p>
<p>R: Most of them?</p>	
<p>N: Most of them. And the others are coming to my place, just to need some advice. What do I do now? Where do I go now?</p>	

What would happen if this and this? And I say, no, if you need talk about things like that, go to the clinic. I am not here in the community for that now, ja {laughs}.

Demanding Attitude

Assumptions

Note. R is an abbreviation for the researcher, N is an abbreviation for the participant.

Before generating a list of the emerged themes from the transcribed interviews the researcher attempted to cluster themes together that were related, as suggested by Smith and Osborn (2004). A final table of themes or master table of themes was created thereafter with a total of ten emerged themes listed therein. The final stage of the analysis entailed the writing-up of the themes as a narrative account (Smith & Osborn, 2003). According to Smith and Osborn (2003) this is a phase in the analysis where themes are expanded on, they are described, explained and illustrated. The researcher thus moved from the emerged themes as basic building blocks of the interview contents to a detailed narrative discussion that is richly supported by verbatim extracts from the transcribed interviews (Smith & Osborn, 2004).

CHAPTER 5

RESULTS AND DISCUSSION

In the following chapter the researcher presents the results and discussion of the qualitative research conducted (anecdotal as well as semi-structured interviews). Attention will be given to the seven categories of people who are prejudiced, who stigmatise and who discriminate as well as the ten themes, which have emerged from the collected data. All types of experienced negativity pointed out by the participants have been recorded, most instances having direct bearing on lay counsellors' HIV and AIDS involvement per se and some less directly related to it.

5.1. Anecdotal Interviews

On face value the results of the ten anecdotal interviews or informal discussions held with HIV/AIDS lay counsellors from the Helderberg AIDS Centre, Somerset West, convinced the current researcher that the lay counsellors experienced or had perceptions of negative attitudes and actions directed towards them as a result of their work with HIV and AIDS. The results additionally indicated that certain people or groups of people were identifiable in this regard, such as: clients, medical staff at the clinic or hospital they worked at, the community and sometimes people known to lay counsellors, for example their families and friends. Areas and incidences of this experienced negativity were mainly centred on the testing and counselling process (VCT and PMTCT) in clinics and hospitals at which lay counsellors worked. The lay counsellors reported that clients, for

example, showed their negative attitudes towards them by acting in a resistant manner and by not co-operating. Sometimes clients ignored the lay counsellors and the advice they offered, or became aggressive when asked certain questions. Medical staff, on the other hand, devaluated and discriminated against lay counsellors by embarrassing them in public. The lay counsellors recalled that this behaviour differed to the manner in which medical staff (specifically nursing sisters) related to other groups of people in the clinic/hospital. Incidences of possible negativity were once-off situations or seemed to be of a chronic nature in other instances. In addition the information supplied by these lay counsellors defined more clearly which topics could be included in the interview schedule for the planned semi-structured interviews.

5.2 Semi-structured Interviews

After listening to the personal testimony of the 25 lay counsellors and transcribing the in-depth, semi-structured interviews the researcher was able to form an understanding of the experiences of negativity, including possible perceptions of prejudice, stigma and discrimination. With the completion of the detailed line-by-line coding of the transcribed interviews (utilising the Atlas ti analyses programme), the information gathered was sorted and categorised into ten main themes, which emerged from the collected data. The ten themes in mention are presented in Table 5.

Table 5

Master Table of Themes

Themes related to Overt and Covert Negativity

1. Mistrust
 2. Blame
 3. Avoidance
 4. Gossiping
 5. Demanding attitudes
 6. Fear
 7. Dishonesty
 8. Ignorance
 9. Provocation
 10. Assumptions
-

These themes related to HIV/AIDS lay counsellors' experiences of negativity, both overt (openly visible) and covert (subdued or hidden). The lay counsellors thus specifically referred to these emergent themes during interviews. Of importance to note is that the listed themes are individually discussed but could possibly overlap or might appear to be interwoven. The experiences of fear might, as an example, have similarities to that of mistrust. Another example is the theme related to avoidance, which might appear to overlap, once again, with the theme related to fear.

The participants identified seven groups of people who in their opinion were prejudiced, stigmatised and discriminated most against them: a) clients, b) medical staff, c) the community, d) the Department of Health, e) lay counsellors' family and friends, f) the NGO or municipality and g) colleagues. The lay counsellors indicated that medical staff specifically refers to nursing sisters. Some of the identified groups had frequent contact with lay counsellors, namely, the community, medical staff, lay counsellors' family and friends, the NGO and municipality employing the lay counsellor and colleagues. Other groups might have a single, once-off meeting with lay counsellors, for example, clients. Medical staff, clients, the Department of Health, colleagues and the NGO or municipality employing lay counsellors represent people who have a professional or work-related relationship with lay counsellors, while lay counsellors' family and friends and the community might implicate their private lives and those they have contact with when they are not working at clinics and hospitals.

The following section sets out to describe how lay counsellors experience negative attitudes and behaviour (implied prejudice, stigma and discrimination) as represented by the ten emerged themes from these individuals and groups of people they interacted with. As mentioned before the themes will be discussed as individual entities, but as they refer to experiences that are related overlapping might be inevitable.

Mistrust

Lay counsellors often experienced mistrust from those seeing them as a member of the out-group, whether it is, for example, from clients, medical staff or the community. The degree to which clients, for example, acted and felt negatively towards lay counsellors often centred on this issue. Lay counsellors conveyed that clients often showed these negative, preconceived attitudes and behaviour towards them that mainly came to the fore when they were counselling and testing them (during VCT and PMTCT) or when doing follow-up counselling. Clients showed lay counsellors that they felt negative towards and thought negatively of them, as they often implied that they did not trust them from the onset, fearing that lay counsellors would disclose their status to other people. These feelings of mistrust directed towards lay counsellors have been experienced by them as extremely negative and devaluating. The mistrust directed towards lay counsellors might be as a result of the extremely sensitive and highly confidential nature of their HIV positive status.

“Maybe they didn’t keep the trust on me that I am gonna keep the confidentiality, whereas I did say that, here we keep the confidentiality.” - L

“No, they are not happy with me. They have a fear of, that I know them. Whereas I don’t know them. Maybe they didn’t keep the trust on me that I am gonna keep the confidentiality, whereas I did say that, here we keep the confidentiality. We

work as a team, so, we do the best for the confidentiality. Maybe they don't think that I am saying the right thing." - S

"They, no, they do not feel easy, at ease with me always, as, I, uhm, I have the confidential, I have to keep the confidentiality, you see? With me, whereas I know their status they worry I am, I will tell others about their status, like that." - N

"The clients fear, they are afraid of me sometimes, some of them, because, I, I did test them and I know. I know what they want to keep a secret rather. Not to tell other people." - J

"I mean, I don't know when they see me now, I don't know whether they feel threatened. Or maybe I will tell somebody of their status or what. I feel some times, uhm, there is no trust between, there is no trust between me and the clients. They do not trust me. Maybe they think I will tell the people, you see that man there, that guy there, he is HIV positive. But no, I, I, no." - N

Clients therefore seemed to perceive lay counsellors to be powerful and potentially dangerous people as they have access to very personal and confidential information. In addition, clients seemed to have the perception that lay counsellors are not to be trusted as they have the ability to either change test results or merely have the power to lie about test results during the testing and counselling process.

“Maybe they change my blood, maybe they have, but now we are doing the test in front of them. We are not going out and in. You just sit in front of them. The tools are here. And the only thing you do, you just phone, dial for that sister to come and prick, make a prick. And then the sister comes in and do the prick – in front of them. So, so I don’t know why now. They have no chance to say, that is not my blood.” - L

“I, I don’t know, maybe take me cheap. Maybe I am hiding something. I am hiding something, maybe she is positive and I am saying she is negative, because I know her.” - S

“ ... she, she don’t believe what I say, or that she is positive.” - T

“They think that we can change it, that we have the, the power to make the test positive. But no, I mean, the nurses do the prick of the finger in front of them. We do not leave the room with the blood. But this is still how they think.” - J

Lay counsellors also feel medical staff have negative perceptions of them and act negatively towards them as they belong to a devaluated group (namely HIV/AIDS lay counsellors) within the clinic or hospital. Quite often medical staff’s behaviour is explicitly clear in illustrating to lay counsellors that they are evaluated negatively. Medical staff has, for example, made it apparent that they do not trust the HIV/AIDS lay

counsellors, which in turn is experienced as disrespect, discrimination and prejudiced attitudes and behaviour from medical staff.

“So there is not trust. There is no teamwork there. No trust at all. No.” - S

“The, the nurses are looking to find something wrong, a reason, no, for not trusting us. They look and look to find something wrong with the HIV’s with the counsellors. With us.” - R

“I don’t think they want to trust us. In the clinic we are at the bottom. We are at the bottom level. Not near the top. They do not feel like giving us a chance, to show them they can trust us, the HIV/AIDS counsellors.” - S

In addition, medical staff has degraded and (as is the opinion of lay counsellors) discriminated against them by constantly checking on them to see whether they are in fact doing their job properly. Medical staff has in effect shown that they often doubt the effectiveness and trustworthiness of HIV/AIDS lay counsellors.

“... you, you are a HIV/AIDS lay counsellor and I think, I might be wrong, but people, the nurses, they ask how effective are you as a counsellor? Are you making a change?” - S

“... one of the sisters there, I don’t know what her story was, or what, she did not tell me in so many words that my work was not right, but she was, like she was

stepping on my toes. Don't know what she thought, but she was always like a little tail. When I turned my back, she was there, checking my work. Not trusting me to do my job properly, ja. She thinks little of my work, I, yes, think so." - K

" ...but they are wondering if we can do this job. Can they leave us with this job, to do it. They want to know if they can trust us with this job." - G

From the above-mentioned quotations from the transcribed interviews it is thus clear that the HIV/AIDS lay counsellor often experienced that people did not trust him or her as individual to keep confidentiality and in other instances they were doubted to be trustworthy in delivering the essential services they volunteered to provide to communities. Clients' mistrust might be understood at hand of the following three theories: Spoilt Identity Theory, Terror Management Theory and the Social Identity Theory. Medical staff's devaluating behaviour towards HIV/AIDS lay counsellors might be grasped by utilising the Sociocultural Approach Theory.

According to the Spoilt Identity Theory (Goffman, 1963) clients might mistrust HIV/AIDS lay counsellors as a result of their specific association with HIV and AIDS. As lay counsellors are not seen as individuals, but rather as a group with a certain characteristic or blemish that classifies them - their involvement with the feared disease AIDS - they are subsequently viewed in a negative light. When utilising the Terror Management Theory (Greenberg et al., 1997) it is understood that clients mistrust HIV/AIDS lay counsellors as they are, once again, strongly associated with the HIV-

virus, the fear of a serious illness and subsequent death. Clients might thus rather mistrust or reject lay counsellors in an effort to keep themselves safe from possible harm. In accordance with the Social Identity Theory (Tajfel & Turner, 1979) clients might place themselves in an in-group and lay counsellors in an out-group. This might happen as lay counsellors are, for example, the bearer of bad news - hence the negative categorisation into the out-group. In an effort to reinstate feelings of low self-worth the in-group (in this case clients) might devalue HIV/AIDS lay counsellors (the out-group). Clients might as a result of a positive HIV-test or the embarrassment of being tested feel the need to boost their group's self-image by devaluating HIV/AIDS lay counsellors.

According to the Sociocultural Approach Theory (Vygotsky, 1986) medical staff might mistrust HIV/AIDS lay counsellors as they feel they are of a low standing within in the culture of the clinic or hospital. HIV/AIDS lay counsellors and the service they render are thus not to be trusted as being of worth, as they are less sophisticated and educated than the nursing staff who is perceived to be closer to the top of the clinic or hospital hierarchy.

Blame

The lay counsellors have experienced that members of the opposing groups (whether it be clients or medical staff) have blamed them for a variety of things. As members of the so-called out-group lay counsellors have experienced that others see them in a negative light and that they consequently accuse them of wrongdoings. Clients, for

example, have blamed the lay counsellors (who counselled and tested them during VCT and PMTCT) for their positive status or any personal problems that they have experienced as a result of their status.

