

# HIV-stigma reduction and responsible disclosure management in a primary health care setting

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## RESEARCH OUTLINE

This study is presented in an article format and includes the following:

### Section A: An overview of the research

The overview allows for a brief literature review, as well as an overview of the research project and its methodology. The detail thereof are provided in the articles.

### Section B: Overview of literature review

The literature review critically evaluates and interprets the body of knowledge that exists relating to the current research to identify gaps that might need further exploration. The review further compares and contrasts previous findings with the present research results. The literature review is presented in two chapters.

**Chapter 1:** An overview of HIV-stigma, its manifestations, outcomes and interventions

**Chapter 2:** HIV disclosure management in primary health care settings

### Section C: Articles

The two articles report on the research and its findings about HIV-stigma reduction and responsible disclosure management in primary health care settings as outlined.

ARTICLE TITLE	JOURNAL FOR SUBMISSION
<b>Article 1:</b> Perceptions of nurses and health care workers of HIV-stigma reduction and disclosure management in primary health care settings.	JOURNAL: The Journal of the Association of Nurses in AIDS Care
<b>Article 2:</b> Experiences of nurses, health care workers, counsellors, people living with HIV and people living close to them of a HIV-stigma reduction and disclosure management intervention in three primary health care settings.	SAHARA-J: Journal of Social Aspects of HIV and AIDS: An Open Access Journal

### Section D: Conclusions, limitations and recommendations

Conclusions are drawn, limitations are discussed and recommendations presented in this section.

## **AUTHORS' CONTRIBUTIONS**

The presented study was planned and conducted by three researchers from the Africa Unit for Transdisciplinary Health Research (AUPHeR) of the North-West University. Each researcher contributed to the study as follows:

<b>NAME</b>	<b>CONTRIBUTION</b>
Ms S Mmuwe Hlahane	PhD Nursing Science student; supported the conceptualization of the focus of the study, co-facilitator in the intervention study, intensive literature overview, data analysis, conceptualising and writing the initial two articles and finalisation thereof.
Prof M Greeff	Supervisor; conceptualised the study, facilitator of the intervention during data gathering, provided critical peer review in-put into the literature review, support in the conceptualisation of the articles, peer review during the writing of the articles and finalisation of the articles.
Prof P Bester	Co-supervisor, provided critical peer review in-put into the literature review, support in the conceptualisation of the articles, peer review during the writing of the articles and finalisation of the articles.

Each researcher in a declaration below confirms their role in the study, its appropriateness and acceptability for submission as a thesis, titled: HIV-stigma reduction and responsible disclosure management in a primary health care setting.

## **DECLARATION**

I hereby declare that I have approved the inclusion of the two (2) articles as mentioned above and that my role in this study complies with what is described above. I hereby grant permission that these articles may be published as part of the PhD thesis of Salamina Mmuwe Hlahane.

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Prof M Greeff

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Prof P Bester

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Ms SM Mmuwe Hlahane

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## **SUMMARY**

Worldwide human immunodeficiency virus (HIV) related stigma is viewed as a complex concept with far reaching consequences for people living with HIV (PLWH), people living close (PLC) to PLWH, communities in different contexts, as well as health care settings especially the primary health care (PHC) settings like clinics. The mentioned HIV-stigma does not only impact the mentioned groups or contexts but also interferes with the disclosure of HIV status in these various groupings or contexts. PHC clinics which forms the focus of this research is the first point of entry for the health care needs of many South Africans including PLWH. Government has accomplished much in HIV management and care through strategies, guidelines and policies but unfortunately failing to specifically manage HIV-stigma or disclosure practices. Literature confirms the existence of several intervention and program studies for HIV-stigma reduction and disclosure management in different contexts or for various target populations but there are seemingly limited studies focusing on specifically PHC settings, indicating a paucity in research in this regard.

This study used a qualitative descriptive design to first explore and describe nurses' and health care workers' (HCWs) perceptions of HIV-stigma reduction and disclosure management practices in three PHC clinics in the North West Province of South Africa. These two groups of participants were selected through purposive sampling. This was followed by the development and implementation of a PHC-based HIV-stigma reduction and responsible disclosure management intervention in the same three clinics, followed by the description of the explored experiences of nurses, HCWs, counsellors, PLWH and people living close (PLC) to PLWH involved in the intervention. The counsellors and PLWH were also selected through purposive sampling, while the PLC were selected by using snowball sampling. The intervention was accomplished through a planned series of workshops in specifically PHC clinics and facilitated by the researchers and a PLWH.

The findings suggested a dissonance between the nurses', HCW's and counsellor's (also present in the clinics) perceptions of the stigma and disclosure management practices, suggesting a disconnection in their relationship. A system disconnect was also noted that negatively impact on these practices. The dissonance and lack of HIV-stigma and disclosure management practices in the clinics unfortunately impact

negatively on PLWH: stigma increases; disclosure decreases; PLWH do not access clinics and default; they have less support and their overall quality of life decreases. Regarding the experiences of nurses, HCWs, counsellors, PLWH and PLC of the PHC-based HIV-stigma reduction and responsible disclosure management intervention, the intervention was seen as successful on several levels. All five groups gained a greater awareness and understanding of stigma as well as experiencing positive effects and empowerment following the intervention. Only two groups, counsellors and PLWH experienced aspects related to counselling. Three of the five groups (nurses, PLWH and PLC) reflected on patient behaviour, assistance to disclose and coping strategies following the intervention. Each group experienced growth but the five groups also had a crossover effect on one another leading to reduction in HIV-stigma and increased disclosure.

This study recommends the need for improved stigma reduction and responsible disclosure management practices in PHC settings. Nurses, HCW and counsellors are the major role players in these practices and should be the main focus during in-service training. The dissonance should be handled. The focus should be on identified constructive practices. The clinic should ensure that it is a support system for PLWH linking wider networks. Clinics should provide well sustained and organised HIV-stigma reduction and responsible disclosure management programs.

**Core concepts:** Disclosure, dissonance, HIV, primary health care, stigma reduction



## **LIST OF ABBREVIATIONS**

AIDS:	Acquired immunodeficiency syndrome
ALO:	Average length of stay
ART:	Antiretroviral Therapy
BOR:	Bed Occupancy Rate
CCMDD:	Central Chronic Medicine Dispensing Distribution
DCST:	District Clinical Specialist Team
HBC:	Home Based Care
HCT:	HIV counselling and testing
HCW:	Health care worker
HIV:	Human Immunodeficiency Virus
HSREC:	Health Science Research Ethics Committee
IACT:	Integrated access to care and treatment
ICDM:	Integrated Chronic Disease Management
ISHP:	Integrated School Health Program
MSM	Men who have sex with men
NCS:	National Core Standards
NDOH:	National Department of Health
NHI:	National Health Insurance
NIMART:	Nurse Initiated Management of Antiretroviral
Nurse:	Professional nurse
PLC:	PLC to PLWH includes children, partners, family, friends, colleagues and spiritual supporters
PLWH:	People living with HIV
PHC:	Primary health care

STI: Sexually transmitted infections

TB: Tuberculosis

WBOT: Ward Based Outreach Teams

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## **SECTION A: OVERVIEW OF THE RESEARCH**

### **1 BACKGROUND**

Thirty years after discovering the Human immunodeficiency virus (HIV) infection, the impact of HIV infection remains a continuing challenge. The United Nations Programme on HIV and AIDS and the Fact sheet on HIV statistics report that by the end of 2017 people living with HIV (PLWH) globally were an estimated 36.9 million, while 1.8 million people were newly infected with HIV (United Nations Programme on HIV and AIDS [UNAIDS], 2018a:18; UNAIDS, 2018b). However, the prevalence differs according to geography and demography. The American, European and Middle Eastern countries' HIV-prevalence rate is 1% compared to the 10% to 20% in Africa (Kaizer Family Foundation, 2013; UNAIDS, 2012:8). Sub-Saharan Africa is hit the hardest by HIV (UNAIDS, 2014a:18), making it a highly noticed illness in this region (Kharsany & Karim, 2016:35; Vermund, Sheldon & Sidat, 2015:2). An estimated 7.5 million of PLWH or Acquired Immune Deficiency Syndrome (AIDS) live in (Statistics South Africa [Stats SA], 2018:1). South Africa therefore ranks first in the top fifteen countries with the highest rate of new HIV infections (UNAIDS, 2014a:18; UNAIDS, 2017a; Zuma, Manzini & Mohlabane, 2014). South Africa has become a hotspot for HIV infection. In 2017 there were almost 200 000 new HIV infections among 15 to 49 year-olds (Human Sciences Research Council [HSRC], 2018). This makes South Africa one of the countries with the most widespread HIV epidemic and thus the largest number of PLWH globally (South African National AIDS Council [SANAC], 2017; UNAIDS, 2017a; UNAIDS, 2014a:26; Zuma *et al.*, 2014:1).

Even though HIV infection has been present for over three decades, it remains poorly understood (Gilbert & Walker, 2010:140) and continues to be a threat in people's lives (Pretorius, 2012:188). As early as 1988 Mann (1988:131) predicted that HIV will present in three waves, with the first being the HIV infection, the second the AIDS phase and the third being the phase of prejudice (Mann, 1988:134). The HIV-infection phase was characterised by a long period of hidden symptoms. In 1982, only two cases had been identified, escalating to more than 600 cases by 1992 and souring to an estimated 300 000 to 750 000 cases in 1994, which heralded the first wave (Catholic Health Care Association of South Africa [CATHCA], 2010). Due to the inconspicuousness of the early symptoms of HIV infection, the disease progressed

unnoticed over a long period of time (Mann, 1988:131), leading to almost catastrophic levels in South Africa (CATHCA, 2010). However, over time people developed AIDS-related illnesses with symptoms that could no longer be hidden, manifesting as the second wave (Del Rio, 2005:682-686). This led to devastating results with 115 167 registered AIDS deaths reported in South Africa by 2018 (Stats SA, 2018:7) with a projected 1 000 annual deaths due to HIV and AIDS (Johnson & Dorrington, 2017:47).

The more AIDS became an identifiable disease, the more it impacted on the socio-economic-, political and cultural dimensions in communities with prejudices leading to the third wave of HIV, referred to as the phase of stigmatisation (Chambers *et al.*, 2015:5; Hoeve, 2015:4). As the initial unhidden symptoms of HIV and later AIDS became visibly ugly, repulsive and disruptive in the social lives of individuals (Herek, 2002:597), it resulted in fear, ignorance, blaming and prejudice (Mann, 1988:133). It also started to interrupt and affect PLWH access to health care (Holzemer *et al.*, 2007b:1002; Li *et al.*, 2013:286) changing health seeking behaviour (Greeff & Phetlhu, 2007:13), as well as prevention processes (Holzemer *et al.*, 2007b:1002).

In the years 2002 – 2008 a group of researchers studied HIV-stigma in an African context (Chirwa *et al.*, 2009:14-21; Dlamini *et al.*, 2007:389-399; Greeff *et al.*, 2008b:78-108; Holzemer & Uys, 2004:165-172; Holzemer *et al.*, 2007a:543; Makoe *et al.*, 2008:137-146; Makoe *et al.*, 2009:1357-1362; Uys *et al.*, 2005: 64-73). The mentioned African studies focussed on understanding HIV-stigma in five African countries and conceptualising an HIV and AIDS stigma model. Uys *et al.* (2009a:1059-1066, Uys *et al.* (2009b:150-159) and Greeff *et al.* (2010:475-486) developed HIV and AIDS stigma instruments and conducted a health care setting-based stigma reduction intervention. The studies supported the definition of stigma by Alonzo and Reynolds (1995), who defines HIV-stigma as a powerful discrediting and tainting social label that radically alters how individuals perceive themselves (Greeff *et al.*, 2008:312-313). This was built on the work of Goffman (1963) who referred to stigma as a “discrediting attribute”.

The outcome of HIV-stigma leads to rejection, devaluation and exclusion of PLWH from communities (Saki *et al.*, 2015:5; Zimbabwe National Network of PLHIV [ZNPP], 2014:14) and are highly challenged (Pretorius, 2012:2). It influences how others see them (received stigma), as well as how they [PLWH] view themselves (internal stigma)

(Greeff *et al.*, 2008:313). In addition, stigmatisation also impacts on the lives of people living close (PLC) to PLWH such as spouses, family members, relatives or even health care workers (HCWs). The latter is referred to as stigma by association (Greeff & Phetlhu, 2007:13; Herek, 2002:596; Hillhorst *et al.*, 2006:390; Holzemer & Uys, 2004:165-166).

Several frameworks and models for HIV-stigma reduction have been mentioned in literature (Campbell *et al.*, 2007; Deacon, Uys & Mohlahlane 2009; Parker & Aggleton, 2003; Pretorius, 2012:31). The *Conceptual Model*, exploring the relationship between HIV-stigma and implementing HIV clinical trials in rural communities, emphasizes HIV-stigma is a barrier to clinical trials in rural settings (review pages and Sengupta *et al.*, 2010:1, 9-10). The *Actor–Partner Independent Model* by Liu, *et al.* (2013:1-2) focuses on the effects of stigma on quality of life as perceived by the PLWH and the caregiver. An *Information and Behavioural Skills Model (IMB)* (Cornman *et al.*, 2011:1625-1639) suggests that education and motivation for behavioural change, through an adapted “Options for Health” process in a PHC setting, are positive approaches to HIV-stigma reduction. *The Structuration Theory: A conceptual Framework for HIV and AIDS Stigma* (Misir, 2015) assessed existing models, highlighting inadequacies and developing a complementary Structuration Theory as a base for further designing of HIV and AIDS stigma reduction interventions (Misir, 2015). The model of the *Popular Opinion Leader* developed by Li *et al.* (2013:333-334) was used as an approach in HIV-stigma reduction in a health care setting where the most popular groupings of individuals in the social system are used to influence a positive change in the lives of individuals.

For the purpose of this study, the conceptual model of HIV and AIDS stigma in Africa as developed by Holzemer *et al.* (2007a) will be used as theoretical framework and will be discussed in more detail. This model (Holzemer *et al.*, 2007a:547) describes the context (environment, health care agents and health care) within which a process with four elements, namely i) stigma triggers, ii) stigmatising behaviours, iii) types of stigma and iv) outcomes of stigma occur. According to this model individuals are affected negatively by certain stigmatising *behaviours* (Holzemer *et al.*, 2007a:547). Furthermore, three *types of stigma*, namely internal, received, as well as associated stigma (Greeff *et al.*, 2008b:105; Holzemer *et al.*, 2007a:547; Uys *et al.*, 2009b:151;



Greeff *et al.*, 2008b:105) are identified. *Internal stigma* refers to thoughts stemming from PLWH's negative perceptions about themselves including social withdrawal, self-exclusion and fear of disclosure (Greeff *et al.*, 2008a:312). This is also referred to as the 'emic' view of stigma (Weiss *et al.*, 1992 *in* Greeff *et al.*, 2008a:313). *Received stigma* is stigmatising behaviour towards PLWH as described by themselves or when others direct stigma remarks to PLWH (Holzemer *et al.*, 2007a:547) which includes acts such as neglecting, fearing, fearing contagion, avoiding, rejecting, labelling, pestering negating, abusing and gossiping (Greeff *et al.*, 2008a:318). Weiss *et al.* (*in* Greeff *et al.*, 2008a:318) refers to this as the 'etic' view of stigma. *Associated stigma* as the third type mentioned involves people living close (PLC) to PLWH, such as a family member or health care worker (Holzemer *et al.*, 2007a:547). Subsequently, PLWH find themselves with poor *outcomes*, resulting in poor quality of life, violence, verbal abuse and poor mental as well as social care (Holzemer *et al.*, 2007a:547). These poor health outcomes exceed physical health and entails stress and discomforting economic demands and forces (Holzemer *et al.*, 2007a:547).

The context as mentioned in the conceptual model of HIV and AIDS stigma in Africa (Holzemer *et al.*, 2007a) refers to three elements: the environment, agents and health care. These elements are discussed below, starting with the environment, followed by agents and lastly the health care setting. Cultural, economic, political, legal and policy aspects play a major role in influencing the approach taken in response to the illness. Holzemer *et al.* (2007a:454) highlights limited understanding of the elements that increase or decrease stigma. Authors like Attel (2013:1) also refer to the importance of environments in HIV-stigma and identify different areas, such as the home, financial institutions, employment institutions and government policies as highly HIV-stigmatizing factors. Brown, BeLue, & Airhihenbuwa *et al.* (2010:1) refer to family, race, culture, religion and spirituality as factors that may contribute to HIV-stigma. However, there are various countries with policies which provide environments that facilitate processes to decrease stigma. The Cuban legal system presents its communities with a supportive environment whereby PLWH are assisted in building their own ability to cope with HIV (Aragonés-López *et al.*, 2012:888-889). In South Africa the Constitution (1996) protects the rights of the citizenry, including access to care for PLWH (South African Constitution, 1996). The second element refers to agent. HIV-stigma is a complex multi-level health matter not only affected by the

context, but also by agents. The infected person himself (PLWH), the family, workplace, and the community are identified as the agents who play a significant role in the context of HIV stigmatization (Holzemer *et al.*, 2007a:546).

The third and last element in the context description refers to the health care setting (Holzemer *et al.*, 2007a:546-547). Aujoulat *et al.* (2002 in Holzemer *et al.*, 2007a:546-547) refer to the health care setting as hospitals, clinics, home-based care settings and the health worker (physicians, nurses and others). These are seen as points where stigma can be triggered. Some of the respondents who are quoted related the negative encounters they had as they disclosed their positive HIV status while under the care of a nurse or health worker (Holzemer *et al.*, 2007a:546-547). Obermeyer, Baijal and Pegurri (2011:1061) refer to health care settings as critical areas where positive interventions in management of stigma can be initiated and implemented, such as couple counselling (Vu *et al.*, 2012:137). Various authors mention how the health care setting can fuel HIV-stigma (Uys *et al.*, 2009a) preventing PLWH from accessing health care and affecting individuals' health seeking patterns (Gitachu, 2017:27). Other authors also refer to health care environments perpetuating stigmatisation when out of fear of infection nurses put on more gloves than necessary, put tablets on dirty tables, count tablets with unwashed hands and subtly refuse to treat a patient adequately or even send them home without treatment (Ndou, Maputle & Risenga, 2015:4). This might interfere with people seeking help timeously, thus delaying their process of recovery (Dong *et al.*, 2018:6; Patankar Fazila & Pandit Daksha, 2014: 53-56; Saki *et al.*, 2015:5) and subsequently affecting the individual's quality of life (Greeff & Phetlhu, 2007:22). A participant was quoted expressing his fears that going to the health facility for follow-up would mean that people would know that he is HIV infected (Kruger *et al.*, 2009:39-40). Most newly diagnosed PLWH consequently miss their appointments and health care workers are mentioned as a deterrent in the health care seeking process of PLWH (Saki, Kermanshahi, Mohammadi & Mohraz 2015:5-6). Greeff and Phetlhu (2007:13) stressed that stigma and discrimination interferes with the willingness and readiness to seek health care.

South Africa renders health care services through the PHC approach (Dennill, King & Swanepoel, 2000:2). Services rendered in PHC range from curative, preventive and promotive, acute and chronic health care, including HIV counselling and testing (HCT)

(Dennill *et al.*, 2000:2-5). PHC services are constantly undergoing restructuring processes. One of these processes was the reengineering of PHC by taking health care services to the community through ward based outreach teams (WBOT) (NDOH 2011:3). The Integrated Chronic Disease Management (ICDM) followed this and intended to integrate the treatment of HIV and AIDS with the management of other chronic illnesses (NDOH, sine anno). HIV and AIDS is now viewed more as a chronic disease (Ernst, 2017:4; Mayer, Shisana & Beyrer, 2016:2484) because people live longer on ART (NDOH, 2013). The following are the identified existing HIV and AIDS policy guidelines in South Africa: NDOH Guidelines for the management of HIV-infected children (NDOH, 2005); NDOH Guidelines for the management of HIV in children (2010); Clinical guidelines for prevention of mother-to-child transmission (PMTCT) (NDOH, 2010); Clinical guidelines for the management of HIV and AIDS in adults and adolescents (NDOH, 2010). These guidelines provide guidance with regard to HIV and AIDS management and care, health education, promotion, prevention, HIV testing, as well as curative care and medication. Provincial guidelines for implementation of three PHC streams (NDOH, 2011b), strategic maternal, new-born, child and women's health and nutrition 2012-2016 (NDOH, 2011a), the 2011-2021 sexual reproductive health and rights guidelines (NDOH, 2011c), national consolidated guidelines on prevention of mother-to-child HIV, management of HIV in children, adolescents and adults (NDOH, 2015); the 2012-2016 and the latest 2017-2022 South Africa's strategic national plan on HIV, tuberculosis (TB) and sexually transmitted infections (STIs) emphasises the need to manage HIV-stigma through community support groups and education programmes (NDOH, 2011; NDOH, 2017). Even the latest guidelines on HIV, TB and STI are not specific on PHC stigma reduction and disclosure management. The documentation deals with stigma in a broader sense, with no clear guidelines on how to manage HIV-stigma.

Brown *et al.* (2003:52-53) reviewed twenty-two (22) articles on HIV and AIDS stigma interventions clustered into information sharing approaches, skills building, counselling approaches and contact with affected groups. Of the twenty-two (22) studies fourteen (14) focussed on increasing tolerance of PLWH by the community, while five (5) tested the willingness of health care workers to care for PLWH (Brown *et al.*, 2003:62-63). The systematic review by Sengupta (2011:1057-1087) was on the effectiveness of the HIV-related interventions in reducing HIV and AIDS stigma. Part

1 of Cross *et al.* (2011a:62-69) refers to health related stigma across different societies and Part 2 focuses on Leprosy with a determination to generate an intervention that could be used across different health conditions (Cross *et al.*, 2011b:71-78). Training and contact, rights based and social capital strategies were identified as key to stigma intervention. Further it was mentioned that no one intervention can be applied across different health conditions and the need for adaption to be specific was highlighted (Cross *et al.*, 2011b:71-78). Uys *et al.* (2009a:1059-1066) conducted an HIV-stigma reduction intervention in five African countries focussing on hospitals as health care settings. Sallar and Somda (2011:294-295) and Sikkema *et al.* (2011:727) also presented stigma reduction interventions within a health care setting, but not a PHC specific context. In addition to the mentioned interventions, the study entitled *A brief HIV Stigma Reduction Intervention for Service Providers* by Wu *et al.* (2008:517) in a PHC setting was reported to have positive results, but it was not specific to HIV-stigma management either. Roehrs (2009:360) investigated legal implications of different HIV and AIDS public health interventions, ranging from prevention, promotion, screening through blood tests, sexual partner notification to commencing ART and treatment. Thus highlighting its importance to PLWH and noting that HIV and AIDS is highly stigmatized (Roehrs, 2009:397). Sikkema *et al.* (2011:727-728) indicates that interventions are accepted by patients and clinic staff and that they are valuable except that their study on HIV stigma was not generalizable to a PHC setting because it was conducted in a large community health centre. An HIV risk reduction intervention was developed for PLWH obtaining care at PHC clinics linking prevention with treatment through modification of "Options intervention" (Cornman *et al.*, 2011:1623,1638). Interventions on HIV-stigma emphasises skills building, health education, health promotion, counselling, including HIV and AIDS awareness, but with very little focus on HIV-stigma reduction management in a PHC setting. There is in fact paucity in literature on HIV-stigma reduction management in a PHC setting.

In the context of HIV-stigma there seems to be a close link to HIV disclosure (Tshweneagae, Oss & Mgutshini, 2015:4; UNAIDS, 2014b:4). The practice in PHC services during HIV counselling is to motivate PLWH to share their positive HIV status with someone (Masquillier *et al.*, 2015:214-226; Meintjes *et al.*, 2017:4) referred to as the 'buddy system'. The buddy system forces an individual to disclose his/her HIV status. However, these policy guidelines do not afford a clear platform for HIV

disclosure management. UNAIDS (2017b:7) advocate for a critical need for a supportive health care environment that will facilitate the processes of non-discrimination to reduce stigma, resulting in high opportunities for disclosure. HIV disclosure is described as a complex and multi-faceted process of decision-making for the PLWH (Klopper, Stellenberg & Van der Merwe, 2014:37-41). The high levels of stigma experienced by PLWH lead to individuals fearing disclosure of their HIV-positive status (Aultman & Borges, 2011:51; Saki *et al.*, 2015:1-5). The identified link between high levels of HIV-stigma and fear of disclosure (Greeff, 2013:312, 318) suggests a correlation between high levels of HIV-stigma with low levels of disclosure.

Researchers present a range of reasons why individuals choose not to disclose, ranging from negative consequences, fear of rejection, abandonment, negative attitudes, blaming, losing one's job and stigma, physical violence and social ostracism (Abubakar *et al.*, 2016:6; George & Lambert, 2015:939-943; International Planned Parenthood Federation [IPPF], 2014:15-30; Saki *et al.*, 2015:3). The reality of the challenges in the disclosure process poses a threat to individuals in that those who do not tell others about their HIV positive status continue with risky behaviours, such as unsafe sexual practices (Kalichman *et al.*, 2016:226; Ncube *et al.*, 2017:36-17). Amongst the reasons cited for disclosure are safer sexual relations, access to health care and increased social care (Abubakar *et al.*, 2016:6; Arrey *et al.*, 2015:7-8; Atuyambe *et al.*, 2014:9). Willingness to disclose particularly to women [as mothers, sisters, girlfriends or wives] than to men is highlighted (Tshweneagae *et al.*, 2015:1).

Researchers developed and applied frameworks and models for HIV positive status disclosure in the varied contexts, such as different settings and relationships and circumstances. Henry *et al.* (2015:311-319) alludes to the fact that before individuals choose to disclose, they assess the reward and consequences very closely. Kalichman *et al.* (2003:330) presented a generalised model of HIV status disclosure and social support, indicating that disclosing HIV status was related to disclosure and social support. In their study Miller and Rubin (2007:587) discussed factors for disclosure of positive HIV status referring to Petrinio's (1991) *Communication Privacy Management Theory*. The premises of this theory state that people construct information, sharing boundaries on important (personal) matters to manage possible risks by determining when, to whom and how much to disclose. A model of HIV

disclosure was developed based on the study by Bairan *et al.* (2007), which revealed that disclosure is related to social relationship (Bairan *et al.*, 2007:248). HIV status disclosure models and the AIDS reporting framework for South African companies (Du Bruyn, 2008:59-60; 72-73) recommend disclosure of HIV and AIDS risks and responses by organisations. It is indicated in a systems dynamic model for intentional transmission of HIV and AIDS using cross impact analysis that people continue to die despite all interventions (Padamallu *et al.*, 2012:320). None of the mentioned studies or frameworks provides a clear guideline for disclosure in a PHC setting. Emler (2008:712-714) identified different themes in disclosure (unintentional disclosure, intentional disclosure and violation of confidentiality) and non-disclosure (protective silence, anticipatory disclosure and violation of confidentiality) in an attempt to manage circumstance in and around disclosure. Greeff (2013:71-95) recently formulated a comprehensive framework for HIV disclosure. This framework refers to different categories of disclosure, namely those who disclosed and those who did not; forced disclosure where PLWH's status is made known to others without their consent and mandatory disclosure, which is a policy in some countries. Furthermore, factors influencing disclosure (managed and concealment disclosure), reasons to disclose (personal and interpersonal needs and response to the needs of others), reasons not to disclose (protecting self and others, relationship and community factors), as well as factors during and after disclosure (negative and positive consequences), with possible steps facilitating disclosure are presented in this framework. She also suggests meaningful steps to facilitate responsible disclosure management (Greeff, 2013:89).

Other studies were undertaken in an attempt to understand HIV-stigma and disclosure within a PHC setting, focussing on different health care settings. A tool named "*To the other side of the mountain*" (NDOH, 2005:11) categorised disclosure as full disclosure, partial disclosure, indirect disclosure and non-disclosure. Smith and Chesney (*cited by Miller & Rubin, 2007:586*) focussed on facilitation of prevention and access to health care in general. The study on HIV-stigma and disclosure by Iwelunmor, Zungu and Airhihenbuwa (2010:1395) aspired to inform the health sector in general. Furthermore, Eustace and Ilagan (2010:2095) envisaged to construct better HIV-disclosure measures in advanced nursing practice. Aragonés-López *et al.* (2012:884) discussed HIV care and ART in a community-based centre, while Madiba (2016)

investigated caregivers' lack of disclosure to children in South Africa and Botswana, and Krauss, Letteney and Okoro (2016:1-7) looked at disclosure and non-disclosure reasons in children in the United States of America (USA). Reference to health care workers was made by Kalembo *et al.* (2018:1-3) in terms of their contribution to disclosure or non-disclosure. Other approaches, such as in Cuba where PLWH were taken through a management process within an enclosure over a specific period of time it was found to assist PLWH towards better health (Aragónés-López *et al.*, 2012:889-891). Obermeyer *et al.* (2011:1015) highlight that the influence of the health care system on disclosure has not been explored extensively. This is confirmed by Aultman and Borges (2011:50), who advocate that there is a critical need for a supportive health care environment that will facilitate the processes of non-discrimination which will result in more opportunities for disclosure. There is thus paucity in the literature on research when it comes to disclosure management in a PHC setting.

## **2 PROBLEM STATEMENT**

From the literature it is evident that there are high levels of HIV infection and large numbers of individuals living with HIV who have to face the challenges of HIV-stigma. Stigma manifests in different areas such as government, the workplace and health care systems whereby individuals are negatively affected. In South Africa, the majority of people access health services through PHC and come into contact with nurses and HCWs who implement programmes for HIV management and care. Closely linked to HIV-stigma is the complex process of disclosure of HIV status. When stigma is high disclosure becomes more difficult. According to the literature a lot of work has covered interventions on stigma reduction, but less is written on disclosure management. The main focus of stigma reduction work is on individuals, specific group (sex workers, pregnant women, men who have sex with men (MSM), communities and hospitals as health care settings. Very little is available specifically for PHC settings. In the PHC settings people are counselled, tested and started on lifelong antiretroviral treatment. However, it seems very little is done regarding stigma reduction and disclosure management in these settings. From the above discussion the following questions arise: 1) how do nurses and HCWs working in PHC clinics perceive HIV-stigma reduction and responsible disclosure management practices in these PHC settings?;

2) what would the nature of a PHC-based intervention focussing on HIV-stigma reduction and responsible disclosure management be like?; 3) what would be the experiences of nurses, HCWs, counsellors, PLWH and PLC of such an intervention in PHC settings?

In view of the discussion above and the problem statement the study aims to address the following questions:

- What are the perceptions of nurses and health care workers (HCWs) of HIV-stigma reduction and disclosure management practices in a PHC setting?
- What would the nature of a PHC-based intervention which focusses on HIV-stigma reduction and responsible disclosure management be and how would this affect experiences of nurses, HCWs, counsellors, PLWH and PLC of such an intervention in PHC settings?

### **3 OBJECTIVES OF THE RESEARCH**

The research objectives of this study aimed to:

- Explore and describe the perceptions of nurses and HCWs working in PHC settings of the HIV-stigma reduction and disclosure management practices in these settings.
- Describe the implementation of a PHC-based HIV-stigma reduction and responsible disclosure management intervention for nurses, HCWs, counsellors, PLWH and PLC.
- Explore and describe the experiences of nurses, HCWs, counsellors, PLWH and PLC to PLWH following the implementation of such an intervention in PHC settings.

### **4 LITERATURE REVIEW**

An initial literature review was conducted using the following search engines and databases: Google Scholar, CINAHL (via EbscoHost), Health Source - Nursing Academic Edition (via EbscoHost), MEDLINE (via EbscoHost), ScienceDirect, Scopus and SAePublications, and PubMed. The following keywords were used in the search strategy: HIV and AIDS, HIV-stigma, disclosure management and PHC. The study employed a qualitative, description design (Sandelowski, 2000:337-339; Sandelowski,



2010:83-84) with a literature review used to position the study. The literature study highlighted what was already known, strengthened the research process and assisted the researcher in drawing conclusions based on the findings of the study (Thorne, 2008:54-55; Botma *et al.*, 2010:196-197). A further literature review was conducted using the same databases as above. Particular attention was paid to the themes as they emerged in this study: conceptualisation of HIV-stigma, manifestation of HIV-stigma, conceptual models, frameworks and theories on HIV-stigma, the impact of stigma, outcomes of stigma, interventions to reduce HIV-stigma impact of HIV, conceptualisation of disclosure of HIV status, reasons for non-disclosure and disclosure of HIV status, outcomes of disclosure of HIV status, approaches to management of disclosure of HIV status, and the PHC system in South Africa.

## **5 RESEARCH METHOD**

### **5.1 Research design**

This study followed a qualitative descriptive design (Sandelowski, 2000:335-339; Sandelowski, 2010:82-84). The design was aimed at exploring and describing the perceptions of nurses and HCWs of HIV-stigma reduction and disclosure management in their practices in PHC settings. Following this, the literature study investigated the process of planning, implementing and evaluating a PHC-based HIV-stigma reduction and responsible disclosure management intervention in a PHC setting which could be applied in the JB Marks Municipal Council, North West Province in South Africa. Another aim was explore and describe the experiences of nurses, HWCs, counsellors, PLWH and PLC following the implementation of such an intervention in PHC settings

### **5.2 Context of the study**

The study was conducted in Mohadin, Promosa and Ikageng, which all form part of the JB Marks Municipal Council. The JB Marks Municipality is an urban area in the Dr Kenneth Kaunda health care district in the rural North West Province (North West, Dr Kenneth Kaunda District, Profile 2017). This selected area includes twelve (12) public health facilities [ten, (10) PHC, one (1) district and one (1) psychiatric hospital] (North West, Dr Kenneth Kaunda District, Profile 2017). The current study was conducted in three (3) of the ten (10) clinics in the areas listed above. The three (3) clinics were identified according to selection criteria (see paragraph 5.3.1.1.2). 46% of the JB

Marks community has piped water, 87% has electricity and 71% has refuse removal services (Tlokwe City Council Final IDP Draft Review, 2018-2019:48). The area has an unemployment rate of 21.6% (Municipalities of South Africa, 2012-2018). Human Sciences Research Council (HSRC) 2017 survey indicates that with a population of 3 million (Statistics SA, 2018:2) the North West Province had an HIV prevalence rate of 22.7% in 2017.

### **5.3 Research method**

This study was conducted in two phases.

#### **5.3.1 Phase 1: The perceptions of nurses and HCWs regarding HIV-stigma reduction and responsible disclosure management in a PHC setting**

##### **5.3.1.1 Sample**

###### *5.3.1.1.1 Population*

Three (3) clinics in JB Marks Municipal Council were selected as settings to conduct the study.

###### *5.3.1.1.2 Sampling of the participating PHC clinics*

The inclusion criteria for the three (3) PHC clinics stipulated that they were rendering comprehensive PHC services including HIV and AIDS management and care, high volume clinics for PLWH care, a variety of cultural groups and communities in Mohadin, Promosa and Ikageng.

###### *5.3.1.1.3 Sampling of participants*

The purposive sample for this study consisted of two groups: nurses working in the selected clinics and HCWs linked to the selected clinics working with PLWH. The inclusion criteria was of such a nature that all the eligible participants fell within the two (2) groups.

#### *5.3.1.1.4 Inclusion criteria for the nurses who participated in this study*

Professional nurses with a diploma or degree in nursing, rendering PHC services, trained in one or more short courses in HIV and AIDS management and care, directly involved in the care and management of PLWH for the past six (6) months, working in the selected clinics in JB Marks Municipal Council, willing to give informed consent to participate voluntarily in the study and agreement to be audio recorded during the interviews.

#### *5.3.1.1.5 Inclusion criteria for HCWs who participated in this study*

HCWs with some training on HIV and AIDS, exposed to care and management of PLWH for the past six (6) months, experienced in home-based care, working in and within the catchment areas of the selected clinics in JB Marks Municipal Council, able to express themselves in Setswana, English or Afrikaans, willing to give informed consent to participate voluntarily in the study and to be audio recorded during the interviews.

The sampling was conducted with the support from various mediators for the different sample groups as listed below:

- The mediator for the nurses was the district director in the North West Department of Health, Dr Kaunda district, who identified the nurses according to the selection criteria.
- The mediator for the HCWs were the nurses in the selected three (3) clinics who identified the HCWs according to the selection criteria.

#### *5.3.1.1.6 Sample size*

Thorne (2008:88) indicates that matters of representation, sample size and sampling processes are inherent to all research plans. It gives a basis for this study to select participants (nurses and HCWs) who were representative of the researched population. The sample size was determined by data saturation and patterns of repetition as described by Botma *et al.* (2010:200). Nine (9) nurses, and eighteen (18) HCWs participated in the study.

### **5.3.1.2 Data collection**

The ethical approval was obtained from the research committee of the School of Nursing Sciences and the research ethics committee of the Faculty of Health Sciences approval number NWU 00008-14-S1 (see addendum A). The researcher further facilitated the process of acquiring approval to conduct the study in the JB Marks city council from the North West Provincial Health Government and Dr Kenneth Kaunda district health office (see addendum B). Once approval was granted, the researcher contacted the mediators to select the participants, secure appointments and engage with the participants as explained. Informed consent was obtained from the participants before the commencement of the interviews (see addendum C1-C4).

#### *5.3.1.2.1 Method of data collection*

This study aimed at exploring and describing the perceptions of nurses and HCWs of HIV-stigma reduction and disclosure management in a PHC setting using semi-structured interviews (see Table 2). The semi-structured interview allowed the researcher to establish facts from the participants, follow up on interesting emerging facts and to probe for more clarity (Botma *et al.*, 2010:208-209). During appointments with nurses and HCWs, the objectives of this study and emphasis on voluntary written informed consent were highlighted (Botma *et al.*, 2010:21; Brink, 2006:39) including maintenance of partial confidentiality by setting group norms on confidentiality as they meet during the phases of the study (Botma *et al.*, 2010:2). Anonymity was ensured by using pseudonyms for participants when the data was coded. The purpose of this research, date, time, venue and the duration of the interviews was indicated to the nurses and HCWs. It was also indicated that they would be audio taped to enhance accuracy during transcription. A specially selected room that fosters participation, ensures privacy and has minimal disturbances was used during the interviews. Participants were informed of their rights to withdraw from the research if they so wished and were also be afforded counselling services in case they felt uncomfortable during the interviews (Botma *et al.*, 2010:209; Brink, 2006:185).

The interview schedules for the various interviews were developed and scrutinised by a panel of experts in the field of study in North-West University (NWU) and evaluated on a few selected participants to assess whether they would expound on the required

information (Botma *et al.*, 2010:208-209; Greeff *et al.*, 2010:227). The researcher familiarised herself with the questions for an orderly process (Botma *et al.*, 2010:209; Greeff *et al.*, 2010:207) during the interviews.

The following communication techniques were used: probing, paraphrasing, reflecting, summarising and clarifying (Botma *et al.*, 2010:206). During the interviews the researcher captured field notes focussing on methodological, theoretical and personal notes (see Addendum F) (Polit & Beck, 2008:405-407). Further, the researcher recorded what she [researcher] heard, saw, thought and experienced during the interviews (Botma *et al.*, 2010:217-219).

### **5.3.1.3 Data analysis**

The digitally audio-recorded interviews were transcribed verbatim and analysed. A thematic data analysis process guided by the steps of Tesch outlined by Creswell (2009:185-186) was used. A systematic process was followed to read and developing a general sense of the entire nurses' and HCWs' transcripts. In-Vivo descriptive codes were used. The identified topics from the transcripts were grouped into a list of well described categories and sub-categories. Relational frameworks were conceptualised thereafter. An appointed co-coder was given a work protocol outlining the objectives of the research, the interview questions, as well as the role of a co-coder in analysing the transcripts. Co-coding was done by appointing an experienced researcher so as to come to a consensus on analysed data (Brink, 2006:185).

## **5.3.2 Phase 2: To explore and describe the experiences of the nurses, HCWs, counsellors, PLWH and PLC to PLWH of the PHC-based HIV-stigma reduction and responsible disclosure management intervention in PHC settings**

### **5.3.2.1 Sample**

#### *5.3.2.1.1 Population*

The second phase of the study was conducted in the three (3) clinics in JB Marks Municipal Council that were selected as settings in the first phase.

#### *5.3.2.1.2 Sampling of the participating PHC clinics*

The inclusion criteria for the three (3) PHC clinics was as stipulated in the first phase of the study. Therefore, the same three PHC clinics that were selected in phase one were included in the second phase of the study.

#### *5.3.2.1.3 Sampling of participating*

Purposive voluntary sampling was used to select five groups of participants including nurses, HCWs, counsellors and PLWH and snowball sampling for PLC to PLWH. The mentioned participants had to be able to speak Setswana, English or Afrikaans and also give written informed consent for their participation. All participants had to be willing to participate in the stigma reduction intervention. A total of six (6) nurses, twelve (12) HCWs, twelve (12) counsellors, thirteen (13) PLWH and seven (7) PLCs were recruited and included.

#### *5.3.2.1.4 Selection criteria for each of the five groups of participants*

*Nurses:* The clinic managers mediated and identified the nurses and those selected were included in the study according to the set criteria: they were working in the selected clinics, held a diploma or degree in nursing, rendering PHC services with training in one or more short courses in HIV and AIDS management and care, directly involved in the care and management of PLWH for the past six (6) months.

*HCWs:* The involved nurses mediated and identified HCWs for this study. The HCWs were selected and included in the study based on their link to the selected clinics, had some training on HIV and AIDS, had been exposed to care and management of PLWH for the past six (6) months, were experienced in home-based care and working in and within the catchment areas of the selected (3) three PHC clinics.