“ You see, the expression told me that, almost looked like I caused the problem, it is my fault, understand?” - B

“ I think you mostly face it that people blame, blame you as counsellor. You did the test. You did the counselling. And you now told me that I am positive.” - M

“The other day this lady came in. I counselled her in June of last year. She came back to the clinic and said, no, I, you are the one that told me that I am HIV positive, that I have a positive status. You tested me in June and you told me that I am positive. It is you, you, ja. Now it is almost as if she is telling me that it is my fault that she is positive, because I tested her and I gave her the news of her status.” - H

Blame shifting also occurred where clients blamed lay counsellors of doing a test incorrectly, in effect accusing lay counsellors of not knowing how to do their jobs properly.

“I mean, then obviously she took it out on me and told me I did not read it right. The test was not done right.” - B

“ She was, like, she was actually saying I did not know how to do the test. That I was wrong here, I mean, really, am I the one who is positive here? Why, I mean, why am I to be blamed now, like, no man. No. ” - R

Clients have been prone to blame lay counsellors for any problems they experienced after they tested HIV-positive, for example their lack of an income, the fact that a partner has left them or other private problems relevant to their lives. Again it seems as if clients blamed lay counsellors for these and other personal problems, as lay counsellors were the ones who conveyed their status to them originally.

“I told her that she was HIV positive and after a time she came and she said, you said I am HIV positive. I don't have something to eat at home. I don't have clothes. My boyfriend left me, so what can I do now. I am looking for something. What can you do for me now? I need money and all of that. You see I referred her to the social worker, but she came to me again. Ja, some of them are like this. You told me that I am HIV positive. So now I have this problem, I have this problem, I have this problem. This problem, it has been there before, but now because we have sat down and I have told you your status, so now they are just taking that chance now.” - N

“ I am here to test you, to help you with the test, to do counselling. Nothing more ... Now I must hear of all these problems at home, like no food, no work. This is not me, I am not, now what must I now do. Is this my fault, like you see

what I mean? They think I told you, so now I must also make the problems go away, because I told you, you are positive, you are positive, you see?" - J

The medical staff also blamed lay counsellors for many mishaps or wrongdoings (for example theft) in the clinic or hospital. They have even gone so far as to accuse lay counsellors of wrongdoings, which in reality has proven not to be their doing at all. As a result of the negative judgements, attitudes and perceptions held towards lay counsellors as a group, medical staff's behaviour has convinced lay counsellors that they were disliked by them. They feel they are discriminated against as members of the out-group.

"It is bad. And some time there was the money that was stolen and they, they say that it is the counsellors, the sister in charge say that it is the counsellor, his staff can't steal the money. Maybe it is the lay counsellors, which are using that room. We are using that room really, but we are not the only ones getting in there. So, you are really in a bad situation." - S

"That is what they say, yes. Like the counsellors should not take their things, should ask if we want something, like that. In front of the other staff." - S

"Uhm, because one time there was something missing. And they, they call us and say it is between us that thing that is missing. It was money, about twenty-six rand. I said to the sister, no we can't do it, because we know how not shining is our future. We cannot steel. You cannot risk it by steeling money, by steeling

money. And unfortunately we never saw it in the clinic. I did not steel your money, you see. They said the money is among you. It can't be my staff. It is there, you can say, maybe you can say that I stole it, but I didn't. And if you are confident about your staff, I am confident about my colleagues. They didn't, they didn't steel the money." - S

"Everything that goes wrong in the clinic - it is the counsellors." - J

"It can't be my staff. It is between you. It is there, you can say, maybe you can say that I stole it, but I didn't. And if you are confident about your staff, I am confident about my colleagues. They didn't, they didn't steel the money." - S

"They always are telling us that we took things from the clinic. We stole it ourselves. We must do it, we have ... they accuse us of many things in the clinic, they, the nurses they think we are guilty, but no. We are not taking those things they tell us about. We must always say, no, we did not do this, no we did not do that, and it hurt us, that guilt, that. We are not the ones that took it." - H

"Whatever happens, it must be the counsellors. That is how they are thinking about us. It is our mistake, our, uhm, how do you say it? It is us, we are the ones that did it. We are wrong here." - D

The interviewed HIV/AIDS lay counsellors conveyed their deep-felt unhappiness as a result of the constant blame others bestow on them. They felt discriminated against and singled-out, as others working in the clinic or hospital were not associated with blame in the same manner as they were experiencing it. It is possible that the blame clients bestowed on lay counsellors could be understood at hand of the Downward Comparison Theory (Wills, 1981). Clients devalue members of the out-group (lay counsellors) by blaming them for wrongdoings. By doing this they are trying to boost their own feelings of low self-worth. Clients might constantly blame lay counsellors as they themselves are feeling humiliated by having to undergo a HIV test or by testing positively.

Medical staff might, according to the Social Dominance Theory (Sidanius & Pratto, 1999), blame HIV/AIDS lay counsellors for wrongdoings, as they feel their own group is too superior or sophisticated to take the blame for any mishaps. The HIV/AIDS lay counsellors, as a less educated group, can thus be blamed for things, which might not have been their doing at all. In an effort to keep their group's image in tact within the clinic or hospital, the medical staff devalues HIV/AIDS lay counsellors in such a manner.

Avoidance

Many lay counsellors bore testimony to the fact that they were often avoided in public - especially by clients and members of the community. The lay counsellors ascribed the clients' behaviour to their association with the HIV test, with AIDS or with their positive

status. The HIV/AIDS lay counsellors stated that people feared that others might see they have contact with them and therefore rather kept a distance from lay counsellors in public.

“Uhhu, no. They sometimes greet me when I am alone. If I walk with someone, then they don’t, no, they don’t know me. They will walk past me.” - T

“But they are avoiding me some times, most of them avoid me.” - N

“...if there is someone sitting outside, they will pretend that they do not know me. Because there sits auntie Sannie and she knows me, Jaco, the AIDS man. Then if I am Jaco the AIDS man she will think I am HIV positive. No, no I do not greet them first. If she goes out of here and she does not greet me, then, then I know, that person I must walk past her, give her the freedom she wants.” - J

“They walk past me, they do, really, they do. When I am in town, they do not stop. In the clinic maybe they know me, but not out in the street, no.” - H

The lay counsellors are troubled by this avoidance and feel clients have preconceived, prejudiced perceptions regarding them and that a stigma is attached to them as well as the situation.

“Ja, I just think some times, why is he avoiding me now, why is he avoiding me now? Because we used to sometimes talk. If I went to the shop we used to talk, but now? I have been with him and I told him his status and he is avoiding me now, why?” - N

“No, you know, if you can see it is someone who is not comfortable and he will find me outside in the street, he will not make eye contact. He will not greet me. Oh, no.” - E

“Shy, whether they have tested positive or negative, yes. But as I say, many people are shy to greet me. Shy to talk to me. It is not nice for me.” - M

“Oh, maybe when you see me, you look that side. If you want to wave at me, wave me, if you don't, go.” - T

Medical staff has shown their dislike of lay counsellors as members of the out-group by often not including them in the activities of their own group. In effect HIV/AIDS lay counsellors have been purposefully ignored, avoided or been kept at a distance. Examples from interviews, which illustrate this type of segregation, are legion.

“I don't think so, because, as I said earlier, the HIV/AIDS counsellor is not really part of the clinic.” - R

“There is no teamwork there, we are not a team at all, no.” - S

“We were seen as lay counsellors and never fitted in with the staff. Yes, you were never part of what happened at the clinic.” - J

“You, you feel left out, I, I feel I don’t want to be there any more. You feel excluded from everything. You aren’t part of the staff there.” - H

“We are separate from them, we are one side and they are on their side. You don’t feel yourself as part of the team. As a counsellor.” - L

As some groups of people perceive the HIV/AIDS lay counsellor to be a member of the so-called out-group, they are often avoided socially, leading to possible feelings of isolation. According to the Social Identity Theory (Tajfel & Turner, 1979) the HIV/AIDS lay counsellors are categorised as members of the out-group in an effort of the in-group to boost their own self-worth. Clients might also avoid HIV/AIDS lay counsellors as they fear other people might assume that they are HIV positive if they interact with them. According to Goffman’s Spoilt Identity Theory (1963) HIV/AIDS lay counsellors are thus devaluated, in this case avoided, as they possess some characteristic (in this instance their connection with HIV and AIDS counselling and testing), which sets them apart from other people in a negative manner. According to the Terror Management Theory (Greenberg et al., 1997) people might additionally try to avoid contact with the

HIV/AIDS lay counsellor as a result of the unmistakable association between them and the deadly HIV-virus.

Gossiping

Gossiping, whether by clients, the community or by medical staff, has been reported to be negative behaviour directed towards HIV/AIDS lay counsellors. It seems as if these groups seek a way to degrade lay counsellors and ultimately to invade their private lives by talking about them in public. The lay counsellors experience this type of negative behaviour as belittling and discriminatory, as lay counsellors and their private matters are often singled-out to be discussed in public.

The community has shown its devaluating properties towards HIV/AIDS lay counsellors by talking about or gossiping about them, their work and their personal lives. According to the lay counsellors people in the community think they almost own the lay counsellors as they work in municipal or public facilities, thus giving them the right to say what they will about them. As HIV/AIDS lay counsellors are strongly associated with the service of HIV/AIDS counselling at clinics and hospitals, people especially take notice of what they do in their private time and personal lives.

“No, I think what, what, in the beginning I was afraid to do the job because I knew people would talk and so on. Because I knew, I, I, knew they would ask some things, would expect something, would say something about HIV.” - J

“They are not, they are, for me the most, the most of the women are the same as the medical staff. It is a lot of gossiping and things like that.” and Sammy, “ Then they also gossip about you because you are a HIV/AIDS counsellor.” - P

“ I was shocked because it was so clear that people talked about me, because I was a HIV/AIDS counsellor at the clinic, ja. Like they say this and this and that. And also they talk about the things I did on the weekend, where I went and so on. I was, no, I was really shocked to hear this.” - S

In addition, members of the community quite frequently put pressure on the lay counsellors to gossip about a patient’s status or private life with them, as they know the lay counsellors have access to this type of confidential information. Lay counsellors are thus of opinion that they can as a result be seen as people who easily gossip themselves. They consequently worry that other people from the community might think they will easily break confidentiality.

“Like this morning I had an issue when I had two men, they came together, uhm, one wanted to test. Afterwards the one came and asked me, what is that one’s status? Then I said, no, I’ can’t tell you, I am not allowed to say. If he feels he wants to discuss it, wants to tell you, then, ja, he can tell you, but I cannot tell you.” - J

“Ja, like they wanted to know. I know, I don’t know what is wrong with her and even if I did, I can’t, I can’t tell you something. Yes, they want to know what the status is.” - N

“This man, the one who tested, he was his, uhm, employer. Yes, yes he came in and he, this was a big man. He was a big, white man. He wanted to know what was wrong with the man who, who was here for the test. And I just told him that, uhm, I could not tell him. This is not for me to tell him, you see? But, yes, they want to know and all of that.” - H

Medical staff has also not stopped short of embarrassing lay counsellors by discussing them and their private lives in front of other people in the clinic or hospital. They have, according to the testimony of lay counsellors, shown their disrespect for lay counsellors’ professional status by often gossiping about them.

“They gossip. Ja, like talk about the other HIV/AIDS counsellors, right here, in front of, ja, there are clients sitting and they hear, also the other staff is there, listening.” - M

“They will do it in front of anyone. It does not matter who it is. Does not matter what it is. It is not only about the work. Maybe it is something that you did over the weekend. Then they say it, talk about it in front of everyone and then everyone knows you did this and that and so on.” - J

“...they talk, they talk, yes, uhm, ja. What did the HIV/AIDS counsellors do over the week-end? Where did they go, like gossiping, talking about us like that, to other nurses in the waiting rooms, in front of some clients even. They have no respect for me, not for us.” - R

“Yes, yes, I think what upsets me the most is the nurses, they will talk to me, like about a HIV/AIDS counsellor’s private life and they do it, yes, in front of all the patients. It is just that, it is something that I, they will tell you sommer like that, it puts me off...” - H

As the passages and extracts above aim to illustrate the constant gossiping about HIV/AIDS lay counsellors as a group by, amongst others, the community and medical staff, was perceived as an extremely negative experience by lay counsellors. They felt that gossiping not only degraded them publicly, but it also discriminated against them personally. The community and even clients gossiped about the HIV/AIDS lay counsellor as he or she is closely associated with HIV, AIDS and the PLWHA. Some of these negative perceptions might be transferred to the HIV/AIDS lay counsellor as a result of his/her constant contact with HIV and AIDS. The community might, for example, assume the lay counsellor him- or herself has a promiscuous lifestyle, is homosexual or is a drug user, simply as those are perceptions held for the PLWHA. According to the Spoilt Identity Theory (Goffman, 1963) the HIV/AIDS lay counsellor’s identity is thus blemished as a result of these existing perceptions, which he or she is related to.

The negative behaviour of medical staff in this instance can be understood at hand of Tajfel and Turner's Social Identity Theory (1979). The medical staff constantly gossips about lay counsellors, sometimes in public, as to enhance their own group's stature (that of the in-group) and in effect to even diminish that of the out-group more – the HIV/AIDS lay counsellors. The self-esteem of their own group (the in-group) is thus boosted by putting the members of the out-group down in this manner.

Demanding Attitudes

The lay counsellors have experienced that clients and members of the community especially exhibit demanding attitudes towards them. Also indicated in this regard was the Department of Health and the NGO or municipality that employ lay counsellors. The lay counsellors are expected to take responsibility for far more than is necessary and these groups insist that they comply with their every demand. They feel clients, for example, have the perception that they are there to unconditionally support, assist and serve them, regardless of the request made by them. Often clients ask for personal assistance, or stated more accurately, demand assistance from them, regardless of the responsibilities and expectations set for lay counsellors by their job descriptions.

“Ja, some time there was a lady. I told her that she was HIV positive and after a time she came and she said, you said I am HIV positive. I don't have something to eat at home. I don't have clothes. My boyfriend left me, so what can I do now. I

am looking for something. What can you do for me now? I need money and all of that. You help me now.” - N

“Yes, some times it happens, but in a case like this I just refer the client, listen, what I am supposed to do is to give you your results. I would like you to join the support group just to, to be with other people who are living with HIV. Because I cannot do all the things you want me to do, I don't have the time.” - T

“And you must set the boundaries. Have your clients ever made you feel, but no, they expect too much from me. I am only the counsellor, I can only do so much, as if it is an expectation.” - Z

In addition to clients and the community the lay counsellors stated their feelings in regards to the demanding nature of the Department of Health. It seems lay counsellors are seen as merely the work force on the ground and nothing more - doing the work the Department of Health have set out to be done. The lay counsellors experience these unrealistic demands by the Department of Health as discriminatory, as expectations for other members of staff in the clinic seem to be more realistic.

“They sit up there and they expect that what happens there on the bottom must go smoothly. No, they really think nothing of us.” - J

“So, that is why I say, they don’t care. You must go on, and go on, and go on, because they press the buttons.” - S

“Who has come from up there to say I appreciate what you do? Good shot. Exactly. They don’t do it. They do not show appreciation for what we, for our work that we do.” - H

“I never thought like that né, but if you sit and just think about it. To think you are working here on at the ground level and they expect that, just a pretty picture. Nothing more really.” - J

Lay counsellors also indicated that the NGO or municipality they work for discriminated against them as a group. NGO’s and municipalities seemingly viewed lay counsellors, as is the case with the Department of Health, as simply being there to do the work set out as is expected of them. Lay counsellors are thus not treated fairly as other employees are, but are merely the “worker ants” doing the work that has been allocated to them.

“We are there in the clinic to work. We are nothing more to them. We must work. We have no rights, nothing, no, uhm. They see us as the workers, the ones that must work.” - J

“The NGO tries, it wants to be good to us I think, but, yes, what they expect is us working and working with the HIV. We get very little, nothing, uhm, yes, nothing more for the work we do. We are there as slaves, to work.” - M

The perception was created by the lay counsellors that people demand too much from them. As a result they feel they have been exploited as a group. According to the Social Identity Theory (Tajfel & Turner, 1979) the clients might show demanding attitudes towards HIV/AIDS lay counsellors as they have placed them in the out-group. This might be the case as lay counsellors were the bearers of bad news, thus placing them in the group labelled “them”. By demanding constant attention and assistance from the lay counsellors clients are thus attempting to rectify the image of their own group. By demanding assistance in finding clothes, food and money they hope to reinstate their group’s scarred ego.

The lay counsellors have indicated that the Department of Health and the NGO/municipality employing them see them as merely the one’s who work with HIV and AIDS. They have also testified that their association with HIV and AIDS have made them a less worthy group in the eyes of the Department of Health, when compared to other staff in the clinic or hospital who do not work with the virus per se. According to the Spoilt Identity Theory (Goffman, 1963) their association with HIV and AIDS have thus given these groups a reason to be demanding and to set unrealistic expectations for them. The lay counsellors are in addition perceived by these groups as little more than workers on the ground level. When utilising the Social Dominance Theory (Sidanius &

Pratto, 1999) it might be clear that the Department of Health and the NHO/ municipality look down on lay counsellors in a demanding fashion as they see them as a less educated, sophisticated or evolved group.

Fear

Groups who are believed to be prejudice, who stigmatise and who act discriminatively towards lay counsellors have showed fear or feelings of threat towards them. Both clients and medical staff have displayed these feelings toward the HIV/AIDS lay counsellor. Clients did not trust lay counsellors as they feared they might disclose their status to other people. Lay counsellors experienced problems in effectively counselling clients as a result of these feelings of fear towards them. Often clients did not want to communicate as a result of these feelings – keeping necessary and important personal information from counsellors during the counselling process.

“They are worried, yes. They think we will talk. We will go out and we will tell other people, that one is positive over there. And then there is nothing, this one will not talk to me really. She is scared, she is worried. They do not trust me always.” - P

“Like I saw how she looked at me. She thought I might tell someone about her status, that she was one of the positives. She looked, uhm, she was worried and not, not at ease, no. She looked scared of people knowing it.” - H

“We’ve had the problem at the clinic that people said we brake the confidentiality, or that they pointed the finger at the counsellors.” - J

“...because the people out there did not really trust me, because they talked and thought, yes, the confidentiality. I was not trusted immediately. They were worried about it.” - N

“The clients think I will show, I will tell other people what happened. They think I will break our confidentiality, like, not keep it tight between us. Then they keep the information. They do not tell me the information what I must know for the testing and for the counselling.” - P

Medical staff has shown fear of lay counsellors. The lay counsellors suspect they feel threatened by them in some way. According to the lay counsellors this might be due to the fact that nursing sisters possibly worry that someone (in this instance the HIV/AIDS lay counsellor) might be busy competing for their jobs and high status within the community.

“Yes, yes, no, definitely, it is a nurse thing. I don’t know why, maybe they feel threatened, they are worrying about their jobs, they feel threatened.” - J

“Ja, some times I feel like they are, that they might be worried that we are taking their jobs, I don’t know. I feel, I’ve got that feeling, because as they see us, it is

just in such a different way. I don't know if they feel more threatened that we are there to take their job, than what we are there for. Because they really, really, really do not respect us in the clinic. That is the other problem." - N

"The nurses, the staff in the clinic, they worry about us. They worry we take their place in the clinic. But we, no, we are only the counsellors, we are here, we are on the ground level. No, we cannot take what is their job. But they feel the worry. They do." - G

"I don't know why, but yes, they think we are out to take it, to take the jobs of the nurses. They think that in the clinic. They say we are like, like, uhm, wanting to rob them of what they earn in the month and so on, you see what I mean?" - K

People's feelings of fear or threat towards the HIV/AIDS lay counsellor has in many cases made it very difficult for them to do their job effectively, as is the case with clients. According to the Spoilt Identity Theory (Goffman, 1963) the lay counsellor's close association with HIV and AIDS (an illness that is known to be deadly) might have given clients a reason to fear them. The HIV/AIDS lay counsellor is thus possibly feared as he or she is the bearer of bad news – in this instance a HIV-positive status. As HIV/AIDS lay counsellors have access to highly confidential information regarding clients and as a positive status is still not condoned by society, clients might also fear lay counsellors could possibly disclose their status to others.

The nursing sisters' fears and worries have placed more strain on their relationship with lay counsellors and might additionally have made the clinic and hospital a less friendly environment to work in as a result. According to the Social Dominance Theory (Sidanius & Pratto, 1999) nursing staff can possibly act negatively towards HIV/AIDS lay counsellors as they fear they are competing with them for their jobs and social standing. Reacting in a negative way the nursing sisters might attempt to protect themselves from the possible threat posed by the lay counsellors.

Dishonesty

The lay counsellors have indicated that clients, especially, have often shown their negativity towards them by being dishonest during counselling sessions. This has resulted in lay counsellors that feel that they are lied to, as a result of negative (and often) preconceived, prejudiced perceptions, that they cannot be trusted and that they do not keep confidentiality. Clients, for example, lie to lay counsellors about the number of times they have been counselled and tested, or about the details of their private lives – information that is of great importance in the delivery of effective counselling, testing and preventative treatment. Clients thus seem to show their negative evaluation of lay counsellors by often trying to deceive them, which lay counsellors internalise as negative attitudes and actions directed towards them personally.

“They think little of me, because they lie, yes, uhm, ja. They lie about things I

need to know from them. They do not think I, they cannot trust me, so they tell me lies.” - H

“Yes, they give us troubles. They lie. They say it is the first time that they are testing, whereas it is the tenth time.” - L

”I think, many times, I think they lie to me. This I cannot. I, no, I, uhm, do not, no, I do not like it very much, this lying thing.” - M

“The clients, the uncles and aunties, the youngsters, they are out sometimes not to, uhm, not to tell the truth, you see? I must get the information about them, the private things from them. But, uhm, no, no. They tell me lies all of the time, they lie to me, yes.” - H

The clients have also shown their dislike or negative evaluation of lay counsellors by spreading lies, stories or half-truths about them, in the hope of causing trouble for them, possibly at work. The possibility exist that these clients might deliberately attempt to harm or injure the lay counsellor, as the counsellor was the person who initially tested, counselled and consequently told the client what his or her test result was. Clients who have maybe not yet come to terms with a positive test result might thus place the lay counsellor in an out-group, seeing him or her as some form of threat or the bearer of bad and unwelcome news. Therefore he or she wishes to harm the lay counsellor by spreading lies about him or her.

“And he smeared the HIV/AIDS counsellor black, his name, and he, this guy was positive himself. Yes, he said, she told me that I am positive, she did. I have AIDS and such things and so. And, I am going to make a case at the police to report her. And he came to work, to the clinic, to the manager and made up a whole lot of stories about something that does not exist. Something I did not do.”

- S

“The people they come, the client, she come and she lie about me, about things I did not do, I did not break the confidentiality, but he, she come and they say I do these things. They tell other people stories and they tell them these lot of lies too. It is not so.” - J

Whether clients lie to lay counsellors during counselling and testing, or whether they set out to spread lies about lay counsellors themselves, lay counsellors experience it as hurtful, negative and discriminatory behaviour towards them. The behaviour of clients who spread lies about lay counsellors can be understood when utilising the Downward Comparison Theory (Wills, 1981). Clients who have tested positively might have a low self-esteem. As lay counsellors conveyed their status to them during the counselling and testing process, they might place them in the out-group and subsequently attempt to better their own self-worth by devaluating the lay counsellor.

Ignorance

In their daily contact with different groups of people the lay counsellors have expressed their frustration and unhappiness with often being treated with ignorance.

The clients have been prone to show ignorance for the words of advice and the general attempt of lay counsellors to educate them on HIV and AIDS. Whether clients were tired of hearing about the realities of HIV and AIDS or whether they were embarrassed by being in the situation of getting tested, the HIV/AIDS lay counsellor experienced their ignorance as a negative behaviour directed at them personally. When clients returned to the clinic with a STI (sexually transmitted infection) after they have been counselled, the lay counsellors are especially unnerved by the ignorance of these clients with whom they have discussed the dangers of unprotected sex.