*Counsellors:* The involved nurses acted as mediators to identify and recruit counsellors for this study. The counsellors were included in the study based on the inclusion criteria that they were linked to the selected clinics, had some training on HIV and AIDS, had been exposed to counselling, care and management of PLWH for the past six (6) months, were experienced in HIV testing and counselling and working in and within the catchment areas of the selected three (3) PHC clinics.

*PLWH:* The involved nurses acted as mediators to identify and recruit PLWH for this study. The inclusion criteria for PLWH were that they needed to be known to the nurses with a relationship of trust, had to be using one of the selected three (3) clinics for HIV management and care, and had been diagnosed with HIV in the past six (6) months.

*PLC to PLWH:* The identification of the PLCs was done by snowball sampling and mediated by the PLWH themselves. The PLC had to be adults identified by the PLWH either as a partner, close family member, child above eighteen (18) years of age, neighbour, friend, colleague or a spiritual leader. The inclusion criteria for PLCs were that they needed to be known and close to PLWH and have a relationship of trust. The names and contact details of the identified nurses, HCWs, counsellors, PLWH and PLC to PLWH were provided to the research assistant by the respective mediators. Appointments were made to meet and explain the study to all participants who were willing to participate. The research assistant, as an independent person, obtained informed consent. The final sample consisted of fifty (50) participants for the PHC-based stigma reduction and responsible disclosure management intervention.

### **5.3.2.2 Data collection**

Data was collected through the implementation of a PHC-based HIV-stigma reduction and responsible disclosure management intervention and followed up by in-depth interviews with the five groups about their experiences of the intervention.

#### *5.3.2.2.1 The stigma reduction and responsible disclosure management intervention*

The intervention consisted of a staggered row of workshops and a project conducted in each of the three PHC clinics. The workshops were planned and facilitated by the study leader, who is an experienced researcher, the researcher and a co-presenter (who was HIV positive). The venue was well ventilated, warm, quiet and far from interruptions by daily activities. The participants were afforded the required privacy during the intervention. The nurses, HCWs, counsellors, PLWH and PLC to PLWH from the three specific clinics were involved in the intervention. The intervention was built on the tenets of 1) increasing knowledge through the understanding of stigma and disclosure, 2) equalising relationships between all parties involved, and 3) building leadership skills by planning and implementing HIV-stigma reduction projects in PHC

clinics to enable people to become advocates of stigma reduction. The workshops and the project were implemented as follows:

### **Workshop with nurses, HCWs and counsellors**

The intervention started with a 1-day workshop with nurses, HCWs and counsellors together. The focus was getting them to understand HIV-stigma and responsible disclosure management of a PLWH of their positive HIV status. The participants shared information of observed stigmatising experiences.

### **Workshop with PLWH**

The former was followed by a 2-day workshop for PLWH focussing on understanding HIV-stigma, coping with it and then preparing them for responsible disclosure management during the intervention. The session was also mentally preparing the PLWH for follow up workshops, involving their own PLC and PLC of other PLWH where possibilities of disclosure of HIV status were inevitable.

### **Workshop with PLWH and PLC**

The last workshop was held over 2 days, followed by a 1-month for the roll-out of group projects and finally a 1-day for PLWH and PLC. The PLC were chosen by the PLWH themselves. The PLC included were either children, friends or their HCWs or counsellor. The first day of the workshop focused on understanding and coping with HIV-stigma for both PLWH and PLC, where they heard one another's experiences of HIV-stigma. The second day was learning about project planning, but also included the planning of a specific PHC-based HIV-stigma reduction project to be implemented over a period of one month. The third day of this workshop was held a month later and the PLWH and PLC provided feedback of their projects. The PLWH and the PLC invited prominent members of the community and the research team to the presentation. The projects were evaluated by the group present and feedback was given to the participants about the successes of the projects or areas that required minor improvements.



#### 5.3.2.2 *Interviews following the HIV-stigma reduction and responsible disclosure management interventions*

After the intervention the participants were contacted via their respective mediators and their participation for this part of the study was confirmed with the research assistant. In-depth interviews were held to explore and describe the nurses, HCWs, counsellors, PLWH and PLC's to PLWH experiences during and after the PHC-based stigma reduction and responsible disclosure management intervention they participated in (Botma *et al.*, 2010:207; De Vos *et al.*, 2011:348-351). The open-ended question was reviewed by experts in the field and tested on selected nurses, HCWs, counsellors, PLWH and PLC to ensure its appropriateness. Prior appointments (confirming the date, times and venue) were made with all the nurses, HCWs, counsellors PLWH and PLC. A private venue with minimal threats was specially arranged for the day of the interviews. The purpose of the research, length of the interview, maintenance of partial confidentiality by setting group norms (during interviews and workshops) and anonymity by using pseudonyms when capturing data, consent for voluntary participation, as well as freedom to withdraw from the interview was explained. The interviews were digitally audio-recorded (Botma *et al.*, 2010:207). The participants would be referred for counselling in case of any discomfort during the interviews. The questions were asked as follows: "Tell me about your experiences of the HIV-stigma reduction and responsible disclosure management workshop and project". The following communication techniques were used: probing, paraphrasing, reflecting, summarising, as well as clarifying (Botma *et al.*, 2010:206) during the interviews. The researcher captured methodological, theoretical and personal field notes on what was heard, seen, thought and experienced (Botma *et al.*, 2010:217-219). There were six (6) nurses, eleven (11) HCWs, twelve (12) counsellors, thirteen (13) PLWH, and seven (7) PLC who took part in the intervention with a total of forty nine (49) participants reached for the interviews (only one HCW registered her unavailability due to personal commitments).

#### **5.3.2.3 Data analysis**

The interviews with the nurses, HCWs, counsellors, PLWH and PLC were transcribed verbatim. The data was analysed through a process of open coding following the steps of Tesch as outlined in Creswell (2009:185-186). After the data gathered from the

participants had been transcribed, it was read so that an overall understanding might be gained. A systematic process of reading the transcripts and noting topics through InVivo and descriptive codes was followed. The categories and sub-categories were grouped and clustered into themes. Relationships among the various categories were identified. The data was co-coded by a co-coder who used the same set of transcripts and consensus was reached through further discussions.

## **6 ETHICAL CONSIDERATIONS**

This study ascribed to the highest standards of research by following the ethical principles stipulated by NDOH (2015:15-17).

### **6.1 Respect**

The participants involved in the study were respected as autonomous. They were provided with detailed information concerning the purpose of this study. A proposal on the whole process of the study was submitted to relevant ethics committees. Such information allowed the nurses, HCWs, counsellors, PLWH and PLC an opportunity to decide on their participation in a well-informed manner. It was explained to the nurses, HCWs, counsellors, PLWH and PLC that they had the right to terminate participation should they not want to continue participating. PLWH were prepared beforehand regarding responsible disclosure management.

### **6.2 Justice**

The right to fair selection and treatment was observed and pursued by the researcher by properly outlining selection criteria of the nurses, HCWs, counsellors, PLWH and PLC to ensure eligible participants for the study. The study was led by an experienced and knowledgeable researcher. The objectives, data collection and voluntary informed consent processes of this study were explained. The possibility of potential emotional and relationship risks were highlighted to the participants. Should any participants experience emotional discomfort in sharing their experiences during the interviews, they [participants] had the choice to withdraw without any prejudice. Counselling support was provided.

### **6.3 Knowledgeable researchers**

Before the commencement of the research, the proposal was presented to a team of experts at the School of Nursing Science, North-West University and the Health Research Ethics Committee (HREC) of the Faculty of Health Sciences at the North-West University (NWU) and the North West provincial DOH ethics committee to ensure that the study does not expose the nurses, HCWs, counsellors, PLWH and PLC to unethical processes. The study was led and conducted by experienced and knowledgeable researchers.

### **6.4 Risks**

PLWH were informed of possible disclosure of HIV status in the presence of PLWH during the workshop. There were potential emotional and relational risks linked to disclosure of HIV status. The PLWH were empowered by gaining understanding on stigma responsible disclosure management. The interview questions were evaluated by experts in the fields to ensure that they are appropriate and were also assessed on a few participants before implementation of the study. Should the participants find themselves being emotionally challenged, counselling was made available.

### **6.5 Beneficence**

This study was executed in such a way that harm was prevented and that the nurses, HCWs, counsellors, PLWH and PLC were freed from any possible harm by weighing the risks against the benefits. PLWH were informed that disclosure of HIV status in the presence of PLWH during the workshop was a possibility. There were potential emotional and relationship risks linked to disclosure of HIV status. The PLWH were empowered by understanding stigma responsible disclosure management. The interview questions were evaluated by experts in the fields to ensure appropriateness. The questions were assessed by being posed to a few participants before implementation of the study. Should the participants find themselves being emotionally challenged, counselling was made available. The participants would benefit through gaining knowledge about HIV-stigma reduction and disclosure management, learning skills to handle HIV-stigma and disclosure, as well as being empowered in project planning and implementation including possibilities of improved relations. Before starting with the research, the proposal was presented to a team of experts at the

School of Nursing Science, North-West University and the Health Research Ethics Committee (HREC) of the Faculty of Health Sciences at the North-West University (NWU) and the North West provincial DOH's ethics committee and obtained ethical clearance (see Addendum A).

In compliance with the above principles this study was led by specialists of the subject matter who guided the process throughout. A risk benefit assessment was done, fairness of selection of participants was based on a set of criteria for inclusion or exclusion. Participants granted voluntary informed consent that was approved by scientific research ethics committees.

## 7 TRUSTWORTHINESS

Trustworthiness of this study was realised through a process proposed by Lincoln and Guba (*in* Krefting 1991:217; Klopper, 2008:70) as outlined by Botma *et al.* (2010:234-235).

**Table 1: Trustworthiness of the study**

Epistemological standards	Strategy	Criteria
<b>Truth value:</b> to ascertain confidence in the findings	Credibility	<ul style="list-style-type: none"> <li>• <i>Prolonged engagement</i> by conducting initial semi-structured interviews during the first phase of the study with the nurses and HCWs, implementing the HIV-stigma reduction and responsible disclosure management intervention for the nurses, HCWs, PLWH and PLC and the in-depth interviews with these five groups.</li> <li>• <i>Reflexivity</i> was obtained by reflecting on the study, capturing field notes throughout the phases of the study and regular discussions with the promoter and co-promoter throughout the course of the study.</li> <li>• The researcher used <i>peer examination</i> and continuous discussions with the promoter and co-promoters throughout the study. The two interview schedules were well thought through and evaluated by experts in the field to ensure feasibility (tell me about your experiences of HIV stigma reduction and disclosure management experiences of the workshop and project?).</li> <li>• <i>Authority</i> was fostered in that the promoter is a well-known researcher in the field of HIV-stigma reduction and both promoter and co-promoter experienced qualitative researchers. The PhD candidate is an expert in PHC.</li> <li>• A co-coder was used during data analysis.</li> </ul>

Epistemological standards	Strategy	Criteria
<b>Applicability:</b> the extent to which the findings of this study can be generalised and applied in other contexts.	Transferability	<ul style="list-style-type: none"> <li>• The samples were selected using well formulated inclusion and exclusion criteria.</li> <li>• The comparison of the demographic data was done by the selection of three clinics</li> <li>• by the DOH's experts.</li> <li>• Data saturation was achieved in the three clinics that included all the various groups.</li> <li>• A thick and dense description was established through a well described context and methodology and ensured that the study can be repeated by others.</li> </ul>
<b>Consistency:</b> establishing that the findings will stay unchanged and consistent should the study be replicated within a similar context.	Dependability	<ul style="list-style-type: none"> <li>• A <i>thick and dense description</i> of the methodology was done that made an audit trail and stepwise replication possible.</li> <li>• An <i>independent co-coder</i> was appointed to analyse the data with a consensus meeting between the researcher and the co-coder for consensus on categories of data that emerged.</li> </ul>
<b>Neutrality:</b> ensuring that the research process is not obstructed by biases	Confirmability	<ul style="list-style-type: none"> <li>• <i>Reflexivity</i> was applied as described above and documents required for auditing will be made available if so required.</li> </ul>
<b>Authenticity:</b> the extent to which the researcher will present what emerges from the research faithfully		<ul style="list-style-type: none"> <li>• The researcher wrote a <i>report</i> that represents the feeling and tone of the nurses, HCWs, PLWH and PLC on the findings of the study as lived by the participants. These findings are enriched by quotes from the interviews with the participants.</li> <li>• The researcher adhered to principles of fairness and honesty in research by presenting a genuine report in a manner that invites readers into a vicarious experience so that they get to live the experiences indirectly.</li> </ul>

## 8 STRUCTURE OF THE STUDY

This study used the article format as follows:

### Section A: Overview of the research

### Section B: Literature review

**Chapter 1:** An overview of HIV-stigma, its manifestations, outcomes and interventions.

**Chapter 2:** HIV disclosure management in primary health care settings.

## **Section C: Articles**

**Article 1:** Perceptions of nurses and health care workers of HIV-stigma reduction and disclosure management in primary health care settings

**Article 2:** Experiences of nurses, health care workers, counsellors, people living with HIV and people living close to them of a HIV-stigma reduction and responsible disclosure management intervention in three primary health care settings.

## **Section D: Conclusions, limitations and recommendations**

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## **SECTION B: LITERATURE REVIEW**

This section is presented in two chapters.

### **CHAPTER 1: AN OVERVIEW OF HIV-STIGMA, ITS MANIFESTATIONS, OUTCOMES AND INTERVENTIONS**

*“Imagine a society of saints, a perfect cloister of exemplary individuals. Crimes or deviance [sic], properly so-called, will there be unknown; but faults, which appear venial to the layman, will there create the same scandal that the ordinary offences does [sic] in ordinary consciousnesses. If then, the society has the power to judge and punish, it will define these acts as criminal (or deviant) and will treat them as such.” – Émile Durkheim (French sociologist; first to explore stigma as a social phenomenon in 1950.)*

#### **1**

##### **1.1 Introduction**

Human immunodeficiency virus (HIV) related stigma exists since the onset of the HIV pandemic and remains high throughout the world (Poindexter, 2013:706). Sidibé (2018) in his report confirms that HIV-stigma emerged with the epidemic since the 1980s and remains a challenge to date. Furthermore Sidibé (2018) also indicated that in 35% of countries reporting on stigma more than 50% of the people in those countries stigmatise PLWH. Stigmatisation associated with the HIV pandemic is an international phenomenon that remains a challenge in global and sub-Saharan health care systems (Ntsepe *et al.*, 2014:139; Tsai, 2015:1; Sidibé, 2018). HIV-stigma research increased significantly in sub-Saharan Africa (Mbonu *et al.*, 2009:1). Since 2001 there has been increased research on HIV-stigma focussing on the individual, family and communities (Makoe *et al.*, 2009:1357-1358; Monjok *et al.*, 2009:21-30; Iwelunmor *et al.*, 2010:1393 & Stangl *et al.*, 2013:2). Health care setting-based studies by Bogart *et al.* (2013:843-844) explored the barriers to care among PLWH; Uys *et al.* (2009a:151) developed a health care setting-based HIV-stigma intervention focusing on nurses and people living with HIV (PLWH); Gilbert and Walker (2010) explored stigma as experienced by patients in HIV and AIDS clinics; Okoror *et al.* (2014:28) explored HIV positive women’s perceptions of stigma in health care settings, while Li *et al.* (2013:327-332) focused on the reduction of HIV-related stigma. These research

studies were predominantly conducted in general health care settings and hospitals (Naidoo *et al.*, 2007:17). A systematic review by Stangl *et al.* (2013:9-28) on HIV-stigma and discrimination interventions revealed considerable progress on work done in the field of HIV-stigma reduction from 2002 to 2013. However, authors (Stangl *et al.*, 2013:9; Gilbert, 2016:14) agree that there are still many challenges for the identification of effective stigma-reduction strategies with purposeful interventions. Poindexter (2013:723) concurs with Stangl *et al.* (2013:9) that HIV-stigma in itself challenges the course of action for managing the related stigma. Poindexter (2013:723) notes that stigmatised people constantly avoid activities that involve HIV, such as participating in HIV-stigma research, disclosing their HIV status or even requesting services that deal with HIV and HIV-stigma. Mbonye *et al.* (2013:3-4) point out that it becomes more difficult for PLWH to lead a normal life at a later stage of taking antiretroviral therapy (ART), because stigmatisation cues resurface, when health care workers (HCW) do follow-up home visits for ART. In general, stigma remains a widespread phenomenon (Phillips, 2011:307; UNAIDS, 2013:3f). Gilbert (2016:9) emphasises that HIV-stigma remains a frightening challenge in South Africa because it is such a complex concept.

In the context of HIV, it is debatable whether the terms *stigma* and *discrimination* should be used interchangeably or separately. Some authors (UNAIDS, 2010a:43; Grossman & Stangl, 2013:1; Ghoma-Linguissi *et al.*, 2015:5 & AVERT, 2018) do not distinguish between *stigma* and *discrimination* when dealing with HIV but refer to both concepts in an undifferentiated manner. Authors like Parker and Aggleton (2003:13-20) and Deacon (2006:418-422), however, make a distinction between *stigma* and *discrimination*; and French *et al.* (2014:105-114) refer to *stigmatisation* only and not to *discrimination*. These two concepts are discussed in more detail further in the review. The two concepts are not used interchangeably in the present study.

In South Africa in particular, stigma is prevalent in the context of HIV and AIDS (Rotheram-Borus *et al.*, 2011:322). Health care settings are a common locus for HIV stigmatisation and can be highly stigmatising (Khali *et al.*, 2015:127; Okoror *et al.*, 2014:28). (PHC) in the public health sector is the entry point to health care services for 80% of the South African population (Dookie & Singh, 2012:2). However HIV-stigma is a known barrier to the uptake of health care services and hampers access

to health care, particularly in the PHC setting (Khalil *et al.*, 2015:129; UNAIDS, 2012:5). Although some studies on HIV-stigma were conducted in health care settings (Karamouzian *et al.*, 2013; Nyblade *et al.*, 2009; Uebel *et al.*, 2013), there is a lack of studies with a primary focus on HIV-stigma reduction in the PHC setting as the first point of entry for health care services and users.

Research between 2002 and 2009 by a team of researchers based in the United States of America (USA), Lesotho, Malawi, South Africa, Swaziland and Tanzania made a prominent contribution to African-based HIV-stigma research. The various stages of that study focussed on understanding HIV-stigma in an African context (Greeff *et al.*, 2008a:311) and the development of a conceptual model of the dynamics of HIV and AIDS stigma process. The conceptual model described the context of HIV-stigma, the health care setting and the various elements of the HIV-stigma process (Holzemer *et al.*, 2007a:541-551). These researchers contributed to the development and validation of an HIV and AIDS stigma instrument measuring HIV-stigma for PLWH (Holzemer *et al.*, 2007b:1002-1012) and an instrument measuring HIV-stigma as experienced and perpetuated by nurses (Uys *et al.*, 2009a:150-159). They furthermore conducted a health care setting-based HIV-stigma reduction intervention for PLWH and nurses (Uys *et al.*, 2009b:162).

In a study led by Greeff during 2010 to 2013 on a stigma reduction intervention focusing on PLWH and PLC (partners, children, family, friends, spiritual leaders and community members), it was found that the intervention succeeded in changing the way PLWH judged themselves and improved relationships amongst PLWH and PLC. The change in behaviour of PLWH resulted in improved health, quality of life and adherence to treatment. It also altered the attitudes of PLC towards PLWH (French *et al.*, 2014:105-110; Chidrawi *et al.*, 2015:1-10).

Greeff also led a major HIV-stigma reduction intervention study between 2013 and 2014. The study was conducted in the North West Province of South Africa and aimed to reduce HIV-stigma in a total community through an HIV-stigma “hub” network intervention. The intervention successfully initiated the onset of changes in the HIV-stigma of a community through the contributions of PLWH and PLC. The changes occurred at both individual and social level and included a reduction in HIV-stigma experiences by PLWH and changed attitudes towards PLWH. A positive change was



also found regarding to the depression levels and well-being of the community as a whole (Prinsloo *et al.*, 2015:3-4). These studies added value to the understanding of HIV-stigma intervention studies in South Africa. This study is also guided by Greeff and aims to fill the gap regarding HIV-stigma reduction interventions specifically within PHC settings.

## **1.2 Conceptualisation of HIV-stigma**

The global HIV crisis is closely related to HIV-stigma (Kalichman, 2014:5-6). In an attempt to conceptualise HIV-stigma, this section reviews HIV-stigma by presenting the definition of stigma, the definition of HIV-stigma, the description of HIV-stigma and discrimination, the manifestations of HIV-stigma as well as the conceptual models, framework and theories on HIV-stigma.

### **1.2.1 Definition of stigma**

The renowned scholars Durkheim (1950) and Goffman (1963:3) explored stigma in contexts other than HIV. The concept *stigma*, however, goes back as far as the ancient Greeks and referred to a “mark” or “labels” attached to individuals or groups to identify them for negative exclusion (Link & Phelan, 2001:365-366). In ancient times, a physical mark was made by a burn or cut in the flesh of an unsavoury individual, traitor, criminal or slave, to identify that person as someone with low moral status (Harvey, 2001:186-187).

Sociologists, psychologists, anthropologists and political scientists have grappled with the definition of stigma. Scholars and researchers such as Monjok *et al.* (2009:23), Bharat (2011:138) and Stangl *et al.* (2013:2) refer to the definition by Goffman (1963:3), a sociologist who describes *stigma* as a discrediting “attribute”. Many researchers still use Goffman’s definition to redefine and elaborate on the concept of stigma and to find applications in relation to the stigmatised. Stigma is described by Herek (2002:594-595) as “*an enduring condition, status, or attribute that is negatively valued by a society and whose possession consequently discredits and disadvantages an individual*”.

People are often socially labelled, stereotyped or stigmatised for deviant behaviour and unacceptable practices that go against social norms (Link & Phelan, 2001:527-

528). The labelling of individuals, also referred to as *stigmatising*, is a form of categorising of people in society and involves identification and devaluation of individuals or groups based on a socially determined attribute, characteristic or identity in a particular social context (Galinsky *et al.*, 2003:224). Certain labels link an individual or group to an attribute or stereotype that is deemed unacceptable by society (Link & Phelan, 2001:366-368). These stereotypes by which individuals and groups are labelled put them at risk for stigmatisation. Stigmatised conditions include cancer, leprosy, epilepsy, alcohol abuse and drug dependence (Abed & Neira-Munoz, 1990; Abouyanni *et al.*, 2000; Farmer & Greenwood, 2001; Skinner *et al.*, 2007:163 and Mahendra *et al.*, 2007); but in current societies and health contexts, HIV remains the most stigmatised condition (Gilbert & Walker, 2010:139-140).

### **1.2.2 Definition of HIV-stigma**

Sultana (2014:180) describes HIV-stigma as “a disrespectful and discreditable issue for PLWH making them vulnerable and debased”. This study gives preference to the HIV-stigma definition by Alonzo and Reynolds (1995:304): “*the stigmatized are a category of people (HIV) who are pejoratively regarded by the broader society as devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse*”. Several researchers describe HIV-stigma and HIV-stigmatising attributes from a social perspective. Stigma as a social phenomenon associated with certain illnesses, is linked to a particular *attribute* (in this case HIV status) or feature of an individual or group in society. Groups or individuals are discredited when they do not meet the expectations of society in a particular context (Holzemer & Uys, 2004:166; Mbonu *et al.*, 2009:1-4; Gilbert & Walker, 2010:140). Various researchers have found that the stigma attached to HIV is accompanied by socially discrediting behaviour such as exclusion, separation, stereotyping, rejection, isolation, the loss of individuals’ livelihoods, as well as derogatory perceptions and discrimination (Campbell *et al.*, 2007:403-405; Bogart *et al.*, 2008:248-252; Tshabalala & Visser, 2011:18; Naughten & Venable, 2012:8-9; Hazenbuehler *et al.*, 2013:831). Harvey (2001:175-176), Herek (2002:594-595) and Harapan *et al.* (2013:29-32) also identify social behaviour that includes aspects of ostracism, shame and condemnation that lead to “blame shedding of character” that discredits, devaluates and discriminates against individuals and groups.

Researchers and theorists view HIV-stigma as a complex concept influenced by multiple factors (Cross *et al.*, 2011:65; Pretorius, 2012:30; Gilbert, 2016:8) and define HIV-stigma as the convergence of interrelated components that exist when elements of labelling, stereotyping, separation, status loss and discrimination occur in the context of HIV. PLWH are affected by the complexity of HIV-stigma, for example being dismissed from a job with no tangible reason, being shunned or ridiculed by others, or excluded, for instance when people refuse to shake hands with PLWH (Siyam'kela, 2003b:96). PLWH and those associated with them are discounted, discredited, subjected to discrimination and treated with prejudice. In this regard, Alonzo and Reynolds (1995:304-305) view HIV-stigma as multidimensional. The researchers explained that although stigma surfaces because of society's perception, PLWH are often blamed for their own HIV infection, as it is viewed as their own fault and the result of their deviant behaviour. PLWH are seen as having practiced undesirable, immoral behaviour that resulted in a "highly contagious" illness that is a threat to society. In most instances, PLWH are punished by the community by being rejected, devalued and excluded from communities (Gilbert & Walker, 2010:139).

The various attempts at describing HIV-stigma above illustrate the complexity of the phenomenon and how difficult it is to understand HIV-stigma. It is thus suggested that HIV-stigma is not well understood by society and health care providers (Khalil *et al.*, 2015:128). These culturally-based and imposed norms and standards against which society measures behaviour, have an extremely negative effect on the self-concept and value of individuals and their relationships with social groups (Goffman, 1963:12). Aultman and Borges (2011:51) describe a discrepancy between the self-concept of PLWH and perceptions, views and concepts that others in communities or societies hold of them. This is described by Goffman (1963) as a "spoiled identity" and creates a social distance between PLWH and the community, to the point that relationships disintegrate and PLWH experience social isolation. The effects of the "spoiled identity" on PLWH include denial, failure to access health care and non-disclosure of HIV positive status. This reduction from "the complete whole" to "an incomplete individual" causes feelings of shame as a result of the emphasis of negative attributes associated with HIV (Aultman & Borges, 2011:51; Siyam'kela, 2003b:14-22).

HIV-stigma focuses intensely on the difference between normal and abnormal behaviour as dictated by society (Siyam'kela, 2003b:122-123). An HIV-positive status carries the connotation of abnormality in terms of lifestyle, social norms and values (Pretorius, 2012:30). HIV-stigma then instils fear in PLWH, which leads to denial and avoidance (Kruger *et al.*, 2009:37; Rispel *et al.*, 2012:265)

### **1.2.3 HIV-stigma and discrimination**

The HIV pandemic has been characterised by a poor understanding of the concepts *stigma* and *discrimination* in the contexts of HIV and AIDS (Dako-Gyeke *et al.*, 2015:280-285). *Stigma* and *discrimination* are often used as synonyms, but Deacon (2006:418-419) argues that it is critical to distinguish between *stigma* and *discrimination* in order to obtain a better understanding of each concept. In some instances, HIV-stigma interventions that tackle discrimination do in actual fact target stigma (Cross *et al.*, 2011:64). Researchers such as Goffman (1963) and Link and Phelan (2001:367-369) typically use terms such as *human segregation*, *stereotyping*, *labelling*, *individual psychological* and *status loss*, and they also distinguish between “us and them” to refer to concepts of stigma as well as discrimination. The distinction between the concepts *stigma* and *discrimination* in the context of HIV will remain blurred, however, until researchers can find clarity on each concept and define each concept meaningfully.

In an attempt to distinguish between the concepts *stigma* and *discrimination*, Parker and Aggleton (2002:3) explain that discrimination is the “manifestation of stigma”. UNAIDS (2013:1) uses a similar distinction and explains that discrimination occurs after stigmatisation. It is argued that stigma and discrimination in the context of HIV are embedded within sexual orientation (Sultana, 2014:180). Furthermore, there is an association with gender issues, such as female sex workers, or men having sex with men; and with racial and sexual orientation issues, especially in the African context. Discrimination is a vicious circle for PLWH as these vulnerable groups are marginalised and subjected to discrimination because their HIV status is associated with their sexual behaviour (Sultana, 2014:183). UNAIDS (*in* AVERT, 2018:6) explains that discrimination ensues as a person is stigmatised. It suggests that discrimination of individuals based on unfair treatment due to perceived HIV status, follows upon stigmatisation of those individuals UNAIDS (*in* AVERT, 2018:6). Parker and Aggleton

(2002:3-4) define discrimination as an unjust, unfair or prejudicial treatment of different categories of people based on labels that followed prejudice. Prejudice is described as an unfair reaction based on opinions people hold about others when they are seen as different and subjected to discrimination without justifiable reasons (The little Oxford dictionary, 2006:194). Researchers concluded that HIV is highly stigmatised in societies because it is not understood, it is incurable, it is fatal and it is seen as the “illness of others” and associated with defiant behaviour (Link & Phelan, 2001:370; Siyam’kela, 2003b:7-8). Although the relationship between stigma and discrimination is acknowledged, this study distinguishes between the two concepts and mainly focuses on *stigmatisation*, in line with Deacon (2006:418-425). French *et al.* (2014:105) refer to stigma preceding discrimination and being an antecedent thereof, implying that the concepts are used separately.

### **1.3 Manifestations of HIV-stigma**

Researchers identified personal environments, communities, financial environments, religious institutions, educational institutions and health care environments as settings in which HIV-stigma manifests (Stutterheim *et al.*, 2014:652-665; Varaz-Diaz *et al.*, 2012:2-3). The discussion below will focus on HIV-stigma manifestations in the government and legal contexts; the workplace and employment context; and the health care context.

#### **1.3.1 HIV-stigma manifestation in governments and legal contexts**

Parker and Aggleton (2002:4-8) confirm that stigma occurs in government and legal contexts. There are laws aimed at protecting PLWH against stigmatisation, but these laws have limitations (Link & Phelan, 2006:529) as they cannot address untoward behaviour that stigmatises. Although behaviour itself can be regulated by law, the *attitude* that leads to stigmatising behaviours cannot (Link & Phelan, 2006:529).

AVERT (2015) discusses stigmatising activities that target PLWH in different countries. In China, for example, screening and HIV testing are mandatory. In Russia and Ukraine protective laws for vulnerable people (e.g. drug users) have been abandoned and in Uganda PLWH are refused employment. In about 35 countries HIV stigmatisation manifests through restriction of travelling or migration of PLWH (UNAIDS (*in* AVERT, 2018:8). Foreigners may be denied entry into some countries or

may be deported if they fall within certain vulnerable groups such as sex workers, females and PLWH UNAIDS (*in* AVERT, 2018). Government laws and policies often perpetuate stigmatisation through discriminatory rules and fail to protect the rights of PLWH (Parker & Aggleton, 2002:5).

In terms of the South African Constitution, however, individuals' rights are protected (South African Constitution, 1996). Everyone has a right to privacy, and the constitution provides for proper assessment of whether the right to privacy was infringed (Roehrs, 2009:369-383). It further provides a platform to confirm whether the infringement was justifiable, such as in the provision of care by a health care team. Stigmatisation through breach of confidentiality is prevented by policy guidelines in South Africa, for example through death certificates that protect patients' confidentiality (Pieterse *et al.*, 2009:3). Death certificates will state opportunistic infections and other reasons as a cause of death, rather than HIV and AIDS (Pieterse *et al.*, 2009:3). However, this practice of avoiding reference to HIV and AIDS in order to avoid stigmatisation, has consequences for the classification of HIV as a cause of death (Birnbau *et al.*, 2011:278-282).

### **1.3.2 HIV-stigma manifestation in the workplace and employment context**

Workplaces as institutions of employment often expose potential employees who are HIV positive to practices that include aspects of stigmatisation. AVERT (2015) describes stigmatisation in the workplace through actions by co-workers against employees who are HIV positive. Co-workers may, among others, refuse to work alongside an HIV-positive employee and may isolate such an individual. As a result, PLWH become anxious about the reaction of their employers and co-workers – should they learn about their HIV-positive status (AVERT, 2015). Women giving birth may experience negative reactions by health workers if health workers' fear of being infected is translated into a negative attitude towards and stigmatisation of the women (Johansen *et al.*, 2015:1-35). The general practice of health workers could in itself be stigmatising if the patient is HIV positive (Mulaudzi *et al.*, 2011:25). Chapter 2 of the South African Bill of Rights guarantees every citizen, including PLWH, the right to fairness in the workplace – including the health care environment – without stigmatisation and discrimination (Constitution of South Africa, 1996).

### 1.3.3 HIV-stigma manifestation in the health care context

Stigmatisation of PLWH may be intentional or unintentional. Stigmatisation in the health care system occurs unintentionally as a result of practices in the health care environment and the behaviour of health care workers (Mutalemwa *et al.*, 2008:221; UNAIDS, 2013:84; Pulerwitz *et al.*, 2015:247). The structural layout of clinics and hospital buildings as HIV centres may cause stigmatisation of HIV-positive individuals who access health care (Mutalemwa *et al.*, 2008:222). If consulting rooms in clinics use specific identification, individuals who use such services will become labelled. Individuals who use health services are automatically stigmatised or labelled, even when they enter clinics (Balasundaram *et al.*, 2014:593). Lack of space in PHC clinics compromises confidentiality with regard to HIV/AIDS and with regard to other conditions as well (Scheffler *et al.*, 2015:1). Mobile health services have also been associated with HIV-stigma, as individuals are often stigmatised when they travel long distances to reach these mobile health services (Campbell *et al.*, 2007:411-412). The health care environment, with its limited resources and lack of policy guidelines in clinics and hospitals for the provision of health services, is perceived as perpetuating HIV-stigma as well (Gagnon, 2014:3; Pulerwitz *et al.*, 2010:275-277). However according to the Integrated Chronic Disease management (ICDM) model HIV management is viewed as a chronic disease like hypertension or diabetes (National Department of Health [NDOH], 2011).

Provision of antiretroviral treatment (ART) to PLWH may also expose them to stigmatisation (Makoe *et al.*, 2009:1357). Patients may be stigmatised in the health care setting by practices such as labelling their beds with warnings like “danger” and by the unnecessary use of protective gloves when medication is being administered to PLWH (Famoroti *et al.*, 2013:3). Health professionals’ practices of maintaining excessive hygienic protective measures are tantamount to stigmatisation (Stutterheim *et al.*, 2014:656). Inappropriate self-protection measures, like wearing gloves, goggles and aprons, or reluctance to treat patients adequately, aggravate the situation (Mahendra *et al.*, 2007:624; Rutledge *et al.*, 2011:674; Gagnon, 2014:3). In some instances linen used by PLWH is left unattended by health workers, out of fear of infection (Bharat, 2011:143). Health workers avoid being in the same room as PLWH or to care for PLWH (Bharat *et al.*, 2011:143). Rutledge *et al.* (2011:674) describe situations in hospitals where files with special identification are left open and where

the HIV status of an individual is visible to all. Bharat (2011:143) refers to several earlier studies that confirmed the stigmatisation of PLWH in health care settings and by health professionals, such as doctors and nurses. Kruger *et al.* (2009:40) also reported on pregnant women who were coerced into terminating their pregnancies because they were HIV positive. Some HIV-positive pregnant women were required to pay an additional fee for health care services, unlike other patients with other health conditions. Other incidents of stigmatisation include cases where women living with HIV were forced to be sterilised, to take contraception or to undergo abortions (AVERT, 2018).

Health care workers' (HCWs) conduct was also deterrent in the health care seeking process of HIV-positive individuals and interfered with the willingness and readiness of PLWH to seek health care (Greeff & Phetlhu, 2007:13). Sub-standard care is practiced, and proper counselling principles are not followed – individuals will merely be told that they are HIV positive, with no further counselling (Campbell *et al.*, 2007:411). PLWH are exposed to stigmatisation in Pakistan by health care workers' refusal or delay to care for PLWH and by denying them access to health (Khalil *et al.*, 2015:136). Dos Santos *et al.* (2014:1-2) reported incidents like neglect and verbal and physical abuse of PLWH in health care settings as signifying the existence of stigma. *et al.* (2014:2352-2354) investigated 11 manifestation elements across different settings, including health care. Different degrees of aggressive behaviour, physical distancing, indifference, avoidance, blaming, exaggerated kindness, exclusion and disclosure of HIV status without consent of PLWH were noted in health care settings.

In data from more than 50 countries, at least one in eight PLWH was denied access to health care. Health workers become judgemental towards PLWH and other vulnerable groups, such as sex workers, MSM and drug users (UNAIDS, 2015:116). Individuals who come into contact with PLWH are also at risk of being stigmatised through their involvement with PLWH, for example nurses, doctors and other health care workers. This is referred to as *associated stigma* (Siyam'kela, 2003a; Greeff, 2008:91). Among nurses the high HIV-stigma levels lead to low job satisfaction, which is aggravated by the high volumes of nurses leaving their jobs (Chirwa *et al.*, 2009:20). Nurses who notice that PLWH are stigmatised, experience fear for similar treatment (Mataboge *et al.*, 2014:1-7). Nurses' experience similar cues of stigmatisation



themselves from others if they care for PLWH (Dlamini *et al.*, 2007:389; Uys *et al.*, 2009b:155).

#### **1.4 Conceptual models, framework and theories on HIV-stigma**

Over the years several researchers attempted to formulate and develop models, frameworks or theories of HIV-stigma. Researchers approach stigma from varying contexts; therefore it is so complex to define the concept, as indicated above. Alonzo and Reynolds (1995:303-307), American behavioural scientists, conducted a study on stigma to explore the HIV-stigma trajectory. These researchers conceptualised the experiences of stigma in relation to PLWH, partners, family and friends over the biophysical dimensions of the disease. They described four phases of stigma: the at-risk phase (pre-stigma and worrying), the diagnostic phase (confronting and altered identity), the latent phase (living between illness and health) and lastly the manifestation phase (social withdrawal and physical death). PLWH develop strategies to avoid and minimise HIV-related stigma as the physical illness manifests. Through sub-culture networks PLWH adopt an HIV identity that influences behaviour and leads to stigma. This demands of the PLWH to gain strength to master the disease and deal with the concealed identity. Alonzo and Reynold (1995:303-304) thus managed to describe the social and psychological responses of PLWH related to the trajectory of the biophysical manifestations of HIV.

In 2003, a framework for a better understanding of HIV-stigma was developed by Parker and Aggleton (2003:13-14), with the aim to bring about social change. The researchers based their model on the argument that social power, inequality and hierarchy are powerful social contextual factors of stigma and discrimination. The insight and knowledge in the study facilitated the development of new interventions to counteract discrimination and to bring about social change in the community through positive community participation.

The Siyam'kela (2003a) HIV and AIDS research project explored HIV-related stigma in an effort to develop stigma indicators. The indicators served the purpose of developing HIV and AIDS tools to measure stigma reduction. The project categorised stigma as experienced internally or enacted externally. *Internal stigma* refers to self-judgement by PLWH, whereas *external enacted stigma* refers to stigma directed at

PLWH by others. The project focused on developing a supportive environment within which HIV-stigmatisation can be managed.

Holzemer *et al.* (2007a:541-549) developed a conceptual model for HIV and AIDS stigma in the African context that described three aspects: the environment, health care setting and agents. Environmental factors include culture, economy, political, legal and policy environments. Health care settings are identified as the health contexts in which stigma is triggered and occurs. The agents of stigma can be the PLWH themselves, family members, work colleagues, community members or health care workers in the primary context in which stigma is triggered and manifests. This stigma process involves four aspects: (1) triggers of stigma; (2) behaviour responses to stigmatisation; (3) manifestation of three types of stigma (received, internal and associated stigma); and (4) specific outcomes of the stigma. Churcher, (2013:13) later added vicarious stigma to the categories of stigma. Vicarious stigma refers to situations where individuals could have heard reports or seen activities that imply stigma. Holzemer *et al.* (2007a:547) further describe triggers like the diagnosis of HIV, certain activities such as PLWH visiting the clinic, and other identified physical changes like loss of weight. Stigma is classified in three types: internal, received and associated stigma. Stigma outcomes are grouped in categories of general health, violence, poor quality of life and reduced access to care. The mental health of PLWH is also affected, as social exclusion, rejection, increased stress levels and economic pressures may lead to mental illness. This model by Holzemer *et al.* (2007a:541-542) is integral to and underpins the current study.

A study titled *Dying Twice* identified drivers of stigma (Campbell *et al.*, 2007:403-404). This multi-level model of the roots of AIDS stigma in two South African communities identified the drivers as fear; available AIDS-related information; lack of social spaces for dialogue about HIV/AIDS; the link between HIV/AIDS, sexual moralities and the control of women and young people; the lack of adequate HIV/AIDS services as well as how poverty shaped people's reactions to HIV/AIDS. The model critically evaluates existing stigma management approaches and argues that the top-down approach alone is not sufficient. It is important that individuals should be able to design their own mechanisms of coping in the comfort of their environment, so that they take ownership of the activities to deal with stigma. Poverty is seen as a factor that promotes

stigmatisation from different avenues of people's lives. A person whose health deteriorates is therefore perceived as a liability by those around him, as he is not able to positively contribute to his own survival and that of others. The infrastructure and design of clinics and hospitals, availability of transport, and availability of skilled health workers in HIV counselling all have an impact on HIV-stigma. Individuals and communities in this model will build social networks and have a sense of ownership of programmes and activities aimed against HIV-stigma.