“...but they do not want to listen. They do not listen to me. I, I, I talk, I talk. I tell them all these things that they must know about the save sex and the protection against the STI, but no. No. They come back to the clinic. They see the sister. And now, now the sister says, she tells me I have not done my job. This one she has the STI again, again.” - P

“The client only wants to leave the room. The client does not want to sit any longer, he wants to leave and go out of the room now. They must sit and they must listen to the information.” - K

“The client, she, he, must look after his own safety with the save sex. I can inform, I can tell them what it is, this and that and that, but they must do it. They do not listen, they do it as they feel like, they feel like doing it.” - P

“Sometimes they just sit there, like, I don’t even think they are listening to a word I am saying to them. But they sit and stare at me. Then, then they go out of my room, out of the clinic, and they do what they feel like doing, you see how it is out there with them? I think I am wasting my time with these people sometimes, you see?” - S

The community has shown great ignorance towards the efforts of lay counsellors to continually educate them in regards to HIV and AIDS. Members of the community might, for example, be in the waiting room of the clinic or hospital where lay counsellors give general information talks on HIV/AIDS to patients other than their own clients. These people often ignore them or do not listen to the advice given by HIV/AIDS lay counsellors. The lay counsellors have indicated in interviews how frustrating it has proven to be trying to reach people who simply do not realise the importance of the matter at hand, who are deaf to their advice on (especially) save sexual practice and healthy living.

“... they are not interested, they are tired of HIV. They don’t even listen to that now. No, they don’t. They don’t. I mean they just are talking to each other. Not asking questions. When we ask them to ask questions, they say, no, we know, we

understand. For the facts, I think they are just talking to each other. That shows you that they are not listening to what I am saying.” - N

“No, I just say to myself, those, those who want to hear what I am saying, they will get the information. Those who do not want to listen, it is up to them. Ja, I just tell myself that.” - S

“I do tell them about safer sex and STI’s, but then they just turn away. They do not want to listen to me when I talk about it. They think they know everything. But still they have the STI’s, like even today still.” - G

Yet another example of the ignorance lay counsellors are confronted with comes from their very own family and friends. Stigmatised perceptions and misinformation have come forth from friends and family who have, for example, had the idea that the lay counsellor might get HIV infected him- or herself by working with people who are HIV positive. It is thus believed by some people close to the lay counsellor (like family and friends) that their mere contact with clients who are HIV positive or who have AIDS is substantial in putting them at risk of infection themselves.

“... no, look, I mean she asked me, do you know what you are letting yourself in for? She was, you, see, she was telling me I could get the virus, HIV, yes. This job will give me the virus, see, you understand? I am risk, yes, risking it.” - T

“... my family thinks like this. I am risking a lot by doing this job. What about me? What about my children? I must be very, uhm, it can be me who is sick next. That is a worry to them.” - C

The medical staff has shown their ignorance towards the all-important contribution made by lay counsellors in many instances. Nursing sisters wished to ignore their advice, assistance or expertise. The lay counsellors indicated that they felt that the medical staff did not value them as professionals, but that they looked down on them as less valued or respected members of staff. The lay counsellors' less educated status and possibly the fact that they were associated with HIV, AIDS and the PLWHA might, according to them, explain this phenomenon.

“Maybe it is about qualifications, you, you did not go to university or so, no degree or something like that. You are only a HIV/AIDS counsellor.” - J

“Uhm, the thing is, you, you are only a HIV/AIDS counsellor, I would say it like you are not seen as a professional person. The fact is you look at the qualification of the nursing sister and where the counsellor only gets two weeks training, and, uhm, you understand, suddenly you work. Where the sister normally goes and study and so on.” - Z

“Uhm, what I actually mean is that, uhm, the HIV/AIDS counsellor is, has always been seen as someone that is just about on the same level as someone that is a

cleaner, this type of thing. Understand? Or someone that has a very low profile, understand? O.K. I am maybe the sister, the nurse, I will always, the counsellor, look, he is not professional, I will undermine him, or something like that, understand ?” - Z

“O.K., O.K., yes, so you find you are not very much respected because of you are sometimes the lowest of the middle lowest staff there. You like you are not exactly treated as you want because of your education because they are all more educated than you.” - N

The medical staff has on many occasions showed their ignorance towards the value of lay counsellors' work by making it clear to them that they think little of them and the service they rendered to the community by, for example, telling lay counsellors that they are a waste of the Department of Health's money. Once again possible preconceived, negative perceptions regarding HIV and AIDS, as well as the PLWHA are associated with the HIV/AIDS lay counsellor. The lay counsellors indicated that medical staff did not see their service as a truly preventative measure for the continued spreading of the HIV-virus. Medical staff thus perceived them to be of lesser value.

“Ja, ja, but not for HIV. They feel that government are spending a lot of money on the HIV and there is no progress. There is nothing that is being done about the HIV. And then one time, one of the sisters said, she actually does not know why government has implementing this VCT, because the counsellors are there, they

are giving the information, but the rate of the HIV is escalating. So what is the use? Of this government VCT, you see? So they are tired of working with this. They don't want to work with HIV, they don't." - N

" ...but now here is HIV, HIV, and government is spending a lot of money on this HIV. Instead of doing something for the others, for other, for maybe other, some projects. Not this HIV." - L

"... and this sister told me to my face, just like that. She asked, do you think you are making a difference? She asked me, what is all of this, what is the, what is the worth of it? This counselling and this testing in the clinic, is it working? Are we having less HIV's?" - P

The medical staff has additionally showed their ignorance towards the contribution made by lay counsellors by often expecting them to do things in the clinic which is not part of their job description or requirement, for example to do filing in the office or to do translation. The lay counsellors feel they are discriminated against in due process and have found this behaviour disrespectful and disruptive, as medical staff expected them to simply do what they ask of them, irrespective of their workload for the day or the fact that they might be busy with clients at the time.

“The positive mothers get milk, when they give them milk, then, it is assumed, like a counsellor does it some times, it is assumed that it is a counsellor’s work. It is not part of a counsellor’s work.” - R

“They would ask us to sort of go and translate for them. You say you, you say maybe you are busy, they become cross with you.” - S

“I mean they, some times they, I don’t know why, they are wanting to use you everywhere. They want to use you everywhere. And even when you are doing the counselling, they will say, no, no, do this now. They limit our times for the counselling now, you see. No, it is not, no.” - N

“...because the sister will always see you as someone to do her jobbies for her, understand? The sister will easily tell you, hey, uhm, pull those files for me, come and translate for me. You are not allowed to translate. Translating is a, it is someone else’s job. Yes, filing is not really your responsibility. It is the sister’s. But she will come and get you to do it.” - Z

The lay counsellors have indicated in interviews that medical staff has shown their negative attitudes, disrespect and acts of discrimination by ignoring the importance of their counselling sessions. The medical staff has often interrupted counselling sessions irrespective of the client and the confidential nature of the counselling process. They have in past instances simply ignored the fact that lay counsellors were counselling a client by deliberately entering the room that was used at the time.

“All of a sudden, you are still busy with your pre-counselling, then, uhm, there is a knock, uhm, sorry, professor so-and-so is here. He needs to use your room. And all of a sudden the whole counselling session is interrupted. And then you need to wait again, maybe, until someone decides to leave a room, and then you can go in.” - Z

“She comes in, she comes, in, she needs something. You, you are busy, but, no, that does not matter, she is in the room.” - J

“... it is her tea break. She wants to be in the room and you must now take your client, the client, and, you, you must look, go outside and look for another space in the hall. She is on her tea break in your room.” - P

The lay counsellors have indicated that they sometimes felt co-workers or colleagues were ignorant of the unique cultural and individual differences between them. They experienced negative attitudes from colleagues and even felt discriminated against at work as a result of their specific cultural backgrounds.

“No, he undermines me, he undermines me because I am a Xhosa. That man, he is not a Xhosa man.” - S

“ ... there are sometimes problems. We are not all the same here. They think bad things of me, because I am not the same, the same, uhm, race or colour as they, like, like they are.” - H

“ ... because I am a coloured lady they think otherwise of me. It is because I am not a black counsellor you see?” - N

In addition the lay counsellors indicated that they experience negative de-evaluative behaviour and attitudes from the Department of Health. The main sentiment that came to the fore was that it was felt that the Department of Health was ignorant of the value of the contribution made by HIV/AIDS lay counsellors. It is believed that they have perceptions that HIV/AIDS lay counsellors are of little worth and therefore their effort is ultimately not being appreciated. According to the lay counsellors it seemed as if they were treated differently by the Department of Health, less positively, than the rest of the clinic staff, possibly as they were associated with those who are HIV positive or dying of AIDS.

“ ... I never felt that, that, the Department of Health for instance, that they ever did something to show their appreciation for the work that the HIV/AIDS counsellors do. I mean, every person just wants a thank you. But I feel the counsellors were not treated fair, because the work that they do and the stress that they take, all the emotions that they go through every day, they deserve a better reward. They deserve more recognition for what they are doing.” - J

“I think they think nothing. For them it is not even about the client or about me. For them it is about the stats only. Yes, they want stats. They don’t give, care for us as HIV/AIDS counsellors. They don’t care what we do. As long as they get the stats, the stats. So, that is why I say, they feel zilts, they feel nothing, boggerol. That is why I say the government feel nothing. They don’t give a damn, I don’t think they care.” - R

The lay counsellors indicated that the Department of Health showed their ignorance, disrespect and discrimination towards them in many ways, for example by not supplying lay counsellors with adequate working space.

“Like the space. You are busy doing counselling and someone wants to use their room and you have to go out. The ones at the top, they think nothing for giving us our own, you know, our own spaces.” - N

“I have no space, no room, no nothing to work in. They, there at the top, they think what? Where do they think I must work, but they are getting more and more counsellors every year, but the space, it is not there for us, no. They must show they care about my work, what I do here. They must make me the room, the space to have the counselling in.” - K

The lay counsellors felt that the Department of Health discriminated against them by being ignorant of their personal needs, for example by not rewarding them properly for the work they do, such as a small salary, no benefits and no permanent appointments.

“Uhm, firstly they must look at something like the salaries, definitely. I just feel there is not enough recognition for it. I mean, they can at least look at something like medical.” - J

“Yes, look, as I said, they do not recognise what we do. They, they, like we, we don't, we don't, they don't even want to give us the little money, the little money that we get now.” - J

“... at the moment I cannot say they are thinking of us, I mean, so that we can benefit from that. I, uhm, don't think so, because really. We could have, what are the other things when you are, money they take off for something? We could have like a provident, provident fund.” - S

The lay counsellors have illustrated that NGO's and municipalities were ignorant of their personal value and that they were not interested in them as individuals. It was felt by them that they were employed to merely produce statistics for the Department of Health. Irrespective of the quality of work they delivered lay counsellors thus felt they were the targets of prejudiced perceptions and discrimination in due process.

“Especially when it comes to the end of the month and she wants her stats and she comes and tells us this and this and this. And then you feel, poe! I have worked hard in the clinic and so on. To think you did the work and they tell you, no, O.K, you can do more and that type of thing, you can work harder. But they don’t see that, they feel you can do better, you must work harder. For them it is about stats, nothing more, it is about stats.” - J

“I don’t know. I think at the end of the day they want stats. They want to know how many people were tested, how many are positive, how many negative. They don’t really, no, don’t do something to show like, that they have done something for us.” - J

The lay counsellors have experienced ignorance as a form of negative attitudes and discrimination from many of the groups of people they have contact with. Whoever the ignorant party was it left lay counsellors feeling frustrated and less valued when people did not appreciate that the service they rendered was of any worth. The behaviour of the family and friends of lay counsellors who feared they would be infected with HIV themselves, merely as they have contact with people who are HIV positive, may be understood at hand of the Terror Management Theory (Greenberg et al., 1997). As HIV and AIDS are widely feared by many people as a deadly disease they might question the lay counsellor on the safety of his or her work (Cree et al., 2002; Crewe, 2002). They might even avoid or reject lay counsellors subsequently as they might fear they can be infected themselves. This phenomenon can also be grasped at hand of the Spoilt Identity

Theory (Goffman, 1963). As HIV/AIDS lay counsellors and the work that they do are closely associated with the fears surrounding HIV and AIDS, their family and friends might assume they can also be contaminated by this deadly virus.

The medical staff who devalue lay counsellors and their work as a result of their association with HIV, AIDS, and the PLWHA can additionally be understood at hand of the Spoilt Identity Theory (Goffman, 1963). HIV/AIDS lay counsellors are looked down on by medical staff and deemed worthless, simply as they have a strong association with the dreaded HIV-virus.

Provocation

The lay counsellors have mentioned in interviews that they are sometimes purposefully provoked, especially by clients, during counselling and testing and that clients have acted negatively towards them by generally not co-operating. Clients have shown a provocative attitude as they implicated not to trust lay counsellors or when they were not comfortable having personal discussions with them. They have ignored lay counsellors during counselling by purposefully pretending not to understand or hearing a question, by trying to shorten the counselling session, by not listening or taking advice offered and by asking them personal questions in response to questions posed to them.

“And then she asked me straight, but do you use a condom, do you condomise. And I turned to her and told her, we are to ask you the questions, not me. Don’t turn the questions back to me.” - P

“ They don’t want to listen when there are things that you must give them. They want to give you a look, a stare and then they ask you stupid things. They test you, you see? - T”

“ Yes, first he started and he tried to shock me with what he said. He wanted to make the interview shorter, tried to end it, that I must let him go ... He wanted me to say something to him because I was shocked. That he shocked me.” - N

“Ja, I feel that people don’t listen to me, really. Some times I feel like, ag, maybe I did not do what I was supposed to do. Why is this now, still happening? Because I have tried to explain, why is it still happening? But no, they do not listen and they do not work with me. They want me to say something, to let them go, maybe.” - N

In addition, medical staff has made their negativity towards HIV/AIDS lay counsellors clear by embarrassing them in front of other people in the clinic or hospital, by screaming at a lay counsellor or by belittling him/her publicly. The lay counsellors have indicated that they are purposefully provoked to see how and if they would react in situations such as these. They are thus convinced that the nursing sisters tested their

boundaries to see how they would behave when purposefully embarrassed by them in public.

“She screams at you here in front of the clients, in front of everyone in the clinic. They think nothing of us, really, I don’t think so.” - J

“The thing is, the sister will call you, will scream, wha-wha-wha. Automatically you feel embarrassed. The clients look at you, like, uhm, no, the sister says, for example, just leave that client and come to me, you understand?” - K

“They scream, they are loud in the halls of the hospitals, but they are looking, they are looking to see what you will say or what you will do when they are loud like this with you.” - P

“They test you these ones in the clinic, the nurses. They test and they know how we feel ashamed when they talk of us in front of the others and also the people in the clinic. They know all of this. But still they do it.” - T

The lay counsellors feel they were purposefully provoked to do or say something unwanted or highly emotional when clients taunted them. It might be that they set out to embarrass, distract or provoke lay counsellors as they perceive them to members of the out-group. Ultimately clients might be attempting to better their own self-worth by provoking lay counsellors to lose their composure in their and other people’s presence.

This is congruent with the Downward Comparison Theory (Wills, 1981), which states that a group might disadvantage or discriminate against a member of another group in an attempt to make themselves appear less poorly.

The Social Identity Theory (Tajfel & Turner, 1979) might also be utilised in understanding the medical staff's negative behaviour. By belittling the HIV/AIDS lay counsellor publicly the so-called in-group (medical staff) is attempting to better their own group's status in comparison to the poor image they have created for the out-group (HIV/AIDS lay counsellors). According to the Sociocultural Approach Theory (Vygotsky, 1986) the nursing sisters might also place HIV/AIDS lay counsellors at the bottom of the clinic or hospital hierarchy, simply as they are less educated or as they work with people whom they do not place in high regard (the PLWHA). As a result nursing sisters might feel it is acceptable for them as a higher-ranking group to embarrass HIV/AIDS lay counsellors by publicly provoking them.

Assumptions

In the semi-structured interviews conducted with HIV/AIDS lay counsellors it was made clear to the current researcher that they experienced that certain groups of people easily made assumptions about them and their work. Assumptions seemed to be made in a natural and automatic manner, ignoring the individual traits of the lay counsellor or the characteristics of a specific situation. These assumptions were

troublesome to lay counsellors and have been experienced negatively as they were not necessarily based on reality per se, but were mere generalisations and assumed truths.

The lay counsellors have reported that clients have little respect for their private time and that they expect assistance from them at any time and at any place. The clients often showed little regard for the fact that lay counsellors worked at a municipal clinic or hospital for a set period of time per day. They have subsequently been bombarded by clients outside of their normal working day to assist with private matters, to solve problems and to give advice – often when they were at home supposedly not working. The lay counsellors have thus come to feel discriminated against as clients assume they have no private life and that they are there merely to serve them when so needed. They feel, once again, as if they are almost “owned” by clients who show little regard for them as individuals.

“And the others are coming to my place, just to need some advice. What do I do now? Where do I go now? What would happen if this and this? And I say, no, if you need to talk about things like that, go to the clinic. I am not here in the community for that now, ja. That is a problem for us when working in the community. We sometimes say it is not good working in the community, because if they see you in the community, you are not at work, they see someone who is going to help us now. They need you, like now! And it is impossible.” - N

“And other clients come even in my house. And when they are in my house, I say, no, we can’t speak that here, because it is not a privacy. Please come tomorrow to my office. This is not for my house.” - P

“They forget, no, they do know I work at the clinic, but no, they come whenever they need me. Like now, now to my house, when I am with my friends, to my church. I must be there always.” - T

Many of the problems lay counsellors experienced with the community concerning preconceived ideas and perceptions furthermore stems from the assumptions members of the community made about lay counsellors and their work in an almost automatic manner. It was, for example, assumed that lay counsellors were HIV positive or that they had AIDS themselves otherwise it was thought they would not be involved in this type of work.

“But the others they think also, also, that we have this virus.” - T

“They say the people who are working with HIV/AIDS they are HIV positive. But they can’t talk. It is something they don’t know.” - M

“The clients, even the people out in the community. Do you know what they are saying? We, us, yes, the counsellor, we have this virus amongst us. We do this work and we have it, we have the, the HIV and AIDS.” - S

Yet another example of the stigmatisation and prejudiced attitudes and perceptions held by the community is the implied truth and assumption that lay counsellors were HIV positive when they were seen wearing AIDS related T-shirts or an AIDS ribbon at work.

“... also the ribbon, the beaded one, then I thought, no, maybe, maybe the people think I am HIV positive. Yes, I think people think you are positive.” - J

“When they see that ribbon? But there are people who might think when you wear it, there are people, ja, ja. You must be positive.” - N

“... you must also be one with the virus, yes, wearing the ribbon says that. That is how they see it, you see?” - G

“I was walking outside of the clinic, it was my tea brake, like twelve or so, and they were saying, look he is one of them, she is having the virus. She is positive like the others who go in there. I never wear that shirt, that HIV T-shirt again. Not that one in public. Not even, not at home, not in my home I wear it never again, no.” - H

According to lay counsellors the community expected them to be a role model for the rest of the community. This implied a life of virtue and a high moral standing. It was assumed by the community that socialising with friends at parties included behaviour of a less moralistic nature, for example drug use or excessive alcohol use. The lay counsellors

felt that they were thus not to use alcohol, to smoke or to go to parties with their friends, as the community saw it as a reflection of what was expected from them. Lay counsellors have not only found it unfair that these assumptions were being made in this manner, but the restriction on their own personal status once again created the assumption that they were in fact “owned” by those they provided a service to.

“Sometimes in places, social places, or where you are maybe at the party, some people they think you are not supposed to be there. I don’t know. I think they think as a counsellor, maybe you must be someone that is, what can I say, who is not going out and have friends. Or you cannot go out to places where there are many people, as I said maybe a party. Or you must not be a party person when you are a counsellor. You can’t party. They tell me in my face. Yes, I was in another place and another lady said, shoe, I did not know that you could also, maybe, you are also, you can also come to such places.” - L

“This lady was telling me, no, she did not think I could also go out and have a good time. She was thinking I must stay at home. I must not take part in parties like this, drinking beer and talking with my friends in this way, no. I don’t understand it, really.” - T

The community was in addition easy to assume that any person entering or standing close to the room the lay counsellor worked in was HIV positive or had AIDS. A stigma is thus attached not only to the area in which the lay counsellor works in the

clinic or hospital, but also to the lay counsellor him-or herself. When lay counsellors were seen with other people, in or out of the clinic or hospital, the community assumed that the person was HIV positive or had AIDS. The lay counsellors thus feel they are discriminated against as people acted negatively towards them when they assumed that they only interacted with people who were HIV positive.

“... when they see you with a file and they see you with another person, then automatically they link the two – that person must be going for an HIV. Yes, yes, the people know by now. If you go there, you are going for HIV.” - J

“And the other day I got a client, when she come in she say she not want to sit. I say no, sit down. She did not want to be long here in the room 84. The room worries her, room 84. They don't want to be long here. I say, why? She say, no, the other people outside, they say if you come in there, in this room, you, they know, they know that you are HIV positive. The clients know you are positive, they know.” - T

“This thing is not nice. The other day they saw me talking with a man from my church, yes, inside of the clinic and they tell me he is positive. Just from seeing. Just from talking. They see me and they think this. I do not like it, this thing.” - J

Interviews have illuminated the fact that nursing sisters made certain negative assumptions regarding lay counsellors and their work with HIV and AIDS. The fact that

lay counsellors work with or have contact with people who have the HIV virus or who have AIDS have been cited by lay counsellors as an important reason nursing staff looked down on, discriminate against and undermined them. As medical staff possibly has a negative association with the virus (HIV as well as AIDS) or the PLWHA specifically, some of these negative attitudes (prejudices and stigmas) and behaviour (discrimination) might be attached to people who work with the PLWHA, as might be the case with HIV/AIDS lay counsellors. Medical staff thus assumed that people who were closely connected to the virus must have some negative aspects related to themselves as well which they in turn react negatively to. Negative assumptions concerning HIV and AIDS were thus possibly connected to the HIV/AIDS lay counsellor.

“Yes, as I say, we only do HIV and that is all that we can do, so. That is how they see it, they look down on those who work with HIV. Yes, you are nothing more. I don’t think they think a lot of it. It is, it is only HIV, yes.” - J

“Like, I don’t know how, how to describe it to you, like, like I, I will never want to do HIV counselling they say it like that. And if I say never, then I talk of a face that, that, that looks down, that feels like not at all in the mood for it, uhm. Oh, you can do it, as long as I don’t have to. Yes, clinic staff that honestly, straight they tell me, I do not want to do that, I do not want to work with those lot, not with HIV and AIDS, you can do it.” - M

“If you work with HIV, with the AIDS people, they think you are like simple, you are not a lot to them, as you work with the virus only that, ja.” - P

The family and friends of lay counsellors have also been identified by them as sources of negativity related to their work. The preconceived, negative assumptions and perceptions held by some family and friends regarding the PLWHA have spilled over to effect the manner in which they reacted or acted towards lay counsellors. The lay counsellors have mentioned that their family and friends often thought ill of the work that they did. Sometimes they could not understand why lay counsellors would want to do the job at hand.

“It is my family, that is what I am saying, I don’t know what they think. Maybe it is that this is not good enough. Or not a type of work that you should do.” - J

“Like, yes, they think it is just a job for those with low, uhm, people who want nothing in life, someone that is not going to grow in his job. This working with HIV.” - W

“Why, she asked me many time. Why do this job. Why work here in the clinic? It is not something that she understands easily. She think, uhm, no, that I can do a better job.” - N

Family and friends have in addition showed lay counsellors that they have negative perceptions of their work or do not take in seriously, as they often joked about it.

“They joke, yes. Friends that, that, make jokes, not friends, people I know, that then talk about HIV and my job and it is this whole joke and yes.” - R

“... as they think it is not a serious thing this counselling I am busy with. No, look, some have looked at it and even laughed, they made it out to be a funny thing, a funny job to have, nothing serious like it really is.” - G

Some friends and family have even suggested that it is an inferior job with little possibilities and that the counsellor should not sink so low as to work with people who are potentially HIV positive or who have AIDS.