Pescosolido *et al.* (2008:431) developed an integrated systemic approach which refers to all systems that are involved in the stigmatising process. The framework brings together theoretical insights from micro, meso and macro levels. The *Framework Integrating Normative Influences* (FINIS) links stigma to social interaction using the labelling theory, social network theory, the limited capacity model of media influence, the social psychology of prejudice and discrimination and theories of the welfare state, as all contributing to an understanding of the complex web of societal expectations shaping stigma. Although this framework focuses on mental illness, it can be applied to HIV in that the judicial, political, medical and social systems are non-supportive to discriminated individuals. This framework can be helpful to unlock those systems that need to support the stigmatised and it may assist in the management of HIV stigmatisation on all levels (Pescosolido *et al.*, 2008:437-438).

Phelan, Link and Dovidio (2008:360) reviewed stigma literature and developed a typology of three functions of stigma and prejudice based on the review of 18 conceptual frameworks of stigma, in a study entitled *Stigma and prejudice: one animal or two*. These typologies were identified as keeping people down (exploitation and domination); keeping people in line with norms (norm enforcement); and keeping people away (avoidance). It manifests when dominant groups exploit people by using their power to make it socially acceptable to use existing inequalities – for example in terms of race and gender – to dominate vulnerable groups. Social prejudice and stigmatisation occur when people fail to conform to the societal standards that are determined and influenced by the dominating group. Avoidance is a common response in individuals, as they avoid people whom they regard as acting abnormally or who are physically abnormal due to disease. According to Phelan *et al.* (2008:361-364), it is

possible to change the above-mentioned three aspects of behaviour in individuals and communities.

Atell (2013:14) contributed to the development of a framework for understanding AIDS-related stigma based on the social contact theory. Levels of personal contacts have an influence on the reduction or increase of stigmatisation, and include casual, residential, occupational and goodwill contacts. Casual contacts such as colleagues, friends or co-workers are superficial and distant and of no meaning. Casual contacts increase prejudice and stigma, whereas significant relationships such as acquaintances reduce prejudice and stigma. Residential contacts are viewed as being of no particular importance. Occupational contact can expose individuals to different levels of social contact. Goodwill contacts are those people with the intention to reduce prejudice by willingly working with PLWH (Atell, 2013:18-19). This theory relies on the assumption that individuals can be easily identified and placed in appropriate support groups and that varying types of contact can increase or decrease the stigmatisation of PLWH.

## **1.5 The stigma impact on the HIV pandemic**

The marked effect or influence of the HIV pandemic dominated health care activities and programmes globally and in South Africa alike. In addition to global funding pouring to affected areas, governments spend a large portion of the health budget on HIV prevention and care. It was estimated that 35.3 million people worldwide were living with HIV in 2013 (UNAIDS, 2013:4; WHO, 2017). The number of new infections declined from 3.4 million in 1996 to 1.4 million in 2017 (UNAIDS, 2015; WHO, 2017). The section that follows, discusses the impact of HIV-stigma from a sub-Saharan as well as a South African perspective, including changes in the HIV epidemic and HIV-stigma levels.

### **1.5.1 The impact of HIV in sub-Saharan Africa and South Africa**

According to the UNAIDS data there were 36.9 million PLWH with 1.8 million new infections globally in 2017 (UNAIDS, 2018:18). The data further indicates that of the global daily 5000 new infections 66% are in sub-Saharan Africa. The impact of HIV is highly noticeable in the sub-Saharan Africa with 19.6 million PLWH in 2017. In South Africa the first cases of HIV were identified in 1982 (Karim & Karim, 2002:37). Since

then the country has continued to experience challenges associated with HIV and AIDS. There has since been an increase from 4.25 million PLWH in 2002 to 7.52 million PLWH in 2018 (Stats SA 2018:7). The high prevalence of PLWH makes South Africa one of the countries most affected by the HIV epidemic globally. South Africa is consequently ranked first among the top twenty African countries with the highest HIV prevalence rate. The success of HIV management and care programmes such as prevention of mother to child transmission indicate that provision of ART yielded positive results however HIV and AIDS remain the leading cause of death in sub-Saharan Africa.

### **1.5.2 Changes in the HIV pandemic**

HIV infection was categorised as a global health threat which manifested in three waves (Mann, 1989:131). First, the HIV infection wave progresses silently to the development of the second wave, which is characterised by visible symptoms of AIDS, and finally to the third wave of HIV-stigma. As the numbers of infected cases progressed to the final phase, many PLWH were dying before the provision of ART, especially in South Africa, where ART was provided only from 2003. Nearly 2.1 million people died of HIV and AIDS in sub-Saharan Africa in 2006, because ART was implemented long after the diagnosis of the disease (Ojikutu, 2007:1-2). HIV became the main cause of death (Bouare, 2009:54) and was perceived as a death sentence for the individual (Del Rio, 2005:682-683). References such as “on death row”, “lightning”, “snatcher”, “a robot” and “has a lift” were often used when an individual tested positive for HIV infection (Uys *et al.*, 2009a:15-17), to express the fear of death.

The provision of ART brought hope for PLWH. In the 1990s many countries made ART available for PLWH. HIV was no longer seen as a fatal condition because people lived longer on treatment. The provision of ART led to mass campaigns of HIV testing, and countries in the sub-Saharan region had an increase in the number of individuals who underwent HIV tests between 2004 and 2011 (UNAIDS, 2012:2). As the uptake of ART subsequently increased (UNAIDS, 2012:2), individuals started living longer than expected. This was the case in South Africa as well, when more children who were given ART grew to an older age (Mahloko & Madiba, 2012:6-7). Because PLWH are living longer when they are on treatment, HIV is now regarded as a chronic disease (Dlamini *et al.*, 2009:377-384) and in the WHO guidelines for HIV management, HIV

infection is indeed described as a chronic disease (WHO, 2016). Nevertheless, in spite of the successes in HIV management and the decline in HIV-related deaths, it still remains a great challenge to reduce HIV-stigma (Chidrawi *et al.*, 2014:222-230), which manifests as the third wave that was predicted by del Rio (2005:685-686).

### **1.5.3 HIV-stigma levels**

The fight against HIV infection is hampered by the related stigma which interferes with management and care processes globally, including South Africa. Holzemer *et al.* (2009a:80-81) identified a reduction of HIV-stigma over time in five African countries. Yet, the number of stigmatising events experienced by PLWH remained significant. The fact that individuals find it difficult to utilise some of the HIV prevention measures – such as HIV counselling and testing (HCT) – is the result of high stigma levels (Ntsepe *et al.*, 2014:145). In South Africa HIV-stigma occurs in different areas, such as health care, the community and vulnerable groups such as MSM (Zahn *et al.*, 2016:1). In a study in South Africa, Neuman and Obermeyer (2013:1796) found that interpersonal and internalised stigma existed and that it also manifested in discriminatory cues of high HIV-stigma levels in health facilities for PLWH.

In sub-Saharan Africa PLWH are disowned by families, and families avoid associations with them (Turner *et al.*, 2015:222). In a study conducted in South Africa by Chidrawi *et al.* (2014:146-150), HIV-stigma indicators identified high HIV-stigma levels in the community as a whole. Another South African based study highlighted the existence of HIV-stigma where PLWH are stigmatised not only in the community but also in the family (Treves- Kagan *et al.*, 2016:5). In some instances family members would not want to share a bed or eating utensils with PLWH. Similarly, Simbayi *et al.* (2007:1823-1831) reported that vulnerable groups like MSM, women and injecting drug users experienced high stigma levels in South Africa. Four hundred and eighty (480) MSM reported higher levels of internalised stigma. Women as a vulnerable group were also found to be similarly affected by high stigma levels, while men were more affected than women in South Africa (Neuman & Obermeyer, 2013:1805). UNAIDS (2018) in their report on HIV stigma and discrimination points out that PLWH most at risk of high HIV-stigma levels are women between the ages of 15 and 29. Injecting drug users also reported high HIV-stigma levels in St Petersburg, Russia and Kohtla Jarve, Estonia (Burke *et al.*, 2015:154). Even though researchers

used different HIV-stigma measuring approaches, they all concluded that HIV-stigma levels are high.

Although several studies identified HIV-stigma, there was no formal survey of HIV-stigma levels until 2014. UNAIDS, (2014) and 16 partners facilitated a study by means of the HIV-stigma index survey in 50 countries, to assess the levels of HIV-stigma in which South Africa also participated. In South Africa the South African National AIDS Council (SANAC) and Human Sciences Research Council (HSRC) conducted this survey in 18 of its 52 districts, with 10 500 participants (Cloete, Simbaya, Zuma, Jooste, Blossie, Zimela, *et al.*, 2014). The survey report indicated moderate external HIV-stigma levels (Cloete, *et al.*, 2014). However, Tsai (2015) concludes that HIV-stigma remains high, as indicated by the high prevalence of internalised HIV-stigma in sub-Saharan Africa. In South Africa, Chidrawi *et al.* (2014:222) confirmed the existence of HIV-stigma in the form of verbal abuse, negative self-perception, health care neglect, social isolation and fear of contagion. The HIV-stigma reduction community “hub” network intervention by Prinsloo and Greeff (2016:173-177) in the North West Province of South Africa, also confirmed the existence of HIV-stigma.

## **1.6 Outcomes of HIV-stigma**

The outcomes of HIV-related stigma in South Africa are profound for individuals, families and communities (Amnesty International, 2014; Turan *et al.*, 2017:283-291) and to health care. These outcomes of HIV-stigma are discussed below in terms of the PLWH, the PLC, the community and the health care system.

### **1.6.1 Outcomes of HIV-stigma for PLWH**

The discussion on outcomes of HIV-stigma for PLWH includes psychosocial health, social isolation, workplace, economic factors, access to health care and well-being.

#### **1.6.1.1 Psychosocial health**

The state of mental, emotional, social and spiritual well-being of an individual is referred to as that person's *psychosocial health*. An HIV diagnosis negatively affects people and this leads to low self-esteem, which in turn affects their mental and psychosocial health (Moskowitz & Seal, 2011:624). Mental health problems that surface in PLWH affect their self-concept (Greeff & Phetlhu, 2007:22). Emotional strain

is a common feature of any life-threatening disease, especially if there is no hope of medical help, or of help in any other form (Makoae *et al.*, 2011:188). PLWH experience stress of disclosing due to risk of stigmatisation; with associated shame, guilt and anger (Turan & Nyblade, 2013:2530). Chidrawi *et al.* (2015:62) observe that poor mental and psychosocial health subsequently affects the quality of life of PLWH. Self-efficacy is affected in that HIV is always seen as the disease of “others”. Lack of spiritual support leaves PLWH with little regard of the self. Spiritual support and religious groups can be of value to the family and the suffering person, but because of stigma PLWH loses out on such valuable relations (Cotton *et al.*, 2006:5). Cloete *et al.* (2010:3) describe the stigmatising belief that HIV infection is limited to women, gays and black people.

#### **1.6.1.2 Social isolation**

Social support structures often disintegrate because of HIV-stigma, and PLWH may be neglected in their family environments as a result (Kohi *et al.*, 2006:408-409). PLWH are often chased away from their homes by partners (Kohi *et al.*, 2006:408-409; Gilbert & Walker, 2010:144) and suffer isolation due to loss of relationships and friendships (Greeff, 2010:2). Such disconnectedness often prevents PLWH from participating in family and religious activities as well (Owolabi *et al.*, 2012:122-127). For some PLWH, self-isolation can be a coping mechanism, even though it may have negative consequences on their mental and physical health (Audet *et al.*, 2013:6). Because of HIV-stigma, PLWH may also deny themselves relationships, marriage or engagement in activities that may enhance their livelihood (Dos Santos *et al.*, 2014:23).

#### **1.6.1.3 Workplace**

The employment environment places tremendous pressure on PLWH. In a study conducted in Ghana a participant reported how he lost permanent employment following the release of his HIV-positive results (Asiedu, 2010:77). Sprague *et al.* (2011:320) found that in Kenya and Zambia training, development and promotion opportunities in the workplace were affected following mandatory HIV disclosure. HIV testing and submission of results were a prerequisite for application for employment in these two countries. Teamwork was affected as co-workers did not want to work



alongside PLWH, creating a hostile environment (Stewart, Pulerwitz & Esu-Williams, 2002). In many instances the workplace breaches the psychological contract with employees who are HIV positive by failing to protect its employees from HIV-related stigma (Bashir, 2011:159). PLWH suffer exclusion in the workplace, risk of termination of employment and violations of confidentiality when HIV status is revealed (Sprague *et al.*, 2011:320).

#### **1.6.1.4 Socio-economic implications**

HIV-stigma has socio-economic implications for PLWH that affect them negatively. Lim *et al.* (2013:8) confirm that HIV-stigma and socio-economic implications are linked. Chidrawi *et al.* (2014:67) interpret the socio-economic challenges of stigma as leading to job loss and inability to provide for retirement. AVERT report on stigma and discrimination indicates that stigma affects PLWH on social support issues, economic challenges, job, financial, food security and mobility needs as challenges (UNAIDS, 2018). In the informal sector, where there are no HIV/AIDs policies, most PLWH are vulnerable and can lose their jobs because of HIV-stigma or when they get sick as the disease progresses. Women from families with lower economic status and are dependent on their husbands are often stigmatised (UNAIDS, 2018). They must then survive on the low earnings of their spouses as they are unemployed. As the retrenched PLWH get sicker, they need care. However, the care of PLWH is costly because it requires nutritious food and regular transport to visit clinics; and PLWH need a carer, who either has to be paid or who is a family member who gives up a job to look after them.

#### **1.6.1.5 Access to health care**

The critical factor in the health of PLWH is access to quality health care, treatment and support. When individuals access health services, they discover their HIV status but also they experience stigmatisation (Okoror *et al.*, 2014:28). Globally, stigma has been described as a major barrier to accessing HIV treatment, which can result in negative health outcomes for PLWH (Khali *et al.*, 2015:129). PLWH do not visit health care clinics, either because of fear or because of lack of health care. A study in India found that PLWH did not actively utilise preventative services for mother-to-child-transmission (PMTCT) for fear of stigmatisation (Rahangdale *et al.*, 2010:836). Kruger

*et al.* (2009:28) reported on the health care seeking behaviour of newly diagnosed PLWH and found that PLWH feared disclosing their HIV status in their follow-up visits to hospitals. Dlamini *et al.* (2009:378) found that stigmatisation in health care (hospitals, clinics and health professionals) is a risk factor for forced disclosure, which makes PLWH shy away from health facilities.

In Lesotho tuberculosis (TB) treatment was made available over ART, denying PLWH access to quality health care (Makoae, 2011:193-194). The unavailability of ART further denies PLWH access to health care, which is tantamount to stigmatisation. In some cases doctors prescribe other medicines said to be cheaper, instead of ART for PLWH. This in itself is a stigmatising act that undermines the integrity of PLWH. Some PLWH were denied reproductive health or family planning services (Dos Santos *et al.*, 2014:8; AVERT, 2015). Weak or poor health workers' patient communication aggravates the situation of stigmatisation and becomes a barrier to access to health care (Remien *et al.*, 2015:16). Likewise, unprofessional conduct and breach of confidentiality by health workers were also identified as access barriers (Nzaumvila & Mabuza, 2015:8-9). It is evident that stigma leads to poor access to health care, inadequate follow-up and inadequate adherence, which result in default of treatment (Burke *et al.*, 2015:159; Mburu *et al.*, 2014:5).

PLWH are often exposed to stigmatising practices, including neglect in health care (Zamberia, 2011:677-680). Nzaumvila and Mabuza (2015:1) identify six main reasons why PLWH do not return to a hospital for their CD4 count namely: 1) they were not informed by the health workers that they needed to come to the clinic and the importance thereof; 2) health services were not comprehensive and health workers focused on one aspect of care; 3) health workers conducted themselves unprofessionally as they breached confidentiality processes and disclosed the HIV status of a person without consent; 4) shortage of medication; 5) lack of privacy that compromised them and exposed them to stigmatisation by others; and 6) lack of money, transport and food.

#### **1.6.1.6 Physical health and well-being**

Well-being encompasses a balance across physical, psychological and social health (Dodge *et al.*, 2012:230). Chidrawi *et al.* (2014:62-65) and Prinsloo *et al.* (2015:72-76)

point out that PLWH have self-efficacy issues that lead to neglect of their health, which is related to poor access to health care and eventually poor quality of work life. A recent study in Kenya and Brazil reported that stigma threatens the health outcomes of PLWH as it limits access to health care (Pulerwitz *et al.*, 2015:247-248). Nzaumvila and Mabuza (2015:2) stress that the health of PLWH is affected if they do not return for follow-up care: most PLWH would only return for health care when there are complications with their health. Chidrawi *et al.* (2014:62) identified diminished physical well-being as an outcome of HIV-stigma for PLWH.

Researchers suggest that the physical health and well-being of PLWH will not change for the better in cases where there is late access to health services, in the late stages of HIV, due to stigma (Peltzer *et al.*, 2011:184). Holzemer *et al.* (2009b:161) explored HIV-stigma and health-related quality of life (QOL) of PLWH, and found a relationship between QOL and HIV-stigma. Ntshakala *et al.* (2012:3-7) also discussed the QOL of PLWH, with a focus on the psychosocial, spiritual, cognitive, environmental, physiological and socioeconomic aspects. A participant in the study reported that taking ART has increased stigma instead of decreasing it. Uys *et al.* (2009b:1059) also indicate that ART increases stigmatisation for PLWH, and that PLWH would therefore sometimes resort to storing their medication in different medication containers, to hide the fact that they are using ARV drugs. PLWH continuously seek to find meaning to their life after being diagnosed, so that they may have a reason to live. As they strive towards life with a purpose, they have to deal with the judgements of others. The spirituality of PLWH is ignored during treatment with ART and even nurses are disconnected in this regard, as they rarely discuss life, health concerns and death with PLWH in enhancing their QOL (Ntshakala *et al.*, 2012:5).

At a cognitive level, it threatens the QOL of PLWH as they might not be in a position to comprehend the information they receive. Instead of positive thoughts, they could be embroiled in thoughts of HIV as a killer disease or HIV as a lifelong infection that inhibits growth and development (Ntshakala *et al.*, 2012:6). Due to stigma, PLWH lose out on valuable relations and their support as well (Cotton *et al.*, 2006:S5). Chidrawi *et al.* (2014:62) also identified diminished physical well-being as an outcome of HIV-stigma for PLWH.

### **1.6.2 Outcomes of HIV-stigma for the people living close to PLWH**

The PLC to PLWH includes children, partners, family, friends, colleagues and spiritual supporters (Greeff & Phetlhu, 2007:13). This close circle of friends and biological relatives as well as spiritual support is an essential element in the life of PLWH to give meaning in their lives and keep people connected (Cotton *et al.*, 2006:S5). However, these groups are at risk of associated HIV-stigma (Greeff & Phetlhu, 2007:13). Social ties and relationships of PLC are disrupted by HIV-stigma as they lose social networks. Stigma further causes anger and frustration among family members in the wake of reports that a loved one is HIV positive (Asiedu, 2010:6-7). There is subsequent family disorganisation due to loss of an active family member, and intimate relationships are severed (Li *et al.*, 2008:431).

When individuals in a family are diagnosed or suspected to be HIV positive they may be marginalised, subjected to discrimination, excluded and bullied, and the entire family may be sanctioned and isolated (Nayar *et al.*, 2014:142). Children of PLWH are also negatively affected by HIV-stigma in that they are shunned by family and community, dropping out of school and losing out on education (Kamau, 2012:233). When the lives of PLWH deteriorate, they become a burden on their partners and relatives. In this situation the children are most affected as they drop out of school to take over the responsibilities of sick PLWH (Barenes *et al.*, 2014:1-2). PLC to PLWH may experience economic instability if they lose their jobs due to stigma (Asiedu, 2010:5).

Health care providers like nurses and doctors as PLC are also affected by stigmatisation when they care for PLWH. Nurses who are caring for PLWH are sometimes stigmatised by their colleagues through association (Chirwa *et al.*, 2009:20). This risk of stigmatisation creates fear in nurses when they have to care for PLWH (Uys *et al.*, 2009a:157), resulting in nurses resigning from health care (Kohi *et al.*, 2009:136). Audet *et al.* (2013:40) found that in some instances nurses blatantly refused to care for PLWH because of stigma.

### **1.6.3 Outcomes of HIV-stigma for the community**

Gilbert and Walker (2010:145) found that in South Africa, HIV-stigma remains high in communities where people refuse to talk about it. This public secrecy about HIV in

structures like churches is confirmed by Gilbert and Walker (2010:145-144), who have found churches avoid talking about it, in case any of their members are infected. Religious groups respond moralistically to HIV - instead of acting with spiritual connectedness, they avoid and judge PLWH (Bauer, 2013:100-118). Several authors indicated general outcomes of HIV-stigma for the community in different levels of intensity (Liamputtong & Haritavorn, 2014:26). The bonding and linkages of communities are interrupted by stigma and this undermines their health outcomes (Hazenbuehler *et al.*, 2013:814). Stigma leads to low self-esteem and lack of social cohesion in the community, breaking down community support systems (Prinsloo *et al.*, 2015:83). It also interferes with the engagement of communities through HIV prevention programmes like HIV counselling and testing (HCT), prevention of mother-to-child transmission (PMTCT), and treatment (Larsson *et al.*, 2015:7). Stigma and gossiping are powerful tools to divide communities, leaving families in a vulnerable economic state and at risk of breakdown of family structures (Dos Santos *et al.*, 2014:5). Eventually communities may experience economic strain because families may no longer be economically self-sustaining (Moyer *et al.*, 2013:136, 141).

#### **1.6.4 Outcomes of HIV-stigma for the health care system**

The South African population is estimated at 49.9 million, with 61% residing in urban areas and in need of basic services; as opposed to the expected regional levels of 37% (Schellack *et al.*, 2011:558). HIV-stigma affects the health care system at different levels: HIV and the related stigma pose far-reaching consequences and out strain on the health workers and the health care system (Nyasulu *et al.*, 2013:232). Lack of psychosocial support for PLWH, infrastructure where people can only be tested in designated areas, poor knowledge of infant feeding and nutrition, and delays in testing individuals and in making their test results available, are the challenges of the day (Dookie & Singh, 2012:3-4; Naidoo, 2012:149). The health care system are put under strain if PLWH present for care only when they are very sick or critical (Kohi *et al.*, 2010:135-136). It was found that in Addis Ababa, HIV-positive patients affect the bed occupancy rate (BOR) in hospitals, and that admissions of PLWH made it difficult to accommodate patients with other conditions (Tamiru & Haidar, 2010:195).

At PHC level, community-based health services are also affected by HIV-stigma as they become the relief base for hospital care. Hospitals cannot cope with the HIV

workload and an alternative is care for PLWH in their homes through home-based care (HBC) programmes, especially before the provision of ART (Tamiru & Haidar, 2011:195). These programmes have their own challenges, such as lack of resources due to poor coordination and lack of support. Families also do not always accept assistance from HBC as they fear HIV-stigma and being associated with HIV. The PHC system is confronted by a quadruple burden of disease: maternal and childhood diseases, violence and injuries, and communicable diseases, including HIV/AIDS and TB (Naidoo, 2012:149; Basu, 2018). The complexities of HIV infection put a strain on health workers (Sehume *et al.*, 2012:12-13), with far-reaching consequences for health care in communities that demand services (De Wet & Du Plooy, 2012:31). Change management approaches such as PHC–Reengineering and Central chronic medicine dispensing and distribution (CCMDD) where PLWH could collect their ART in different localities most convenient to them [PLWH] have been implemented (NDOH, 2016).

Likewise, health care providers like doctors and nurses are also affected by stigmatisation when they are caring for PLWH. As a result, a strong element of neglect of PLWH is identified among health care providers (Dlamini *et al.*, 2009:396). Nurses who do not neglect PLWH and show caring for PLWH are sometimes stigmatised by their colleagues through association (Chirwa *et al.*, 2009:20). This risk of stigmatisation creates fear in nurses when they are caring for PLWH (Uys *et al.*, 2009a:157), resulting in nurses resigning from health care (Kohi *et al.* 2010:136) or refusing to care for PLWH (Audet *et al.*, 2013:40). The HIV burden and its related stigma have also physically and psychologically affected health workers, resulting in poor performance of duties (Ndou *et al.*, 2014:255). A study of doctors' attitudes towards the care of children with HIV in South Africa suggests that the health care system has challenges with doctors who have no hope and are demoralised because of the HIV pandemic (Fransman *et al.*, 2000:2).

Some community members opted to seek treatment at clinics outside their residential areas (Linda, 2013:23), thus increasing the number of patients accessing health services such as ART in those clinics. The increased numbers of patients in the clinics results in overcrowding in some clinics and trigger challenges in terms of resources for those clinics. The most visibly affected resources are human resources and skills

base, which require more training of health workers and resources for all patients, including PLWH (Raza & Mash 2012:9, 23; Crowley & Mayers, 2015:9). The ART programme was primarily managed by nurses, even though they were not initiating treatment. The health care system operated with nurses who used their skills in order work and care for PLWH. In the implementation of policies nurses encountered challenges such as inconsistencies in protocols and guidelines, which leaves nurses no option but to use their own discretion, and often also to perform duties outside their scope of practice due to lack of support (De Wet & du Plooy, 2012:31; 34), particularly in PHC clinics. In addition, the health care system is highly strained by demands from the community (De Wet & Du Plooy, 2012:31).

In programmes such as prevention of mother-to-child transmission (PMTCT), it is difficult to treat partners, and health services are compelled to extend their hours of service to include weekends so that partners of women who are on PMTCT can access the clinics when they are home during weekends (Sripipatana *et al.*, 2007:107-110). Health care institutions invite partners of PLWH in writing but because of HIV-stigma these partners do not visit clinics (Sripipatana *et al.*, 2007:110-112).

The HIV management and care programmes had specific targets such as reducing new infections by 50%, according to the strategic plan 2012-2016 (NDOH, 2011:12). HIV-stigma is said to be hampering these programmes, with the result that targets for prevention and treatment are not met. The stigma thus interferes with the uptake of PMTCT, HIV testing and the administration of ART (Mall *et al.*, 2013:201), because PLWH are afraid to report to clinics and they default treatment (Mahajan *et al.*, 2008: 146-151).

## **1.7 Interventions to reduce HIV-stigma**

Over the past few years researchers developed and implemented HIV-stigma reduction interventions to address the problem of HIV-stigma. Several authors systematically reviewed the available literature on HIV-stigma (Brown *et al.*, 2003; Brown *et al.*, 2011; Sengupta *et al.*, 2011, Stangl *et al.*, 2013 & Nayar *et al.*, 2014).

Brown *et al.* (2003:49), in their systematic review, analysed 14 out of 22 identified studies on stigma reduction in developed and developing countries. The selected studies were classified according to the goals and target population: (1) increased

tolerance towards PLWH among the general population, (2) interventions to increase willingness of health care providers to work with PLWH and (3) improved coping strategies for dealing with AIDS stigma among PLWH (Brown *et al.*, 2003:53). The interventions included information-based approaches, skills building, counselling approaches and contact with affected groups. The outcomes in terms of the general population tolerance showed mixed success with regard to stigma reduction interventions on a small scale and for a short period of time. There was a positive effect and change regarding attitude of different groups towards PLWH, willingness of health care workers to care for PLWH, and PLWH coping with perceived stigma (Brown *et al.*, 2003:62;63;64). The review concluded that no single intervention on its own was sufficient to reduce HIV-stigma. It was emphasised that there was a need for more comprehensive studies that lasted longer and differentiated in terms of gender impact (Brown *et al.*, 2003:66).

In 2011, Brown *et al.* (2011:15-16) did another systematic review that focused on community-based interventions. The community-based approaches show that HIV-stigma can be addressed at individual as well as community level. The identified studies indicate that a variety of strategies can be employed to reduce stigma, such as information, counselling, coping skills, acquisition and contact. They reported a bias because only successful studies were reported on, and there were no reports of failed or unsuccessful HIV-stigma reduction interventions, or on the reasons for such failures. The majority of interventions were not evaluated rigorously. In the identified intervention studies, gender-based differences were not sufficiently explored. Most of the studies looked at short term and not long term impact, and evaluation of studies occurred shortly after the intervention (Brown *et al.*, 2011:20-21).

Sengupta *et al.* (2011:1084-1085) reviewed randomised control trials with a pre- and post-test, and compared it with a non-randomised group with a pre- and a post-test. These randomised trials included three studies in African, two in Asian and one in European countries. The studies focussed on students, health care providers, community level interventions and working women. The non-randomised trials used informal approaches and highlighted the current gaps of evidence-based interventions to reduce HIV-stigma. These gaps included fewer interventions targeting HIV-stigma, the use of inadequate measures to evaluate HIV-stigma reduction, the value and



relevance of HIV-stigma reduction for public health as well as poor quality, rigor and internal validity of these studies (Sengupta *et al.*, 2011:1084). The value of these studies is that they identified gaps that call for further research to improve HIV-stigma reduction interventions. The review concluded that only three of the studies were considered of good quality, although 14 of the 19 studies demonstrated effectiveness in the HIV-stigma reduction (Sengupta *et al.*, 2013:1086). The significance of the studies for public health was also questioned.

In a systematic review of stigma reduction interventions to reduce HIV-stigma and discrimination from 2002 to 2013, Stangl *et al.* (2013:26) aimed at identifying effective interventions that could be scaled up and integrated nationally to improve the success of a global AIDS response. The review targeted interventions to obtain a more complete picture of a full range of effective interventions. It included 2 368 peer-reviewed articles, of which 48 articles were targeting 14 populations in 28 countries. Different strategies, such as an information approach, skills-building approach, and a contact and counselling approach were used in most interventions to reduce HIV-stigma and discrimination, while structural and biomedical components were found in ten of them (Stangl *et al.*, 2013). However, some interventions targeted the socio-ecological level or a single domain of stigma. The majority of studies were able to demonstrate a reduction in HIV-stigma, but they failed to measure how the HIV health-related outcomes were affected by HIV-stigma reduction intervention. They concluded that although considerable progress has been made, there were still critical challenges and gaps that needed up-scaling. The interpretation and comparison of the results of the studies were hampered by lack of uniformity and validity (Stangl *et al.*, 2013:28).

The literature review by Nayar *et al.* (2014:143) identified interventions to reduce stigma and discrimination for child health, to improve the survival of children in low and middle income countries. Discriminatory practices that obstructed access to health care for children were identified. The findings were divided into HIV-stigma in the context of PMTCT; neonatal survival; healthy early childhood development; nutrition; marginalised groups and child survival (Nayar *et al.*, 2014:147). The review revealed very little empirical research on interventions that directly aim to reduce stigma in children in low and middle income countries. This review by Nayar *et al.* (2014:156) motivated for the evaluation of interventions that focus on vulnerable groups; on the

advantageous use of identified stigma; on neglect and exclusion to improve child health; on information programmes on stigma to develop measures for better child health outcomes; and on managing HIV-stigma directly to improve child health and survival (Nayar *et al.*, 2014:157).

Other authors reported on single HIV-stigma studies (Uys *et al.*, 2009:1059-1064; Chidrawi *et al.*, 2014:222-232 and French *et al.*, 2015:81-96). An HIV-stigma reduction intervention that was based in a health setting, involved both nurses and PLWH. The aim was to reduce stigma by increasing their knowledge of HIV through sharing information on HIV and HIV-stigma; by increasing contact between nurses and PLWH; and by empowering them to become advocates of stigma reduction through self-planned stigma reduction projects. PLWH reported reduced stigma with increased self-esteem following the stigma intervention. Although nurses did not report any reduction in stigma or increase in self-efficacy, their HIV testing behaviour increased remarkably (Uys *et al.*, 2009b:1059-1064).

The study that involved Chidrawi *et al.* (2014:222) and French *et al.* (2015:81-96) provided a comprehensive HIV-stigma-reduction and wellness-enhancement community intervention with PLWH and PLC (partners, children, family, friends, spiritual leaders & community leaders) (Chidrawi *et al.*, 2014:228; French *et al.*, 2015:94). The intervention was successful in that knowledge about stigma increased. Coping with stigma and improved relationships reduced PLWH's feelings of stigmatisation and made them more willing to disclose. In addition, PLC became aware of how they stigmatise PLWH and they were empowered to take a lead in the community and facilitate stigma reduction. Chidrawi *et al.* (2014:229) concluded that the intervention also effected a positive change in health behaviour of PLWH and reduced their HIV-stigma experiences, with improved quality of life.

An intervention study through a community-based HIV-stigma reduction "hub" network by Prinsloo and Greeff (2016:166) focused on changing the attitude of a total community towards PLWH. PLWH and PLC as community mobilisers shared information and empowered their own community regarding HIV-stigma reduction. Workshops for both PLWH and the community were conducted on "understanding stigma" and "coping with HIV-stigma". Door-to-door education about "understanding HIV-stigma" followed. Support groups and a psychodrama group formed part of the

intervention. The HIV-stigma reduction community “hub” network intervention, involving PLWH and PLC sharing their knowledge and empowering their own community to reduce HIV-stigma, was successful: there was evidence of reduced HIV-stigma experiences by PLWH, willingness of PLWH and PLC to talk about their HIV status, and changed behaviour of communities towards PLWH (Prinsloo and Greeff, 2016:176).

## **1.8 Summary**

This literature overview focused on the conceptualisation of HIV-stigma, its manifestation, outcomes and interventions management. It facilitates a deeper understanding of these phenomena related to HIV-stigma. HIV-stigma, as a concept, is described as socially discrediting behaviour. In some instances it leads to the loss of an individuals’ livelihood as well as creating derogatory perceptions and discriminating practices. HIV-stigma according to various researchers, pose a critical area of concern for PLWH, the community and the health care system, globally as well as in sub-Saharan health care system. Literature provides evidence that HIV-stigma manifests in government, legal, occupational and health care contexts. Official regulations in different countries endeavour to protect PLWH against stigma. The constitution of South Africa offers such a framework, where the rights of individuals, including PLWH, are protected. Conversely, in countries like China, Russia and Uganda, individuals are stigmatised through mandatory HIV testing, refusal of entry into the country or refusal of employment for HIV-positive people. A health care system sometimes unintentionally stigmatises PLWH in its environment and through identifiable practices. Stigmatisation is aggravated if clinics use dedicated buildings as health care units for HIV patients, and even by the mere act of providing antiretroviral therapy at a specific clinic. Stigmatisation has a huge impact on PLWH, people living close to them, their communities and health care systems in general. The intense and devastating levels of HIV-stigma severely affect those who are totally dependent on these systems for their care. Over the years, the biomedical approach and provision of antiretroviral therapy to HIV care took precedence over the reduction of HIV-stigma and disclosure management – thus, HIV-stigma continue to exist with profound outcomes for individuals, families and communities.

HIV-stigma is a traumatic experience for stigmatised people and results in feelings of worthlessness; loss of purpose in life; isolating of the self; loss of social support; and loss of work opportunities – all these factors place PLWH in dire need for care and access to health services. PLWH often avoid the use of preventative services, such as prevention of mother-to-child transmission, or are not informed by health workers to return for further care once diagnosed with HIV. Unintegrated health services, especially for HIV care, discourage patients from moving from one point of care in the clinic to another; this situation is further complicated by the unprofessional conduct of some health workers and by compromised privacy. Lack of resources in health care systems also contributed to stigmatisation, especially if affected by antiretroviral treatment regimens. People often then would not return to clinics for follow-up care. Loss of economic viability because of HIV-stigma result in lack of money and transport for PLWH, preventing them from visiting clinics. Stigma further interferes with the health seeking behaviour of PLWH and limits their access to health care. Unfortunately PLWH are seriously affected by HIV-stigma. Stigma however also affects people living close to them such as family, friends and health care workers.

Over the years researchers developed and implemented various HIV-stigma reduction interventions to address the problem of HIV-stigma. The identified interventions mainly focussed on aspects ranging from increasing tolerance of the general population towards PLWH, increasing willingness of health care workers to care for PLWH, improving coping strategies to deal with HIV-stigma, counselling, giving information and increasing knowledge, skills building, improving contact with PLWH and building of relationships and general empowering strategies. It is however noted that the health-focussed interventions were more in general health care environments such as hospitals and not PHC settings. HIV-stigma is however closely linked with disclosure. The next section of the literature overview focusses on the disclosure and management of stigma and disclosure in PHC settings.

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## **CHAPTER 2: DISCLOSURE AND HIV-STIGMA AND DISCLOSURE MANAGEMENT IN PRIMARY HEALTH CARE SETTINGS**

### **2**

#### **2.1 Introduction**

In the previous chapter a deeper understanding of stigma was sought by considering the conceptualisation of stigma, definitions, models and frameworks of stigma and the impact thereof. It focusses on the levels and outcomes of stigma and existing interventions to reduce HIV-stigma. However, HIV-stigma is linked and complicated by the disclosure process, which can be beneficial or detrimental to PLWH and PLC to PLWH. Research (Atuyambe *et al.*, 2014:1, Takada *et al.*, 2014:26) concluded that the proper management of HIV positive status disclosure can help to prevent HIV transmission and can increase social support for PLWH. In the process of disclosure, PLWH need to know whether they want to disclose, what they want to disclose and when and to whom to disclose. Disclosure should be a choice (Broeckaert & Challacombe, 2016; Arrey *et al.*, 2015:1; O'Grady, 2009:59-70; Greeff, 2013:85). Klopper *et al.* (2014:37) conducted a study at a PHC clinic in South Africa that indicated that stigma of PLWH remains the main barrier to disclosure. This chapter focuses on obtaining a deeper understanding of disclosure, by investigating what disclosure is, types of disclosure, reasons why people disclose or not, positive and negative outcomes of disclosure, the context of stigma in PHC settings and approaches to the existing management of disclosure in PHC settings. It also focuses on HIV and related stigma management in PHC settings.

#### **2.2 Conceptualising disclosure of HIV status**

HIV-stigma is linked to the complex process of disclosure of one's HIV status (a, 2013:85-88; Cederbaum *et al.*, 2013:2541-2544; Przybyla *et al.*, 2014:677). Disclosure is a negotiated process over a lifetime and is the responsibility of health workers, PLWH and the community (Dageid *et al.*, 2012:926; Greeff, 2013:84). If HIV stigmatisation is high, it leads to non-disclosure (Le Roux-Kemp, 2013:1; Yako & Memeza, 2013:84; Arnold *et al.*, 2014:719; Longinetti *et al.*, 2014:7; Idindili, *et al.*, 2015:6-7). Greeff *et al.* (2008a:323) suggested that disclosure of HIV positive status

could be meaningfully integrated into stigma reduction interventions as these two processes are closely related.

### **2.2.1 Types of disclosure**

Various types of disclosure are identified by different researchers. Disclosure, in general, means making something known that was previously unknown or concealed (The Little Oxford English Dictionary, 2006:193). In the context of this study, disclosure relates to making the HIV status of an infected person known. Greeff (2013:85) identifies three types of disclosure: voluntary, forced and mandatory disclosure. Moyer *et al.* (2013:63-65) also refer to three categories of HIV disclosure: voluntary or consented disclosure, involuntary or non-consensual disclosure and obligatory or forced disclosure. Emlet (2008:712-713) identified different themes in disclosure: unintentional disclosure, intentional disclosure (violation of confidentiality), non-disclosure that included protective silence, anticipatory disclosure and protective disclosure. A tool named “on the other side of the mountain” (NDOH, 2005:11) categorised disclosure as full disclosure, partial disclosure, indirect disclosure and non-disclosure. For the purpose of this study disclosure will be discussed under the categories of voluntary, forced and mandatory disclosure.

*Voluntary* disclosure was described as PLWH’s desire to disclose voluntarily through an anticipatory process of weighing the benefits of disclosing (Emlet, 2008:714). PLWH employ voluntary disclosure in choosing to disclose or choosing not to disclose their positive HIV status (Greeff, 2013:85). The process of weighing options starts slowly and gradually progresses towards full disclosure (NDOH, 2005:11). PLWH start by telling PLC to PLWH like family or friends, and gradually expands the circle of those they tell voluntarily to include colleagues and many others. PLWH choose to disclose their HIV positive status when they are ready to do so (Greeff, 2013:85; Moyer *et al.*, 2013:64). Tactics such as “testing together”, taking their ART openly and not hiding it, voluntarily participating in a support group in order to disclose are inherent to voluntary disclosure of HIV positive status of PLWH (Moyer *et al.*, 2014:63-65). Often PLWH are governed by a principle of moral obligation for disclosure of their HIV positive status to their partners (Patel *et al.*, 2012:358).

In *forced disclosure*, PLC to PLWH – like nurses, doctors, HCWs, counsellors, friends, and family – often disclose the HIV status of PLWH without their permission (Greeff,

2013:85). It is also described as involuntary disclosure (NDOH, 2005:13). Forced disclosure is challenging and associated with violation of confidentiality, as others would disclose on behalf of the affected individual without his/her permission (Emlet, 2008:714-717). In maternal and child health programmes, mothers with babies are often put on a “no baby breast feeding programme” to protect their babies against mother-to-child transmission and they use protective disclosure (Emlet, 2008:717). Sadoh and Sadoh (2009:30-31) reported that extended family members would force such mothers to breast feed against the health care advice, compromising the health of their babies. Loss of body weight is often associated with dreaded diseases such as HIV (NDOH, 2005:13). Often, when illness has reached a stage where PLWH are very sick, they are easily identified on the basis of suspicion and symptoms, leading to forced disclosure (Linda, 2013:24). Poindexter and Shippy (2010:375-376) refer to forced disclosure as *unintended disclosure*, which is self-proclamation by the body through the physical changes it is undergoing. These authors explain that the physique of PLWH often changes when they lose weight as well as changes in skin tone. Health care practices such as discussing patients’ condition during doctors’ ward rounds or the use of coded language compromise PLWH’s confidentiality in hospitals (Moyer *et al.*, 2013:67-68). In Kenya, access to ART is subject to confirmation that the PLWH disclosed to someone (Moyer *et al.*, 2013:68). This practice forces the PLWH to disclose to people living close (PLC) to them as a support structure for treatment adherence. When the buddy system was introduced in Botswana to support PLWH, adherence improved and better outcomes were achieved (Zuyderduin *et al.*, 2009:11-13). These practices of forced disclosure have a high risk. PLWH are at the mercy of the person rendering services. PLWH are further expected to bring the PLC to whom they have disclosed to the clinic in order to access ART (Moyer *et al.*, 2013:68).