“It is just, just not good enough for people. It is not the type of job where people will say, he is good at his job.” - J

“To tell you the truth, it is not a good job to have. It is a job, but not a good job, where you can show your strong points. You work in the clinic and you are like stuck. They say you can't grow, no opportunities for you. You must do the same job from Monday to Friday, over and over. Because you are doing HIV, there is no challenges for you.” - P

The HIV/AIDS lay counsellors indicated that they were looked down on by the Department of Health, as they primarily worked with those who were HIV infected. According to the lay counsellors it is thus assumed by the Department of Health that those who work with HIV and AIDS are of little worth and personal value.

“ I don't think they think anything of it. It, it is only HIV and yes, only HIV.” - H

“But they don't care. They don't care what you do. For them it is about the money and not about the people. My point is they don't care about you or the clients. It is only HIV. It is AIDS, you see?” - J

Groups of people who interact with the HIV/AIDS lay counsellor often assumed certain things about lay counsellors naturally and without exception. Whether this is to be accurate or true seems to be of less importance. The community's assumption that HIV/AIDS lay counsellors were HIV positive themselves, as an example, can be explained by the Spoilt Identity Theory by Goffman (1963). The community might strongly associate HIV/AIDS lay counsellors with the terrors of HIV and AIDS as a result of their work. They thus automatically act negatively towards lay counsellors as they fear the illness and subsequent death.

5.3 Conclusion

In conclusion to this chapter, it is clear from the results of the present study that the HIV/AIDS lay counsellors do experience negativity that might be related to the same

experiences of negativity by the PLWHA. It seems that people who are guilty of negativity towards HIV/AIDS lay counsellors have a set of preconceived or associated perceptions and attitudes regarding them and the service they render. People seemingly have a set schema of thinking and reacting in relation to lay counsellors in an almost automatic manner. Whether personal, past experiences have guided the formation of these existing perceptions or whether they have been acquired via other people's example (social learning) is unclear to the current researcher. The effect of this negativity on HIV/AIDS lay counsellors was however clearly stated in the conducted interviews. They experienced built-up frustration, anger, isolation, additional stress, a loss of interest in the job at hand and even the wish not to continue working as a lay counsellor.

CHAPTER 6

Construction of Item Pool

In the following chapter the current researcher will discuss the four steps taken in the construction of the item pool in mention. These steps have been taken in accordance with the guidelines presented by de Vellis (1991) and include: a) the objective of the scale, b) the generation of an item pool, c) the format of the scale and d) the review of the scale by experts.

6.1 Step 1: Objective of the Item Pool

As a first step in the construction of the present item pool the current researcher set out to clearly determine what the objective or purpose of the scale was. It was to measure experiences of negativity, such as prejudice, stigma and discrimination, in HIV/AIDS lay counsellors. In refining the objective of the constructed item pool the researcher focussed on three pertinent issues stipulated by de Vellis (1991): a) what theory underlies the measurement undertaken by the developed scale, b) at which level of specificity are the constructs measured in the constructed scale and c) what is to be included in the measurement of the scale.

As past studies have not focussed on the subject matter of the present study per se, no guidance in terms of related theory could be found by the current researcher. The

theories related to the negativity experienced by the PLWHA thus served as a tentative theoretical model, as similarities between the experiences of the PLWHA and the HIV/AIDS lay counsellors have been evident. In terms of specificity, the constructed scale was to measure the specific negative attitudes and behaviours of others towards the HIV/AIDS lay counsellors as a result of their association and involvement with HIV and AIDS. Additionally, the constructs measured might seem to be interwoven or overlapping, but the current researcher clearly defined the distinct characteristics of each in relation to the specific situation in which they occurred (in this case situations related to the experiences of negativity by HIV/AIDS lay counsellors). As the constructs measured are not that distinct from each other, the items that were developed was relatively broad with respect to the situations to which they apply. Apparently similar items might thus measure quite different constructs (de Vellis, 1991).

6.2 Step 2: Generation of Item Pool

According to the guidelines supplied by de Vellis (1991) the present researcher developed the item pool by creating items that directly reflected the stipulated purpose of the scale (as set out in Step 1). A superfluous and seemingly over-inclusive set of items was created, as to describe the phenomenon to its fullest. The large and comprehensive item pool, with 55 items, that was created would: a) eventually allow the researcher to be more critical in selecting suitable items for the final scale and b) protect against poor internal consistency. In focussing on the quality of items, the researcher again followed the suggestions made by de Vellis (1991). For more clarity items were not to be too

lengthy, easy to read, not to contain more than one main idea per item and were to be either positively or negatively worded. In this instance the researcher chose to word items negatively.

In constructing a single item, the researcher merged three types of information. In the first instance the category or group of persons who has proven to be negative was represented, for example, clients or medical staff. In the second instance attention was given to one of the emerged themes from the collected data, for example: avoidance, blame, mistrust or provocation. In the last instance a negative experience or situation was highlighted, for example prejudice, stigma or discrimination. Taking item one as an example (see Appendix C), it reads as follows: Clients think I lie to them about their status. The category or group in mention pertains to clients. The negative situation can be related to prejudiced perceptions of the HIV/AIDS lay counsellor. The theme in mention in this specific item is lastly related to mistrust. In this manner items were constructed to, as a collection, form a broad base of information, which covers most aspects related to the negative experiences of HIV/AIDS lay counsellors.

Three of the categories or groups of people identified by lay counsellors (clients, the community and medical staff) showed the greatest prevalence of all the groups for the occurrence of negativity (prejudice, stigma and discrimination included) in the transcribed interviews. More items were therefore generated for these three categories than the remainder of people identified by lay counsellors (namely family and friends).

6.3 Step 3: Response Format

In writing items the present researcher considered which response format should be used. The Likert scale was chosen as it is an ideal option when the aim is to measure opinions, beliefs and attitudes (de Vellis, 1991). This is the case in the present study, which measures the opinions of HIV/AIDS lay counsellors regarding their experiences of negativity. Items would be presented as statements with a range of response options (which would agree with the statement to varying degrees) following it. A four-point Likert response format was decided on with response options including: never, sometimes, often and very often. These options proved to reflect true differences of opinion.

6.4 Step 4: Review by Experts

The initial large item pool (N = 55) was submitted to a panel of experts who evaluated the items. The experts indicated whether or not the current researcher aptly defined the phenomenon in mention (de Vellis, 1991). Each item was evaluated in terms of what the scale intended to measure. In addition items were assessed in relation to their relevance to the constructs, which were measured by the present scale (de Vellis, 1991). The panel of experts also indicated whether the wording of items allowed for clarity and conciseness, as stipulated by de Vellis (1991). Items, which were not suitable to be included in the scale, were thus omitted by the panel of experts in due process. At this

stage 39 items remained in the item pool. A narrowing down process of items subsequently evolved as the research progressed.

Although the present researcher reported all negative experiences of HIV/AIDS lay counsellors in her thematic analysis of the collected data she realised that certain items were bound to be excluded. The researcher reduced the 39 remaining items to 30 items for the reasons presented in the following paragraphs. As some items rather reflected issues related to general work satisfaction, for example items concerning medical staff's demanding attitudes towards lay counsellors, they could not be included. Furthermore, in some instances a clear connection between negativity experienced and HIV/AIDS involvement was not made. The items related to race differences between colleagues are examples of this. Yet other items were omitted, as they might not be applicable to participants outside of South Africa, such as items related to, for example, the NGO or municipality employing lay counsellors, or some items related to the Department of Health. Items for the final scale were thus chosen on the basis of their reflection of the scale's stipulated objective and purpose. The items that were however omitted at this stage are listed in Appendix D, as they can possibly be utilised in future research concerning general experiences pertaining to lay counsellors' work satisfaction.

The scale comprising of 30 items was again submitted to the panel of judges who assisted the present researcher in finalising it, for example by changing the wording of some of the items in an attempt to avoid ambiguity.

Table 6 below serves as an illustration of how final items were constructed and includes the following elements: a) the item, b) the category or group showing negativity, c) the construct measured and d) the emerged theme, which has been incorporated in each item. It is important to note that the constructs for each item might overlap and that more than one construct may possibly have bearing on a single item. Eleven items, item one to 11 of the constructed scale, relate to clients (see Appendix C). Seven items, items 12 to 18, concern medical staff as well as ten items, items 19 to 28, which concern the community. As lay counsellors paid less attention to their family and friends in the conducted interviews, fewer items (items 29 and 30) were to be constructed for these specific groups.

Table 6

Elements of Constructed Items

Item 1: *Clients think I lie to them about their status.*

Category: Clients Construct: Prejudice Theme: Mistrust

Item 2: *Clients think I will disclose their status to other people.*

Category: Clients Construct: Prejudice Theme: Fear

Item 3: *Clients blame me for their test results.*

Category: Clients Construct: Discrimination Theme: Blame

Item 4: *Clients blame me for their personal problems resulting from their HIV test.*

Category: Clients Construct: Discrimination Theme: Blame

Item 5: *Clients try to avoid me when they see me outside of the clinic/ hospital.*

Category: Clients Construct: Discrimination Theme: Avoidance

Item 6: *Clients try to deceive me when I am counselling them on HIV/AIDS issues.*

Category: Clients Construct: Discrimination Theme: Dishonesty

Item 7: *When I counsel a client about sex, he or she confronts me about my personal sex life.*

Category: Clients Construct: Discrimination Theme: Provocation

Item 8: *Clients have unrealistic expectations of me when I offer them support.*

Category: Clients Construct: Prejudice Theme: Demanding Attitudes

Item 9: *When I counsel clients they are not prepared to tell me the truth about their private sex lives.*

Category: Clients Construct: Discrimination Theme: Dishonesty

Item 10: *Clients gossips about my personal life to others (e.g. medical staff) to get me into trouble at work.*

Category: Clients Construct: Discrimination Theme: Dishonesty

Item 11: *Clients expect advice or assistance from me in my private time.*

Category: Clients Construct: Prejudice Theme: Assumptions

Item 12: *Medical staff in the clinic/ hospital does not trust me.*

Category: Medical Staff Construct: Prejudice Theme: Mistrust

Item 13: *Medical staff embarrasses (e.g. screams at) me in front of other people in the clinic/ hospital.*

Category: Medical Staff Construct: Discrimination Theme: Provocation

Item 14: *Medical staff looks down on me as a HIV/AIDS counsellor.*

Category: Medical Staff Construct: Prejudice Theme: Ignorance

Item 15: *Medical staff thinks little of my HIV/AIDS service to the community.*

Category: Medical Staff Construct: Prejudice Theme: Ignorance

Item 16: *Medical staff gossips about my private life.*

Category: Medical Staff Construct: Discrimination Theme: Gossiping

Item 17: *Medical staff puts pressure on me to gossip about a client's status with them.*

Category: Medical Staff Construct: Discrimination Theme: Gossiping

Item 18: *Medical staff does not think I am well trained in HIV/AIDS counselling (e.g. they check my work).*

Category: Medical Staff Construct: Prejudice Theme: Ignorance

Item 19: *The community gossips about me being a HIV/AIDS lay counsellor.*

Category: Community Construct: Discrimination Theme: Gossiping

Item 20: *The community puts pressure on me to disclose a client's status to them.*

Category: Community Construct: Discrimination Theme: Gossiping

Item 21: *The community thinks I do this job because I am HIV positive myself.*

Category: Community Construct: Stigma Theme: Assumptions

Item 22: *The community expects me to set an example for the rest of the community (e.g. lead a virtuous life).*

Category: Community Construct: Prejudice Theme: Assumptions

Item 23: *The community treats me as if I am preoccupied with HIV and AIDS.*

Category: Community Construct: Discrimination Theme: Assumptions

Item 24: *The community thinks any person I associate with is HIV positive.*

Category: Community Construct: Stigma Theme: Assumptions

Item 25: *The AIDS ribbon and T-shirt I wear make people think I am also HIV positive.*

Category: Community Construct: Stigma Theme: Assumptions

Item 26: *When people see me they immediately associate me with HIV and AIDS.*

Category: Community Construct: Stigma Theme: Assumptions

Item 27: *Patients in the waiting room think everyone is HIV positive who enters my counselling room.*

Category: Community Construct: Prejudice Theme: Assumptions

Item 28: *When I give information talks on HIV/AIDS people react negatively towards me.*

Category: Community Construct: Discrimination Theme: Ignorance

Item 29: *My family do not understand why I want to do this job.*

Category: Family Construct: Prejudice Theme: Ignorance and Assumptions

Item 30: *My friends joke about my job.*

Category: Friends Construct: Discrimination Theme: Ignorance and Assumptions

CHAPTER 7

Conclusion

In conclusion of this text the researcher will present a short summery of the contributions made by the present study as well as recommendation for future research. Possible shortcomings pertaining to the present study will also be discussed.