*Mandatory* disclosure does not consider whether the individual chooses to disclose or not. It is the result of stipulated rules and regulations. Some countries formulated regulations and laws that make it mandatory for PLWH to disclose their HIV status (Obermeyer *et al.*, 2013:6; Greeff, 2013:85). A study that was conducted by Lichtenstein *et al.* (2014:372) in North Carolina and Alabama in the United States of America compared attitudes and practices of service providers in relation to counselling clients about mandatory disclosure. As part of public health laws for HIV control, service providers in the United States are supposed to counsel clients about

disclosure to their sexual partners and report anyone who fails to comply. In the USA, PLWH are therefore forced to disclose their HIV positive status to their sexual partners, and counselling involve warnings, signed consent forms and information about the legal consequences of failing to disclose one's HIV positive status. In Alabama, however, the mandatory disclosure of HIV positive status was opposed and a PLWH advocacy approach for disclosure was adopted (Lichtenstein *et al.*, 2014:377).

Cuba also made HIV management and care processes mandatory in 1986 (Fink, 2003:712-716). The country made it compulsory for all who worked outside Cuba since 1975 to be tested for HIV. It was also compulsory for all blood donors and those who had been outside Cuba in Africa since 1981 to be tested for HIV (Fink, 2003:713-716). These strict laws that mandated HIV disclosure were, however, viewed negatively by nurses and doctors because it hampered HIV testing and health seeking behaviour (Lichtenstein *et al.*, 2014:376-378).

Forty three (43) countries, territories and areas in the world restrict entry, stay and residence of PLWH in and within their borders (UNAIDS, 2013:91-97). Countries in the Middle East and North Africa continue to practice laws that violate the human rights of PLWH. Individuals who relocate or migrate are tested without informed consent. Sometimes individuals are tested with counselling but denied visas if found to be HIV positive. The practice deeply invades human rights as the PLWH are not afforded an opportunity to collect their belongings and migrant workers are not allowed to collect the last salary payment (UNAIDS, 2010a:2-23).

In South Africa the legal processes such as the constitution of the country, statutes by parliament, regulations, common or unwritten laws, court decisions, policies, charters and codes protect the rights of all individuals, including PLWH (NDOH, 2005:18-19). Because the privacy of PLWH is protected, HIV positive status disclosure is not mandatory (Selebogo, 2014:45).

### **2.3 Reasons for disclosure and non-disclosure of HIV status**

Ssali *et al.* (2010:675-681) explored the different reasons for disclosure and non-disclosure of HIV status to family, friends and others. It was found that disclosure and non-disclosure both require tailored interventions to improve disclosure to different groups like spouses, sexual partners, family, friends and others. Greeff (2013:86)

indicates that the choice to disclose or not lies with PLWH. The choice is influenced by the social environment, cultural attitudes, and relational aspects in which PLWH find themselves (Dageid *et al.*, 2012:926). PLWH engage with the disclosure process according to specific circumstances (Bird & Voison, 2010:368; Greeff, 2013:85; Moyer *et al.*, 2013:63).

### **2.3.1 Stigma-related reasons for non-disclosure of HIV status**

Barriers to disclosing HIV status include fear of stigma and potential consequences such as rejection, abandonment and violence (Gari *et al.*, 2010:1; Varas-Diaz, 2013:1-2). Reasons for non-disclosure revolve around the implications that affect the lives of PLWH (Greeff, 2013:86). Greeff (2013:85-86) identified the reasons for non-disclosure as protecting self, protecting others, relationship and community factors due to stigma.

#### **2.3.1.1 Protecting self**

PLWH are often stressed by speaking about their HIV positive status. They experience anxiety and attempt to defend themselves by choosing not to disclose (Greeff, 2013:85). Greeff (2013:85-86) identified a number of reasons for PLWH choosing not to disclose such as: denial by self or people close to PLWH; loss of privacy, vulnerability; self-blame; fear of consequences of stigma (like rejection and being labelled); comfort in keeping the secret; ensuring life continues as before; difficulty with communication and self-concept; verbal and physical abuse; loss of a home; financial and job implications; and losing health benefits. PLWH –and especially women – are often accused of infidelity and termed morally irresponsible and careless (Malatji *et al.*, 2014:415). PLWH often choose not to disclose in an attempt to avoid being blamed and stigmatised by others. The blaming of PLWH leads to ridicule and name calling (Greeff, 2013:86). Their intimate relationships suffer when they share their HIV positive status with their partners (Mamogobo *et al.*, 2013:44). Spouses are often deserted when they disclose their HIV status (Malatji *et al.*, 2014:418). Disclosure becomes complex because of its consequences. PLWH tend to avert the instability that might follow the disclosure of their HIV status, such as divorce, humiliation, abandonment and psychosocial effects due to stigmatisation (Gari *et al.*, 2010:1, 2; Salako *et al.*, 2016:21-22).

Disclosure of HIV status triggers negative reactions of stigmatisation, such as rejection by family and not being forgiven by partners (Tshweneagae *et al.*, 2015:5). PLWH often find themselves without social support as PLC and the community retract their social assistance following disclosure of HIV status. Furthermore, the community stigmatises PLWH through judgement – labelling them as killers (Malatji *et al.*, 2014:418).

PLWH fear negative reactions of disclosure (Gaskins *et al.*, 2011:367-373). PLWH also registered fear of physical assault and verbal abuse and fear of being sexually assaulted, making it even more difficult to disclose. Relationships become so violent that women are forced into sexual relations without protection and use of condoms, with heightened fear of violent killings due to HIV-stigma following disclosure of one's HIV status (Malatjie *et al.*, 2014:416). PLWH do not disclose for fear of being stigmatised following disclosure of their HIV status (Sadoh & Sadoh, 2009:30). Malatjie *et al.* (2014:416) found that family members and the community look at PLWH with suspicion and label them with terms like *prostitutes* and *evil*. Isolation by others contribute to PLWH choosing not to disclose. PLWH in India, Ghana and South Africa fear that their confidants will disclose without their consent, with subsequent accusation and abandonment (Mbonu *et al.*, 2009:3-6; Dageid *et al.*, 2012:933).

### **2.3.1.2 Protecting others from HIV-stigma**

Because family members of PLWH are often stigmatised through association, PLWH choose not to disclose in an effort to save their families the embarrassment. The relationship of PLWH and the family becomes shallow and PLWH fear that they will become a burden to the family (Gaskins *et al.*, 2011:367-373). To protect others, PLWH engage in superficial relationships (Greeff, 2013:86). Family members would react in shock at the news of their loved one's HIV-positive status. Therefore, PLWH tend to avoid exposing the loved ones to the trauma of discovering their HIV-positive status, so they stop visiting family (Linda, 2013:22). PLWH explained that they did not disclose their HIV status, in order to protect either an elderly, frail or sick parent (Linda, 2013:22).

PLWH and caregivers would not disclose HIV positive status because of not being well prepared to respond to difficult questions by the children (Demmer, 2011:875-877).

The protection of children from stressful situations of stigmatisation was one of the reasons for not disclosing HIV positive status (Yeap *et al.*, 2010:1104-1105). Children bear the brunt of the negativity of stigmatisation (Greeff, 2013:86). PLWH prefer not to disclose their HIV positive status in situations where children are involved, because of the anticipated challenges. They would fear that the children would be stigmatised, with negative consequences for their emotional and physical health (Vreeman *et al.*, 2013:1).

### **2.3.1.3 Relationship affected by HIV-stigma**

Distrustful relationships with health workers; confidentiality; fear of disruption of close relationships and fear of being chased away from own home are cited as reasons not to disclose HIV positive status (Greeff, 2013:86). Intimate relationships are often affected by disclosure and therefore, PLWH refrain from disclosing HIV positive status (Clum *et al.*, 2013:191).

Shisana *et al.* (2016:235) point out that marriage patterns and its impact on HIV have not been well distinguished. They found that HIV incidence was low among married spouses who were living together, but higher among unmarried partners who were co-habiting. Those who were co-habiting were within the unemployed, poor economic brackets staying in informal settlements with very low social cohesion. Cohabiting encourages loose relationships and multiple sexual partners with a high risk of contracting HIV. Non-committal relationships do not support disclosure processes of HIV positive status (Shisana *et al.*, 2016:239).

Disclosure of HIV status is deemed important for PLWH and their partners, as well as prevention and management processes (Haberlen *et al.*, 2015:241). Haberlen *et al.* (2015:246) report that disclosure of HIV positive status in newer relationships may be difficult and would require support because disclosure could have positive but also negative outcomes. In a relationship with children involved, disclosure of parental HIV positive status affect the children. Cederbaum *et al.* (2013:158-159) concluded that although disclosure of chronic illness by parents may reduce emotional strain of children, HIV causes a lot of stress for children. It is further explained that in as much as HIV disclosure is stressful, it can also yield positive results by improving parent-child relationships. Children of HIV positive parents often adopt new roles of care



taking and premature parenting (Cederbaum *et al.*, 2013:159). Children assume a protective role of concealing parents' HIV status and subsequently suffer stress (Bogart *et al.*, 2008:251-253). The children also do not receive assistance and support from circles outside the family. Disclosure of parental HIV status affects parent-child relationship to the extent that children may engage in risky behaviours (Kyaddondo *et al.*, 2013:40). Disclosure of a mother's HIV status opens up more possibilities for conversation between the HIV positive parent and the child (Rochat *et al.*, 2014:335-337). In these cases, the children's questions were more related to death and dying, which could indicate the level of stress children experience during the disclosure of parental HIV status. It is suggested that a partner's knowledge of a mother's HIV positive status nurtures a good relationship and supports an HIV positive mother's disclosure to the child (Rochat *et al.*, 2014:335). Communication between adolescent children and their parents is vital in the disclosure of HIV positive status (Mburu *et al.*, 2014:1). However, the process of disclosure includes various factors that either hamper or enhance the process. Dictating community practices prevent parents from talking about sexuality with their children, which impacts negatively on disclosure. Parental disclosures of HIV positive status enhances better communication between the parent and the adolescent. Disclosure of the adolescents' HIV positive status may facilitate access to care and support (Mburu *et al.*, 2014:1).

#### **2.3.1.4 Community factors**

The degree of education of the community and the degree of HIV-stigma in the community like rejection, ridicule and blame, are identified as reasons for non-disclosure of HIV positive status by PLWH (Greeff, 2013:86). The negative experiences of PLWH following disclosure as experienced by other PLWH who disclosed their HIV positive status, is also cited as a reason for not disclosing HIV positive status (Greeff, 2013:86). The choice not to disclose is compounded by previous stigmatising experiences of others or self in the community (Yang *et al.*, 2006:722). In the HIV and AIDS information reporting on the challenges associated with disclosing ones status, Worth, Patton and Goldstein (2008) indicated that PLWH will not disclose to communities as they fear ostracism and community rejection (Benard 2010). A study on social sharing of personal information found that sharing a life-threatening condition evokes negativity from others about the affected party

(Cantisano *et al.*, 2012:1263-1265). In a comparison among diabetes, cancer and HIV positive individuals, it was found that PLWH were more apprehensive than diabetic and cancer individuals in terms of disclosure of their illnesses. PLWH felt the disclosure would reflect negatively on them, they would be rejected by communities and would also lose control over their decision to disclose. As such the study found that PLWH disclosed their illness far less than the cancer and diabetic individuals (Cantisano *et al.*, 2012:1261).

### **2.3.2 Stigma-related reasons for disclosure of HIV status**

The decision to disclose HIV positive status is motivated by circumstances and is weighed for the potential benefits (Greeff, 2013:85). The reasons to disclose HIV status will be discussed below, as categorised by Greeff (2013:85) into personal needs, response to the needs of others and fulfilling interpersonal needs.

#### **2.3.2.1 Response to personal needs**

Greeff (2013:85) highlighted personal stress, the burden of leading a double life and wanting to break the silence as reasons for HIV positive status disclosure. Furthermore, there is also a willingness to learn about a person's HIV status, develop better coping mechanisms; access to support (emotional, material, tangible and health related); access to medical and financial services, improved mental health, decrease in depressive symptoms, greater quality of life and forced choice of disclosure (physical health and visibility of symptoms). The choice of PLWH to disclose is additionally motivated by the need to gain support (Smith *et al.*, 2008:1271), as PLWH need financial support in order to procure the amenities that are needed on a daily basis (Sadoh & Sadoh, 2009:30-31, Greeff, 2013:85). Disclosure for PLWH would relieve the stress caused by a secret they are harbouring (Gaskins *et al.*, 2011:363-373).

PLWH require health care services and treatment (Greeff, 2013:85). Patel *et al.* (2012: 358) and Fay *et al.* explain that disclosure of HIV positive status may increase access to medical care for PLWH. It makes it easy for PLWH to receive HIV and AIDS management and care, including ART, when staff in the clinics have information about an individual's HIV status. PLWH would disclose to increase their chances to access services like ART, and including PMTCT programmes (Malatjie *et al.*, 2014:417).

In terms of social relationships, a model of HIV disclosure revealed a correlation between disclosure and social relationships for basic support (Bairan *et al.*, 2007:248). Basic needs are important for day to day living for all individuals, including PLWH. Housing, food and employment are pivotal in the lives of PLWH and disclosing HIV positive status (Dageid *et al.*, 2012:931). By disclosing, PLWH stand to gain *emotional support* and increased social care, leading to a better life (Patel *et al.*, 2012:360-361; Olagbuji *et al.*, 2011:486). Emotional support will build self-esteem and have a positive effect on compliance to treatment (Jagannath *et al.*, 2011:290). Emotional stability facilitates decision making. PLWH's chances to make decisions for healthy living and a safer sexual life could be optimised by disclosure (Moskowitz & Seal, 2011:624).

### **2.3.2.2 Response to the needs of others**

Responses to the needs of others are identified as: Fear of what will happen to their children, involvement in preventative activities, wanting to break discrimination and stigma in the community, a desire to change the perceptions of the illness, a need for, a duty to inform/educate others and helping others not to make the same mistakes (Greeff, 2013:85). The need to tell others is critical for PLWH. The partners, children and family around PLWH can also be affected by HIV-stigma (Greene *et al.*, 2013:138). Within family circles PLC are often protected. PLWH may consider it to be to the disadvantage of PLC to disclose (Greene *et al.*, 2013:149). In cases where the PLC had a recent emotionally charging experience in relation to HIV or a death of a family member due to HIV and AIDS, the PLWH would choose not to disclose (Greene *et al.*, 2013:149). Cantrell *et al.* (2013:302) developed a paediatric HIV disclosure process, involving a process-oriented framework which allows developmental discussion around HIV disclosure between the care givers and the HIV positive child. The framework takes the child's developmental readiness into consideration supporting the child's conceptualisation of his condition.

PLC should be able to make informed decisions about receiving the news of the HIV positive status of the PLWH. The thought of their children suffering after the death of the PLWH, prompts them to disclose their HIV status (Greeff, 2013:85). PLWH disclosed because of the need to protect others. They do not only want to protect others emotionally, but also physically from getting infected. It has been found that PLWH disclosed their HIV positive status to protect those caring for them from

accidental infection through injury while taking care of them (Grodensky *et al.*, 2015:19).

Economic needs motivate PLWH to disclose in order to gain support for the family (Greene *et al.*, 2013:148). In disclosing their HIV status, PLWH wish to increase their own social support and support for their children (Greene *et al.*, 2013:152). PLWH prepare for their children should they be orphaned, so that they should not suffer. PLWH aim at changing the communities' perception of HIV and make them understand the disease (Greeff, 2013:85-86). Poindexter and Shippy (2010:37) explain that PLWH feel the need to have control over their circumstances – protecting them from stigmatisation following disclosure. PLWH who disclose their HIV status to sexual partners tend to enjoy better sexual relations (Patel *et al.*, 2012:361).

### **2.3.2.3 Fulfilling interpersonal needs**

The readiness to inform others, the importance of being involved in peer or community education and support and the fulfilment of interpersonal needs make disclosure almost therapeutic (Greeff, 2013:85). Poindexter and Shippy (2010:379) explain that PLWH experience transformation over the difficult disclosure process. Alternatively, they come to disclose their HIV status willingly. At this stage PLWH are in a position to make a decision to disclose. A Kenyan study demonstrated that disclosure of HIV status increased the possibilities of protection of others by PLWH (Moyer *et al.*, 2013:69). Even though the disclosure process in the Kenyan study was obligatory, the PLWH's desire to inform and protect others was facilitated. Experiencing fulfilment after disclosure came about in the following ways: sisterhood, healing from the burden of secrecy, understanding the meaning of being HIV positive and leading a normal life (Machtinger *et al.*, 2015:187). Disclosure leads to honest and healthier relationships for PLWH. PLWH have the desire to tell others in an attempt to avoid being gossiped about (Manyedi *et al.*, 2010:39).

## **2.4 Outcomes of disclosure of HIV status**

It is emphasised that disclosure of a person's HIV status can either be detrimental or beneficial to the individual's health and well-being (French *et al.*, 2014:105). Stigmatisation is highlighted as one of the challenges in the disclosure of HIV status (Vreeman *et al.*, 2013:1).

## **2.4.1 Positive outcomes of HIV status disclosure**

When disclosure is guided and supported, it often results in positive outcomes for the individual, the community and the health care system (Greeff, 2013:88). Personal gains and benefits to others are discussed below.

### **2.4.1.1 Personal gains**

PLWH experience personal gains from partners and relatives. Adherence to ART improves on disclosing their HIV positive status (Mwanga & Mmbaga, 2012:43). Disclosure opens up more personal opportunities for active participation in the community (Smit *et al.*, 2012:1; Patel *et al.*, 2012:358). PLWH are able to negotiate their own positions in different community networks for social benefits through disclosure (Tom, 2013:1). Disclosure also has positive benefits such as: personal gains for the individual, heightened sense of self-understanding; a positive feelings of relief and freedom; a sense of accomplishment and pride; empowerment and purpose; feelings of reward; welcome relief from the burden of secrecy and rumours; ease of further disclosure; helping to clear one's conscience; serving as a psychological shield to protect oneself from indulging in unprotected sex; a less stressful and more productive life; authenticity in relationships with others; improved coping mechanisms and improved health; catalyst for access to essential resources; and taking positive leadership roles in the community (Greeff, 2013:88-89).

### **2.4.1.2 Benefits to others**

Mwanga and Mbaga (2012:43) suggest that disclosure facilitates prevention of the spread of HIV infection to others. When HIV positive status is disclosed, the partner will make informed decisions concerning intimate sexual relations or the injection of drugs. Positive leadership roles develop in the community further increasing social support for the PLWH. If community members know that an individual is HIV positive, community structures like non-governmental organisations give support to the PLWH (Cluver *et al.*, 2015:57).

Health professionals in the health care system believe that disclosure of HIV status will provide health care environments that create access to health resources. O'Malley *et al.* (2015:5-6) report that health professionals strongly motivated that disclosure of

HIV status will improve adherence, reduce risky sexual behaviour and improve the individuals' ability to recognise side effects. They also found that communication between the health professionals and patient would improve. PLWH accessing health care and treatment have the advantage of improved well-being (Cluver *et al.*, 2015:57).

Even in the employment sector, disclosure of HIV positive status of employees is beneficial. Various companies that disclose to the employer are able to avert the systemic negative economic impact of HIV (Mokoaleli-Mokoteli & Ojah, 2010:1). They are able to plan and work on critical issues such as making HIV testing and treatment available in the workplace, including training and information sessions for employees (Feeley *et al.*, 2013:98)

#### **2.4.2 Negative outcomes of HIV status disclosure**

Negative consequences of disclosure of HIV status include consequences to self; reactions by PLWH; reactions by the partner and reactions by family and community (Greeff, 2013:87).

##### **2.4.2.1 Consequences to the self**

These consequences include negative self-evaluation, a low self-esteem, negative feelings and denial, fear of being a disgrace to the self and family and affected physical health. PLWH are denied social support in the process. They internalise the attribute that they do not conform to societal norms (Greeff *et al.*, 2008a:316). As they disclose, PLWH are emotionally affected and present guilt and shame (Cantisano *et al.*, 2012:1264). Because of these feelings of shame, PLWH evaluate themselves negatively, lose self-esteem and experience anxiety. The negative reactions about the self result in self-exclusion, leading to social withdrawal (Greeff *et al.*, 2008a:316).

##### **2.4.2.2 Reactions by the PLWH**

Greeff (2013:87-88) reports that PLWH contemplate suicide, have negative perceptions about themselves, withdraw from societal activities and also do not access information, treatment and care out of fear. PLWH react in fear of negative outcomes of disclosure of HIV positive status like divorce, discrimination and stigma in disclosing (Mwanga & Mmbaga, 2012:44). They are emotionally charged and mentally affected,

as they are rejected by partners after disclosing (Greeff, 2008a:322). Linda (2013:22) explains that some PLWH had doubts about disclosing their HIV positive status experiencing worry and fear. It is difficult for most PLWH to disclose as seen in their default reaction of hiding their status until it reveals itself when they get sick and weak (Linda, 2013:22). The author also mentions that for some, disclosure of HIV positive status brought relief. The element of relief made the PLWH “feel free”.

#### **2.4.2.3 Reactions by the partner**

Some partners may present negative responses while others are supportive of PLWH on disclosure of their HIV positive status. On disclosing, PLWH lose material and financial support from their partner (Mwanga & Mmbaga, 2012:42). The PLWH are ruled by negative attitudes and fear of rejection by the partner and then decide not to disclose (Greeff *et al.*, 2008a:322). Hostility may be experienced and the partner may evict the PLWH from their homes. Greeff *et al.* (2008a:322) also reported that some partners chase the PLWH away from their homes as soon as they are discharged from hospital, which makes it even more difficult for PLWH. Partners also avoid physical contact with PLWH (Greeff *et al.*, 2008a:322). One participant in a study by Linda (2013:23) recounted how she was rejected by a partner following disclosure of her HIV positive status. She was deserted by the partner and had no means of supporting her children.

#### **2.4.2.4 Reaction by family and community**

A study on disclosure of HIV status, experiences and perceptions of PLWH and nurses, highlights that families and communities reacted differently to disclosure of HIV status by PLWH (Greeff *et al.*, 2008a:321). PLWH were blamed for not conforming to societal expectations and for having poor morals. The family feared embarrassment – PLWH were kept in seclusion so that they would not be seen by others. In some instances when PLWH’s physical health was good, the community did not always believe that the individual was infected. The community’s understanding was, that if an individual were HIV positive, the symptoms must be visible and the individual would be very sick. Family avoid physical contact with PLWH for fear of infection. There is an element of shock, disbelief and denial, with serious implications for PLWH being expelled from home and family circles (Greeff *et al.*, 2008a:322).

Failure to follow a structured process for disclosure of HIV positive status can have detrimental outcomes for the individual, family and community (French *et al.*, 2015:95). The reality of the challenges in the disclosure process poses a threat to PLWH. When individuals' disclosure processes are not guided and supported, their fears become a reality and they will continue with risky behaviours, such as unsafe sexual practices (Eustace & Ilagan, 2010:2095). Matlakala and Mokoena (2011:485) found that disclosure of HIV status of PLWH to family members often results in rejection of the PLWH. A certain study that focused on youth being HIV positive found that violence, exclusion and rejection are commonly experienced by the youth who disclosed their HIV status (Martinez & Chakraborty, 2014:559).

Linda (2013:22) explained that other people reacted with shock and were devastated by the news that someone they know is HIV positive. In communities disclosure without clear delineated pathways can be atrocious and fatal. For example Gugu Dlamini – despite being an activist on HIV matters – suffered the harshness of an unguided disclosure process and was killed in the community (McNeil, 1998). In the community PLWH were excluded from economic development processes such as being denied housing or employment (Senyolo *et al.*, 2015:103-105). The authors also mentioned that after disclosing, PLWH were labelled and isolated by communities.

## **2.5 Approaches to management of disclosure of HIV status**

The disclosure of HIV positive status by PLWH is often desired, but the circumstances and timing of disclosure will vary. Before individuals disclose their HIV status, they should properly assess the rewards (benefits) and consequences (risks) the disclosure may have on their personal and social lives (Serovich *et al.*, 2008:23). Bird and Voison (2010:368) proposed a model of HIV disclosure in casual sexual encounters among MSM. HIV disclosure is a complex phenomenon that engages both cognitive beliefs about the risks of disclosure, beliefs about personal responsibility and privacy and assumptions about a partner's HIV status, the sexual setting, and what sexual risk is occurring. An individual's decision to disclose is likely to be influenced by many factors. The model suggests that it is essential that the interconnectedness between cognitive and contextual domains be fully considered as the individual explores his/her HIV status disclosure.



It is explained that HIV status disclosure is an intricate process which cannot always be an immediate action but rather evolves over time (Rotheram-Borus *et al.*, 2011:322). Linda (2013:25) explains that disclosure is not linear or unilateral and occurs during varying time periods. Some find it comfortable to disclose within a shorter period while others take long before they can disclose. The need, reasons and practical things affecting PLWH's life are assessed; PLWH weigh reactions of the recipients of the disclosed information; as they strive to adhere and remain on treatment PLWH, negotiate their disclosure; and they also adjust their way of living to accommodate some of their activities of HIV management like drinking ART or disclosure of HIV status. In addition, the people to whom PLWH disclose, are afforded time to accept and adjust to the disclosure. Chidrawi *et al.* (2014:227) confirms that PLWH disclose at different times: some PLWH disclose immediately after diagnosis while others disclose in a week, a month or even years later. Different researchers' approaches to disclosure of HIV positive status are outlined below.

Kimberly *et al.* (1998:320-321) discuss the disclosure process application following the stories of five women disclosing their HIV positive status. Even though the stories of the five women were different, as related by themselves, it was apparent that all followed a pattern captured in the six steps of disclosing. The steps for disclosure are identified by Kimberly *et al.* (1998:320-321) as follows: Adjust to the diagnosis and shock of HIV infection and taking different time periods to start the process of disclosure; evaluate personal disclosure skill; take inventory and deciding who to disclose to ranging from family, friends to the broader community or network; evaluate potential recipients' circumstances; anticipate reactions of the recipients; and evaluate motivation for disclosure, looking into social support and someone to talk to which includes PLWH's obligation to inform the next person.

The NDOH (2005:38) in South Africa outlines broad and limited principles that guide disclosure of HIV positive status to family, children, partner and to public in the guiding toolkit. It only states that if PLWH want to disclose, they should consider why, when, to whom, and how they want to disclose. Miller and Rubin (2007:587) in their discussion of factors for disclosure of HIV positive status, make the assumption that people when communicating important (personal) matters follow a process and

calculate the risks, provide information to limit and control boundaries, use decision-making rules to determine when, to whom, and how much to disclose.

Greeff (2013:89-90) describes a practical approach for responsible disclosure management:

- Understand the concepts disclosure and non-disclosure;
- Gain knowledge of the total context of disclosure process (before during and after disclosure);
- Know the reasons why you are disclosing or not disclosing your status;
- Make a list of necessary circumstances explaining why you are disclosing and weigh the benefits and disadvantages;
- Weigh up both the positive and negative consequences of disclosing;
- Make a list and weigh up the consequences;
- Make a list of the necessary circumstances explaining why you are disclosing or not disclosing;
- Make a list of what will make it easier for you to disclose, for example, counselling, privacy, place and the nature of the relationship;
- Make a list of ways not to disclose;
- Choose whether you are going to disclose or keep silent. If you are going to disclose, continue with the exercise;
- Make a list of the feelings you are experiencing at the moment;
- Decide to whom you are going to disclose;
- Decide how much you are going to disclose;
- Evaluate the knowledge that the person has to whom you are going to disclose;

- Determine when the time will be right for you to disclose and list possible post-disclosure coping problems.

The disclosure approach as described by Greeff (2013:85) suggests that non-disclosure and disclosure should be understood before the process can continue. It can only be reasonable if reasons, positive and negative consequences, advantages and disadvantages for disclosure can also be identified. There needs to be an exploration of circumstances in terms of personal feelings, how much and to whom to disclose. Another consideration is the right time to disclose and how to cope after disclosure.

Greeff (2013:76-77) discusses theories that underpin strategies that assist PLWH to disclose. The *Disease progression theory* allows PLWH to talk about their HIV status as their illness progresses. The symptoms of the disease become so noticeable that it gets difficult to hide the illness on a day to day basis. This allows for protection of others and of oneself against stigmatisation. In *Consequence theory*, PLWH start by weighing what is beneficial against the negative outcomes disclosure of HIV positive status. PLWH will lean more towards what is positive than what would be detrimental for their survival following disclosure. HIV disclosure decision making focuses on the social environment and the relationship and network environment. The social environment assesses the cultural platform and community prescripts of behaviour before consideration not to disclose or not. The auditing of social relationship networks assists PLWH in deciding to whom they will disclose. Finally PLWH use the *Communication privacy management model*. It assists with the assessment of personal needs, the needs of others and whether to infringe their own privacy in a controlled manner through boundary systems developed for control of information. This process will ultimately assist PLWH to answer the why, who, what, how, and when during the process of disclosure.

The national guideline for adherence of HIV, TB and non-communicable diseases (NCD) promotes adherence integration with chronic disease management (NDOH, 2016:26) through fast lanes, decanting to clinic and community clubs, including pick up points for chronic diseases. Similarly these guidelines poorly refer to HIV-stigma reduction but substantially makes reference to disclosure. However, there is special

reference to non-disclosure below two years, partial disclosure from three to nine years and full disclosure from 10 years of age to adolescence (NDOH, 2016:105).

## **2.6 The primary health care system in South Africa**

The health care system in South Africa renders health services, including HIV/AIDS management, to 80% of the population through a PHC approach (Gibson *et al.*, 2013:1). Following the Alma Ata Declaration (1978), conference member countries (including South Africa) committed to rendering comprehensive PHC services (Dennill *et al.*, 2000:4). In 1994 South Africa recommitted to render comprehensive services through the district health system in hospitals, clinics and on community level (Dennill *et al.*, 2000:41). The years between 1994 and 1997 were transitional to free PHC services, and as a result head counts in clinics increased drastically against the static resources (Wilkinson *et al.*, 2001:665). The overly burdened services, shortage of staff and supplies became the daily realities in the PHC clinics (Sprague *et al.*, 2011:311-324; Uebel *et al.*, 2013:132-163). Nurses and doctors were, and still are, overburdened by the large numbers of PLWH they had to care for (Moosa & Gibbs, 2014:148-149). When numbers of patients increase in hospitals, patients are referred to PHC clinics; this includes large numbers of PLWH (Nyasulu *et al.*, 2016:233; Morsheimer *et al.*, 2014:148-152). These referrals to PHC clinics continued to increase the workload in PHC facilities where services are mainly rendered by nurses as the backbone of the health care system. In addition, nurses have to work in the complexities of the quadruple burden of disease that includes HIV and AIDS (Moosa & Gibbs, 2014:151-152).

### **2.6.1 HIV and related stigma management in primary health care settings**

The report of the international conference of 1978 on PHC states that PHC is “*essential care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development, in the spirit of self-reliance and self-determination*” (Dennill *et al.*, 2000:2). It is care made available for individuals and families with different health conditions and infectious diseases Dennill *et al.*, 2000:2-3). PHC is needed to prevent and control diseases and provide care for the sick. In the wake of the changing health demands, complicated by disease patterns that are

changing, the Dennill *et al.* (2000:1-38) highlighted the critical operational areas to be managed for better health outcomes in PHC as being the availability of human, financial and material resources; the right attitude to treat all with respect; and the use of HCWs at a specific level. The delivery of health care services is assessed through the guidance of policies, social, economic and health status indicators at PHC level (Dennill *et al.*, 2000:20-23). However, the PHC guiding characteristics that were set out, were not followed, and this resulted in a more curative-oriented service.

Only in later years did the focus shift to affordable and accessible PHC (Petersen & Swartz, 2002:1005). Petersen and Swartz (2002:1005-1007) explain that health care is demand-driven and vertical health programmes have been implemented since the late 1980s. Added to this was the management of HIV and AIDS as a new separate programme (Tollman *et al.*, 2008:893). The programme was implemented following the first diagnosis of HIV and AIDS in 1982 and the first HIV and AIDS related death recorded between 1981 and 1982 in South Africa (Simelela & Venter, 2014:249). The implementation of HIV and AIDS treatment continued in isolation of other health services (Uebel *et al.*, 2013:173).

In the 1980s and 1990s very little effort was put into managing HIV, except for preventative measures such as condom distribution and health education (Simelela & Venter, 2014:249). HIV and AIDS became an evolving health care challenge that required urgent attention and priority (ANC, 1994:31, 42). The HIV epidemic coincided with the inception of the democratic government in South Africa and the development of the new district health system as a vehicle for PHC (Dookie & Singh, 2012:1). The Networking HIV/AIDS Community of South Africa (NACOSA) drafted the National AIDS Plan which was adopted in 1994, but not implemented due to denialism by political leadership in the country. The above-mentioned political denialism was a serious hindrance to the progress on the management of HIV infection (Joachim & Sinclair, 2013:1). Amidst all the confusion, the South African National AIDS Council (SANAC) was formed in year 2000 (McNeil, 2012). The first 2000-2005 HIV, AIDS and STD national strategic plan was also formulated in 2000 (NDOH, 2000-2005), but the comprehensive mass scale-up plan for ART roll-out remained absent from that plan. Certain clinics did, however, start to provide ART and individuals were counselled before and after testing. McNeil (2012) describes how in 2003 the Treatment Action

Campaign (TAC) went on a campaign to force government to provide ART, which was then availed to PLWH in 2004. During this period, only appropriately trained doctors could prescribe ART for PLWH in hospitals and clinics that met specific criteria of accreditation to provide ART. In 2006 the second 5-year HIV and AIDS strategic plan 2007-2011 was launched, calling for a multi-sectoral response with a stronger emphasis on ART.

In 2009 the newly appointed minister of health in South Africa, Dr A. Motsoaledi, made a commitment to test individuals for HIV and treat all HIV positive children and mothers with ART (Simelela & Venter, 2014:250-251). In order to realise this commitment, South Africa trained 250 nurses in 2010, increasing the number of nurses to 23 000 by the end of 2013. These nurses were trained in nurse-initiated management of antiretroviral therapy (NIMART), and rolled out to 3500 health care facilities to increase the availability of ART (Bekker *et al.*, 2014; Grimsrud *et al.*, 2015). NIMART was accompanied by certain implementation challenges that related to confidence in clinical care of the nurses, non-availability of material and human resources including the ART itself (Georgeu *et al.*, 2012:50-66). The availability of ART was a challenge in 2010, when only 25% of the PLWH could be provided with ART in that year. In 2011 the third 2012-2016 national HIV strategic plan was developed, with the major focus on reducing new HIV infections by 50% and initiation of 80% of PLWH on antiretroviral treatment (ART). It would also ensure that 70% of PLWH were retained on treatment five years after initiation. Key objectives of the plan included reducing the number of new TB infections and deaths from TB by 50%; accessibility to legal framework for protection of human rights; and reduction in self-reported stigma related to HIV and TB by at least 50% (NSP, 2012-2016:12). The framework, however, did not outline how HIV-stigma should be reduced. The most recent NSTP 2017-2022 entrenches the fight against stigma within human rights principles and approaches which are more community based (NSTP, 2017-2022:30-31).

The President's Emergency Plan for AIDS Relief (PEPFAR) supported the implementation of the model for integrated chronic disease management (ICDM) by the National Department of Health (NDOH, 2011a:16). ICDM refers to managing PLWH on ART but no mention is made of HIV-stigma reduction. The model strives to empower individuals to be responsible for their own health. The approach in ICDM

follows primary prevention through health promotion, secondary prevention by treatment and care and secondary prevention that includes rehabilitation and palliative care. The directive for clinics to implement the ICDM model, which included HIV care into PHC for improved access to health care, was guided by the National Strategic Plan on HIV, STI and TB framework 2012-2016 (NDOH, 2012a:51). The framework also guided the provision of ART to pregnant women after 14 weeks of gestation, and lifelong treatment for mothers and for those with a CD4 count of 350 and below (NDOH, 2012a), which was a great achievement. Furthermore a one-pill ART treatment was made available in 2014 (NDOH, 2014) and in 2016 it was announced that ART would be available to all (Child, 2013). These initiatives intensified the curative approach to HIV management, but HIV-stigma reduction featured minimally in the process.

The health care system as originally planned to function from a PHC philosophy, was affected by HIV and had to provide health care in different ways to deal with the scourge of this disease (Sobnach *et al.*, 2012:196). In response to the burden of disease, authorities shifted resources in PHC and cut budgets in some of the higher levels of care in order to deal with HIV. In an attempt to improve health services, the South African government introduced the National Health Insurance (NHI) in the phase of the above-mentioned shortage of resources as well as the quadruple burden of disease (Naidoo, 2012:149-150). The health care system had to be reorganised in order to keep up with the fast-changing environment of health care service demand. A new approach to health service delivery was implemented in South Africa in 2011, referred to as PHC re-engineering (Pillay & Skordis-Worrall, 2013:321-331). The main focus of the process was to increase life expectancy, decrease maternal and child mortality, combat HIV and AIDS, tuberculosis and other diseases, and strengthen the health care system as aligned to the key outputs of NSDA, 2010-2014 (Naledi *et al.*, 2011:23). The new accelerated approaches of change programmes in PHC re-engineering included the district clinical specialist teams (DCST). These teams emphasized the strengthening of the district health system through training different categories of health workers; supporting health programme collaboration and implementation; providing clinical guidance and supervision (Voce *et al.*, 2011:56-57); ward based outreach teams (WBOT) that consisted of nurses as team leaders and HCWs working in the communities with a direct link to a clinic within the specific

geographical ward coverage taking health care into communities; and lastly the integrated school health programme (ISHP) team that implemented basic health screening and preventative care in early childhood centres, primary and secondary schools, including reproductive health services and HIV counselling and testing (HCT).

There is more emphasis on quality in the National Core Standards (NCS) that provide a framework for the mentioned PHC re-engineering (NDOH, 2011b:8). The NCS processes are also implemented to ensure compliance of health facilities and clinics to specific standards for health care (NDOH, 2011b:8-10). The process ensures quality care in the clinics and hospitals in South Africa, with the current focus being the six key priority areas outlined to fast track quality health services. These six key priority standards are prevention, management and control of infection, cleanliness, managing values and attitudes of health service providers, ensuring safety and security of patients and staff and making medicines and supplies available in the hospitals and clinics (NDOH, 2011b:15).

In addition to the quest for access and improved PHC services and HIV management, the Operation Phakisa Ideal Clinic Realisation Programme was implemented (Ideal clinics projects) (NDOH, 2015a:3), while PHC services still have to cope with all the above-mentioned challenges on a daily basis (NDOH, 2015b:3-4). The guidelines on Ideal Clinics makes the availability of resources mandatory, including the establishment of good infrastructure, adequate staff, adequate medicine and supplies, good administrative processes, adequate bulk supplies that use applicable clinical policies, protocols, guidelines and partner-to-stakeholder support (NDOH, 2014:3). The availability of resources in health will foster the long outstanding programme of National Health Insurance (NHI) for quality PHC services (NDOH, 2014:4). Government is striving towards improving access to health care services for all patients including PLWH. Nurses learn and implement these top-down change programmes to improve access and health services including HIV management and care in the hospitals and clinics.

### **2.6.2 HIV-stigma management approaches in primary health care settings**

In the context of all these developments in hospitals and the PHC setting with a mass influx of HIV patients, overburdening the services and having limited resources, the government attempted to improve HIV management by establishing guidelines for



health services. An international project on devolving ART provision to PHC addressed challenges that hamper health service delivery at PHC clinics, like HIV-stigma (Pfeiffer, Montoya, Baptista, Karagiani, De Morais Pugas *et al.*, 2010:9-10). In addressing stigma, managers were guided in educating PLWH about processes that would promote working together with other PLWH, providing leadership on importance of reducing HIV-stigma and promoting community campaigns against HIV-stigma (Pfeiffer, *et al.*, 2010:9-10). The project referred to addressing HIV-stigma among different groups within communities and did not guide HIV-stigma reduction in a PHC clinic.

In terms of financial support for HIV and AIDS, the Presidential Emergency Plan for AIDS Relief (PEPFAR) was the main sponsor for the period 2003-2008, focussing on HIV and AIDS as an emergency in South Africa. In this period many nurses were trained on ART roll-out. In the South African Health Review [SAHR] 2012/13, it is mentioned that the funding period has since been extended to 2017, as government was not ready to take over this huge task (Venter, 2012/13:38-44). The need to build further capacity in ART roll-out was identified and even though reduced by 50% yearly, the funding has been continued to 2017 (Venter, 2012/13:38-44). Capacity building and sustainability are planned through the integration of HIV with broader health programmes. The PEPFAR funding furthermore made provision for research to evaluate the impact of the relief funding on the different ways of fighting HIV.