7.1 Contribution to Current Research

The HIV/AIDS lay counsellor plays an all-important role in the fight against HIV and AIDS. As caregivers and the HIV/AIDS lay counsellor specifically has been the subject matter of very few previous studies (both locally and overseas), the current researcher believes this study's contribution lies therein that its focus has been on this important, but neglected group. As the current study paid the greatest of attention to the personal, lived experiences of this group (via in-depth interviews and the analysis thereof) it is believed that the HIV/AIDS lay counsellor's voice as the target of negativity has been heard. In generating information about the experiences of HIV/AIDS lay counsellors the researcher hoped to contribute to the value attached to and the understanding of this group and the challenges their work pose to them. As the results of this study clearly indicate the HIV/AIDS lay counsellors (as secondary targets) have also experienced the debilitating negativity so easily attributed to the PLWHA.

Local as well as international researchers have indicated (A. Pedersen, Australia, personal communication, February 28, 2004; H. van Rooyen, South Africa, personal communication, March 2, 2004) that more studies should investigate HIV/AIDS related negativity. The current study thus contributes to the already existing pool of local and international research regarding HIV/AIDS related negativity, such as prejudice, stigma and discrimination.

The current researcher has set out to construct an item pool that measures the experiences of negativity by HIV/AIDS lay counsellors. As a final contribution, the current study thus offers future researchers working in related fields the opportunity of utilising these items. Previous researchers (France, 2002) have indicated that a gap exist in the quantitative measurement of negativity experienced by people other than the PLWHA. As HIV/AIDS is rife in many countries, particularly Africa, the current study provides a possible model for a better understanding of the manifestation of negativity experienced by HIV/AIDS lay counsellors.

7.2 Recommendations

It is the recommendation of the current researcher that the constructed items should be administered in other contexts with similar populations (HIV/AIDS lay counsellors) in South Africa. By doing this it can be established whether other HIV/AIDS lay counsellors experience similar problems. Utilising the information gathered from the

current study deficits in the selection process and training of HIV/AIDS lay counsellors can be addressed.

A further recommendation by the present researcher is that the constructed item pool should be analysed statistically, in terms of item analysis as well as validity and reliability.

The experiences of negativity by HIV/AIDS lay counsellors can be brought into relation with the general work satisfaction of this group, although this issue is not directly addressed in the constructed scale per se. The information gathered (see the items in Addendum D) can be incorporated in addressing problems related to this issue. As a recommendation of this study, the current researcher thus suggests that ways must be found to better assist and support these HIV/AIDS lay counsellors in coping with the experienced negativity related to their work.

As a last suggestion it is also recommended that the groups identified as those who are most negative towards lay counsellors might, with practical and ethical implications taken into consideration, be made aware of their negative reactions towards the HIV/AIDS lay counsellor. Workshops, information and educational sessions can be organised between groups (for instance the medical staff of a clinic or representatives of the Department of Health) as to bring role-players into contact with each other. Ultimately the aim would be to use the gathered data in combating the negativity experienced by HIV/AIDS lay counsellors.

7.3 Shortcomings

The present study relied on the stories told and the experiences shared by 25 HIV/AIDS lay counsellors from the Western Cape, South Africa, as this was a convenient sample to the current researcher. The aim was to keep the items, which were subsequently constructed from the gathered data, applicable to an international context. A possible shortcoming however might be that the sample could be perceived as unrepresentative of all HIV/AIDS lay counsellors in South Africa, thus making generalisation to other lay counsellors a great challenge.

As the Interpretive Phenomenological Analysis (IPA) approach greatly relies on the researcher to describe the phenomenon the study focuses on, the present researcher could possibly question her ability to do so convincingly. As many of the HIV/AIDS lay counsellors were from a very different background than the current researcher (especially in terms of culture and language) the possibility exist that her interpretation and analysis of what was being said might have been influenced by her own shortcomings in understanding their realities fully.

REFERENCES

- Arboleda-Flórez, J. (2003). Considerations on the stigma of mental illness. *The Canadian Journal of Psychiatry*, 48(10), 645-650.
- Aubeeluck, A. (2004). *What is IPA?* Retrieved October 20, 2005, from <http://www.ibs.derby.ac.uk>
- Baron, A. B., & Byrne, D. (2003). *Social Psychology*. (10th ed.). Boston: Allyn and Bacon.
- Bennett, L., Ross, M. W., & Sunderland, R. (1996). The relationship between recognition, rewards and burnout in AIDS caring. *AIDS Care*, 8(2), 415-155.
- Berpenberg, J. L., Finlay, K. A., Stephan, W. G., & Stephan, C. (2002). Prejudice toward people with cancer or AIDS: Applying the Integrated Threat Model. *Journal of Applied Biobehavioural Research*, 7(2), 75-86.
- Bharat, S. (2003). *Research on AIDS related stigma: Some methodological issues*. Retrieved February 9, 2004, from <http://www.hdnet.org/Stig>
- Brown, L., Macintyre, K., & Trujillo, L. (2003). Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Education and Prevention*, 15(1), 49-69.
- Brümmer, W. (2004, May 11). *Studie: 50% van pasiënte het MIV Vigs neem hospitale oor: Groot tekort aan personeel vir nasionale behandelingsprogram*. Retrieved May 13, 2004, from <http://www.dieburger.com>
- Crandall, C. S., & Glor, J. (1997). AIDS-Related stigmatization: Instrumental and symbolic attitudes. *Journal of Applied Social Psychology*, 7(27), 95 – 123.
- Cree, V., Kay, H., Tisdall, K., & Wallace, T. (2002) Silenced by stigma. *Community*

- Care*, 7(18), 38 – 40.
- Crewe, M. (2002). Reflections on the South African HIV/AIDS epidemic. *Society in Transition*, 33(3), 446 – 454.
- Davids, A. E. (2004). *New definitions*. Retrieved October 15, 2005, from <http://www.stopstigma.samhsa.gov>
- De Bruyn, T. (1999, March). *Stigma and Discrimination: Definitions and Concepts*. Retrieved October 10, 2005, from <http://www.aidslaw.ca>
- De Vellis, R. F. (1991). *Scale development: Theory and applications*. Newbury Park: Sage Publications.
- Field, A. (2000). *Discovering statistics using SPSS for Windows*. London: Sage Publications.
- Flaskerud, J. H. (1998). Health problems of low-income female caregivers of adults with HIV/AIDS. *Health Care for Women International*, 19(1), 23-37.
- Fontenberry, J. D., Mc Farlane, M., Bleakley, A., Bull, S., Fishbein, M., Grimley, D. M., et al. (2002). Relationships of stigma and shame to Gonorrhoea and HIV screening. *American Journal of Public Health*, 92(3), 378-381.
- France, N. (2002). *Stigma and HIV/AIDS in Africa: Review of issues and responses based on literature review, focus group discussions and stigma-AIDS e-mail discussion forum*. Retrieved March 14, 2004, from [http://www.hdnet.org/mainlinks /projects/ stigma.htm](http://www.hdnet.org/mainlinks/projects/stigma.htm)
- Fredriksson, J., & Berry, S. (2002). *South Africa HIV/AIDS statistics*. Retrieved May 6, 2004, from <http://www.avert.org/safricastats.htm>

- Gaebel, W., & Baumann, A. E. (2003). Interventions to reduce the stigma associated with severe mental illness: Experiences from the Open Doors Program in Germany. *Canadian Journal of Psychiatry, 48*(10), 657-662.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs: Prentice-Hall.
- Greenberg, J., Solomon, S., & Pyszczynski, T. (1997). Terror management theory of self-esteem and cultural worldviews: Empirical assessments and conceptual refinements. In M. P. Zanna (Ed.), *Advances in experimental and social psychology* (pp. 61-39). New York: Academic Press.
- Grinstead, O. A., & Van der Straten, A. (2000). Counsellors' perspective on the experience of providing HIV counselling in Kenya and Tanzania: The voluntary HIV-1 counselling and testing efficacy study. *AIDS Care, 12*(5), 625-643.
- Herek, G. M. (2002). Thinking about AIDS and stigma: A psychologist's perspective. *Journal of Law, Medicine & Ethics, 30*(4), 594-607.
- Herek, G. M., & Capitanio, J. P. (1993). Public reactions to AIDS in the United States: A second decade of stigma. *American Journal of Public Health, 83*(4), 574-577.
- Herek, G. M., & Capitanio, J. P. (1997). AIDS stigma and contact with persons with AIDS: Effects of direct and vicarious contact. *Applied Social Psychology, 27*(1), 1-36.
- Herek, G. M., & Glunt, E. K. (1991). AIDS-related attitudes in the United States: A preliminary conceptualization. *Journal of Sex Research, 28*(1), 99-124.
- Herek, G. M., & Mitnick, L. (1996, April). *AIDS and stigma: A conceptual framework*

and research agenda. Workshop conveyed by the Office on AIDS of the National Institute of Mental Health.

HIV/AIDS in Sub-Saharan Africa. (2002, September 3). Retrieved May 5, 2004, from <http://www.state.gov/r/pa/prs/ps/2002/13227.htm>

Hutchinson, S., Pulerwitz, J., Esu-Williams, E., & Stewart, R. (2003, May). *HIV/AIDS workplace programs: Mobilizing managers, crafting policies, educating workers.* Retrieved February 9, 2004, from [http://popcouncil.org/horizons/newsletter/horizons\(6\)_1.html](http://popcouncil.org/horizons/newsletter/horizons(6)_1.html)

Increased use of primary health services and HIV/AIDS prevention/mitigation practices. (2003). Retrieved May 6, 2004, from <http://www.sn.apc.org/usaidsa/uss03.html>

Insideout Research. (2003). *Siyam'kela HIV/AIDS stigma indicators: A tool for measuring the process of HIV/AIDS stigma mitigation.* Retrieved February 25, 2004, from <http://www.policyproject.com>

James, A. B. (2004, June 1). *Definitions and overview of prejudice and discrimination.* Retrieved October 18, 2005, from <http://www.faculty.nwc.edu>

Lester, S. (1999, May). *An Introduction to Phenomenological Research.* Retrieved October 18, 2005, from <http://www.devmts.demon.co.uk>

Lew-Ting, C. Y., & Hsu, M. L. (2002). Pattern of responses to HIV transmission questions: Rethinking HIV knowledge and its relevance to AIDS prejudice. *AIDS Care, 14*(4), 549-557.

Link, B. G., Struening, E. L., Neese-Todd, S., Amussen, S., & Phelan, J. C. (2001). Stigma as a barrier to recovery: The consequence of stigma for the self-esteem of people with mental illnesses. *American Psychiatric Association, 52*(12),

- 1621-1626.
- Maslanka, H. (1996). Burnout, social support and AIDS volunteers. *AIDS Care*, 8(2), 195-207.
- Miller, C., & Kaiser, C. R. (2001). A theoretical perspective on coping with stigma. *Journal of Social Issues*, 57(1), 73-92.
- Monico, S. M., Tanga, E. O., Nuwagaba, A., Aggleton, P., & Tyrer, P. (2001, August). *Uganda: HIV and AIDS-related discrimination, stigmatization and denial*. Retrieved February 19, 2004, from www.unaids.org
- Nissan, S. J. (2005, August). *What is IPA?* Retrieved October 20, 2005, from <http://www.psyc.bbk.ac.uk>
- Noble, R., Berry, S., & Fredriksson, J. (2005, March). *South Africa HIV/ AIDS Statistics*. Retrieved June 21, 2005, from www.avert.org/safricastats.htm
- Oyserman, D., & Swim, J. K. (2001). Stigma: An insider's view. *Journal of Social Issues*, 57(1), 1-14.
- Parker, R., Aggleton, P., Attawell, K., Pulerwitz, J., & Brown, L. (2002, May). *HIV/AIDS-related stigma and discrimination: A conceptual framework and agenda for action*. Retrieved February 25, 2004, from www.popcouncil.org
- Person, B., Sy, F., Holton, K., Govert, B., & Liang, A. (2004). Fear and stigma: The epidemic within the SARS outbreak. *Emerging Infectious Diseases*, 10(2), 358-363.
- Plous, S. (Ed.). (2003). *Understanding prejudice and discrimination*. Boston: McGraw-Hill.