The roll-out of ART presented challenges ranging from human to material resources (Zachariah *et al.*, 2009:550). This resulted in task shifting, where nurses were doing work beyond their scope demanding that and skilled nurses cope with demands placed on them. Nurses started to treat opportunistic infections and they prescribed ART to meet the demands of increasing numbers of PLWH needing ART (Zachariah *et al.*, 2009:551). Change took place even among HCWs. HCWs started providing services that they have not provided before such as managing HIV support groups and empowering PLWH who were taking ART. The changes were effected in the Policy Guidelines for Continuous Training on Management of HIV (Sehume *et al.*, 2012:18). Nyasulu *et al.* (2013:233) describe step-by-step initiation of ART by the nurses, but make no mention of HIV-stigma reduction in the process at all. The HIV stigma and discrimination report by UNAIDS, (2018) mentioned that the HIV pre-exposure

prophylaxis (PrEP) treatment in South Africa was implemented in 2015, estimating to reach 30, 000 to 35, 000 individuals. The 2017-2022 NSTP aimed to expand PrPEP and predict to reach 85858 people by 2022 (UNAIDS, 2018). However, in this explanation there is no reference to clear guidelines on HIV-stigma reduction and disclosure.

The following South African based HIV management and care sources regarding HIV and stigma reduction are discussed hereafter. The ANC health plan indicates that non-discrimination of PLWH must be advocated for (ANC, 1994:42), but it does not indicate how HIV-stigma reduction should be managed. The National Strategic Plan on HIV, STIs and TB 2000-2005, presents recommendations to develop concerted effort by all stake holders to protect human rights, counter discrimination and reduce stigmatisation (NDOH, 2000-2005:10). Again, HIV-stigma is mentioned but no clear action guidelines presented. The National Strategic Plan on HIV, STIs and TB 2007-2011 discusses the prevalence of stigma, denialism, exclusion and discrimination. Once again, no mention of the implementation of stigma reduction (NDOH, 2007-2011:33).

The National Strategic Plan on HIV, STIs and TB 2012-2016 outlines the vision of zero discrimination with HIV, STIs and TB. They introduce goals to reduce self-reported stigma and discrimination related to HIV and TB by 50% and a strategic objective to ensure protection of human rights and to increase access to justice. The primary objective is to address issues of stigma, discrimination, human rights violation and gender inequality in order to reduce HIV and TB stigma and discrimination (NDOH, 2012-2016:15, 21 & 53). However, the 2012/16 NSP does not outline any steps to reduce HIV-stigma. The 2017-2022 NSTP focusses on HIV and TB community support groups revitalisation and merger including community social mobilisation strategy (NDOH 2017:31, 74). It approaches the revitalising process through development and implementation of plans, training of outreach peer educators, community dialogues as well as integrating stigma in all programmes for key and vulnerable groups. The key role players are identified as PLWH, people affected by TB, SANAC, Department of Social Development (DSD), DOH, Human Science Research Council (HSRC) and civil society groups inclusive of human and legal rights

groups. The main focus of the 2017-2022 interventions on stigma reduction is in the community and not PHC settings.

In 2012/13 the South African Health Review (Bamford, 2012/13:49-55) identified key initiatives in reducing maternal and child mortality. The need to reduce HIV-stigma and promote disclosure is mentioned in three areas: global strategy for women and children's health; commission of information and accountability for women and children's health; and the commission to child survival a promise renewed and global strategy for elimination of new HIV infections among children, including ministerial mortality committees. Yet, there is no specifications that guide the process of reducing HIV-stigma.

For the Gauteng Health annual report 2014/2015 (Gauteng Department of Health, [GDOH] 2014/2015: 7-9; 38-65), reports are tabled on district health services performance indicators. Indicators that assist in measuring performance for managing HIV and AIDS are highlighted for the hospitals and clinics, but HIV-stigma reduction and disclosure management in a PHC setting does not form part of these indicators. The National HIV counselling and testing guideline (NDOH, 2015:6-7) refers to protection of human rights and does not outline the HIV-stigma reduction or disclosure process. The National Development Plan (NDP) vision 2030 gives guidance to performance of national department of health with reference to HIV and AIDS, but no direct discussion on HIV-stigma reduction in a setting (NDOH, 2014). The National Department of health annual report (2014-2015:35) also discusses HIV and AIDS with no specific reference to HIV-stigma reduction and disclosure management. The objective of the international HIV and AIDS management care 90 90 90 strategy is, that by 2020, 90% of infected persons should be diagnosed, 90% of those diagnosed should be put on treatment, and 90% should be virally suppressed. This robust approach does not seem to guide HIV-stigma reduction or responsible disclosure management in PHC settings either.

All these government programmes adopted a much more physical and biomedical approach in the management of HIV. The major focus was on making ART available to all those who need it following the process of HIV counselling and testing. Most (if not all) documents mention HIV-stigma reduction only very vaguely and do not give

much information on disclosure management. There is still no guide or clarity for people in the health care service to understand the managing of HIV-stigma, impacting health care, limiting access to health care wherein PLWH are not adhering to ART, defaulting treatment, with continued fear of disclosing their HIV positive status. The approaches to PHC services refer to HIV-stigma reduction or management but very little (if any) make an attempt to describe HIV-stigma reduction in PHC setting. Reference is made to HIV-stigma reduction noting that there are no clear guidelines on the approach in a PHC setting. Literature on HIV-stigma reduction and responsible disclosure management confirm enormous amounts of work done on various aspects of HIV-stigma reduction and disclosure management in different areas but not specifically in a PHC setting.

## **2.7 Summary**

HIV-stigma is closely linked to the process of disclosure. The three main categories of disclosure were identified as voluntary, forced and mandatory disclosure. Another form of disclosure – described as anticipatory disclosure – has also been mentioned. Research revealed several reasons for disclosure and non-disclosure of HIV status. Reasons of non-disclosure are fear of stigma and potential consequences thereof, while reasons for disclosure include protecting oneself, others and relationships. Disclosure is motivated by benefits such as accessing resources like health care, social support and physical and mental health. Disclosure could result in positive outcomes for PLWH but may also experience negative outcomes, depending on the reactions of others. It brings about personal gains and opportunities, from positive feelings of relief, improved coping mechanisms to access to resources and benefits such as HIV prevention, among others. PLWH approach the disclosure process by assessing the rewards and risks that affect both their personal and social lives. They ultimately make a decision whether to disclose or not, at what point to disclose and to whom they should disclose their HIV positive status.

South Africa is regarded as a world leader in the provision of ART. There has also been great international financial support for South Africa for the provision of ART. Lately there has been a strong political will to manage HIV. It has become clear, that in South Africa, the majority of the population, including PLWH, access health services at PHC level. PHC is the first point of entry for health care based on the principles of

equity, effectiveness, efficiency, affordability, availability and accessibility. It renders comprehensive PHC services including HIV and AIDS management and care. Relevant literature indicates that the main thrust of HIV management is the provision of ART. Less focus is placed on HIV-stigma reduction and responsible disclosure management. There are several health care management approaches and even guidelines focussed on ART. HIV-stigma is managed mainly through community education, but none of this places sufficient emphasis on HIV-stigma reduction and disclosure management in PHC settings. Therefore, HIV-stigma continues to hamper access to health care services and interfere with the disclosure processes. The policy guidelines mention HIV-stigma reduction, but there are no existing frameworks and no steps are outlined to guide HIV-stigma reduction and responsible disclosure management, especially in a PHC context.

Until now, the critical challenge of stigmatisation in PHC settings has been given very little attention, if any. It is probably the single most important factor for success regarding the needs of those living with the virus and their families. The current study attempts to address the gap regarding HIV-stigma reduction and responsible disclosure management in a PHC setting.

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## **SECTION C: ARTICLES**

### **ARTICLE 1: PERCEPTIONS OF NURSES AND HEALTH CARE WORKERS OF HIV-STIGMA REDUCTION AND DISCLOSURE MANAGEMENT IN PRIMARY HEALTH CARE SETTINGS**

#### **JOURNAL: THE JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE**

The referencing in this article is guided by the journal stipulations with the formatting following the rest of the thesis (Guidelines for the submission of an article to AIDS care are in addendum H).



## **Perceptions of nurses and health care workers of HIV-stigma reduction and disclosure management in primary health care settings**

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## **Abstract**

Primary health care (PHC) is the first point of entry for the people living with HIV (PLWH) into the health care system in South Africa. It however seems the main focus is on antiretroviral therapy (ART) and less attention given to HIV-stigma reduction and disclosure management practices. This study explored and described the perceptions of nurses and health care workers (HCWs) of the latter. In a qualitative descriptive study nine (9) nurses and eighteen (18) HCWs were selected from three PHC settings using purposive sampling. Data was collected through semi-structured interviews and thematically analysed. Nurses were less focussed on their own role and criticised the counselors. They identify constructive and ineffective nursing behaviours and focussed more on structural aspects. Challenging disclosure practices and a supportive environment were mentioned. The HCWs focussed on behaviours of nurses towards PLWH and some organisational problems. HCWs had a much stronger awareness of PLWHs' feelings and needs and identified problems with disclosure management in the environment. Both groups identified a lack in specific health education practices.

*Keywords:* Disclosure, health care system, health care workers, HIV, nurses, stigma.

## **Introduction and background**

Human Immunodeficiency Virus (HIV) related stigma exists since the onset of the HIV pandemic in the 1980s and remains high throughout the world (Kontomanolis *et al.*, 2017:12, 115,116). Stigmatisation associated with this HIV pandemic is a global phenomenon, challenges health care systems and is also evident in sub-Saharan Africa (Tsai, 2015:1). South Africa as part of sub-Saharan Africa provides public health care services for the majority of the population through a PHC system (Dookie & Singh, 2012:2). Within PHC clinics the majority of patients are people living with HIV (PLWH) (Long *et al.*, 2016:1). Unfortunately these clinics are seen as a common locus for high HIV stigmatisation (Khalil *et al.*, 2015:127). The services in these PHC clinics are rendered by doctors, nurses and health care workers (HCWs) who are pivotal in the roll-out, provision of and follow-up of antiretroviral therapy (ART) in all clinics (National Department of Health [NDOH], 2012:5-7). HCWs refer to community members chosen within their communities, to provide basic health care, including HIV care and counselling (NDOH, 2012:10). This article focuses mainly on the perceptions of nurses and HCWs regarding HIV-stigma reduction and disclosure management as the first contact to provide care to PLWH in PHC settings.

### **Defining HIV-stigma**

HIV-stigma is a complex phenomenon and many researchers attempted to define this concept. Different descriptions of HIV-stigma include issues of inequality, fear, prejudice (UNAIDS, 2015) as well as disrespect and discrediting behaviour. Others have defined HIV-stigma within a social context as negative social behaviour of exclusion, rejection and isolation (Dos Santos *et al.*, 2014:1-2). For the purpose of this article the definition by Alonzo and Reynolds (1995:304) is used, namely: “...*the stigmatized are a category of people (HIV) who are pejoratively regarded by the broader society as devalued, shunned or otherwise*

*lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse”.*

### **Conceptual models, frameworks and theories on HIV-stigma**

As seen from the complexity of HIV-stigma depicted above, several researchers attempted to conceptualise stigma through models, frameworks and theories over the years. Reference is made to a few prominent models and frameworks. Alonzo and Reynolds already in 1995 conducted a study on stigma to explore the HIV-stigma trajectory. The trajectory referred to people being at risk of becoming HIV positive; being diagnosed; being asymptomatic and finally the stigma phase with obvious symptoms of the illness (Alonzo & Reynolds, 1995:303-307). Parker and Aggleton (2003:13-14) developed a framework aimed to bring about social change that posed an argument that social power, inequality and hierarchy are powerful social contextual factors to stigma and discrimination. The Siyam’kela (2003) HIV and AIDS research project explored HIV-related stigma to develop stigma indicators. The indicators served the purpose of developing HIV tools to measure stigma reduction. The project categorised stigma as sensed internally and enacted externally.

Holzemer *et al.* (2007:541-549) developed a conceptual model for HIV and AIDS stigma in the African context that described three aspects of importance during the stigma process: the environment (culture, economy, political, legal and policy); health care setting (hospitals, clinics and health workers); and agents (PLWH themselves, family members, work colleagues, community members and health care workers). The stigma process consists of four aspects namely: triggers of stigma; behaviour responses to stigmatisation; manifestation of three types of stigma (received, internal and associated stigma); and specific outcomes of the stigma.

In a study titled 'Dying Twice', a multi-level model of the roots of AIDS stigma in two South African communities, the drivers of stigma were identified as fear; available AIDS information; lack of social space for HIV discussions; link of HIV and AIDS and morality; lack of resources and the impact of poverty in HIV (Campbell *et al.*, 2007:403-404). This model critically evaluated existing stigma management approaches. It needs to be based on bottom-up processes of communities' understanding of stigma challenges and own mitigation processes (Campbell *et al.*, 2007:413). Another model developed by Gilbert (2016:13) referred to the stigma process and adds social context, agents (person, family, workplace and community) and health care systems as forces that shape stigma. The Gilbert model suggests that understanding stigma from the perspective of these forces can help health professionals to focus on specific issues when managing HIV-stigma.

### **Manifestations of HIV-stigma**

Within the government and legal context, Link and Phelan (2006:529) refer to the limitations in legal frameworks that fail to protect PLWH. Countries differ in handling HIV such as mandatory HIV testing in China; while others disregard and abandon laws that protect PLWH such as Australia (Sidibé, 2018) in the Avert report. However, chapter 2 of the South African constitution provides for the protection of the rights of all people including that of PLWH through the Bill of Rights, stating that everyone has the right to access health care regardless of one's HIV status (South African Constitution, 1996). Different countries report on work-place stigmatisation. A Nigerian study reported on PLWH being stigmatised by co-workers who refused to share working space with them (Aguwa *et al.*, 2016:98). Although South Africa has applicable policies regarding HIV and related stigma in the workplace, a study by Khan *et al.* (2014:204) confirmed the existence of workplace stigma. Health workers in health care settings also display stigmatising behaviour through their fear of HIV infection while caring for PLWH (Brisdon *et al.*, 2017:185-188).

Stigmatisation in the health care environment could also occur unintentionally through the structural layout of clinics and hospitals, health care practices and intentionally through the behaviour of health care workers as already mentioned (Scheffler *et al.*, 2015:1). Smaller sized health care buildings and labelled HIV centres are stigmatising. Although the roll-out of ART to PLWH was with good intentions, little attention was granted to stigma (Makoae *et al.*, 2009:1357). Limited resources and lack of policy guidelines in clinics and hospitals for the provision of health services to PLWH might add to stigma (*et al.*, 2014:652-665). HIV-related stigma in health care settings manifests as neglect, abuse, aggressive behaviour, blaming, even exaggerated kindness towards PLWH or disclosure of their HIV status without their consent (Stutterheim *et al.*, 2014:652-665). Through association, health workers who work with PLWH also experience stigmatisation cues whilst other health workers display a fear of stigma (Mataboge *et al.*, 2014:1-7).

### **Outcomes of HIV-stigma**

These outcomes impact negatively on the individual, family, community and health care (Nzaummvila & Mabuza, 2015:1). The outcomes of HIV-related stigma are discussed in terms of the PLWH, the people living close (PLC) to PLWH, the community and the health care system.

### **Outcomes of HIV-stigma on PLWH**

In the context of psychosocial health, HIV-stigma results in low self-esteem making it difficult for PLWH to disclose (Patel *et al.*, 2012:364-365). Social outcomes are the disintegration of family support leading to the neglect of PLWH (Kohi *et al.*, 2006:408-409); self-isolation and denying themselves intimate relationships (Prinsloo *et al.*, 2015:262-263). The employment environment breaches the psychological contract with PLWH and fail to protect them from HIV-related stigma (Bashir, 2011:159). PLWH suffer through hostile work environments of exclusion in the workplace, with the risk of termination of employment and

violations of confidentiality when their HIV status is revealed. There is limited access to health care due to fear of stigma, inadequate follow-up and poor adherence result in PLWH defaulting treatment leading to diminished physical well-being and eventually poor quality of life (Prinsloo *et al.*, 2015:75-80).

### **Outcomes of HIV-stigma on people living close to PLWH**

Children, partners, family, friends, colleagues and spiritual supporters are being stigmatised by association with PLWH and are as such marginalised, subjected to discrimination, excluded and bullied, or the entire family may be sanctioned and isolated (Nayar *et al.*, 2014:155). Stigma disrupts social ties, causes anger and frustration and family disorganisation due to loss of active members and intimate relationships (Asiedu, 2010:6-7). PLWH burden their families with children most often affected and sometimes having to drop out of school to take over the responsibilities of ill PLWH (Barenes *et al.*, 2014:1-2). PLC may experience economic instability if they lose their employment due to stigma (Asiedu, 2010:5).

### **Outcomes of HIV-stigma on the community**

People in churches adopt a judgemental view and avoid talking about HIV and as such PLWH suffer in silence within their congregations due to stigma (Gilbert & Walker, 2010:144-145). The health behaviour of communities at large is such that they do not utilise or access available health services because of fear of being identified with HIV which then undermine their health outcomes (Chidrawi *et al.*, 2014:230-231). PLWH recent using these health care services because of the stigma occurring in these facilities (UNAIDS, 2017:2-4) The lack of general social cohesion result in the destruction of family structures and community support systems (Prinsloo *et al.*, 2015:83).

### **Outcomes of HIV-stigma on the health care system**

In South Africa, hospitals have increased numbers of sick PLWH staying longer in the hospitals, as they only access health care when they are really sick to avoid stigma (Long *et al.*, 2016: 10). This increases the workload of hospital staff (Tamiru & Haidar, 2010:195). In an attempt to manage this influx of patients, the health care system integrated HIV services into general PHC, adding to the strain of health workers in clinics (Mathibe *et al.*, 2015:8-9). This situation is worsened by PLWH who are hiding from their own communities by using clinics in other areas. The increased numbers of PLWH in the clinics then bring along other health care system challenges such as long waiting times. Privacy is compromised by poor PHC infrastructure, designating PLWH to specific areas for care (Mathibe *et al.*, 2015:8). Practices such as delayed provision of PLWH's test results further create negativity towards the health care system (Dookie & Singh, 2012:3-4). The health care system loses patients who miss appointments due to stigmatising behaviour like unprofessional conduct by health care providers and also due to a shortage of resources like staff (Mathibe *et al.*, 2015:6). Nurses also become either directly or indirectly physically or psychologically negatively affected by HIV-stigma in the process of caring for PLWH (Ndou *et al.*, 2015:3). This leads to HIV-stigma-related staff attitudes that build a negative reputation of health care (Mathibe *et al.*, 2015:7). The stigma related to HIV is however also closely linked to disclosure of patients' positive HIV status (Greeff, 2013:85-88).

### **Conceptualising disclosure of HIV status**

There are mainly three disclosure types described in literature namely, voluntary (self-disclosure), forced (unintended disclosure for instance self-proclamation by the body through the physical changes it is undergoing denoting to illness) and mandatory (obligatory by laws, rules and policies) (Greeff, 2013:85). Disclosure of HIV status can be a worthwhile process where PLWH can achieve freedom and emotional healing, protect others, and build social



support systems with neighbours. It can also pose difficulties as it is a stressful event that can create worry and cause fear of various losses such as housing, friends, social support and even health care for PLWH (French *et al.*, 2014:105-115). According to Greeff (2013:85), reasons for not disclosing are mainly for self-protection, protecting others, interpersonal relationships, community factors and personal needs. It may also be in response to their needs and fulfilling their interpersonal needs for disclosure. She further mentioned the reasons for disclosure as personal needs, response to the needs of others, and fulfilling interpersonal needs. Another reason is that PLWH would gain access to health care as well as social and emotional support (Patel *et al.*, 2012:361-364).

### **HIV related stigma reduction and disclosure management approaches in primary health care**

PHC remains largely the health service delivery base for the broader community. In South Africa during the 1980s and 1990s, very little effort was put into managing HIV in general nor HIV-related stigma and disclosure, except for preventative measures such as condom distribution and health education (Simelela and Venter, 2014:249). The South African government later developed strategies and programs to manage HIV. The first HIV, AIDS and sexual transmitted disease (STD) national strategic plan of 2000-2005 guided the provision of ART. The strategic plan unfortunately only mentioned HIV-stigma reduction and disclosure but did not provide practical guidelines (NDOH, 2000-2005). The 2012-2016 National HIV and AIDS strategic plan (NDOH, 2012-2016) focussed on the roll-out of ART in PHC by nurses and reduction of self-reported stigma by 50% with little guidance on stigma reduction in PHC (NDOH, 2012-2016: 12, 36). The National Strategic Plan (NSP) of 2012-2016 implemented a legal framework to protect human rights and highlighted the reduction of self-reported stigma related to HIV and Tuberculosis (TB) through community dialogues (NDOH, 2012-2016:12). The integrated chronic disease management (ICDM)

model (NDOH, 2012:51) used an integrated approach to care for patients with chronic diseases including HIV and related stigma but did not outline detailed stigma reduction processes. Furthermore, the recent National Health Insurance (NHI) system, aims to strengthen the health care system by incorporating PHC re-engineering (Voce & Bhana, 2014:46-47) but doesn't specify stigma reduction. In the NHI, access to health care is improved by decongesting the clinics of stable chronic disease patients and PLWH through collecting medication at central chronic medicine dispensing distribution (CCMDD) pick up points (NDOH, 2016). In the highlighted strategies and programs there are no clear guidelines on HIV-stigma reduction or any mention of disclosure management in PHC settings.

An accelerated approach program implemented in PHC in South Africa, includes PHC re-engineering with district clinical specialist teams (DCST) who train different categories of health workers, support health program collaboration and implementation, provide clinical guidance and supervision (Voce & Bhana, 2014:56-57). It provides ward based outreach teams (WBOT) with a nurse as a team leader and HCWs linking with the clinics working within communities and integrated school health programs (ISHP) teams to provide basic health screening and preventative care to different ages of school children within maternal and child health care but HIV related stigma not addressed.

The National Core Standards (NCS) (NDOH, 2011b:8-10), list six (6) key areas (values and attitudes of health care staff, cleanliness in facilities, waiting times, patient and staff safety and security, infection prevention and control and availability of medicines and supplies) (NDOH, 2011b:15) to improve quality of health services. The Operation Phakisa Ideal Clinic Realisation Program for access, aims to improve PHC services and HIV management (NDOH, 2015:3) through improvement of infrastructure, adequate staff, adequate medicine and supplies, administrative processes, adequate bulk supplies that use

applicable clinical policies, protocols, guidelines as well as partner to stakeholder support (NDOH, 2015:3). The main focus of the mentioned approaches are improved access to quality health care services including HIV and maternal and child health. Unfortunately once again little emphasis was placed on stigma reduction and disclosure management in PHC settings.

A government initiated strategy for HIV and related stigma, was a program named “To the other side of the mountain” (toolkits 1 and 5)” (NDOH, 2005:38, 63). It described the ‘who, what, when and how’ of disclosure and approaches to disclosure through educating family members so as to reach the community. The program, like many others however, did not address HIV-stigma reduction and disclosure management in PHC settings. The integrated access to care and treatment program (I ACT) (NDOH, 2009:7) empowers PLWH and others to lead healthy lives, but like other identified programs and guidelines has no focus on HIV-stigma reduction and disclosure management in PHC settings. Nurses are also continuously taken out of the clinics to learn and implement these top down change program to improve access and health services including HIV management and care in the hospitals and clinics (Davies *et al.*, 2013:3) with no clear implementation guidelines.

South Africa made remarkable progress implementing different change programs and strategies for HIV (NDOH, 2012-2016:8). The South African government did an enormous amount of work on HIV management through development of good national policy documents, strategies, guidelines, stigma campaigns, training, HIV counselling and testing, improving access to health care, improving on the quality of health care services including early diagnosis and treatment of patients and PLWH. Nurses and HCWs were pivotal in the implementation of most of these government initiatives through a mix of biomedical, behavioural, social and structural interventions (NDOH, 2012-2016:14). However, HIV-stigma continues to threaten and devalue the mentioned progress (NDOH, 2012-2016:31)

## **Problem statement**

In the context of the literature reviewed, it is evident that HIV-stigma is a complex reality in the South African PHC system and the lives of PLWH. Stigma infiltrates different areas and manifests in government, the workplace and health care settings, with outcomes impacting negatively on PLWH, PLC to them, the community and the health care system. In South Africa, the majority of the community access health services through PHC as the first point of entry. These services are mainly rendered by nurses and HCWs, who work with PLWH by implementing strategies and programs on HIV management and care. It is usually where individuals learn about their HIV status, how it will affect them, start treatment and build a relationship with their carers. Different HIV management strategies and programs were developed and implemented over the years. Unfortunately the health care system focussed mainly on policies and guidelines to improve access to health care; to improve the quality of health care services; training of health workers on HIV management and care, counselling, testing and provision of ART. From the literature it is clear that little was done for HIV-stigma reduction and responsible disclosure management specifically in PHC settings. Very little is done in the PHC clinics where PLWH are tested, diagnosed, counselled and start their treatment and to which they have to remain on for their entire life. The question “how do nurses and HCWs, working in PHC, perceive HIV-stigma reduction and responsible disclosure management in these PHC settings?” thus arises to truly understand these practices in the PHC settings as they exist.

## **Research objective**

The research objective of this study was to explore and describe the perceptions of nurses and HCWs working in PHC settings of the HIV-stigma reduction and disclosure management practices in these settings.

## **Research design**

The qualitative descriptive design described by Sandelowski (2000:339) was used to explore and describe the perceptions of nurses and HCWs of both HIV-stigma reduction and disclosure management practices in PHC settings in the J.B. Marks municipality of the Dr Kenneth Kaunda district of the North West Province, South Africa as the context of this study. The Dr Kenneth Kaunda district is also an NHI pilot site. The selected area constitutes of ten (10) PHC clinics in which health care services are mainly provided by nurses and HCWs. In these PHC clinics PLWH are diagnosed, counselled and provided with the required treatment and monitored for adherence.

## **Research method**

Semi-structured interviews were conducted (Botma *et al.*, 2010:208-209) with both nurses and HCWs to gather data for this study.

## **Sample**

Only three (3) of the ten (10) clinics were selected to participate in this study due to the intensity of the intervention that would follow the interviews described in this article. The choice of which three clinics to include was given to the sub-district management team of the Department of Health. The inclusion of the clinics was based on the fact that the clinics were rendering comprehensive PHC to high numbers of PLWH, as well as a variety of cultural groups and communities. The sub-district management team acted as the gatekeepers for the various clinics and mediated with the clinic managers for the researchers to gain access to these clinics. The clinic operational managers were visited by the researchers to explain the research, as well as which inclusion and exclusion criteria should be used for the potential participants. The nurses that were selected via purposive sampling had to be working in the selected PHC clinics for a minimum of six months, had a diploma or degree in nursing with a South African Nursing Council (SANC) registration, trained in one or more short courses in

HIV management and care, and were directly involved in the everyday care and management of PLWH.

The nurses, who specifically worked with the HCWs then mediated and identified the group of HCWs who were linked to the same three selected clinics. To be included the HCWs had to have some training in HIV, had been exposed to care and management of PLWH for the past six (6) months or more, were experienced in home based care, and were working within the catchment areas of the three selected clinics in the city council. The nurses and HCWs had to be able to express themselves either in Setswana, English or Afrikaans.

The names of the nurses and HCWs who were willing to participate and their contact details were then forwarded by the mediators to the researchers. The trained research assistant acted as an independent person to obtain the informed consent from the two groups. The research was explained to them and some time allowed to make the decision to participate. They were informed that the interviews were going to be digitally voice recorded and that their confidentiality would be protected after the interview and during dissemination of the research. Their right to withdraw at any stage of the study was explained to them (Botma *et al.*, 2010:2, 21). Appointments were made with the participants and interviews set up at a venue of their choice that ensured privacy. Data saturation as described by Botma *et al.* (2010:200) was reached with the sample size consisting of nine (9) nurses and eighteen (18) HCWs (see Table 1 for the sample distribution).

**Table 1:**  
**Sample distribution per clinic during the interviews of nurses and HCWs**

	CLINICS	NURSES	HEALTH CARE WORKER
	A	3	7
	B	4	6
	C	2	5
<b>TOTAL</b>	<b>n = 3</b>	<b>n = 9</b>	<b>n = 18</b>

## Data collection

Approval to conduct the study was obtained from the Health Research Ethics Committee (HREC) NWU-00008-14-A1, as well as the North West Provincial Department of Health prior to commencement of data collection. The selected participants were informed by the research assistant of the date, time and venue where the interviews would be conducted. The interviews for the nurses and HCW were guided by open ended questions which were formulated and evaluated beforehand by experts. An initial interview evaluated whether the questions elucidated the required information (Botma *et al.*, 2010:208-209). The same set of questions (see Table 2) asked to nurses were slightly adjusted to laymen's language for interviews with HCWs.

**Table 2:**  
**Questions for nurses and HCWs**

Questions for nurses	Questions for HCWs
What are your views of the HIV-stigma reduction practices here at the clinic?	What are your views of the HIV-stigma reduction practices here at the clinic?
What do you see as the strengths of the HIV-stigma reduction practices here in the clinic?	What do you see as the strengths of the HIV-stigma reduction practices here in the clinic?
What do you see as limitations of the HIV-stigma reduction practice here in the clinic?	What do you see as limitations of the HIV-stigma reduction practice here in the clinic?
What do you think can be done to improve the HIV-stigma reduction practices here in the clinic?	What do you think can be done to improve the HIV-stigma reduction practices here in the clinic?
What are your views of the HIV disclosure management practices here in the clinic?	What are your views of the practices here in the clinic to help people living with HIV to tell other people about their HIV positive status?
What do you see as strengths in the HIV disclosure management practices here in the clinic?	What do you see as strengths of the practices in the clinic to help people living with HIV to tell other people about their HIV positive status?
What do you see as the limitations in the HIV disclosure management practices here in the clinic?	What do you see as the limitations of the practices here in the clinic to help people living HIV to tell other people about their HIV positive status?
What do you think can be done to improve the HIV disclosure management practices here in the clinic?	What do you think can be done to improve the practices here in the clinic to help people living with to HIV to tell other people about their HIV status?
Is there anything else you would like to add?	Is there anything else you would like to add?

The participants were, as far as possible, afforded privacy and comfort with minimal disturbances during the interviews. In the event of any emotional discomfort experienced by the participants, they were made aware of the availability of counselling should they be in need thereof. During the interviews different communication techniques such as probing, paraphrasing, reflecting, summarising and clarifying were used (Botma *et al.*, 2010:206). The

interviews lasted for one hour to one hour and thirty minutes. Methodological, theoretical and personal field notes were immediately captured after the interviews (Botma *et al*, 2010:217-219).

### **Data analysis**

The digitally audio-recorded interviews were transcribed verbatim to enable analysis. A generic process for data analysis was followed. The systematic process of thematic data analysis was guided by the steps of Tesch outlined by Creswell (2009:185-186). All transcripts of the nurses and the HCWs were read to get a sense of the whole. A systematic process was then followed to read the transcripts and noting the topics through In-Vivo and descriptive codes. After a few transcripts, identified topics were clustered into a list of categories and sub-categories using the most descriptive words. These were then clustered into relational themes and a relational framework conceptualised. A co-coder was given the same set of transcripts for co-coding and consensus reached through discussions.

### **Trustworthiness**

Trustworthiness was guided by the principles of Lincoln and Guba (*in* Krefting 1991:217) as outlined by Botma *et al*. (2010:234-235). Truth value was ensured through the strategy of credibility by prolonged engagement with the participants during interviews. Reflexivity was achieved through study leader guidance as well as the written field notes. A co-coder was used during data analysis. The interview technique used was well thought through with questions evaluated by experts. The researcher, who is experienced in working in the field of PHC, guided by experienced study leaders in research, commanded authority in the study. Applicability was obtained through the strategy of transferability by selecting a sample using well formulated inclusion and exclusion criteria, defined by the choice of clinics done by the Department of Health. The comparison of the demographic data was done by the selection of the three clinics by the Department of Health's experts with knowledge of



the demographics of the clinics that included HIV management and care and knew which clinics would be best. Data saturation was achieved in the three clinics that included both groups of nurses and HCWs. A thick and dense description was established through a well described context and methodology and insured that the study can be repeated by others. Consistency was attained through the strategy of dependability with the mentioned thick and dense description of the methodology that made an audit trail and stepwise replication possible. Neutrality was obtained through the strategy of confirmability acquired with reflexivity mentioned in truth value. Authenticity was realised in the way in which the findings are reflected by bringing in quotes of participants reflecting the true tone of what was said.

#### **Additional ethical considerations**

The additional ethical considerations not addressed so far refer to risks and benefits, remuneration, privacy and confidentiality as well as data storage.

*Risks and benefits:* A risk-benefit analysis was done for the participating nurses and HCWs. The risks in this study were minimal as the questions in the interview were not sensitive in nature. However the participants could fear losing their anonymity and sharing information that could be used against them. In reducing the risks, information was coded and names removed. Data were grouped during dissemination. Support was available if any emotional discomfort occurred. There were no direct benefits for the participants but the scientific community are indirectly benefitting by understanding what is lacking in PHC settings regarding HIV-stigma reduction and disclosure management actions better. This could guide future actions.

*Remuneration:* No monetary remuneration or transportation was provided as the interviews were conducted during working hours at the participants' workplace and lasted for

not more than an hour and a half in their respective clinics at a date and time most suitable to the participants.

*Privacy and confidentiality:* Data was collected in a private room. The transcriber and co-coder signed confidentiality agreements. The participants' confidentiality was ensured by changing identifying data into codes during the transcriptions and deleting the voice recording as soon as it was transferred to the password protected computer.

*Data storage:* Both hard and electronic copies were safely stored and only accessed by the researchers. The hard copies are kept in safe locked cabinets, in the research unit and the electronic data stored on the researchers password protected computer. Data will be stored for five years at the university.

## Findings

The findings reflect nurses' and HCWs' perceptions of HIV-stigma reduction as well as disclosure management in PHC settings. See a summative outline of the themes, categories and sub-categories on nurses' perceptions of HIV-stigma reduction and disclosure management in PHC settings in table 3.

**Table 3:  
HIV-stigma reduction and disclosure management in primary health care settings:  
Nurses' perceptions**

<b>HIV-STIGMA REDUCTION PRACTICES</b>	
<b>Themes</b>	<b>Categories and subcategories</b>
Constructive nursing behaviour and practices	<b>Equality of patients and various illnesses</b> <ul style="list-style-type: none"> <li>• Treating HIV as any other chronic disease</li> </ul>
Less effective nursing practices	<b>Good logistical arrangements</b> <ul style="list-style-type: none"> <li>• Patients line up in the same queues</li> <li>• Similar files and packaging of medicines</li> </ul> <b>Stigmatising behaviour</b> <ul style="list-style-type: none"> <li>• Labelling of patients compromise HIV-stigma reduction</li> <li>• Identified various stigmatising behaviour among other nurses</li> </ul>
Lacking counsellor practices	<b>The training of counsellors is seen as superficial</b> <b>Counselling lacks depth and support needed</b> <b>Counsellors need to be trained in professional counselling</b> <b>Counsellors to take their work serious to earn the respect of other professionals</b> <b>During patient consultation trust building should be a priority</b>
Poor structural layout increases stigma	<b>The structural layout of the clinics exposes people to stigma</b> <b>Poor logistical arrangements</b>
Unique ART storage needed	<b>Stored in special rooms and separate cabinets</b> <b>Prepacked ART unique identifier</b>

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## HIV-STIGMA REDUCTION PRACTICES

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### HIV DISCLOSURE MANAGEMENT

<b>Themes</b>	<b>Categories and subcategories</b>
<b>Challenging disclosure practices</b>	<b>Assurances of confidentiality and non-labelling following disclosure</b>
	<b>Challenges in disclosure management</b>
	<ul style="list-style-type: none"><li>• Patients' records management</li><li>• Some instances when nurses change shifts during handover disclosure occurs</li><li>• Need to practice confidentiality in disclosure</li></ul>
<b>Noticeable practices of maintaining confidentiality and privacy</b>	<b>Confidentiality and privacy on patient information maintained</b>
<b>Supportive environment and follow-up</b>	<b>Counselling to enable disclosure</b>
	<ul style="list-style-type: none"><li>• Privacy during counselling needs to be ensured</li><li>• Couple counselling can be helpful to PLWH</li><li>• Counselling of partners and significant others can help PLWH</li><li>• In post-test counselling disclosure be encouraged</li></ul>
	<b>Benefit of follow-up</b>
	<ul style="list-style-type: none"><li>• Counselling makes home visits and patient tracing possible</li></ul>
	<b>Lacking skills and development</b>
	<ul style="list-style-type: none"><li>• PLWH require the necessary skill to convey bad news of HIV positive status</li><li>• Skills development for effective HIV counselling</li><li>• Too little HCWs for support groups on a continuous basis</li></ul>
<b>Benefits of disclosure for PLWH</b>	<b>Personal benefits</b>
	<ul style="list-style-type: none"><li>• Feelings of freedom</li><li>• More empowered about their rights</li><li>• Sharing disclosure experiences to gain support</li><li>• Openness is encouraged</li><li>• Prevention is practiced better</li></ul>
	<b>Benefits for PLWH in their homes</b>
	<ul style="list-style-type: none"><li>• Disclosure to family members can strengthen support at home</li><li>• PLWH get better care within families when they have disclosed</li></ul>
	<b>Benefits to children at home</b>
	<ul style="list-style-type: none"><li>• Feeding children and improved breast feeding practices</li></ul>
	<b>Benefits to others if discloses</b>
	<ul style="list-style-type: none"><li>• Educate others</li><li>• Able to help and refer others at home</li></ul>
	<b>HEALTH EDUCATION PRACTICES</b>
<b>Lacking health and HIV-stigma education</b>	<b>Community based health promotion should form part of the health education</b>
	<b>Health education can be in different forms e.g. talks, radio information</b>
	<b>Health education on HIV-stigma limited and lacks depth</b>

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### **Nurses' perceptions of HIV-stigma reduction and disclosure management in PHC settings**

In reflecting on the nurses' perceptions of HIV-stigma reduction, five themes were identified namely: constructive nursing behaviour and practices; less effective nursing practices; lacking counsellor practices; poor structural layout in the PHC setting that increases stigma and unique ART storage needed. Regarding nurses perceptions of HIV status disclosure management, four themes were identified namely: challenging disclosure practices; notable practices of maintaining confidentiality and privacy; supportive

environment and follow-up; benefits of disclosure for PLWH. A specific theme on lacking health and HIV-stigma education as part of health education practices emerged. The discussion of the identified themes, categories and sub-categories are enriched with quotes from the nurses.

### **Nurses' perceptions of HIV-stigma reduction in PHC settings**

The perceptions of nurses regarding HIV-stigma reduction in PHC settings indicated positive and negative behaviours which were mainly of a structural and organisational nature and focused more on practices, structural layout and use of ART and less on stigma as such. Nurses focussed also more on counsellor practices as if placing the responsibility of HIV-stigma reduction on the HCWs.

- Constructive nursing behaviour and practices

Nurses reflected on equality of patients treated with various illnesses and good logistical arrangements. They see themselves as treating HIV positive patients similar to all patients with other chronic diseases and integrating patients into the clinic: “... *we treat HIV as any other chronic disease*”. Regarding good logistical arrangements to reduce HIV related stigma, the nurses allowed patients to line up in the same queue with fellow patients with chronic diseases and not having a separate queue for HIV management. Nurses use similar files and medication packages for the patients and said: “*Our files are all the same for all the chronic diseases, we don't have a specific file for HIV positives*”.

- Less effective nursing practices

Nurses perceived stigmatising behaviour and poor logistical arrangements as less effective nursing practices that increase HIV-stigma in the clinics. Nurses' labelling of patients was perceived as stigmatising as evidenced in the following quote: “*You find that other people refer to a patient as “oh that one of the ARV ...”*” Nurses referred to stigmatising behaviour among nurses like the rudeness towards PLWH, deterring them from seeking

health care and default: “...it’s us that make the rate of defaulters”. This attitude compromises stigma reduction.

- Lacking counsellor practices

The perceptions of nurses on the practice of counsellors in the PHC settings are that their training is superficial and that they are not fully informed about HIV. Counselling of patients lacks depth, counsellors need support and should be trained in professional counselling to conduct the counselling in a knowledgeable manner: “*The so-called counsellors, most of them are not fully equipped with information regarding HIV and its management...*” and “... *it is very shallow, they need to be trained to conduct counselling professionally*”. Nurses emphasise that counsellors need to be more serious about their work in order to earn the respect of other professionals. They further emphasised that a relationship of building trust with PLWH during consultation must be a priority but they do not see this happening: “*The HCWs must make sure that patients trust them. They must have this relationship with the patients so that the patients trust that they will not talk about them*”.

- Poor structural layout increases stigma

According to the nurses the poor structural layout in the PHC clinics does not foster HIV-stigma reduction and increases stigma, compromising the efforts to treat patients equally. Counselling rooms that are situated close to the patient waiting area in the clinics expose people to stigma: “...*our consulting rooms are right in front of your waiting area, so when patients leave the counselling room and she’s just been told that she is HIV positive, she walks right into patients who can see the facial expression and everything else*”. This also goes for the handling of medication. The poor logistical arrangements cause a differentiation in handling of medication of patients with different health problems contributing to stigmatisation in the clinics: “...*and then you come to take your package of ARV’s. I have to take your file, go into that room, which has a cupboard of pre-packing (medication), take out*

*the brown envelope with your things.....”, “ .....and then I pass with it in front of every other patient that is sitting in the cue.”* In this manner, patients queuing for a consultation can identify the patient receiving treatment for HIV if it is dispensed from specific packaging from a specific room, nearby the waiting area.

- Unique ART storage

According to the nurses, the storage of ART in special rooms and separate cabinets is problematic. Storing ART separately from other chronic medication can easily reveal individuals' diagnosis: *“The thing is their medication, it's not stored the same place as those of chronic, you see”*. The pre-packed ART becomes a unique identifier of PLWH in the clinics: *“... the medication packaging that is a limitation.”*

#### **Nurses' perceptions of HIV status disclosure management in PHC settings**

The perceptions of nurses focussed on four themes namely: challenging disclosure practices; noticeable practices of maintaining confidentiality and privacy; supportive environments and follow up; and benefits of disclosure for PLWH.

- Challenging disclosure practices

Nurses doubted whether they give enough assurance for confidentiality and non-labelling of patients following disclosure as quoted, *“... I don't know if we reassure people enough that whatever medication you are coming to take here no one will know”*. They are of the opinion that confidentiality is undermined in the clinics and say: *“...we struggle with confidentiality.”*; *“Yes we speak openly, we don't have confidentiality.”* Another nurse said, *“We talk.....we fail there...”*. Some practices of labelling patients' files undermine the assurance of confidentiality, *“....except for that files that are marked in blue, gets locked up...”*.

The nurses identified specific challenges in disclosure management namely, patients' records management; some instances when nurses change shifts disclosure occurs during

handover; and the need to practice confidentiality in disclosure. Nurses saw patients' records management as key in disclosure management. As doctors and nurses write in patients files it is not always possible for them to do so without others noting the contents of what was written such as prescribed medication, "*... and then the script for the ARV's is different than the other chronic medication scripts so everybody can see...*".

During change of shifts with handover and also when giving instructions about collecting patients' medication from the pharmacy, disclosure of HIV status could occur, "*... disclosure part of it and the management of patients with HIV only happens, let me say for those who are working shifts.... the other nurse tried to help, let's say to call for the pharmacy, to collect something for her about medication and whatsoever.*" Those patients and health workers sitting around who are ignorant of the patients' HIV status, can overhear the diagnosis of the patients and medication administered during that communication with another team of health workers coming in for a new shift. The nurses mentioned the need for both nurses and HCWs to practice and keep patients' diagnosis confidential after disclosure: "*when the patients tell you about their diagnosis such information must be kept confidential..... the HCWs must keep confidentiality*".

- Noticeable practices of maintaining confidentiality and privacy

Nurses noted that there are perceived noticeable practices of maintaining confidentiality and privacy on patient information maintained in the clinics: "*... I never heard a nurse gossip..... I think it's done really well, because it's done with confidentiality and privacy with one client in a room*". Nurses also believe that patients' files are kept confidential and say "*... Well, there's always patient privacy, and the files.... So the files are only seen by the nurses, and not even the patients.*"

- Supportive environment and follow-up

Under supportive environment and follow-up, three categories were mentioned namely: counselling to enable disclosure; benefit of follow up; and lacking skills and development. Nurses saw counselling as an important facilitation towards disclosure. HCWs should however always ensure privacy during counselling in the clinics. They also saw couple counselling as enabling disclosure, “... *I think couple counselling can be done and testing...they can disclose*”. The nurses motivated that partners and significant others must also be counselled to disclose to PLWH. The inclusion of the partners and significant others could assist PLWH in their sexual relations, “...*they can practice safe sex if they know another’s HIV status....*”. Nurses recommended that disclosure is encouraged in post–test counselling: “... *in post-test counselling we talk about how to disclose and to whom*”.

Nurses indicated that a benefit of follow-up is that counselling makes home visits possible with improved defaulter tracing and testing of PLC: “...*the out-reach personnel, to remind those people*” that “*guys at least remember your treatment that, this is important, to encourage them somehow for others to test*”.

Nurses mentioned that they lack the skills to enable PLWH to convey bad news of their HIV positive status. Improved training of counsellors would assist and empower PLWH to be able to convey news of their HIV positive status: “... *improvement of the training of the counselors is needed....*”. “*They must assist the patient on how to convey bad message to others...*”. Nurses also questioned the level of development of skills of HCWs for effective counseling, “... *I don’t think there is enough health care education given on HIV ... definitely thinking shortage of knowledge about the disease...*”. “*The so called counsellors... most of them are not fully equipped with the information regarding HIV and its management*”. They



mentioned that limited HCWs jeopardises support groups on a continuous basis: “*support groups are needed on a continuous basis to assist PLWH to disclose*”.

- Benefits of disclosure for PLWH

Personal benefits mentioned by nurses are summarized in five sub-categories: feelings of freedom; PLWH are more empowered about their rights; sharing disclosure experiences to gain support; openness is encouraged; and prevention is practiced better. The positive gains for PLWH from the disclosure of a positive HIV status in the clinics brings feelings of freedom: “*I believe that helps that if a person has disclosed, it will help in that when you have to take your medication, you won’t hide them...*”. Empowerment about rights was seen in not “*...have to hide your ARV’s*”. When sharing their HIV status, PLWH gain support: “*... PLWH get support by disclosing to a family member*”. Openness about HIV status is encouraged in support groups: “*openness on their status which will enhance mutual support...*”. Prevention is practiced better if PLC to PLWH know the status of their partners because PLWH would be able to negotiate safe sex with their sexual partners.

Disclosure to family members can strengthen support at home for PLWH and ensure better care within families: “*...generate support from their family members*”; and “*understanding will be enhanced and the PLWH doesn’t need to hide the tablets or anything related to the condition*”. PLWH would receive better care within families when they have disclosed: “*...their families will take care of them...*”.

According to the nurses, children could also benefit from disclosure: “*...care of own children and breast feeding without fear*”. It becomes a struggle for nurses to support feeding of PLWHs’ children if they did not disclose to the families: “*...we struggle for the baby to breast feed or not to breast feed. The grandmother will be fighting why you can’t breast feed?*”. The mother who did not disclose HIV positive status is unable to keep the baby from

the breast as instructed at the clinic as family members will be concerned as to why she is not breastfeeding.

The nurses viewed that disclosure by PLWH would benefit others as PLWH could educate them: “...*educate others in the prevention of the spread of HIV*”. They would also be able to help and refer others at home when they themselves have disclosed, “...*encourage them to test and to support their relative at home who’s having the HIV.*”

### **Lacking health and HIV-stigma education**

HIV-stigma health education was not a specific focus according to the objectives of this study but it emerged as an important theme. It encapsulated three categories namely: community-based health promotion should form part of health education; health education can be in different forms e.g. talks, radio information; and health education on HIV-stigma limited and lacks depth.

Nurses indicated that health education can be more effective if the involvement of community-based health promotion forms part of health education: “*People that do not come to the clinic, they also need to be educated, inclusion of health promoters, community based health promoters, that go to the community and teach, slots in meetings, in community meetings*”. Nurses also believe that health education on HIV should mix various approaches such as: “...*talks or radio information...*”.

In general, health education on HIV-stigma is limited and lacks depth. Health talks need to include HIV-stigma reduction: “...*deepen health talks to include stigma reduction*”. The pre- and post-test counselling process does not equip PLWH enough to deal with their situation: “*The pre and post-test counselling not in depth enough about how life is going to change if positive.*” The training of the counsellors is also superficial and lacks depth: “...*improvement on the training of counsellors is needed.*”; “... *if they were trained...by the people that understand the psychological effect of it.*” Then it would have the needed effect.

## HCWs perceptions of HIV-stigma reduction and disclosure management in PHC

### settings

The findings of the HCWs' perceptions of HIV-stigma reduction identified five themes namely: nurses' positive and negative behaviour towards PLWH; staff shortage and limited resources have a negative impact; limited space leads to logistical problems; strong awareness of patients' feelings and needs; and suggested supportive practices. HCWs' perceptions of HIV status disclosure management also identified five themes namely: nurses' behaviour can limit disclosure; logistical problems limit disclosure; facilitating aspects; awareness of patients' feelings and need; and supportive environment. A specific theme of lacking health education also emerged as part of the findings. See a summative outline of the themes, categories and sub-categories on HCWs perceptions of HIV-stigma reduction and disclosure management in PHC settings in table 4.

**Table 4:**  
**HIV-stigma reduction and disclosure management in primary health care settings:**  
**Health care workers' perceptions**

<b>HIV-STIGMA REDUCTION PRACTICES</b>	
<b>Themes</b>	<b>Categories and subcategories</b>
Nurses positive and negative behaviour towards PLWH	<b>Positive behaviour:</b> <ul style="list-style-type: none"> <li>• Equality of patients                             <ul style="list-style-type: none"> <li>* Patients with HIV treated (no) different to patients with other diseases</li> </ul> </li> <li>• Efforts to maintain privacy and professionalism towards PLWH</li> </ul>
Staff shortage and limited resources have a negative impact	<b>Negative behaviour:</b> <ul style="list-style-type: none"> <li>• Lack of privacy and confidentiality</li> <li>• Act rudely towards PLWH</li> <li>• Display judgemental behaviour</li> <li>• Stigmatising behaviour                             <ul style="list-style-type: none"> <li>*Identify diagnosis in front of other patients</li> </ul> </li> </ul>
Limited space leads to logistical problems	<b>Impacts on the quality, friendliness and efficiency of patient care</b> <b>Increases stress</b> <b>Shortage of medication leads to patients having to revisit the clinic</b> <b>Limited space contributes to overcrowding</b> <b>Longer queues</b>
Strong awareness of patients' feelings and needs	<b>More time spent at clinic causing fatigue for staff and patients</b> <b>Fearful of nurses and exposure</b> <ul style="list-style-type: none"> <li>• PLWH fearful of nurses and prefer talking to HCWs</li> <li>• Fear of exposure of one's diagnosis</li> <li>• Fearful of visiting the nearest clinic that will stigmatize</li> </ul>
Suggested supportive practices	<b>Feel ashamed and rejected because of diagnosis</b> <b>Fear home visits will identify them and families</b> <b>Need for self-acceptance and by others</b> <b>Encourage and give hope</b> <b>Provide support groups</b>
<b>HIV DISCLOSURE MANAGEMENT</b>	
<b>Themes</b>	<b>Categories and subcategories</b>
Nurses behaviour can limit disclosure	Seen as unwelcoming, stigmatising and unprofessional towards PLWH
Logistical problems limits disclosure	Blood results take too long

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## HIV-STIGMA REDUCTION PRACTICES

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<b>Facilitating aspect</b>	<b>Self-acceptance facilitates disclosure and making a person strong</b>
<b>Awareness of patients' feelings and needs</b>	<b>Fearful to disclose</b>
<b>Supportive environment</b>	<b>Needs for disclosure counselling</b>
	<b>Need for building trusting relationships</b>
	<ul style="list-style-type: none"> <li>• Trust relationship with family needs to be developed</li> <li>• People need to be encouraged to disclose to get support</li> </ul>
	<b>Establish wider support</b>
	<ul style="list-style-type: none"> <li>• Encouraged PLWH to disclose to get support</li> <li>• Carers and traditional healers must be empowered on HIV-stigma and disclosure</li> </ul>

## HEALTH EDUCATION PRACTICES

<b>Health education lacking</b>	<b>To little focus on stigma and disclosure</b>
	<ul style="list-style-type: none"> <li>• Health talks are too general and not specific on HIV-stigma or disclosure</li> <li>• Patients need to be equipped with knowledge and skills on:             <ul style="list-style-type: none"> <li>* HIV and related stigma and disclosure</li> <li>* How to disclose</li> <li>* How to cope with stigma</li> </ul> </li> </ul>
	<b>Need positive encouragement</b>
	<ul style="list-style-type: none"> <li>• Should include support about HIV diagnosis and stigma</li> </ul>
	<b>Motivation to disclose</b>
	<ul style="list-style-type: none"> <li>• Campaigns and pamphlets</li> <li>• Health promotion through home visits</li> </ul>
	<b>Nurses need regular meetings and workshops about:</b>
	<ul style="list-style-type: none"> <li>• confidentiality</li> <li>• stigma and disclosure</li> </ul>

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### HCWs' perceptions on HIV-stigma reduction in PHC settings

The perceptions of HCWs focussed more on nurses' behaviour and were contradictory regarding positive or negative behaviour. They also saw logistical problems contributing to stigma but were much more in touch with patients' feelings and needs.

- Nurses' positive and negative behaviour towards PLWH

Both the positive and negative behaviours of nurses towards PLWH were mentioned with the negative mentioned more often. Regarding the positive, HCWs indicated that there is equality of patient treatment in as much as PLWH are not being treated differently from any other patients. All patients are placed in the same queue: *"They make them to stand in the same queue with all patients"*. HCWs witnessed efforts made by nurses to maintain privacy and professionalism towards PLWH: *"...taking the people in a private room; "... they make sure that patients are treated equally and professionally"*.

The negative behaviour of nurses however outweighed the positive behaviour by far. According to the HCWs, the provision of confidentiality during counselling is intricate in the

clinics and is seen that nurses do not provide confidentiality during counselling or have confidentiality practices that expose patients' diagnosis: "...you see patients in a room where counselling is done when they test for HIV... and they say you must start treatment...". The HCWs' perceptions are that PLWH experience going to the clinic monthly as exposing their HIV diagnosis. PLWH fear exposure of their diagnosis and avoid going to the clinics closest to them out of fear of stigma: "*Most of the time they don't want their diagnosis to be known. They go to other clinics than theirs...*". PLWH often refuse to go inside the clinic fearing that their status will become known when seen in the clinic: "...maybe she is afraid to be seen in the clinic and they will know his status...".

HCWs perceived nurses as rude towards PLWH, by not treating them well and ignoring them: "The sister not talking to them well, which is not good. They are supposed to sit down and take care of them because they are also people just like them". PLWH default on their antiretroviral therapy (ART) due to being uncomfortable with the harassing behaviour of nurses in front of other patients: "...some of them you can look through their eyes, sometimes they will just harass you".

Nurses were perceived as displaying judgemental behaviour when addressing PLWH. PLWH seem to become the disease without a personal identity in the eye of the nursing staff: "... oh that one of the ARV's" or "...that one of the HIV", it's as if you have forgotten a person's name...". This behaviour inhibits the patients to feel free to enter the PHC clinics to receive treatment: "*Most of the defaulters ... they say we are not treated well*". Nurses do not assist PLWH to understand their condition and are rather judgemental: "*They are supposed to explain to them, you know what, this sickness wants 1, 2, 3. You are supposed to be like this, you are supposed to feel free*"; "*Instead of teaching them... how to live, how to take care of themselves they are judging them, which is not good*". HCWs specifically mentioned how

nurses stigmatize by identifying PLWHs diagnosis in front of others: “...you know that you are HIV positive, in front of the other people”.

- Staff shortage and limited resources have a negative impact

Staff shortage and limited resources have a negative impact on staff and patients. It affects the quality, friendliness and efficiency of patient care and increased stress, as well as shortage of medication forcing patients to revisit the clinic. It forces nurses to improvise, resulting in practices that are not supportive of stigma reduction efforts: “*The shortage of resources contribute to overcrowding, less patient privacy, longer queues as well as stress for both PLWH and the staff*”. Stress impacts on the quality of work resulting in: “...unfriendliness and subsequently affecting efficiency in patient care”. Unavailable stock leads to PLWH having to return to clinics: “*PLWH have to revisit the clinic because of shortage of medication resulting in defaulting on treatment due to not having another day available during the month to attend the PHC clinic*”.

- Limited space leads to logistical problems

This theme highlighted limited space and logistical problems. The limited space contributes to overcrowding, longer queues and more time spent at clinics causing fatigue for both staff and patients. The HCWs mentioned that the small space available that cannot accommodate the many patients in the clinics. The long queues then cause PLWH to spend much longer time at clinics resulting in fatigue for both the staff and patients: “...patients have to spend more time in the clinics and get tired and staff is overworked...”.

- Strong awareness of patients’ feelings and needs

HCWs had a strong awareness of patients’ feelings and needs and mentioned that PLWH’s feelings of fear of the nurses and preferring to talk to HCWs: “*Maybe she is afraid to talk with the sisters...Most of the time, when they come for their treatment, they never go straight to the sisters,...they rather start with the HCWs*”. PLWH feel ashamed and rejected

because of their diagnosis. They fear being identified by home visits: *“As we go in the communities, the first time we start going in the community, only to find in the household when you enter, they say go away, get out of here”*. PLWH have a need for self-acceptance and acceptance by their families: *“They want to accept their HIV status and their family must also take them as they are”*.

- Suggested supportive practices

HCWs suggested encouraging supportive practices that would give hope and the provision of support groups for PLWH to disclose through open discussion between them and the nurses in the clinics: *“...you take the patient you try to show the patient the reality of life.”*, *“... you are going to show her this advantage and the disadvantage of being negative to the status”*. Truthful, supportive engagement with PLWH would give hope for life.

They also emphasised the need for the establishment of these support groups that are functional, well-resourced and supported by the clinics. The involvement of nurses in the process by providing space is seen as paramount: *“... the clinics must help the establishment of support groups for PLWH”*; *“The support groups must be functional and be given resources and allow PLWH to talk and share”*.

### **HCWs’ perceptions of HIV status disclosure management in PHC settings**

The following themes were identified regarding the perceptions of HCWs about HIV status disclosure: nurses’ behaviour can limit disclosure; logistical problems that limit disclosure; facilitating aspects; awareness of patients’ feelings and needs; and supportive environment.

- Nurses’ behaviour can limit disclosure

HCWs perceived nurses’ behaviour as unwelcoming, stigmatising and unprofessional towards PLWH: *“... when it comes to HIV people when the nurses in the clinic see them*

outside, they will just point fingers at them...”; “They are being shouted at....that is why they are not able to come to the clinic they are not welcome ...”.

- Logistical problems limits disclosure

The logistical problems in health care which make health care processes take longer affect the process of disclosure. A delay in the receiving of blood results could impact on the PLWH’s being ready to hear a diagnosis and disclosing: “*The person wants to talk about his status but the blood results take long for the patient*”.

- Facilitating aspect

Self-acceptance is viewed by HCWs to facilitate disclosure and making a person stronger because they have accepted their own diagnosis and can talk about it: “*You can accept your status then when we encourage you at the clinic, how to disclose to other people, you go back, where you were counselled, you take those two things, then you become a strong person*”.

- Awareness of patients’ feelings and needs

HCWs were emphatic about the PLWHs’ feelings of fear to disclose because of the untoward behaviour of nurses towards them: “...*they are afraid of nurses and will not disclose...*”. The need for disclosure counselling to facilitate disclosure of HIV status was mentioned: “*The PLWH must be assisted and counselled to talk openly about their status*”.

- Supportive environment

HCWs mentioned how PLWH are encouraged to disclose to family and others if they have a trusting relationship and feel safe enough to do so: “*We encourage disclosure to family or anyone that can be trusted*”. Talking freely will increase their chances of getting support: “*PLWH should be encouraged to talk to someone so as to get support*”. HCWs also mentioned the importance of empowering carers and traditional healers on HIV-stigma and



disclosure: *“Carers must be trained on stigma to assist the PLWH to disclose”*; *“The traditional healers must be trained on HIV, they must not talk about the illness of people”*.

### **Health education lacking**

Like nurses HCWs also referred to the lack of health education. HCWs indicated that health talks are too general and not focussed specifically on HIV-stigma and disclosure:

*“...the health education does not have stigma information and also no disclosure its general”*. PLWH need to be equipped with knowledge and skills on HIV-stigma and disclosure, as well as how to disclose and cope with stigma: *“...people must be given information on stigma, be taught how to disclose and managing after they have opened up about their status”*.

The need for positive encouragement should include support about HIV diagnosis and stigma: *“You know the PLWH must be supported immediately when they are told they are HIV positive and must be told about stigma they will get”*. PLWH can be motivated to disclose: *“If they don’t talk they end up being depressed and they end up not taking medication well, hiding it”*. Other methods that can be used are campaigns and pamphlets. HCWs’ also mentioned that health promotion through home visits can strengthen HIV-stigma reduction and disclosure education.

HCWs felt that nurses need workshops to deal with the concept of confidentiality in HIV: *“The nurses must get workshops on how to keep things confidential for HIV patient”*. Regular meetings and workshops were also suggested for nurses to discuss HIV-stigma and disclosure management.

Figure1 gives a relational framework of the nurses’ and HCWs’ perceptions of HIV-stigma reduction and disclosure management practices in PHC clinics and the impact this has on PLWH.

## Discussion

The findings suggest that in PHC clinics the nurses and HCWs are the parties involved in what little or much HIV-stigma reduction and disclosure management happens in the clinics. However, there seems to be a dissonance between these nurses', HCWs' and counsellors' (also present in the clinics) perceptions about HIV-stigma reduction and disclosure management practices in the PHC clinics that were in the study. There are several factors in the dissonance denoting to a relationship disconnect between the nurses, HCWs and counsellors found in their distinguishable roles but also their focus. The HCWs in their function moving from the clinics to the community are expected to keep patients information confidential which in some instances is not happening (Grant *et al.*, 2017: 4).

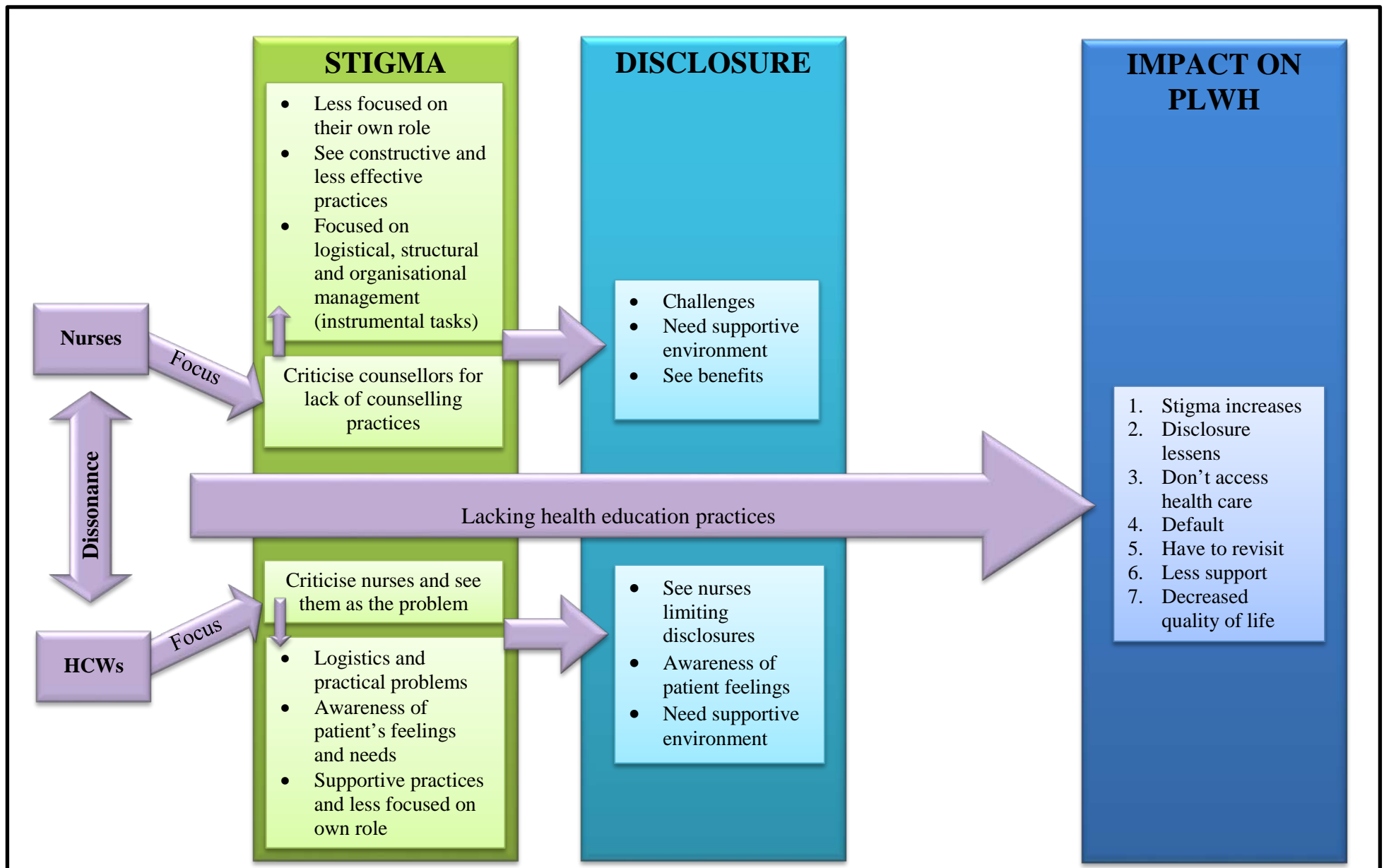


Figure 1: A relational framework of HIV-stigma reduction and disclosure management in a PHC setting

It seems in this relationship dissonance that nurses and HCWs blame others for the absence of stigma reduction and disclosure management in the PHC clinics and take little of the blame themselves. The dissonance is depicted in the study by Grant *et al.* (2017:7-8) when referring to three areas that are affected by the trust relationship namely, trust and confidentiality, trust and the community including trust and teamwork in the health care system, and thirdly HCWs that lack confidentiality and the necessary skills as well as knowledge to execute their functions well in the health care system linking to the community. This dissonance in the perceptions of nurses and HCWs can further be interpreted as a system disconnect impacting negatively on HIV-stigma reduction and disclosure management in the clinics. Grant *et al.* (2017:8) confirms this perception of disconnection when referring to instances where clinic staff is said to undermine the credibility the HCWs, which is translated to lack of respect and negatively influencing the HCWs role in health care.

Nurses in this study critiqued counsellors for lack of counselling practices. They attribute the lack of stigma reduction and disclosure management in the clinics by what they perceive as the counselors lack of skill, ineffective counselling practices and lack of trust relationship. They suggest that these counselors need to be trained to improve their counselling skills to be more professional. Mbale *et al.* (2017:195) recommended that HCWs need ongoing training to improve their quality of counselling. Dos Santos *et al.* (2014:17) suggested that, building a relationship of trust between the counsellors and PLWH is critical for effective counselling. The HCWs on the other hand criticised the nurses and blamed them for not managing stigma in the clinics. They perceive them as the problem for HIV-stigma, blaming them as the cause for non-disclosure by PLWH in the clinics. Although not directly said by HCWs, a study in Ghana on attitudes and behaviours on nurses towards PLWH, found that nurses with negative behaviour towards patients discourage them utilising HIV counseling and testing (HCT) and complying with treatment (Dapaah, 2016:6).

Nurses seem to focus less on their own role in stigma reduction and become more involved with aspects like logistics, structural and organisational management. The study by Koto and Maharaj (2016:56-57) confirm the finding that nurses are more focussed on structural (infrastructure, availability of resources) and organisational matters (own safety and workload) than direct focus on the HIV and related stigma. However in this present study nurses showed some objectivity by acknowledging certain constructive and less effective practices of nurses in the clinics. The constructive practices of treating PLWH similar to patients with other chronic diseases and using the same queue in the clinics regardless of diagnosis were acknowledged. The less effective stigmatising behaviour among nurses like the rudeness towards PLWH, deterring them from seeking health care and defaulting was also found by Mathibe *et al.* (2015). Mathibe *et al.* (2015:7) found that rude and unfriendly staff behaviour was mentioned as a dissatisfying factor by PLWH.

Like nurses the HCWs seem to be less focussed on their own role in stigma reduction but in their case their focus is on criticising the nurse by referring to their lack of providing privacy and maintaining confidentiality. They see nurses as rude and judgemental. The 2018 Avert reported that nurses refused to care for sex workers and breached confidentiality (Sidibé, 2018). In their [HCWs] case the power relationship is displayed by the nurses who use them when the clinic is busy but fail to give them due recognition (Grant *et al.*, 2017:5). They further also referred to logistical problems such as shortage of staff, medication and limited space in the clinic. They had a greater awareness of patients' feelings of fear, shame and experiencing rejection or being stigmatised by identification. The patients' experiences of nurses' refusal to care made others to fear seeking health care (Sidibé, 2018). PLWH need supportive practices that are welcoming, comfortable and that ignite open discussion between them and nurses. HCWs mentioned supportive practices such as support groups for PLWH and truthful engagement. A systematic review of literature on the impact of support groups for PLWH by Bateganya *et al.*

(2015:6-7) reported on the positive impact on mortality, morbidity, retention in care, quality of life and on ongoing HIV transmission support groups have on reducing mortality and morbidity, increasing retention in care and improving quality of life of PLWH.

When it comes to disclosure however, both nurses and HCWs mentioned the need for supportive environments like counselling that enables disclosure [nurses] and need for building a trust relationship and establishment of support groups [HCWs]. Nurses however outlined a supportive counselling environment that ensure privacy and provide opportunities for home visits and patient tracing. Counselors need to be skilled. Nurses however mentioned challenges like assurances of confidentiality and non-labelling following disclosure of patients' diagnosis. A similar situation is cited in a study in Lesotho where nurses state that confidentiality is highly compromised due to poor infrastructure, few counselling and consulting rooms which are sometimes divided by a curtain and people inside can hear what others are saying (Koto & Maharaj 2016:56). Nurses also see specific benefits that disclosure offers PLWH personal benefits like freedom and accessing support in their homes, better child support and gaining knowledge through HIV-stigma education. Tshweneagae *et al.* (2015:5) affirms that disclosure of positive HIV status is beneficial for PLWH and PLC as participants in their study indicated that they got family support and also that their partners were willing to disclose following their [PLWH] disclosure. HCWs specifically saw that an environment that enhances the building of a trusting relationship, even with families, for support need to be developed. They were sensitive to patients' feeling fearful to disclose and their need for counselling in order to disclose. They also perceive establishment of wider support through empowerment of carers and traditional healers as important. The wider empowerment on counselling and stigma reduction is emphasised by Moradi *et al.* (2014:1428) stating that comprehensive training on counselling for stigma reduction should be conducted for officials, families and the broader community.

Both of these groups however mentioned the lack of health education practices in stigma and disclosure. The nurses saw HIV-stigma education as limited and lacking depth and could be better facilitated through media. HIV-stigma reduction and disclosure management should form part of community based health promotion through talks and radio information. In their study Moradi *et al.* (2014:1428) motivated that HIV-stigma training would facilitate stigma reduction. The HCWs had the need for more focussed education including stigma and disclosure. Nurses need to meet regularly to discuss confidentiality, stigma and disclosure. The finding in this article on health education aligns with the recommendation that nurses and others who work with PLWH should be taught on HIV-stigma reduction especially in PHC settings (Pretorius *et al.*, 2016:193-194). The study by Bogart *et al.* (2013:846-848) indicated that counselors should educate PLWH not only on internal stigma but also include external stigma.

The perceptions of nurses and HCWs however also clearly illuminated the fact that PLWH suffer due to the practices mentioned. It became evident that due to these practices stigma increases in the PHC settings and PLWH disclose lesser (Arnold *et al.*, 2014:719); or do not access the clinics and default (Mburu *et al.*, 2014:5), or poor logistics lead to having to re-visit the clinic (Borgat *et al.*, 2013). In general they have less support (Zhang *et al.*, 2016:127-129) that could have been available to them. Overall their quality of life then decreases as also reported by (Chidrawi *et al.*, 2015:62).

### **Recommendations**

From the mentioned findings clear recommendations can be made to improve stigma reduction and responsible disclosure management practices in PHC settings. Nurses, HCW and counsellors as the mayor role players in these practices should become the main focus when introducing stigma reduction and disclosure management programmes and providing specific in-service training in the PHC clinics. The dissonance in perceptions about HIV-stigma reduction and disclosure management practices between nurses, HCW and counsellors and the relationship

disconnect should be handled by firstly ensuring opportunities where they can regularly meet, have open discussions and build relationships through honesty and trust. The focus should be on making them all aware of their blaming behaviour and not taking own responsibility for the situation as it exists in the clinics. They should be made aware of what it is they are doing: *nurses* - focused on logistics and less on patient feelings, being rude, unfriendly and judgemental, sometimes breaking confidentiality leading to non-disclosure, and not providing privacy. They should work on the less effective practices mentioned and build on the constructive practices mentioned by them (treating patient the same in relationships but also in logistical issues such as allowing all patients to be in the same queues. For *HCW and counsellors* – becoming more aware about their own role in stigma practices (breaking trust and confidentiality, not having the proper skills and knowledge), criticise nurses less and work on improving their own knowledge and skills through training – knowledge about understanding stigma; stigma reduction; coping with stigma and responsible disclosure management; and counselling skills to handle discussions about stigma with patients and teach them to handle disclosure responsibly. To work on trust and more meaningful relationships with HIV patients by using their strengths of being in touch with HIV patients' feelings.

The clinic as a support system to patients could be improved through creating a general pleasant atmosphere in the clinics, having truthful engagements with patients, ensuring confidentiality, initiating and maintaining support groups, facilitating family support, doing home visits, and drawing in a wider support network e.g. carers and traditional healers. An effective referral system can be developed to refer patients to a broader network to fulfil all their needs.

Well sustained and organised stigma reduction and responsible disclosure management programmes involving nurses, HCW and counsellors should exist in the clinics through regular training and counselling sessions with patients on understanding stigma, how to reduce stigma,



how to cope with stigma, and responsible disclosure management. The educational programmes can be extended to media releases, community talks and clinic activities e.g. community engagement days that could include psychodrama etc.

The general systems disconnect should be addressed by conducting an intensive audit to identify limitations and to see how shortages of staff, limited space, privacy issues, medication dispensing practices etc. could be addressed to ensure best practices.

The focus on HIV patients should specifically address: stigma reduction; responsible disclosure management; their accessing PHC clinics; improving their adherence to medication; making it easier for patients when visiting clinics due to order and well organized systems for seeing the doctor, getting their medication, receiving counselling or education in a non-stigmatising manner; providing more opportunities for support through a wider network and good referral system that could address all their needs and improve their overall health.

### **Limitations of the study**

More clinics could have been included but the intensity of the intervention that followed in the larger study limited this possibility. Each clinic further had limited nurses working with HIV patients due to limited staff allocation and shortages but care was taken to include all available staff.

### **Key consideration**

- There is an absence of stigma reduction and disclosure management practices in the clinics
- Relationships between nurses and HCWs should be improved to ensure a healthy and supportive environment.
- Skills development to enhance empathic practices and improve support to PLWH should be introduced.
- Much clearer operational procedures should be available in PHC clinics to guide nurses and HCWs on how to reduce HIV-stigma and responsibly manage disclosure

- An urgent need exists for the development and implementation of a stigma reduction and responsible disclosure management intervention for PHC settings.

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**ARTICLE 2: EXPERIENCES OF NURSES, HEALTH CARE WORKERS, COUNSELLORS, PEOPLE LIVING WITH HIV AND PEOPLE LIVING CLOSE TO THEM OF A HIV-STIGMA REDUCTION AND DISCLOSURE MANAGEMENT INTERVENTION IN THREE PRIMARY HEALTH CARE SETTINGS**

**SAHARA -J: JOURNAL OF SOCIAL ASPECTS OF HIV AND AIDS: AN OPEN ACCESS JOURNAL**

Referencing in this article is guided by the requirements of the journal, which is APA style. However this article is also aligned with the structure and format of this thesis (Guidelines for the submission of an article to this journal are in Appendix D).

# **Experiences of nurses, health care workers, counsellors, people living with HIV and people living close to them of a HIV-stigma reduction and responsible disclosure management intervention in three primary health care settings**

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## Abstract

HIV-stigma exists in different environments including health care settings and this makes disclosure difficult. Stigma and disclosure are closely related concepts dictating that the two concepts cannot be managed individually due to their complexity. Researchers developed HIV-stigma reduction and disclosure management interventions for different settings except for Primary health care (PHC) specific contexts, which is the first point of entry into the health care system of South Africa. This particular study developed and implemented a PHC based HIV-stigma-reduction and disclosure management intervention. This article explores and describes the experiences of nurses, health care workers (HCWs), counsellors, people living with HIV (PLWH) and people living close (PLC) to PLWH who participated in the HIV-stigma-reduction and responsible disclosure management intervention. A qualitative descriptive design was used and six nurses, eleven HCWs, twelve counsellors, twelve PLWH and seven PLCs participated in the intervention conducted in three PHC clinics. Data was gathered through in-depth interviews and analysed by means of open coding. The participants (nurses, HCWs, counsellors, PLWH, and PLC) showed similarities in their experiences; they had similarities regarding their awareness and understanding of HIV-stigma leading to positive effects and empowerment. Following the intervention the counsellors and PLWH reflected upon their similar experiences with renewed confirmation, interest and need of counselling and support whereas nurses. PLWH and the PLC noted changes in patients' behaviour, assistance to disclose and coping strategies following the intervention. There were also unique findings reflected in the experiences of the nurses' awareness of the negative view patients held of the staff and a greater need for service improvement was noticed. The PLC focused on environmental stumbling blocks and empowerment in project management and leadership following the intervention. Recommendations were made that a PHC-based HIV-stigma reduction and responsible disclosure management intervention should be an ongoing process in the PHC clinics. The tenets

thereof are sharing knowledge, building and equalising relationships and empowerment of the people for the benefit of PLWH.

*Keywords:* HIV, stigma, disclosure, intervention, primary health care

## Background

It is estimated that South Africa has the largest number of people living with HIV (PLWH) in the world, 7.1 million, of whom 3.7 million access antiretroviral therapy (ART) mostly through primary health care (PHC) facilities (National Department of Health (NDOH), 2017:4-8). PHC is usually the first point of entry for the majority of people – including PLWH – to access health care services (Dookie & Singh, 2012:2). According to Khalil, Naeem, Zaman, Gul and Das (2015:127-129) and Okoror, Rhonda BeLue, Zungu, Adam and Airhihenbuwa (2014:28), health care settings have unfortunately become a prime locus for HIV-stigmatisation and HIV-stigma thus remaining a challenge. As soon as stigma is high, disclosure becomes problematic. Stigma and disclosure are thus concepts which cannot be managed separately as they impact health care and PLWH simultaneously (Greeff, 2013:85-88).

The literature on HIV-stigma-reduction and disclosure management interventions indicate that to date, these interventions have been mostly hospital or community based. There are very few, if any, interventions focusing on HIV-stigma reduction and disclosure management in PHC settings. This article focuses specifically on the experiences of various groups of people that were part of an intervention specifically developed and implemented to fill the gap in HIV-stigma-reduction and disclosure management interventions in PHC settings. It delineates the experiences of nurses, health care workers (HCWs), counsellors, PLWH and people living close (PLC) to them, of an HIV-stigma-reduction and responsible disclosure management intervention conducted in three PHC clinics in a selected district in South Africa. *HCWs* in this article refer to people within communities that providing basic health care and HIV care and counselling linked to PHC (National Department of Health [NDOH], 2012:10). *Counsellors* are HCWs with additional knowledge and skills in HIV counselling. *PLC* encompassed partners, children, close family members, friends, spiritual leaders and community members.



HIV-stigma is seen as a complex concept influenced by multiple factors (Gilbert, 2016:8). Although many definitions exist for HIV-stigma, the definition that will be used in this article is by Alonzo and Reynolds (1995:304): “*The stigmatized are a category of people (HIV) who are pejoratively regarded by the broader society as devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse*”.

As already mentioned, HIV-stigma is inextricably linked to the process of disclosure of a person's HIV status (Greeff, 2013:85-88) as a process negotiated over a lifetime and not a once-off process (Dageid, Govender & Gordon, 2012:2; Greeff, 2013:84). HIV status disclosure is opening up about a person's HIV status by the PLWH or others permitted to do so (Obermeyer *et al.*, 2011:1015). However, various categories of disclosure are mentioned by Greeff (2013:85): Voluntary disclosure, where PLWHs' desire to disclose voluntarily while weighing the benefits of disclosing; forced disclosure, when PLWH have their HIV status information divulged by others without permission; and mandatory disclosure, that allows PLWH to do so based on certain rules and regulations. Greeff, Uys, Holzemer, Makoae, Dlamini, Kohi, Chirwa, Naidoo and Phetlhu (2008:4) add responsible disclosure management in HIV to this discussion and present this as taking control over the decision to disclose or not.

### **Outcomes of HIV-stigma on the PLWH, PLC, community and health care system**

The PLWH, PLC, the community and the health care system are all affected by HIV-stigma. PLWH are psychologically affected (Turan & Nyblade, 2013:2530), they lose their social support, relationships and friendships (Greeff, 2010:2) and their quality of life declines (Chidrawi, Greeff & Temane, 2014:62) because of the stigma they experience. Those who witnessed stigmatisation of other PLWH experience fear of similar treatment (Mataboge, Peu, Chinuoya, Rikhotso, Ngunyulu & Mulaudzi 2014:1-7) and prefer not to disclose and withdraw. This disconnectedness separates PLWH from family and others (Owolabi, Araoye, Osagbemi,

Odeigah, Ogundiran, & Hussain, 2012:122-127). They can no longer provide for their economic needs often due to job loss or severe illness (Chidrawi, Greeff & Temane 2014:67). PLWH shy away from hospitals and clinics and do not use HIV preventative health care services for fear the consequences of disclosure in health care settings and for fear of being judged (United Nations Programme on HIV and AIDS, [UNAIDS], 2018:9). Subsequently, they experience diminished physical well-being (Chidrawi *et al.*, 2014:62).

HIV-stigma also disrupts lives and relationships of PLC to PLWH (Greeff & Phetlhu, 2007:13; Mburu, Hodgson, Kalibala, Haamujompa, Cataldo, Lowenthal *et al.*, 2014:6). Families of PLWH are bullied and sanctioned (Nayar, Stangl, Zalduondo & Brady 2014:142) and children are shunned by their families and community and often drop out of school (Kamau, 2012:233). The children's roles often change as they become responsible to care for their sick and HIV-positive parents (Barennes, Tat, Reinharz & Vibol, 2014:1-2). Quite often, the financial burden increases due to the PLWH no longer being able to work or their illness requiring additional expenditures such as travelling or more food (Etiaba, Onwujekwe, Torpey, Uzochukwu & Chiegil, 2016:11-12).