- Prasad, R. S. (2001). Development of the HIV/AIDS Q-Sort Instrument to measure physician attitudes. *Family Medicine*, 33(10), 772-779.
- Quinn, A. (2004, April 7). *HIV infects one in four young S. African women – Survey*. Retrieved May 6, 2004, from http://nlm.nih.gov/medlineplus/news/fullstory_17053.html
- Qukula, T. (2003). *Draft guidelines on the management of the lay counsellor programme in the Western Cape*. Cape Town, Provincial VCT Programme, Department of Health, TB/HIV Directorate.
- Rohleder, P. A. (2003). “*What I did is just to talk; nothing else*”: *The experiences of HIV/AIDS counsellors attached to Lifeline, Khayelitsha, Cape Town*. Unpublished master’s thesis, University of Stellenbosch, Stellenbosch, South Africa.
- Rosen, L. (2001, December). *AIDS in Africa*. Retrieved May 6, 2004, from <http://www.prcdc.org/summeries/aidsinafrica/aidsinafrica.html>
- Ross, M. W., Greenfield, S. A., & Bennett, L. (1999). Predictors of dropout and burnout in AIDS volunteers: A longitudinal study. *AIDS Care*, 11(6), 723-732.
- Sidanius, J., & Pratto, F. (1999). *Social dominance: An intergroup theory of social hierarchy and oppression*. New York: Cambridge University Press.
- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analyses. In Smith (Eds.), *Qualitative Psychology: A practical guide to research methods* (p. 51 – 80). London: SAGE Publications.
- Smith, J. A., & Osborn, M. (2004). Interpretative phenomenological analyses. In Breakwell (Eds.), *Doing Social Psychology research* (p. 229 – 254). Oxford: BPS Blackwell.

- Stewart, R., Pulerwitz, J., & Esu-Williams, E. (2002, June). *Addressing HIV/AIDS stigma and discrimination in a workplace program: Emerging findings*. Retrieved March 14, 2004, from <http://popcouncil.org>
- Swim, J. K., & Stangor, C. (Eds.). (1998). *The target's perspective*. San Diego: Academic Press.
- Tajfel, H., & Turner, J. C. (1979). An integrative theory of intergroup conflict. In W. G. Austin, & S. Worchel (Eds.), *The Social Psychology of intergroup relations* (pp. 33-48). Monterey: Brooks & Cole.
- Valdiserri, R. O. (2002). HIV/AIDS stigma: An impediment to public health. *American Journal of Public Health, 92*(3), 341-344.
- Vygotsky, L. S. (1986). *Thought and Language*. Cambridge: MIT Press.
- Wills, T. A. (1981). Downward comparison principles in social psychology. *Psychological Bulletin, 90*(2), 245 – 271.

APPENDIX A

Introduction Letter

37 Eagle Crescent
Somerset West
7130

10 March 2004

Helderberg AIDS Centre
74 Andries Pretorius Street
Somerset West
7130

Dear Mr. Van Biljon

INTERVIEWS: HIV/AIDS LAY COUNSELLORS

I trust this correspondence finds you well and thank you for receiving this letter. I am currently a Masters Degree student at the Department of Psychology (Stellenbosch University) and I am in the process of conducting a research study, which investigates perceived negativity as experienced by HIV/AIDS Lay Counsellors working in the Western Cape region.

My dilemma is that I cannot find an existing measuring instrument or questionnaire that measures this phenomenon in this specific group. I have, with the guidance of my study leader, Ms Elna Theron, and as a result of a wide literary search, thus concluded that a gap exists in this field of research concerning HIV/AIDS Lay Counsellors. We have subsequently decided to develop a questionnaire, which will measure this phenomenon in HIV/AIDS Lay Counsellors. In generating valid and relevant items for the instrument or

scale in question, I have decided to gather information via in-depth, qualitative interviews with HIV/AIDS lay counsellors, as to determine what their own personal experiences and feelings are in relation to this issue. Interviews will be conducted in the Metro, Wine Lands/ West Coast and Boland/ Overberg regions. Please receive more information on the study, as I would subsequently like to ask permission to conduct interviews with the lay counsellors in your employment.

Study Objectives:

The general research objectives of this study are:

- to create a scale or instrument which will measure perceived negativity, like stigma, prejudice and discrimination experienced by HIV/AIDS lay counsellors
- to create a better understanding of and to contribute to research on stigma, prejudice and discrimination
- to gather information which will ultimately lead to a better understanding of the experiences and challenges related to HIV/AIDS lay counsellors and their work
- to generate information which can be utilized in assisting and supporting HIV/AIDS lay counsellors in coping with their work
- to generate knowledge and insight regarding stigma, prejudice and discrimination that can be utilized in combating AIDS stigma, prejudice and discrimination in South Africa

Time Frame:

The study has been undertaken at the beginning of 2004 and it is estimated that it will be completed at the end of 2005.

Method:

Semi-structured, in-depth, interviews will be conducted with HIV/AIDS lay counsellors as to determine what their personal experiences as counsellors have been and whether they have experienced negativity like stigma, prejudice and discrimination. Interviews will be recorded, transcribed and analysed. Emerging themes and information categories will be generated with an item pool finally being constructed from the gathered information. Generated scale items will be reviewed by experts in the field of scale development, omitting irrelevant, unclear or invalid items.

Participant Logistics:**Interviews:**

- Lay counsellors will be introduced to the researcher, the study and its general objectives at a group meeting before the onset of interviews.
- Lay Counsellors will partake in the study on a purely voluntary basis and will not be pressured to do so at any given time.
- Interviews will be arranged at times suitable to lay counsellors after working hours. Interviews will be undertaken in privacy, at a destination in close proximity to counsellors. Lay counsellors will not incur any costs in travelling to or back from the interview venue.
- Interviews will be conducted in either Afrikaans or English, with an estimated duration of an hour to an hour and a half.
- Lay counsellors will have the right to withdraw from an interview at any time or to skip any question asked, if he or she desired to do so.

- Lay counsellors will have the right to follow-up counselling with a professional in their area during the months following the interview, if the discussion regarding their work was of an upsetting nature to them.

Confidentiality and Anonymity:

- Lay counsellors taking part in the study have the right to confidentiality. Counsellors' direct words (in the case of interviews) will not be revealed directly to anyone outside of the study boundaries (for example an employer).

- Counsellors will not be identifiable by name or surname. They will be free to choose an alternative name (in the case of interviews) and will not be requested to identify themselves in writing.

Thank you for the receipt of this letter. I hope it gives you an understanding of the proposed study. Please do not hesitate in contacting me for additional information regarding the matter.

Kind Regards

Ms Suné van der Westhuizen

Contact Details: Tel: (021) 852 0838
 Cell: 082 390 5494
 e-mail: sune@wanteddesign.co.za

Study Leader: Ms Elna Theron
 Department of Psychology
 Stellenbosch University
 Tel: (021) 808 3466

APPENDIX B

Letter of Consent

Dear Participant

Thank you for your willingness to be part of this study. Please take time to read more about it.

WHAT IS THE STUDY ABOUT?

We would like you to take part in a study that is interested in HIV/AIDS counsellors and their experiences of being a counsellor, how they feel and think about it. We would like to know what your own experiences have been as a counsellor and if these experiences have been positive or negative. We hope you can tell us whether you think people have thought or behaved differently towards you since you have been an HIV/AIDS counsellor. We hope this research will contribute to a better understanding of the problems HIV/AIDS counsellors' experience in their work.

WHAT AM I LETTING MYSELF IN FOR?

If you agree to be a part of this study, a Masters Degree student from the University of Stellenbosch would like to talk to you about your work as a counsellor. This interview will last for about one hour and will be conducted after work. It will be conducted in

private, in a place that is close and comfortable to you and during a time that suits you.

You will be asked questions about your experiences as an HIV/AIDS counsellor.

WHAT ARE MY RIGHTS?

You have the right to confidentiality

The things that you will say during the interview will not be shown or discussed with someone else directly (for example your employer). No one will know that the things you have mentioned in the interview were your words directly.

You have the right to anonymity

Your name will not be written on your interview, your identity will not be revealed. Your interview will not be shown or given to your employer or anyone else directly.

You have the right to withdraw from the interview

If you are not comfortable with a question, you can stop the interview or go on to the following question. You will not be forced to answer a question.

You have the right to follow-up counselling

If you experience problems after the interview, or if the things that you have discussed in the interview bother you, you have the right to follow-up counselling. The Masters Degree student will organise a counselling session for you with a professional therapist.

I understand that my involvement is voluntary. I am aware of the possible risks and benefits related to my involvement. I understand that I can freely answer questions, that I can choose not to answer certain questions and that I can stop the interview at any time, if it so pleases me.

.....

Participant's Signature

.....

Date

.....

Interviewer's Signature

.....

Date

APPENDIX C

Constructed Item Pool

Please answer <u>ALL</u> of the following questions Mark with an X					
	ITEMS:	Never	Some- times	Often	Very Often
1	Clients think I lie to them about their status.				
2	Clients think I will disclose their status to other people.				
3	Clients blame me for their test results.				
4	Clients blame me for their personal problems resulting from their HIV test.				
5	Clients try to avoid me when they see me outside of the clinic/ hospital.				
6	Clients try to deceive me when I am counselling them on HIV/AIDS issues.				
7	When I counsel a client about sex, he or she confronts me about my personal sex life.				
8	Clients have unrealistic expectations of me when I offer them support.				
9	When I counsel clients they are not prepared to tell me the truth about their private sex lives.				
10	Clients gossip about my personal life to others (e.g. medical staff) to get me into trouble at work.				
11	Clients expect advice or assistance from me in my private time.				
12	Medical staff in the clinic/ hospital does not trust me.				
13	Medical staff embarrasses (e.g. screams at) me in front of other people in the clinic/ hospital.				
14	Medical staff looks down on me as a HIV/AIDS counsellor.				
15	Medical staff thinks little of my HIV/AIDS service to the community.				
16	Medical staff gossips about my private life.				
17	Medical staff puts pressure on me to gossip about a client's status with them.				
18	Medical staff does not think I am well trained in HIV/AIDS counselling (e.g. they check my work).				
19	The community gossips about me being a HIV/AIDS lay counsellor.				

		Never	Sometimes	Often	Very Often
20	The community puts pressure on me to disclose a client's status to them.				
21	The community thinks I do this job because I am HIV positive myself.				
22	The community expects me to set an example for the rest of the community (e.g. lead a virtuous life).				
23	The community treats me as if I am preoccupied with HIV and AIDS.				
24	The community thinks any person I associate with is HIV positive.				
25	The AIDS ribbon and T-shirt I wear make people think I am also HIV positive.				
26	When people see me they immediately associate me with HIV and AIDS.				
27	Patients in the waiting room think everyone is HIV positive who enters my counselling room.				
28	When I give information talks on HIV/AIDS people react negatively towards me.				
29	My family do not understand why I want to do this job.				
30	My friends joke about my job.				

APPENDIX D
Additional Items

	ITEMS:
1	Medical staff blames me for things that go wrong in the clinic/ hospital (e.g. misplaced equipment).
2	Medical staff does not include me in activities in the clinic/ hospital.
3	Medical staff demands that I do things for them that is not part of my job.
4	The Department of Health does not think I am worth a lot.
5	The Department of Health does not supply me with adequate working space.
6	The Department of Health does not reward me properly for the work that I do.
7	My cultural background makes it difficult to work with other counsellors.
8	The NGO/Municipality I work for expects too much from me in this job.
9	I have too much work to do in a day.