For the community, stigma can be seen in the prevalent public secrecy on HIV. Religious groups, for example, respond moralistically to HIV. Instead of providing spiritual support, they avoid and judge PLWH (Bauer, 2013:100-118). The community bonds are affected by stigma and erodes the health of communities (Hazenbuehler, Phelan & Link 2013:814). Stigma compromises social cohesion in the community and dismantles community support systems (Prinsloo, Greeff, Kruger & Ellis, 2016:264; 270). Even the mental well-being of an entire community can be affected by depression as seen in a study by Prinsloo and Greeff (2016:269-270) where low levels of depression are present in a community with high stigma levels.

Lastly, the complexities of HIV infection overburden health care systems when HCWs should care for many patients (Sehume, Zungu & Hoque, 2012:12-14). This poses far-reaching

consequences along with the increase in the community's demands for services (De Wet & Du Plooy, 2012:31) mainly in PHC clinics. Large amounts of people accessing health care through these PHC clinics strain resources, equipment and appropriately trained staff. This makes the management of HIV and related stigma difficult in these PHC settings (Crowley & Stellenberg, 2014:4-6). Infrastructure challenges arise such as a lack of space in PHC clinics – which compromises confidentiality and thus leads to stigmatisation (Scheffler, Visagie & Schneider, 2015:1). When individuals access these health services and find out about their HIV status, they face the risk of experiencing stigmatisation (Okoror *et al.*, 2014:28). Often this leads to PLWH not accessing the PHC services as required (Okoror *et al.*, 2014:28) and not adhering to their ART (Dlamini, Wantland, Makoe, Chirwa & Kohi, 2009:378; Rotheram-Borus, Tomlinson, Scheffler & Le Roux, 2015:3). Some patients opt to access HIV treatment in clinics far away from their homes – where they are not known – for fear of stigma and thereby causing overcrowding in those clinics (Audet, McGowan, Wallston & Kipp, 2013:40). It is unfortunately also true that as stigma increases, disclosure of a positive HIV status decreases (French, Greeff & Watson, 2014:105). HIV stigmatisation in health care settings also interferes with prevention of mother-to-child transmission (PMTCT), HIV testing and the administration of ART (Rotheram-Borus *et al.*, 2015:3). According to the AVERT report on stigma and discrimination, certain practices and behaviours of health care workers such as advice demotivating PLWH from having sex because of their HIV-status, mandatory HIV testing without consent or appropriate counselling, less contact with PLWH by health providers, delay or deny treatment, isolate denying women living with HIV, reproductive health services or subjecting them to involuntary sterilisation violation of patient's privacy and confidentiality, including disclosure of HIV status without patients' permission (UNAIDS, 2018). The high burden of disease, also affects the PHC system (Naidoo, 2012:149), by putting a further strain on the health workers. The complications of HIV when people present late in their illness for health care (Sehume *et al.*, 2012:12-13)

aggravate the situation. HIV-stigma also personally affects health workers and instils fear in them – some nurses refuse to care for PLWH (Audet *et al.*, 2013:3).

### **Disclosure management**

HIV-stigma and disclosure are closely linked. Stigma cannot be managed apart from disclosure. Greeff (2013:85) categorises disclosure into voluntary, forced and mandatory disclosure while Moyer, Igonya, Both, Cherutich and Hardon (2013:63-65) similarly refer to three categories of HIV disclosure: voluntary or consented disclosure, involuntary or non-consensual disclosure and obligatory or forced disclosure. A tool named “On the other side of the mountain” (NDOH, 2005:11) categorised disclosure as full disclosure, partial disclosure, indirect disclosure and non-disclosure. Emlet (2008:712-713) identified different themes in disclosure: unintentional disclosure, intentional disclosure, violation of confidentiality, non-disclosure (including protective silence), anticipatory disclosure and protective disclosure. This study discusses disclosure under voluntary, forced and mandatory disclosure. Concerning *voluntary* disclosure, PLWHs’ desire is to disclose voluntarily while they weigh the benefits of disclosing (Emlet, 2008:714). PLWH are *forced to disclose* their positive HIV status when others (PLC to PLWH like nurses, doctors, HCW, counsellors, friends, and family) divulge their positive HIV status without their permission (Greeff, 2013:85). Physical changes in a sick and debilitating body leads to suspicions of HIV diagnosis and leads to forced disclosure of HIV status (Linda, 2013:24; Poindexter & Snippy, 2010:375-376). PLWH are often expected to bring the PLC, to whom they have disclosed, to the clinic in order to access ART (Moyer *et al.*, 2013:68). *Mandatory* disclosure does not consider whether the individual chooses to disclose or not but occurs within stipulated rules and regulations. Greeff (2013:86) indicates that the choice to disclose or not lies with the PLWH, with the benefits and implications affecting their lives.

HIV status disclosure is explained as an intricate process and cannot always be an immediate action but evolves over time (Rotheram-Borus *et al.*, 2011:322). Although not clearly

described as a process or in steps, Linda (2013:25) explains that disclosure is not linear or unilateral and occurs during varying time periods. Chidrawi *et al.* (2014:227) support the fact that PLWH disclose at different times, some wait longer and others disclose shortly after being diagnosed HIV positive. The disclosure of HIV positive status by PLWH is often desired, but the circumstances and timing of disclosure may vary. PLWH should always assess the benefits and risks to their personal and social lives before disclosing (Serovich, 2008:23). Kimberly, Serovich and Greene (1995:15-18) identified disclosure to take place in the following steps: adjust to the diagnosis, evaluate personal skills, decide who to disclose to, evaluate the recipients' circumstances, anticipate their reactions, and evaluate motivation to disclose. Greeff (2013:89-90) gives guidance to a practical approach for responsible disclosure management. Focus is on understanding disclosure, knowing why PLWH want to disclose, weighing the benefits and risks, and working through the disclosure action by focussing on who, how, what, when and where. The timing is of utmost importance. Greeff (2013:76-77) specifically refers to theories that underpin strategies to assist PLWH to disclose. The *Disease progression theory* allows PLWH to talk about their HIV status as the disease becomes too conspicuous to hide; *Consequence theory*, where PLWH start weighing benefits against negative outcomes of disclosing a positive HIV status; and the *Communication privacy management model*, used by counsellors to assist PLWH to answer the why, who, what, how, and when during the process of disclosure.

### **HIV management in primary health care settings**

In the South African health care system HIV management is largely biomedical in nature. The curative treatment process for HIV were guided by various progressive national strategic plans (NSTP) on HIV, STI and TB (2000-2005, 2006-2011, 2012-2016) including the most recent NSTP of 2017-2022 (NDOH, 2017:5-6). In relation to HIV, in general, the different NSTPs were focused on prevention programs; early case detection and diagnosis of HIV; treatment initiation and provision of ART; as well as adherence to and retention on of treatment.

The identified NSTPs were implemented through programs such as nurses initiated management of antiretroviral therapy (NIMART), IDEAL Clinic realisation, National Health Insurance (NHI), National Core Standards (NCS), PHC re-engineering [with the three streams into integrated into school health programs (ISHP), district clinical specialist teams (DCST) and ward-based outreach teams (WBOT)] and integrated chronic disease management (ICDM). These programs targeted vulnerable individuals, families, and communities and health care in general (NDOH, 2011a; NDOH, 2011b; NDOH, 2017). One program titled “to the other side of the mountain”, with five tool kits included aspects disclosure, rights, communication, facilitation and advocacy on HIV stigma but were not PHC specific (NDOH, 2005)

The literature overview of the current study on the NDOH identified NSTPs for the years 2000-2022 on HIV, TB and AIDS, indicates that they [NSTPs] provided guidance for support of HIV management and care and directed the provision of ART but very little, if any, clear guidance was provided for stigma reduction and disclosure management. It emphasized stigma reduction but provided no specifics on how to do it, in especially in the PHC settings. The latest NSTP of 2017-2022 refers to stigma reduction as one of its focal areas (NDOH, 2017). It is based on human rights, the law, a multi-sectorial approach, education and information sharing (NSTP, 2017-2022:31, 74). The 2017-2022 NSTP envisages to reduce HIV and TB stigma by half by 2022. However, once again, it does not outline HIV-stigma reduction and the disclosure management processes in PHC settings. All the mentioned strategies and programs over the past few years fell short of providing clear guidelines as on how to reduce stigma and disclosure, specifically in PHC settings. It can therefore be concluded that although stigma impacts negatively on PLWH in PHC settings, little has been done with regards to HIV-stigma reduction and disclosure management in PHC settings.

## **Trends on HIV-stigma-reduction and disclosure management interventions**

Looking at stigma reduction studies that were reviewed, it becomes clear that most were done in settings other than PHC. It was done on individuals, the communities and general health care and basically with a variety of focusses. Several systematic reviews were done. In their review Brown, Trujillo and Macintyre (2003:49-64) identified 22 articles and analysed 14 stigma reduction interventions in developed and developing countries. The interventions were grouped according to their setting, type of intervention goals and target population. They showed mixed success with regard to stigma reduction interventions on a small scale and for a short period of time. They categorised the studies into those aimed at increasing the tolerance of the community towards PLWH, increasing willingness of health care providers to treat PLWH, improving coping strategies of the HIV-stigma by those at risk and PLWH. The tested interventions were said to use information based approaches, skills building, counselling approaches and increasing contact between PLWH and others. There was a positive effect and change regarding the attitude of different groups towards PLWH, willingness of health care workers to care for PLWH, and PLWH coping with perceived stigma. The review concluded that no single intervention was sufficient to reduce HIV-stigma on its own. The need for longer term, comprehensive studies with an impact on gender was highlighted.

The review by Mahajan, Sayles, Patel, Remien, Sawires, Ortiz, Szekeres and Coates (2008:9-10; 13-14) only selected published HIV-stigma reduction articles which they categorised into: theory based analyses, psychometric measurement, stigma assessment, stigma reduction interventions and legal or policy analyses. This review focussed on defining, measuring, reducing stigma and assessing the impact on HIV treatment and care. The review further identified gaps and possible good improvements in the existing interventions. They found that stigma reduction interventions leaned towards intrapersonal levels (counselling, cognitive-behavioural therapy, self-help and support groups, treatment and empowerment) interpersonal

levels (on care and support, home and community based care and rehabilitation); community levels (through education, mass media making contact with PLWH) and institutional level (through training programs, policy development, governmental and human rights-based approaches). The identified interventions were also inclined to information sharing, capacity building or counselling. The review recommended that multi-faceted and multi-level approaches need to be employed in mitigating HIV-stigma within a broad spectrum of stigma occurrences.

Sengupta, Banks, Jonas, Miles and Smith (2011:1077-1085) conducted a systematic review on stigma reduction intervention studies assessing their internal quality to reduce stigma. There were 14 studies that were included in the review out of the identified 19. Most of the studies were conducted in European, Asian and African countries. The studies focussed on students, communities, women and families. This review used the categorisation of Brown *et al.* (2003) of information-based approaches (written information), skill building (hands-on learning strategies for resolving negative attitudes), counselling approaches (PLWH support groups and resources), and contact with PLWH (testimonials, interaction between PLWH and the general public) as for Stangl, Lloyd, Brady, Hollard and Baral (2013). In as much as the reviewed studies showed some effectiveness in HIV-stigma reduction it was noted that HIV target specific interventions were not enough. The studies used inadequate measures for HIV-stigma reduction evaluation and did not establish whether statistically the stigma reduction had public statistical significance. Thus good quality studies were generally lacking.

A further systematic review was conducted by Stangl *et al.* (2013:1-6; 10-11) on studies and reports that assessed how effective the interventions were on HIV-stigma reduction from 2002 to 2013. A number of 2368 articles and reports were reviewed. Only 48 that were selected. The studies covered large parts of the world. It targeted PLWH, individuals (students, youth etc), families, community members, health care settings (health workers) including groupings such as sex workers and men who have sex with men. The interventions mostly employed one or



multiple strategies of stigma reduction and aligned to the categories of Brown *et al.* (2003) namely information-based approaches, skills building, counselling/support, and contact with affected groups. The majority of interventions proved to be successful according to their reports, however the reviewers maintain there are still gaps regarding effective stigma reduction interventions more so that others were not evaluated (Stangl, *et al.*, 2013:2-11).

The review by Nayar, Stangl, DE Zalduondo and Brady (2014:143-147) identified interventions to reduce stigma and discrimination for child health, to improve the survival of children in low and middle income countries. The focus was on HIV-stigma in the context of prevention of mother-to-child transmission (PMTCT); neonatal survival; healthy early childhood development; nutrition; marginalised groups and child survival. They also noted that HIV stigmatisation occurs in relation to HIV-stigma in the context of PMTCT, neonatal survival and health, healthy early childhood development, nutrition, marginalised groups and child survival. They concluded that it was important for researchers to focus more on interventions that will deal directly with stigma reduction in children taking all factors mentioned into consideration.

Chollier, Tomkinson and Philibert (2016:72-73) did a short systematic review on sexually transmitted diseases (STIs)/HIV-stigma and health and identified HIV-stigma reduction interventions. The review described stigma theories and models as well as stigma affecting access to health care but the number of reviewed articles was not stated. They assessed stigma in general health care where patients and PLWH are stigmatised even and are also stigmatised by health workers despite the professional environment. The reviewers found that different HIV-stigma reduction interventions mainly targeted PLWH experiencing stigma or self-stigmatising, community members for stigma reduction and professionals like teachers and carers. The researchers referred to the classification by Brown *et al.* (2003) and identified HIV-stigma reduction interventions that mainly focused on information sharing, skills building, and training, counselling and therapeutic approaches and contact or interaction with PLWH interventions.

Mak, Mo, Ma and Lam (2017:30-38) reviewed studies on effectiveness of HIV-stigma reduction programs. In total 5686 articles were identified which were scaled down to 77 through their inclusion and exclusion criteria wherein meta-analysis was used for 42 articles and a systematic review for the remaining 35 articles. The studies targeted PLWH, health professionals, communities and students. The analysed and reviewed studies were based on HIV-stigma knowledge improvement and dealing with attitudes towards PLWH. The effectiveness of the intervention was also based on the number of sessions the targeted group was exposed to.

The study by Thapa, Hannes, Cargo, Buve, Aro and Mathei (2017:547) used a scoping review to gather information on diverse qualitative and quantitative research, peer reviewed reports and theoretical articles to develop a framework for a systematic review on the efficacy of HIV-stigma reduction interventions. The identified concepts included the creation of concepts, behaviour change, organising the community, and discussions changing stigmatising attitude, fear, health service access, improving knowledge, law, social trust, and support. These culminated into three main areas: awareness creation strategy that worked on knowledge improvement, strategy that influences behaviours that helped to change stigmatising attitudes and strategy for provision of support and development of regulations and laws which enforced the actual change in peoples stigmatising behaviours. They found that most of the multiple strategy interventions were more effective in influencing behaviour towards use of HIV testing and other services.

A study using a scoping review was done by Stockton, Giger and Nyblade, (2018:13-18) looking into the non-communicable diseases (NCD) and HIV-stigma. They focussed on PLWH and HIV negative people in a health care setting and reviewed sixteen (16) articles out of 663 that were identified based on their inclusion and exclusion criteria. Some of the strategies used by the reviewed studies in dealing with stigma was training of health personnel, infrastructure and care strategies. The themes that emerged from the review were 1) HIV-stigma and the NCD

care continuum, 2) stigma related to NCD, 3) intersectional stigma and 4) integration of NCD and HIV care. It was interesting to note that while the first and the second themes were emphatic on the fact that where there is stigma, it becomes difficult for disclosure in both HIV and NCD. HIV-stigma hampers access to health care and has the potential to interfere with care of patients with NCD because of the fear of disclosure of HIV status, shame, embarrassment and negative perceptions of health care.

The literature further the literature identified some single studies reporting on stigma reduction interventions in health care settings. Studies by Holzemer *et al.* (2009:80) were among the first big studies in five African countries looking into HIV-stigma issues. The study measured and reported on high stigma levels experienced by nurses and PLWH in the aforementioned setting. In the same study Uys *et al.* (2009:1059-1064) reported on HIV-stigma-reduction intervention focussing on nurses and PLWH in health care settings. There was shared HIV-stigma information among nurses and PLWH on understanding and coping with stigma, increasing contact with PLWH and empowerment.

A health care setting-based HIV-stigma reduction intervention targeting health care providers and PLWH was conducted by Li, Wu, Liang, Lin, Guan, Jia *et al.* (2013:289-291), the first ever PHC setting focussed study in China. The intervention aimed at reducing health care providers stigmatising attitude towards PLWH in the clinics. The study found that elimination of environmental obstacles alone was not sufficient for persons' behavioural change. A combination of structural and individual behaviour components proved success. The intervention was successful as stigmatising attitudes and behaviours by health service providers towards PLWH were reduced.

Geibel, Hossain, Pulerwitz, Sultana, Hossain, Roy *et al.* (2017: 544-542) evaluated a health care setting-based stigma reduction intervention conducted in a health care. They targeted health service providers who were directly rendering services for young PLWH. They had 300

health care providers who were given questionnaires to respond complete and were also trained on HIV-stigma. A second HIV-stigma training session was done which was followed by a client satisfaction survey. The study noted that health care providers' stigmatised young PLWH because of their [health care providers] own fears of infection and moral judgement against the young PLWH. According to the study the intervention yielded good results, especially on an ongoing basis. It also followed the trend of sharing information by training the health care providers. Another health care setting-based study on older black women (OBW) was conducted with 35 OBW and indicated that despite adherence to treatment, OBW suffer stigmatisation due to multiple factors and environments they find themselves in. This study concluded that the HIV-stigma reduction intervention was successful. The most challenging part was that the intervention had a narrowed its focus on specific populations like OBW. They suggested that intersectional stigma reduction could be of beneficial and for OBW in particular and should incorporate HIV-stigma reduction interventions with successful ageing strategies (Sangaramoorthy, Jamison and Dyer 2017: 5523-529).

Intervention studies led by Greeff shifted the focus onto the community, and extending it to PLWH and people living close (PLC) to PLWH as seen in French, Greeff & Watson, (2014:105-115) and Chidrawi *et al.* (2014:1-239). The study on HIV-stigma reduction and disclosure management intervention focussed on PLWH and their PLCs (partners, children, family, friends, spiritual leaders and community leaders) at a community level. The broad tenets in the intervention were to increase HIV-stigma knowledge, equalise and enhance relationships, as well as the acquisition of leadership skills. There was an increase in knowledge, equalising relationships and coping with stigma by both PLWH and PLC.

The studies on HIV-stigma reduction on a community level were further expanded by Greeff where Prinsloo *et al.* (2017:210-211) looked at whether the community as such could change their outlook on HIV-stigma. The HIV-stigma reduction "hub network" intervention

focused on changing the attitude of a total community towards PLWH. PLWH and PLC as community mobilisers shared information and empowered their own community with regard to HIV-stigma reduction. Workshops for both PLWH and the community were conducted on “understanding stigma” and “coping with HIV-stigma”. Door-to-door education about “understanding HIV-stigma” followed. Support groups and a psychodrama group formed part of the intervention. The HIV-stigma reduction community “hub network” intervention, involving PLWH and PLC sharing their knowledge and empowering their own community to reduce HIV-stigma, was successful. There was evidence of reduced HIV-stigma experiences by PLWH, willingness of PLWH and PLC to talk about their HIV status, and changed behaviour of communities towards PLWH. The depression level of the total community decreased due to the intervention.

When looking at interventions on HIV status disclosure management several studies were described in the literature but again there seems to be a lack of disclosure management interventions in PHC settings. A systematic review on increasing HIV status disclosure was conducted by Kennedy, Fonner, Armstrong, O’Reily and Sweat (2015:7-8; 21) including PLWH, sexual partners or family, maternal disclosure and voluntary partner notification mainly in the sub-Saharan area. The review included 13 articles from 1990 to 2014 that met their criteria. Their results showed that most recent disclosure interventions increased the disclosure rate of PLWH HIV statuses. The studies varied based on population, settings, intervention approaches, and measuring the outcomes of disclosure. The reviewers could thus not concretely combine the results into a meta-analysis.

The intervention by Greene, Carpenter, Catona and Masamen-Conrad (2013:152-154) targeting targeted male and female PLWH and aimed to increase their ability to choose HIV disclosure options that would enhance their access to social support in American countries. In assessing the effectiveness of the intervention they looked at quantitative measure before and

after the intervention, disclosure efficacy, disclosure anxiety, worry about disclosure and qualitative measures. The intervention indicated varying success. The PLWH were able to assess the risks and benefits of disclosure and which approach to follow in disclosing.

A team of researchers (Rochat, Arteche, Stein, Mkwanazi & Bland, 2014; Rochat, Arteche, Stein, Mitchell & Bland, 2015; Rochat, Mitchell, Stein, Mkwanazi & Bland, 2016) implemented and evaluated the Amagugu disclosure intervention and framework between 2014 and 2016. It is a home-based parent to child disclosure intervention program that used information and activities for disclosure and engagement in health care and planning the custody of children. They targeted children and families in the community. Their focus was on maternal HIV disclosure to young HIV-uninfected children: an evaluation of a family-centred intervention (Rochat, Arteche, Stein, Mkwanazi & Bland, 2014). In 2015 the focus was on maternal disclosure to young children in rural South Africa. In 2016 the team also presented a maternal positive HIV status disclosure intervention to their uninfected children. They stated that the intervention made it manageable for HIV positive parents to disclose to their children, the disclosure enhanced their health and such mothers were eager to help others in the community with wider sustainable benefits.

Chaudoir, Fisher and Simon (2011:1622-1626) used the Disclosure Process Model and reviewed literature on disclosure to identify gaps and also present implications even beyond. Their review identified 210 articles wherein 84% was in United States, 14% in Africa and 8% in European countries. These studies targeted adults in general, including men having sex with men. The recipients' of disclosed information were family, friends or sexual partners. According to the review the studies referred to five types of antecedents, namely disclosure goals, stigma, disease progression, confidant serostatus, and confidant relationship. In their discussion they state that PLWH will most probably disclose when they have strong goals to disclose, disclosing to a confidant of important relationship and when they accepted their HIV positive diagnosis.

They also suggest that PLWH will possibly not disclose if they are against disclosure or in situations where stigma levels are high. They concluded that research did not strongly address when is it better to disclose or not to disclose and what are the most likely consequences of disclosure. Their model would thus assist in providing responses to such questions.

The South African NDOH (2005:38) outlined broad and limited principles that guide disclosure of HIV positive status to the family, children, their partners, and to the public in the toolkit. It only mentioned that if PLWH want to disclose, they need to consider why, when, to whom, what and how they want to disclose. The guidelines do not give a clear description of how to execute the referred to disclosure.

### **Problem statement**

In the context of the literature reviewed, it is evident that PHC settings being the first point of entry for health care services for different people including PLWH is affected by stigma. Closely linked to stigma is the complex process of disclosure of HIV status which remains a challenge. When stigma is high disclosure becomes a challenge. Literature indicates that a considerable amount of work has been done with regards to HIV-stigma reduction and disclosure management interventions. However, the majority of the interventions focus on individuals, specific groups (sex workers, pregnant women, MSM), communities and hospitals as health care settings but not specifically on PHC settings. PLWH, PLC, the community and the health care system are all affected by the existence of stigma which interferes with various processes in HIV management and care. Although government did a lot of work in HIV management and care, by using strategies, guidelines and policies, HIV-stigma reduction and disclosure management were never adequately addressed and no reference made to specifically PHC settings. The mentioned progress in HIV management and care, focussed mainly on HIV counselling and testing, provision of ART, health education, prevention programmes like condom distribution, improving the health care system and access to these health care systems.

The reviewed literature in this study showed trends that the existing HIV-stigma reduction and disclosure management interventions, models, approaches and guidelines including programs were based on specific aspects. These included information sharing, skills building, counselling, increasing contact or tolerance of the general population towards PLWH, increasing willingness of health care workers to care for PLWH, improving coping strategies to deal with HIV-stigma, counselling, increasing the subject knowledge, building of relationships and general empowering strategies. Those that had their focus on health care were more on general health care or hospitals and not within the PHC setting. When looking at the PHC settings it seems as though very little has been done in terms of stigma reduction and disclosure management, of which the current study aimed to fill the mentioned gap. This article looks at a description of a PHC-based stigma reduction and responsible disclosure management intervention and the experiences of the nurses, HCWs, counsellors, PLWH and the PLC who were involved in the intervention. From the above discussion the following questions arise: 1) what would the nature of a PHC-based intervention focussing on HIV-stigma reduction and responsible disclosure management be; and 2) what would be the experiences of nurses, HCW, counsellors, PLWH and PLC of such an intervention in PHC settings?

### **Research objective**

The study aimed at describing the implementation of a PHC-based HIV-stigma reduction and responsible disclosure management intervention for nurses, HCWs, counsellors, PLWH and PLC, as well as exploring and describing the experiences of these groups following the implementation of such an intervention in PHC settings.

### **Research design**

The design chosen for this study was the qualitative descriptive design described by Sandelowski (2000:339). The study was conducted in three of the ten PHC clinics, in the JB



Marks municipality of the Dr Kenneth Kaunda district of the North West Province, South Africa as this province reflects high numbers of PLWH.

### **Research method**

In-depth interviews with nurses, HCWs, counsellors, PLWH and PLC to PLWH after a PHC-based intervention on stigma reduction and responsible disclosure management (Botma, Greeff, Mulaudzi & Wright, 2010:208-209) in three (3) PHC clinics were used in this phase of the study.

### **Sample**

#### **The people involved in the PHC-based stigma reduction and responsible disclosure management intervention**

The district management team of the DOH identified the *clinics* that would be included in the study. Three of the ten PHC clinics were included in the study as they were rendering PHC services, including HIV and AIDS management and care and included several communities. Purposive voluntary sampling was used to select five groups of participants: nurses, HCWs, counsellors and PLWH and snowball sampling for PLC to PLWH. The mentioned participants had to be able to speak Setswana, English or Afrikaans and also give written informed consent for their participation.

*Nurses:* The clinic managers were mediators for the nurses who were identified. The selected nurses were included in the study according to the set criteria: they were working in the selected clinics, held a diploma or degree in nursing, rendering PHC services, trained in one or more short courses in HIV and AIDS management and care, and were directly involved in the care and management of PLWH for the past six months. A total of six nurses took part in the study.

*HCW:* The involved nurses were mediators who identified HCW for this study. The HCW were selected and included in the study based on their link to the selected clinics, had some training on HIV and AIDS, had been exposed to care and management of PLWH for the past six months, were experienced in home based care and working in and within the catchment areas of

the selected three PHC clinics. They were willing to participate in the intervention. A total of twelve HCWs took part.

*Counsellors:* The involved nurses acted as mediators to identify and recruit counsellors for this study. The counsellors were included in the study based on the inclusion criteria that they were linked to the selected clinics, had some training on HIV and AIDS, had been exposed to counselling, care and management of PLWH for the past six months, were experienced in HIV testing and counselling and working in and within the catchment areas of the selected three PHC clinics. They had to be willing to participate in the HIV-stigma reduction intervention. A total of twelve counsellors took part.

*PLWH:* The involved nurses acted as mediators to identify and recruit PLWH for this study. The inclusion criteria for PLWH were that they needed to be known to the nurses with a relationship of trust, had to be using one of the selected three clinics for HIV management and care, and had been diagnosed with HIV in the past six months. They had to be willing to participate in the intervention. A total of thirteen PLWH were recruited and included in the study.

*PLC:* The identification of the PLCs was done by snowball sampling and mediated by the PLWH themselves. The PLC had to be an adult identified by the PLWH either as a partner, close family member, child above eighteen years of age, neighbour, friend, colleague or a spiritual leader. The inclusion criteria for PLCs were that they needed to be known and close to PLWH, have a relationship of trust, and willing to participate in the intervention. A total of seven PLCs were included. The names and contact details of the identified nurses, HCW, counsellors, PLWH and PLC were provided by the respective mediators to the research assistant. Appointments were made to meet and explain the study to all participants who were willing to participate. The research assistant as an independent person obtained informed consent. The final combined sample consisted of 50 participants outlined in table 1.

**Table 1:**  
**Total numbers of participants in the PHC-based HIV-stigma reduction and responsible disclosure management intervention**

Participants	Clinic A	Clinic B	Clinic C	Total interviewed
Nurses	2	2	2	6
HCWs	4	4	3	12
Counsellors	5	3	4	12
PLWH	3	6	3	13
PLC	4	2	1	7

**The sample for the interviews with nurses, HCW, counsellors, PLWH and PLC**

The same participants mentioned in the previous discussion were the ones that were included for the in-depth interviews. The numbers of the participants across the four groups six nurses, eleven HCWs, twelve counsellors, thirteen PLWH, and seven PLC remained the same as in the intervention except for one HCW who did not participate due to personal commitments making a total of forty nine participants. The final common selection criterion for the eligibility of all five groups of participants to be included in the interviews, were that they had to have been actively involved in the PHC-based HIV-stigma reduction and responsible disclosure management workshops and projects of the intervention and completed the full intervention. They had to be willing to give consent to being voice-recorded during the interviews. Appointments were set up by the researcher and research assistant to answer any questions the participants might have during this phase of the study.

**Data collection**

The scientific committee of the School of Nursing Science, the Health Research Ethics Committee (HREC) (NWU-00008-14-A1), as well as the North West Provincial Department of Health and the district gave permission to conduct the research prior to commencement of the data collection.

## **The PHC-based HIV-stigma reduction and responsible disclosure management intervention**

A series of workshops and a project was conducted in each of the three PHC clinics. The workshops were facilitated by the study leader who is an experienced researcher, the researcher and a co-presenter who was HIV positive. The venue was well ventilated, warm, quiet, far from daily disturbing activities and afforded the participants privacy.

The intervention involved nurses, HCWs, councillors, PLWH and PLC from the three specific clinics. The intervention was built on the tenets of 1) increasing knowledge through the understanding of stigma and disclosure, 2) equalise relationships between all parties involved, and 3) building leadership skills by planning and implementing HIV-stigma reduction projects in PHC clinics to enable people to become advocates of stigma reduction.

### ***Layout of the various workshops of the PHC-based HIV-stigma reduction and responsible disclosure management intervention***

As indicated this process was repeated for each of the three PHC clinics over a one month period per clinic see figure 1 for a layout of the total intervention.

- The intervention started with a 1-day workshop with nurses, HCW and counsellors together. The focus was on getting them to understand HIV-stigma and responsible disclosure management of a PLWH of their positive HIV status. The participants shared information of observed stigmatising experiences.
- This was followed by a 2-day workshop for PLWH focussing on understanding HIV-stigma, coping with it and then to prepare them for responsible disclosure management during the intervention. The session was also preparing the PLWH mentally for follow up workshops, involving their own PLC and PLC of other PLWH where possibilities of disclosure of HIV status were inevitable.
- The last 3-day workshop (split into 2 days, 1 month, 1 day) followed with PLWH and PLC chosen by the PLWH themselves. The PLC included were either children, friends or even

their HCW or counsellor. The first day of the workshop focused on understanding and coping with HIV-stigma for both PLWH and PLC, where they got to hear one another's experiences of HIV-stigma. The second day was learning about project planning. It was also about learning how to plan a specific PHC-based HIV-stigma reduction project that they had to execute during the following months. See table 2 for a layout of the projects. The third day of this workshop took place one month later to provide feedback of their projects. The PLWH and the PLC invited prominent members of the community and the research team for the presentation. The projects were evaluated by the group present and feedback was given to the participants on successes of the projects or areas that required small improvements.

#### *A layout of the total intervention*

Figure 1 depicts the PHC- based HIV-stigma reduction and responsible disclosure management intervention that involves five groups of participants namely: the nurses, HCWs, counsellors, PLWH and PLC. It outlines the different workshops conducted in the three different PHC clinics including a stigma reduction project per clinic. The project was planned and executed by PLWH and PLC. Lastly, it indicates the evaluation of the intervention through interviews with the five groups of participants.

Table 2 outlines the three projects that were executed by each clinic. Each team designed a name for the project and formulated a vision and objectives for their project. A team leader was nominated to work with the research team and report on their progress and implementation of the project. Guidance was provided when necessary. They were also assisted in writing letters to communicate with people like the clinic managers. Tasks were assigned to the rest of the team members. These projects managed to reach a total of 272 people during the intervention.

**Interviews with nurses, HCWs, counsellors, PLWH and PLC on their experiences of the implemented PHC-based HIV-stigma reduction and responsible disclosure management intervention**

Two weeks after the intervention the participants were contacted via their respective mediators. The research assistant confirmed participation for this part of the study. Only one HCW indicated unavailability to be interviewed. The research assistant informed all the participants of the date, time, venue and transport arrangements. An open-ended question was formulated and evaluated by experts for its applicability to elicit appropriate information.

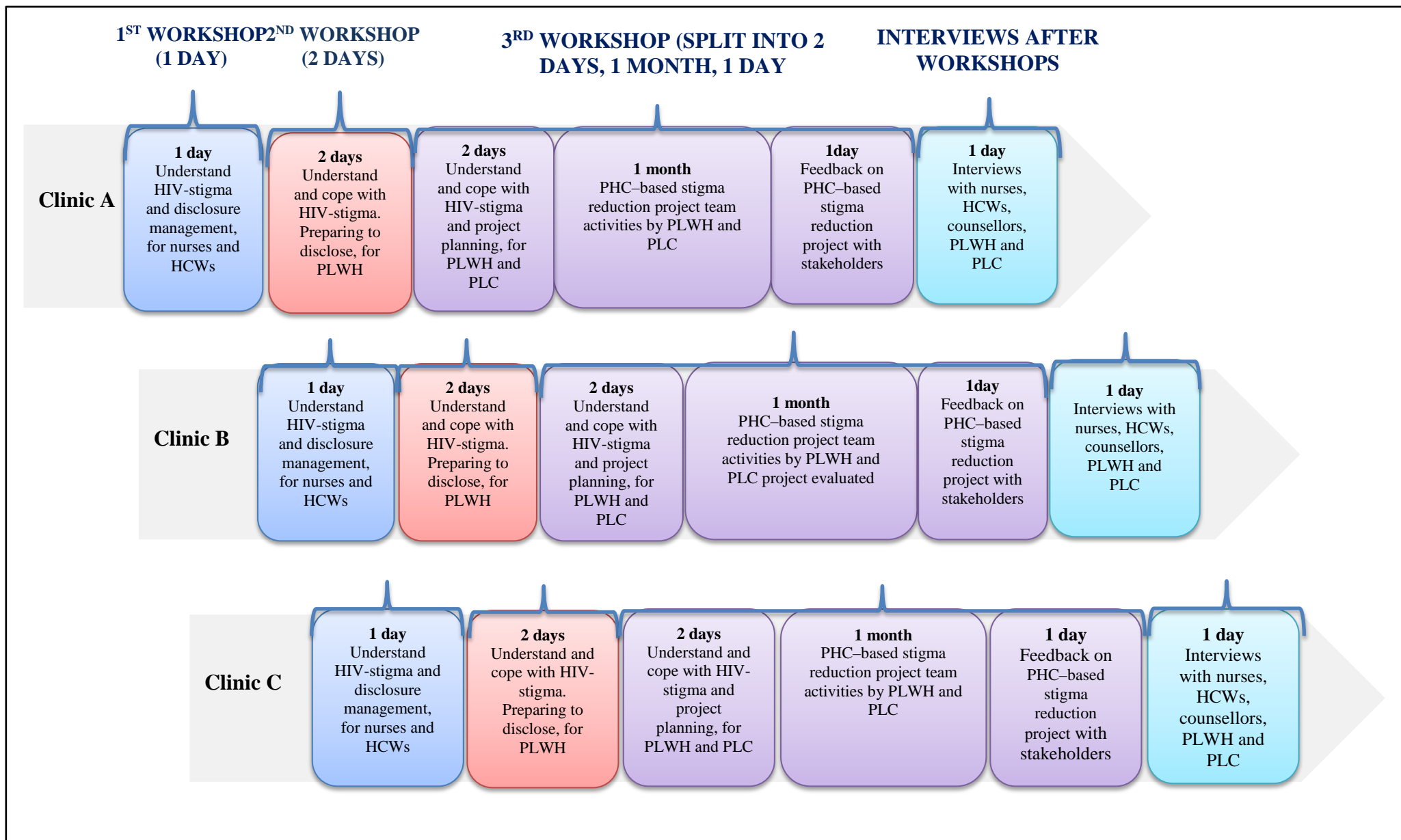


Figure 1: HIV-stigma reduction and responsible disclosure management intervention in PHC settings

**Table 2:**  
**HIV-stigma reduction projects of the three selected clinic**

<b>Designated group</b>	<b>Vision and objectives</b>	<b>Target</b>	<b>Activities</b>	<b>Total reached</b>
<b>Clinic A:</b> “Iphemeleng” (Protect yourselves)	<b>Vision:</b> To educate the nurses, HCWs, counsellors and clinic visitors on HIV-stigma. <b>Objectives:</b> <ul style="list-style-type: none"> <li>To make the management of the clinic aware of the present HIV stigmatisation practices.</li> <li>To create awareness and support group amongst other PLWH at the clinic of HIV stigmatisation.</li> <li>To create a short questionnaire which will document that people experience stigma.</li> <li>To create a psycho drama depicting stigma practices.</li> </ul>	PLWH and others visiting the clinic  Clinic staff  Senior officials in the department of health	<ul style="list-style-type: none"> <li>Presented a letter to management of the clinic making them aware of stigmatising practices identified in the clinic.</li> <li>Informed the clinic about the experienced problems with the AA project (project where PLWH collect medicine without visiting the clinic).</li> <li>Formulated a short demographic questionnaire (where do you stay? Have you experienced stigma? what type of stigma? did you experience HIV-stigma at the clinic?)</li> <li>Educate people about HIV-stigma, and how it affects PLWH.</li> <li>The group pitched a tent with chairs inside that could accommodate those visiting the clinic.</li> <li>They did psycho drama on HIV-stigma depicting stigmatising actions.</li> <li>They taught those stigmatising to stop.</li> <li>Taught people how to cope with stigma.</li> <li>Health talk on HIV-stigma.</li> <li>Mass campaign in and around the clinic making people aware of stigmatising cues and urging people not to stigmatise PLWH.</li> <li>A support group was formed for PLWH.</li> <li>Reporting back meeting to the Department of Health on the HIV-stigma project.</li> </ul>	<b>125</b>
<b>Clinic B:</b> “Mmogo ka lentswe le le lengwe go lwantsha sekgomaredi” (Together as one voice against HIV-stigma)	<b>Vision:</b> To have the clinic function as a clinic with low HIV stigmatisation. <b>Objective:</b> <ul style="list-style-type: none"> <li>To educate the nurses, HcWs and counsellors on HIV-stigma.</li> <li>To make the management of the clinic and of the Department of Health aware of the present HIV stigmatisation</li> </ul>	Sister in charge of the clinic  HCWs and counsellors  Clinic staff  All visiting the clinics  PLWH Department of Health	<ul style="list-style-type: none"> <li>Meeting with clinic authorities for permission to conduct the HIV-stigma project, to secure a date to inform them of stigma practices identified at the clinic and also a date to meet with nurses, as well as a date for HCWs and counsellors for a talk on HIV-stigma in the clinic (However they were not able to meet all relevant authorities).</li> <li>Inform in writing clinic staff on HIV-stigma practices at the clinic affecting PLWH (files stickers, attitude of nurses shouting at PLWH, breaking</li> </ul>	<b>79</b>



Designated group	Vision and objectives	Target	Activities	Total reached
	<p>practices in the clinic.</p> <ul style="list-style-type: none"> <li>To create awareness amongst other clinic visitors on HIV stigmatisation.</li> </ul>	senior officials	<p>confidentiality, gossiping about PLWH, ill-informed advice to PLWH on disclosure practices during counselling).</p> <ul style="list-style-type: none"> <li>Educational poster on HIV-stigma displayed at the clinic.</li> <li>HIV-stigma talk: what is stigma, how it affects people reducing stigma (The attendees were presented with tea and cake).</li> <li>Presenting a psycho drama in a tent on HIV-stigma and stigma reduction.</li> <li>Distribution of pamphlets on HIV-stigma in English, Afrikaans and Setswana.</li> <li>The clinic however also invited the group to present the psycho drama at one of the clinics health promotion function.</li> <li>Reporting back meeting to the Department of Health on HIV-stigma project.</li> </ul>	
<b>Clinic C:</b> “Itsoseng” (Wake-up)	<p><b>Vision:</b> To educate the clinic visitors on HIV-stigma and make an impact on the clinic staff to stop stigmatisation.</p> <p><b>Objectives:</b></p> <ul style="list-style-type: none"> <li>To educate clinic visitors during the morning health talk about HIV-stigma and behaviours.</li> <li>To make the management of clinic aware of the present HIV stigmatisation practices.</li> <li>To educate clinic staff and clinic visitors by speaking to them, also giving them reading pamphlets about HIV-stigma.</li> <li>To educate the clinic visitors by doing a psycho drama.</li> <li>To educate PLWH who come to the clinic about HIV-stigma in a support group.</li> </ul>	<p>Clinic staff, PLWH and everybody attending the clinic that morning</p> <p>Clinic management</p> <p>All people and patients visiting the clinic</p> <p>PLWH and other patients</p> <p>Clinic stakeholders and clinic management</p>	<ul style="list-style-type: none"> <li>HIV-stigma and challenges faced by PLWH were presented to clinic management.</li> <li>HIV-stigma talk was done on what is stigma, how it affects people.</li> <li>Poster on HIV-stigma education displayed at the clinic.</li> <li>Distributed pamphlets at the clinic for everybody at the clinic.</li> <li>Psycho drama on HIV-stigma which was also attended by doctors.</li> <li>Presented the HIV-stigma project report to the clinic manager and the Department of Health officials.</li> <li>Vegetable garden and presented vegetables to people who needed them.</li> </ul>	<b>68</b>
<b>Total reached for all three clinics</b>				<b>272</b>

The question had been evaluated prior to being used. The question was: “Tell me about your experiences of the HIV-stigma reduction and responsible disclosure management workshop and project”.

It was stated that the interviews will last for more or less an hour- to an hour- and a- half, be voice-recorded and that confidentiality would be maintained. Participants were assured that should they wish to discontinue participation they would be free to withdraw (Botma *et al.*, 2010:207). The participants were afforded privacy with minimal disturbances during the interviews. In the case of any discomfort in sharing their experiences of the intervention, counselling was made available. The interviewer used different communication techniques such as paraphrasing, reflection, clarification, probing and summarising. Observational, methodological and personal field notes were recorded to assist in verifying the captured information (Botma *et al.*, 2010:206-217).

### **Data analysis**

The interviews were transcribed. The data was analysed using a process of open coding following the steps of Tesch as outlined in Creswell (2009:185-186). The transcribed data for the five groups of participants was read to gain a greater understanding of the whole. A systematic process of reading the transcripts and noting topics through InVivo and descriptive codes was followed. Categories and sub-categories were grouped and clustered into themes. Relationships among the various categories were identified. The data was co-coded by a co-coder who used the same set of transcripts and consensus was reached.

### **Trustworthiness**

Trustworthiness of this study was guided by the principles of Lincoln and Guba (*in* Krefting 1991:217; Klopper, 2008:70) as outlined by Botma *et al.* (2010:234-235). **Truth value** was ensured through the strategy of credibility by *prolonged engagement*. Time was spent with the participants during the workshops. They executed the planned projects by themselves and

were supported by the researchers. Reflexivity was realised through written field notes during and after the interviews as well as discussions with the study leaders during guidance. A co-coder coded the analysed data. Experts evaluated the relevance of the formulated questions before the interviews. The subject leadership skills of the study leaders in research and the researcher experienced in PHC lent credibility in the execution of the study. The *interview technique* used principles of qualitative research. Interviews were conducted by knowledgeable researchers and a research assistant using well formulated questions that were affirmed by the experienced study leader. The *transferability* strategy was realised by the *selection of the sample* that was guided by a set of inclusion and exclusion criteria for the clinics and the participants in ensuring **applicability**. The DOH authorities knew the clinics that were in the sample in terms of their demographics of being high volume PHC clinics including HIV management and care and ascertained that those clinics were the best to illicit the required data. The interviews were conducted such that *data reached saturation* where themes were repeating themselves. A *thick and dense* description of the research methodology was confirmed. The intervention for the study was clearly described. **Consistency** was attained through the strategy of the possibility for a *dependability* audit where traceable variability ascribed to identifiable sources such as in literature review and the participants. *Stepwise replication* wherein it was possible that the study could be repeated in other situations with well described and clear methodology. A *co-coder* was used during the analysis of data where data was analysed by the researcher and subjected to coding by an independent co-coder. **Neutrality** was attained through *reflexivity*. The research documents are available for auditing or assessing if required. Upon realising **authenticity**, the researcher quoted what the participants said to fairly *reflect* the realities of their [nurses, HCWs, counsellors, PLWH and PLC] experiences of the HIV-stigma reduction and responsible disclosure management intervention in PHC clinics. A genuine report is presented such that it affords the reader an insight into the study – as though the reader had been a part of it.

### **Additional ethical consideration**

The study endeavoured to comply with ethical stipulations (NDOH, 2015:14-17). *Entry:* Ethics approval was obtained from the School of Nursing Science of the North–West University, the Faculty of Health Sciences’ Health Research Ethics Committee (HREC), and the Department of Health (DOH) of the North West Province. The additional ethical considerations not addressed so far refer to risks and benefits, remuneration, privacy and confidentiality and data storage.

*Risks and benefits:* An analysis of the potential risks and the benefits for all the participants was done. The interview question was structured in such a way that it was not sensitive and it would cause minimal discomfort. It was envisaged that the intervention assisted the participants to understand stigma and disclosure. Information was coded. Use of real names was avoided. Should there be any emotional discomfort support was made available. The information presented by the stigma reduction and disclosure management intervention would indirectly benefit the scientific community and PHC settings in guiding future action to reduce stigma and handle disclosure effectively. *Remuneration:* There was no monetary gain for the participants. Only deserving participants were provided with transport as the interviews were conducted during working hours and lasted for less than an hour-and-a-half. The interviews were held in their respective clinics at a date and time most suitable to the participants. *Privacy and confidentiality:* Data that could identify the participants was coded during the transcriptions and the voice recordings were deleted immediately after it was transferred to the password protected computer. Privacy was maintained during data collection in a private room and a confidentiality agreement clause was signed by the transcriber and the co-coder. *Data storage:* The hard copies are kept in safe locked cabinets, in the research unit and the electronic data on password protected computers. The information can only be accessed by the researchers and will be stored for a period of five years according to the prescripts of the university.

## Findings

The findings of the interviews with the nurses, HCWs, counsellors, PLWH and PLC regarding their experiences of a PHC-based HIV-stigma reduction and responsible disclosure management intervention that they underwent are discussed. There were similarities as well as unique findings among the different participant groups as outlined in table 3. In terms of similarities all five groups (nurses, HCWs, counsellors, PLWH and PLC) referred to two themes 1) a better awareness and understanding of HIV-stigma, 2) and the positive effects and empowerment following the intervention. Two groups (counsellors and PLWH) reflected on the theme of renewed confirmation of counselling as well as interest and need for counselling and support. Three groups (nurses, PLWH and PLC) reflected on the theme of changes in patient behaviour, assistance to disclose and coping strategies. In terms of those findings considered unique – only nurses reflected on the theme of awareness of patients' negative view of staff and a greater need for improvement of services. Unique findings mentioned by PLC were environmental stumbling blocks for effective HIV and care as well as empowerment in project management leadership. These themes are referring to the affiliated categories and sub-categories in table 3 and are enriched with quotes where applicable.

### **Awareness and understanding of HIV-stigma**

Following the HIV-stigma reduction and disclosure management intervention, all five groups revealed their experiences of a greater awareness and understanding of HIV-stigma. They varied in how they expressed this experience. The **nurses** said that their understanding of HIV-stigma improved. They became more aware that PLC sometimes emotionally abuse PLWH and said: *“[t]he people being very up front about their own personal experience, about being identified as HIV positive, ... in the role play they showed [the] experience [of] emotional abuse from PLC”*. There was a greater awareness of expressed experiences of loneliness and little support experienced by PLWH: *“PLWH were very real in displaying their experienced emotions*

*of loneliness... ”. According to the nurses health promotion is inhibited (as they noted it from the sketch) and that PLWH do not trust the staff and HCWs. They also indicated that wrongful use of medication by PLWH is as a result of stigma and said: “[S]tigma causes people to use medication wrongly.... and when no one is watching”.*

Firstly, the HCWs in their critical awareness of HIV-stigma referred to HIV stigmatisation causing discomfort to PLWH. They mentioned their fear of rejection and hurt experienced by PLWH and said: *“It was evident in their drama that they struggle to tell people about their status because they’ve seen people being rejected, hurt and gossiped about within the community”*. HCWs also highlighted their fear of HIV infection as follows: *“[W]e’re scared of being infected with HIV”*. Participation in relational negotiation by PLWH is inhibited and also in seeking health care as stated: *“ [L]ow testing rates in the clinic,... people not wanting to come to get their medication regularly”*. HCWs realised that PLWH are at times emotionally abused by community members as related: *“When a person know your HIV status, they can blackmail you to do things you don’t really want to do by threatening you that they are gong to disclose your HIV status to the whole community”*. Secondly, the HCWs stated that they became aware of how their contact with patients could stigmatize PLWH. They mentioned that they did not meet with PLWH in the clinic nor in their homes so that they are not stigmatised by HCW home visits, however, that alone was stigmatising: *“[W]e meet PLWH away from the clinic, friends and families.... to save them the embarrassment of entering the clinic but this was stigma”*. HCWs also mentioned that mobile phone reminders for collection of ART was stigmatising and quoted PLWH at the clinic saying: *“I got the SMS’s”*.

**Table 3:**

**The experiences of nurses, HCWS, counsellors, PLWH and PLC of the HIV-stigma reduction and responsible disclosure management intervention in Primary health care settings**

THEMES	NURSES	HCWS	COUNSELLORS	PLWH	PLC
<b>SIMILARITIES (nurses, HCWS, counsellors, PLWH, PLC)</b>					
<b>Awareness and understanding of HIV-stigma</b>	Improved understanding HIV-stigma	Critical awareness of stigmatisation	Heightened awareness of stigma	A better understanding of stigma	Improved understanding of stigmatisation
<b>Positive effects and empowerment following the intervention</b>	Positive effects of the intervention	Positive effects of the intervention	Evidence of emotional strength after the intervention	Empowerment through the intervention	Enhanced positive experiences
<b>SIMILARITIES (counsellors, PLWH)</b>					
<b>Renewed confirmation, interest and need of counselling and support</b>			Renewed confirmation of counselling and support	Renewed interest and need for support groups	
<b>SIMILARITIES (nurses, PLWH, PLC)</b>					
<b>Changes in patient behaviour, assistance to disclose and coping strategies</b>	Observed changes in patient behaviour			Offered PLWH assistance to disclose	Improved coping strategies for stigma reduction
<b>UNIQUE (nurses)</b>					
<b>Awareness of patients' negative view of staff and greater need for service improvement</b>	Awareness of patients' negative view of staff Greater awareness of need for improvement of services				
<b>UNIQUE (PLC)</b>					
<b>Environmental stumbling blocks and empowerment in project management and leadership</b>					Environmental stumbling blocks for effective HIV and care  Empowerment in project management and personal leadership

According to HCWs it is cumulatively assumed that people who collect medication through “sms” reminders are HIV positive. Other specific stigmatising practices such as going into the community to trace treatment defaulters were referred to and the HCWs said: “[T]he community would conclude that the person visited is HIV positive”. Throughout the workshop HCWs became aware of their perceptions and pre-conceived ideas about PLWH and admitted that they did not always take PLWH’s complaints seriously as reflected.

**Counsellors** expressed heightened awareness of the reality of stigma through improved understanding of the meaning of stigma – that it is a real, serious, and everyday occurrence and said: “Then when you ask them that is when say, they have been afraid to disclose because they thought they’d tell people or shout at them. It is the way stigma is and PLWH have to deal with stigmatising behaviour on a daily basis”. The counsellors who attended the intervention realised that stigma is an unnecessary occurrence. They also indicated that stigmatising behaviour focussed on others and said: “[S]tigmatising behaviour comes from PLWHs’ family, friends, community members and people working in the clinics.... and the pain attached to these experiences can be severe at times for others”. In other instances, the PLWH stigmatise themselves by being self-aware because of the HIV positive diagnosis.

The realisation of the negative impact of stigma following the workshop affirmed the counsellors’ heightened awareness of stigma. Counsellors noted how PLWH were left to deal with their own negative experiences expressed as follows: “ PLWH carry their burden alone, they manage their own discomfort of being stigmatised...”. The workshop presented how physically or mentally sick PLWH become due to the negative impact of stigma and said: “PLWH if you find out about their status .....end up very sick at home because you are afraid other people will talk about you”. Counsellors also reflected on their heightened awareness of stigma as they noted that stigma



impacts negatively on PLWHs' health care behaviour and indicated that: "PLWH *not to take their medication regularly (they are scared someone will see them and guess their status or they will go to another clinic (not situated in their area) for medication*". PLWH still perceive that HIV is a death sentence and say: "*Others will say what does it help in taking the pills, I am going to die*". The counsellors further noted that disclosure of HIV status is deeply feared. A general fear of disclosure was identified by the counsellors throughout the workshop and role play and stated that: "*[I]t is not easy to end up talking about your HIV*". Accidental disclosure is also feared as related: "*[S]ometimes the neighbours' gossip about other people who are HIV positive*". It is expected of PLWH to communicate their status within the health care environment as stated by the counsellors: "*PLWH to disclose their HIV status at least to one person within their family or community in order to generate support within their immediate environment.*" This health care practice can possibly be interpreted as a form of forced disclosure.

**PLWH** said they had a better understanding of stigma and referred to gained awareness of stigma. They mentioned that they enjoyed the workshop and acquired excellent stigma knowledge and stated: "*[E]njoyed the workshop and gained excellent stigma knowledge*". They also became aware of stigmatising behaviour and said: "*[B]ecame greatly aware of what behaviour is stigmatising*". PLWH stated that through the intervention they came to understand how they withdrew from the community: "*[P]eople feeling that they have no roles or no part to play in the community.... and it hurts and they have feelings of worthlessness*". Stigmatising behaviour reduces community support and inhibits good communication within families and within the community. PLWH stated that they: "*[U]nderstood this thing of saying painful degrading words to one another....my mother used to degrade me with words, after drinking alcohol that I am going to die of AIDS, that I am a slut, I love men*"; "*she told me the way I am a prostitute, I am going to die*".

According to them such utterances inhibited good communication and reduced PLWH community support for PLWH.

The PLC indicated that they had improved understanding of stigmatisation on intrapersonal, interpersonal and community levels following the intervention. On an intrapersonal level, PLC noted that non-disclosure decreases health. They also mentioned that stigmatisation leads to unhealthy behaviour [of PLWH] in this quote: “*PLWH find themselves engaging in unhealthy behaviour and not taking the tablets at the correct times*”. On interpersonal level PLC realised that they themselves stigmatise PLWH by standing in judgment of others. This is evident in the following quotation: “*There is something that we call confidentiality, you may be a church goer but at the same time you don’t know what is confidentiality, when you go home, you just break everything to your family, by that time it is where you stigmatize that person you see*”. Some people avoid association with PLWH said: “*[T]hey decide not to have contact with PLWH in order not be infected*”. The intervention made the PLC to note that stigma cannot be ignored in the community and needs to be dealt with sensitively and responsibly as quoted: “*[s]tigma must be managed in the community so that the community stops stigmatising*”. They also realised the need for openness to differences in people and emphasised that: “*[R]eceive different kinds of patients with understanding*”. The intervention had them emphasise that people are equal in the community as said: “*People are equal and should be treated equally*”.

### **Positive effects and empowerment following the intervention**

In the second theme, the five groups of participants experienced positive effects and empowerment following the intervention through diverse communication approaches. The nurses experienced the intervention to be relevant and inclusive. They mentioned that the participants had ample opportunity to learn about stigma, as they stated: “*[...] the stigma reduction intervention*

*created enough opportunities for HCWs, counsellors, PLWH, PLC, and nurses to learn about the stigma related to HIV and stigmatising behaviour". During the intervention, different categories were included, which facilitated a change in how staff and patients viewed each other: "With staff and patients being part of the same stigma reduction intervention [...] people's perceptions of each other started to change for the better". Nurses realised that all role players should be involved in the intervention and verbalised that: "[...] everybody need to be exposed to this proposed stigma reduction intervention". They further indicated that an improvement on community involvement is needed and said that "[...] community involvement in dealing with and treating of PLWH must improve". They also noted a level of self-acceptance by PLWH that triggered a positive change in their personal health. After the stigma reduction intervention, nurses became aware that PLWH presented positive changes in personal health care and this resulted in an improved self-acceptance by PLWH and said: "So right now, they are no longer hiding [...] if you see them they improved, because you will be looking at the weight, looking at the BP and hear sense when you speak to them". Nurses stated that: "[...] there is a change that took place because they come to the clinic and their results ... are good showing that they are taking medication well". Throughout the stigma reduction intervention, PLWH encouraged other patients to seek the necessary support in dealing deal with their diagnosis as quoted: "I heard them motivating other patients so that they become open and are able to disclose and get support".*

**HCWs** identified a change towards a positive attitude within themselves as well as in the nurses after the intervention. They realised that respectful behaviour was necessary and that they should welcome PLWH. They stated that "[...] by accepting the PLWH as our people the behaviour of health care workers in the clinics will be more respectful and welcoming". They should treat PLWH like others for safer emotional atmosphere in the clinic and said: "[...] there is no longer that

*fear that when you [PLWH] come to the clinic you are scared that you will not be treated well [...] we treat all patients the same*". Other changed clinic practices were implemented after the stigma reduction intervention and they mentioned that *"HIV-specific packages were removed from HIV medicines"*. According to HCWs, stigmatising signs were also removed from clinic doors. To address long queues in the clinics, the HCWs said that *"[...] a system was followed allowing PLWH to collect pre-packed treatment [...]"*. They [the HCWs] also indicated that the clinic accommodated patients after the usual clinic hours and said that *"[...] the clinic working hours were extended beyond four and some clinics were even operating on weekends to accommodate patients who come from work"*. Another measure introduced in the clinic as mentioned by the HCW was that a person with proper identification was trusted by the PLWH and was allowed to fetch medication from the clinic on behalf of the PLWH.

Patient contentment increased – they were happier to attend the clinic, as they said *"[...] after the project we saw changes, patients were happy to come to the clinic"*. As stated by the HCWs there were fewer complaints about the service in the clinics as quoted: *"[...] there was no one that came to complain here about the clinic because the workshop brought changes"*. The clinic had fewer patients who defaulted: *"[...] our patients' defaulter rate has gone down"*. According to HCW the PLWH showed interest in themselves with improved self-care and self-acceptance. HCW quoted that the PLWH indicated decreasing stigma in saying that *"[...] I feel the stigma is becoming less [...] the nurses are treating us well"*. Positive intrapersonal changes of happiness in PLWH were evident after the stigma reduction intervention, as they quoted: *"We saw more PLWH who appeared happier in themselves"*. HCWs verbalised that *"[...] the clinic is doing the things that were mentioned in the workshop to reduce stigma"*. HCW experienced positive interpersonal changes in relationships in PLWH with freedom in relationships after the intervention was

completed, as evidenced by this quote: “[...] *people to disclose to their PLC [...] after many years of being HIV positive [...] they had freedom in their relationships after the workshop*”. They also mentioned that their [PLWH] relationships with PLC had enhanced. The workshop motivated the PLWH to disclose their status to their loved ones and enhance romantic relationships, as stated by a HCW: “[...] *they were also able to talk to their partners about their status*”. The freedom of interaction extended to others following the workshop: “[...] *PLWH interacted with a big circle of people [...]*”.

The workshop gave them a greater understanding of disclosure and they saw an increase in disclosure by PLWH: “[...] *the workshop motivated PLWH to disclose to their family [...] so that they live free and able to take your medication*”. Furthermore the workshop explained the HIV disclosure practices and generated a better understanding of HIV-stigma, which assisted the HCW in facilitating and improving disclosure process, as stated by HCW: “*I learnt the importance of disclosure [...] I can motivate PLWH to disclose and the facilitation process of disclosure is enhanced in the support group*”.

The behaviour towards PLWH changed as they received more support in the clinics through support groups, which prompted support in the community following the intervention, as said by HCWs: “[...] *support in the clinics was not effective [...] the workshop now showed a greater need for support in the community [...] this helped us [...] to open support groups*”. The need for support of PLWH instead of gossiping and stigmatisation was noted by HCWs in the workshop when they said: “*It is important to support the PLWH and not gossip about them*”. The HCW noted that others needed be invited to existing support groups and that more support groups should be initiated. The intervention was seen as well-received by the community, and it helped the HCW with door-to-door

visitations to communities, as said by HCWs: “[...] *the PLWH submitted a request for HCW to facilitate door-to-door visits in the community*”.

**Counsellors** were able to identify how PLWH moved from a prison of secrecy to freedom of disclosure as the workshop progressed. Witnessing other people’s journeys as part of the role play gave clarity in people’s understanding of stigma, and counsellors observed that “*the workshop made it become clearer and for people clarity to understand stigma*”. The counsellors noted greater freedom on the part of PLWH as the workshop made them see the impact of stigma and the importance of talking about the disease. They [the counsellors] said: “*...it gave them greater freedom as they [the PLWH] started talking about their diagnosis and acknowledging the impact of the diagnosis on themselves*”. They also reported on the new boldness that they saw the PLWH exhibit as, they explained that the “*PLWH displayed a new boldness to disclose their HIV status and to educate people*”. The workshop encouraged the PLWH to stand up for themselves, as quoted by the counsellors: “[...] *seeing other PLWH doing it in front of an audience I am motivated to talk for myself and say what I need*”. According to the counsellors, the aspect of self-stigmatisation was clarified for PLWH in the role play when saying that the “*PLWH realised that often they stigmatise themselves by not telling the truth about their condition*”.

Moreover, according to the counsellors, the PLWH started feeling free to live unashamedly: “[...] *they are free and can live without shame*”. PLWH gained freedom to enjoy their romantic lives: “[...] *living consciously with their diagnosis, they can engage responsibly in romantic relationships [...] by disclosing their HIV status*”. The counsellors saw increased self-confidence in disclosure and said that “[...] *they [the PLWH] present with increased self-confidence in their own abilities and health status demonstrated in the sketch*”. In this workshop, PLWH spoke much of fear

of gossiping and its effect in their lives, and seemed to have learnt to deal with it: “[...] [they] have lost their fear of gossiping by the end of the intervention”.

The stigma reduction intervention presented an opportunity for counsellors to move from despair to courageously unlearning their own stigmatisation behaviour. They said: “*we realised through the stigma reduction intervention that we should not be ashamed to associate with PLWH*”. They also indicated that they felt free to touch PLWH in a normal way, and stated that “[...] *due to not knowing, they [the counsellors] were scared to touch PLWH in a normal way – this became clear in the sketch*”. Counsellors developed greater openness to tests when saying that “[...] *we are more open to be tested after seeing the openness to test in the sketch for the stigma reduction intervention*”. The workshop encouraged PLWH to be self-accepting, as stated by the counsellors: “[...] *the importance of accepting one-self after the diagnosis of HIV is confirmed in the intervention*”. The intervention brought about greater awareness of respectful behaviour: “[...] *the workshop emphasised and made us more aware that respectful behaviour is important when working with PLWH*”. The counsellors further experienced that PLWH were becoming more supportive to others following the intervention. They stated that within a more supportive environment, PLWH were becoming more supportive towards others: “[...] *PLWH can also be able to advice other HIV positive people in order to structure their lives in a healthy way.*”

PLWH mentioned that they felt empowered by the intervention and referred to enhanced intrapersonal strength of PLWH and enhanced interpersonal strength. As far as enhanced intrapersonal strength is concerned, PLWH stated that the knowledge they gained replaced the fear and problems of stigma. They responded positively and responsibly to questions about the disease: “*So I said to her I know that I am going to die, but if I am taking care of myself and drinking my medication without hiding myself I will not die right now*”. Reduced inner pain and shame were

experienced by PLWH after they attended the stigma reduction intervention as evident in the following quotations: “*Yes my heart was at peace I was no more having stress ....the first day I was afraid, hurting but after you encouraged me in the intervention I have less pain*”. They also learnt self-acceptance and believe in-self following the intervention as said: “*..... a person should not give up on who they are, ....you must not belittle yourself in life....that I am HIV positive there is nothing else that I am going to do in life*”. PLWH experienced encouragement to live positively and with hope. PLWH stated: “*I realised that this disease does not kill, you should just take the pills....on time, as directed*”. They also indicated that there is no stress anymore because the intervention taught them not to allow people to put them down, as stated in the following quotations: “*I will never give up in life, I won't .... life is going on...* ”.

Regarding enhanced interpersonal strength PLWH indicated that it gave them courage to go forward and teach others about stigma as evidenced in the following quotations: “*....I am more than a conqueror, I am more as myself.....I will go and teach others about stigma*”. PLWH stated that the intervention assisted them to open up communication about HIV matters and to be comfortable to talk and share issues related to HIV. They stated that: “*....they accept it, they are HIV positive, they live with and that is why they are free to share with people of HIV*”. They learnt how to express the pain of stigma as stated by the following quotations: “*...the words that came up encouraged me more I can tell people how I feel because of stigma*”. PLWH also felt that they made new friends and found a new family within the clinic and the community by sharing experiences with other PLWH as said: “*.... so at the end of the day they accept me, they give me hug wherever I go and if I'm in public I am open*”.

Lastly within the theme positive effects and empowerment following the intervention, the PLC reported enhanced positive experiences. They had feelings of courage to support the PLWH.



They also mentioned feeling of freedom to engage PLWH. The intervention filled them with hope that their loved ones [PLWH] are not dying: “...*I have a feeling of hope and a feeling of pride and satisfaction.* The intervention gave them some level of pride and satisfaction with the information that was shared with them in the workshop.

### **Renewed confirmation, interest and need of counselling and support**

It was interesting to note similarities in the intervention experiences of the two groups that are directly involved with PLWH, namely counsellors (doing the counselling) and PLWH (who are the recipients of counselling services). Regarding this theme the **counsellors** mentioned that after the intervention their role was validated. The intervention confirmed that counselling is recognised as a necessary process utilised more than before and said. “...*we counsellors have a valuable contribution to make as part of the services for PLWH ....more people are testing.....our job have been recognised*”. According to the counsellors, the intervention assisted in people acknowledging and appreciating their counselling knowledge and skills as part of the health care services in the clinic. The counsellors’ knowledge and skills are said to be appreciated as stated: “...*we do a good job on counselling for HIV testing*”. Due to the intervention, PLWH displayed a greater openness to interact with counsellors: “...*the people communicate more with counsellors and show a need of interaction towards disclosure*”. There was a general experience of counselling progressing beyond emotional pain after the intervention was completed, as some of the counsellors are also PLWH themselves stated: “*being HIV positive is not an easy thing but only if you have accepted it becomes better.....as a counsellor living with the disease and you know how difficult it is for PLWH*”. The intervention demonstrated that people’s emotional burden was lessened as they were more encouraged and more willing to talk about their positive HIV status than keeping it to themselves and said: “...*the workshop was good.....after speaking about HIV and the stigma something falls of*

*from your heart*". Even though the counsellors were an available resource, they seemed not valued. This experience changed after the intervention to a feeling that the counsellors, as available resources are a value proposition in the care of PLWH. This experience is evident in the following quotation: "*.... Since the workshop our services are appreciated by all ....more people are coming for counselling now*".

Since the intervention, there was an experience that the support groups were revived and new ones initialised. The counsellors noted that new and existing support groups are utilised without fear of stigmatisation and said: "*....the workshop showed that support groups are important...now we see PLWH using support groups without fear of stigma*". According to the counsellors there was increased opportunity to share and support each and stated that: "*....the workshop gave us an opportunity to be able to share information and more people started supporting each other*". A stronger message of hope and friendship was experienced as related in this quote: "*....we must support PLWH and give them hope....and act friendly and accept them because if they take their treatment they will be better*". The counsellors evaluated the psychodrama as enlightening and enhancing the understanding of those who cannot read. They said: "*The workshop was good because even the people who cannot read were able to understand how people are stigmatised and how a person can disclose from the psychodrama*".

Closely aligned, the **PLWH** mentioned a greater need for support of groups in the community and said that "*[...] more support groups must be formed in the community so that PLWH can be supported in their communities*". They also observed new interest in joining support groups as opposed to before the intervention and said: "*....not many people were using support groups but .....now more people are interested in joining support groups*". PLWH noted support groups as

valuable after the intervention following the intervention as stated “[...] *support groups are valuable because people benefit and get help when they attend support groups*”.

### **Changes in patient behaviour, assistance to disclose, and coping strategies**

Only three groups (nurses, PLWH, and PLC) referred to changes in patient behaviour, assistance to disclose, and coping strategies. In this theme the nurses experienced positive changes in patient behaviour of increased disclosure practices, denoting a reduction in stigmatisation in their respective clinics. The nurses noted less stigma and improved disclosure when stating that “[...] *after the intervention it became evident that PLWH realised less stigma and improved process of responsible disclosure*”. Moreover, the stigma reduction intervention dealt with disseminating more knowledge and generating a greater understanding of disclosure and increased disclosure practices; in this regard the nurses noted that “[...] *increased disclosure practices were identified [...] after the intervention because people had greater understanding of disclosure*”. The nurses further noted *positive* changes in patient behaviour and referred to reduced stigma which assisted people in talking openly about their statuses: “[...] *reduced stigma freed people to talk openly about their HIV status, telling others about HIV*”. They also noted that within a month of implementing the stigma reduction intervention there was an increase in individual and couple testing. The nurses said that “[...] *the number of patients that visited the clinic increased with more individuals and couples testing for HIV*”.

In this theme PLWH noted that the stigma reduction intervention assisted PLWH in disclosure of their statuses. They indicated that the intervention brought comfort to risk disclosure of HIV statuses when stating that “[...] *I never told people about it [HIV positive status][...] I have just told my mother after the workshop. I can tell now [...] she said I should have told her [...], she would have long supported me*”. An opportunity was created for others to also disclose their

statuses: *“During the intervention people had an opportunity to disclose their status, as part of the drama. Most of them disclosed to their PLC”*. PLWH reacted positively to the intervention and reported that the facilitation methods that were used facilitated humour and freedom: *“[...] I loved the sketch, and enjoyed it, it’s like we are in another world full of joy... laugh and have fun”*. The stigma intervention workshop gave PLWH the courage to disclose their HIV statuses: *“[...] if it was not for the project we also would not have been able to disclose or even do that sketch [...] people encouraged us and we had strength to disclose”*. This workshop assisted PLWH with enhancing access to health care services: *“[...] more people are going for health care in the clinics [...] you can see with increasing numbers of patients”*.

The PLC experienced improved coping strategies for stigma reduction. They mentioned that an improved understanding of stigma assisted them in coping: *“[...] I came to the workshop now I understand stigma and what it means”*. They grew to understand that spirituality and relying on God would assist them in managing stigma: *“[...] it is only through God only that we can defeat stigma and you can be strong living with HIV [...]”*. The intervention taught them [the PLC] and the PLWH how to handle the realities of stigma and act positively when stating that *“[...] I am also HIV positive and before [the intervention] I did not know what to do when people looked at me and say she lost weight, I used to hide myself, but I will no longer hide [...]”*. Getting involved and participating in community projects became a strategy for the PLC through the intervention. They stated that *“[...] I will work in the community projects to help myself cope with stigma and also teach others in the community how to cope”*. The PLC mentioned that learning to be positive about change is important in coping with stigma. They also referred to improving and acknowledging personal coping strategies and skills: *“[...] as they are HIV positive this workshop helped them be strong and improve daily on fighting the stigma [...]”*.

### **Awareness of patients' negative views of staff and a greater need for service improvement**

Only the nurses mentioned the themes of nurses' awareness of patients' negative views of staff, and expressed a greater awareness of the need for improved services. They noted that the staff's lack of confidentiality was the biggest reason that PLWH distrusted them, and said: “[...] I also identified that some of us [staff] lack confidentiality and PLWH distrust us putting off the clients [...] Lack of confidentiality and gossiping about PLWH happen on a daily basis”. The nurses also had a greater awareness of the need to improve health services by reducing stigma for the benefit of PLWH. They acceded that HIV stigmatisation affects the quality of services when relating that “[...] stigma must be managed by all in the clinics as it affects services so we can improvement and make better services”. The nurses also noted that both patients and staff contribute to stigmatisation and indicated that “[...] patients stigmatise themselves if they do not come to the clinic [...] It showed in the workshop and how staff handles some of the patients is not good because there is stigma in it”. They proposed an improved collaborative approach to deal with stigma and disclosure in the clinics: “The patients must work together with staff to manage stigma and help each other so that they can talk about HIV”.

### **Environmental stumbling blocks and empowerment in project management and leadership**

A unique theme for PLC on environmental stumbling blocks for effective HIV care and empowerment in project management and leadership emerged following the intervention. In this theme the PLC mentioned that stigma is still high in the clinics due to detrimental aspects in the clinic environment and physical layout. They referred to a lack of positive attitudes in saying that “[...] positive attitude is not there in the clinics”. Moreover, “there is lack of support for PLWH in the clinics...”. The PLC further mentioned a lack of understanding of painful and difficult experiences: “They lack understanding of painful and difficult experiences of the PLWH due to

*stigma [...]*” and “[...] *they lack understanding of painful and difficult experiences of the PLWH due to stigma [...]*”. They further referred to a lack of confidentiality, which affects relationships of trust: “*People do not keep confidentiality about the PLWH and this affects the trust of PLWH in the clinic*”.

The workshop yielded positive results for the PLC as they said that they gained management and personal leadership skills through community project management. They gained new insight into community project management and noted that the projects were helpful. The PLC said that “[...] *the projects can help us to help the community*”. They [PLC] can also focus on a specific target: “[...] *the project can be done for specific things like HIV or any project in the community.*” According to the PLC the projects can encourage disclosure: “*The project improved communications and will help PLWH to talk and disclose*”.

The PLC also enhanced personal leadership skills. The workshop assisted them in becoming leaders in stigma reduction. They gained coping skills on a personal level, and in facilitating coping in others, said that “*I learnt how to cope with this stigma and I can also assist others to cope when we do education*”. As such, their communication skills were enhanced and they were also able to motivate others in dealing with matters of stigmatisation and disclosure: “*I am able to communicate [...] I encourage others to disclose*”. The PLC mentioned that through the project they developed self-trust. The project facilitated a change in attitude toward being more supportive, and the PLC described that “[...] *from now on I will support PLWH [...], they are part of us*”. The element of a sense of belonging became stronger, and in the process seeking God’s help became important.

## **Limitations**

The intensity of the intervention limited the inclusion of more clinics. The limited allocation of nurses to clinics and staff shortages limited the inclusion of all nurses; however, those nurses working with the PLWH were definitely included. Care was taken to include all available staff.

## **Discussion**

From the interviews with the five groups (nurses, HCWs, counsellors, PLWH, and PLC of three PHC clinics) it became clear that the PHC-based stigma reduction and responsible disclosure management intervention based on the workshops and HIV-stigma reduction projects conducted in the PHC clinics, was seen as successful on several levels. All five groups gained a greater awareness and understanding of stigma, confirmed the positive effect of the intervention and felt empowered. The specific roles that the various groups have, led to more specific benefits more applicable to them. Literature reviewed by the researcher could confirm some of the findings.

*Nurses* became much more aware of PLWH's experiences of stigma and that they as nurses were not trusted by PLWH. Dawson-Rose, Webel, Solymar, Báez, Holzemer, Rivero-Méndez, Eller, Reid, Johnson, Kemppainen, Reyes, Nokes, Mogobe, Sabone, Ntsayagae, Shaibu, Corless, Wantland, Lindgren, Nicholas, Ellah Matshediso (2016:10-11) in their study on building trust and relationships between patients and providers dealing specifically with PLWH confirms that health care providers including nurses were aware of the level of mistrust PLWH had about them. The study by Gwadz, de Guzman, Freeman, Kutnick, Silverman, Leonard, Ritchie, Muñoz-Plaza, Salomon, Wolfe, Hilliard, Cleland and Honig (2016:4-10) describe how drug user- PLWH were treated with an element of distrust by health care providers who often doubted if they [PLWH] ever took their HIV medication confirming the lack of a trust relationship between the health care provider and the PLWH. This PHC-base stigma reduction and responsible disclosure management

intervention however had a positive effect that lead to nurses developing a greater awareness of everyone's roles and how initial negative perceptions could and have been changed. Literature confirms that different roles played by different people are important in HIV care. The study by Frain (2016:129) recognised and used different role players in addressing HIV care with student nurses: case manager provided physical and mental health services information; local AIDS organisation contacts were provided; pharmacist spoke about ART availability, drug resistance and interaction; the HIV nurse provided information on comorbidities, patient education, patient retention in care as well as nurses' roles and the HIV research nurse presented information on studies on HIV and lastly PLWH spoke about the HIV disease evolution and their concerns. Frain (2016:129-130) further mentioned that the nursing students' attitude towards PLWH changed for the better following the inclusion of HIV care in their training. The study by Chidrawi *et al.* (2016:203) also indicates that HIV-stigma reduced, where different role players were involved: the PLWH stigma experiences decreased and people living close (PLC) stigmatising behaviour concurrently changed over time following the stigma reduction intervention they implemented.

They saw how PLWH became more empowered through self-acceptance that lead to better self-care and health services access. Nurses had a change in their behaviour towards PLWH. They saw that if stigma decreases due to several factors, disclosure increased and that testing behaviour improved as well as adherence to ART. Li *et al.* (2013:287-289) confirm that a health care setting-based HIV-stigma reduction intervention that included doctors and nurses reduced stigmatization and increased PLWH support by health care providers through information and resources provision for the health care providers. The findings of the current PHC-based stigma reduction and responsible disclosure management study further showed that nurses were much more attuned to PLWH's negative view of them and made several changes in themselves and the clinic to reduce



stigma and improved access to health care services. In this current study the nurses moved towards a more collaborative approach. Ndou, Maputle and Risenga (2015: 5) confirmed that HIV related interventions within a PHC setting might contribute to stable and functional relationships between health professionals in general and patients. Even though PLWH mentioned some positive behaviours of nurses towards them, they were also able to identify nurses' stigmatising attitudes behaviour indicating a negative view of nurses by them (Dapaah 2016:2-5).

*HCWs* could see the discomfort of PLWH but also became much more aware of how their own conduct could stigmatize PLWH. The intervention according to them made a change in them but also the nurses. *HCW's* actions became more respectful and they could see how clinic practices changed due to the changes the nurses were implementing. The findings on the *HCWs* in this current study of stigma reduction and responsible disclosure management in PHC settings seem unique. They noticed that PLWH were much more content, had less complaints, defaulted less, self-care improved, they were happier and disclosure was done more often and openly. Literature suggests that *HCWs* are valuable, with proper training and support they could provide the necessary support in HIV management and care for PLWH (Mwai, Mburu, Torpey, Frost, Ford & Seely 2013:11).

The *counsellors* developed a much greater awareness of how stigma impacted the everyday lives of PLWH leading to poor health care behaviour and limited disclosure. The intervention had a positive effect on them where they felt themselves moving from despair and unlearning their own stigmatizing behaviour. *Counsellors* in this study felt they became more respectful and admitted to now feeling more comfortable to even touch the PLWH, as well as go for testing themselves. They could see how the intervention empowered PLWH to move from a prison of secrecy to freedom to disclose. They saw a boldness and courage in them and could see improvements in their intimate relationships and PLWH becoming more supportive towards others. The *counsellors* now felt

validated and recognized again as counsellors and that they have an important role to play in the provision of health care services. Anderson and Potgieter (2012:6) in their study on implementation of evaluation of a voluntary counselling and testing programme (VCT) for HIV and AIDS confirm that counsellors have an important role as it was stated by a participant in the mentioned study. The systematic review by Mwai *et al.* (2013:11) highlighted that HCWs play an important role during HIV counselling and need to be health recognized by authorities in the care of PLWH. In the current PHC-based HIV-stigma reduction and responsible disclosure management study, counsellors experienced a greater openness from the PLWH to interact with them and join support groups. Hope and friendship developed amongst counsellors and PLWH. Counsellors in this study further also mention that they [counsellors] see their work as valuable however they do not have support. Even though not an intervention the study by Visser and Mabota (2015:174-175) indicate that counsellors see their work as important however they experience high levels of emotional stress and lack of support. Ziraba Madise, Kimani, Oti, Mgomell, Matilu and Ezeh (2011:5) confirm that HIV counseling is important.

The *PLWH* could now recognize stigma and identify how it manifests and how it reduces their opportunity for support and communication as shown by the finding of the current study. In their study Saki, Mohammed, Kermanshahi, Mohammadi and Mhras (2015:5-6) mentioned that PLWH identified stigmatising bad behaviour of health professionals which made them not to disclose their HIV status resulting in lack of social support. The intervention conducted in this study however, empowered PLWH on an intra and interpersonal level. On the intrapersonal level, knowledge replaced fear, and shame and pain were reduced. PLWH felt that they could accept themselves, live with hope and experience less stress. Saki *et al.* (2015:6) confirm that increasing individuals' general knowledge on HIV and related stigma lessen PLWH's social difficulties. Stigma

reduction interventions could empower PLWH to identify and manage stigma such that they were able to accept themselves as stated by Chidrawi *et al.* (2016:202). As mentioned, in the current study on the interpersonal level, they felt stronger to teach others, talk more freely and express their pain, as well as make friends with others. This led to them now expressing a greater need for support groups. Disclosure came more easily for them as they felt assisted to disclose, more comfortable to disclose and that it was facilitated with humour and freedom. The comprehensive HIV-stigma reduction community intervention by French *et al.* (2015:113) concluded that PLWH were assisted to disclose through the mentioned intervention. This supports the finding that the current stigma reduction and responsible disclosure management intervention could facilitate an increase in disclosure.

The *PLC* developed an awareness of stigma on an intra-, interpersonal and community level. The intervention freed them up to once again engage with PLWH which gave them courage to support PLWH. They suddenly had new hope that their loved ones were not going to die. They developed a pride and satisfaction. They could now see what was causing stigma in clinics but gained management and leadership skills to cope with it. In general they felt that they were coping better and could handle the realities of stigma in their communities. Pretorius *et al.* (2015:192-193) confirm that through a stigma reduction intervention the *PLC* became more supportive towards PLWH. In this study it can be concluded the intervention was effective as it could change how *PLCs* viewed and engaged with PLWH. According to Kruger *et al.* (2018: 7-9) knowledge empowerment that involved PLWH and traditional leaders on HIV-stigma removed boundaries between them [PLWH and traditional healers], reduced fear and stigma and afforded PLWH with more support opportunities in the community.

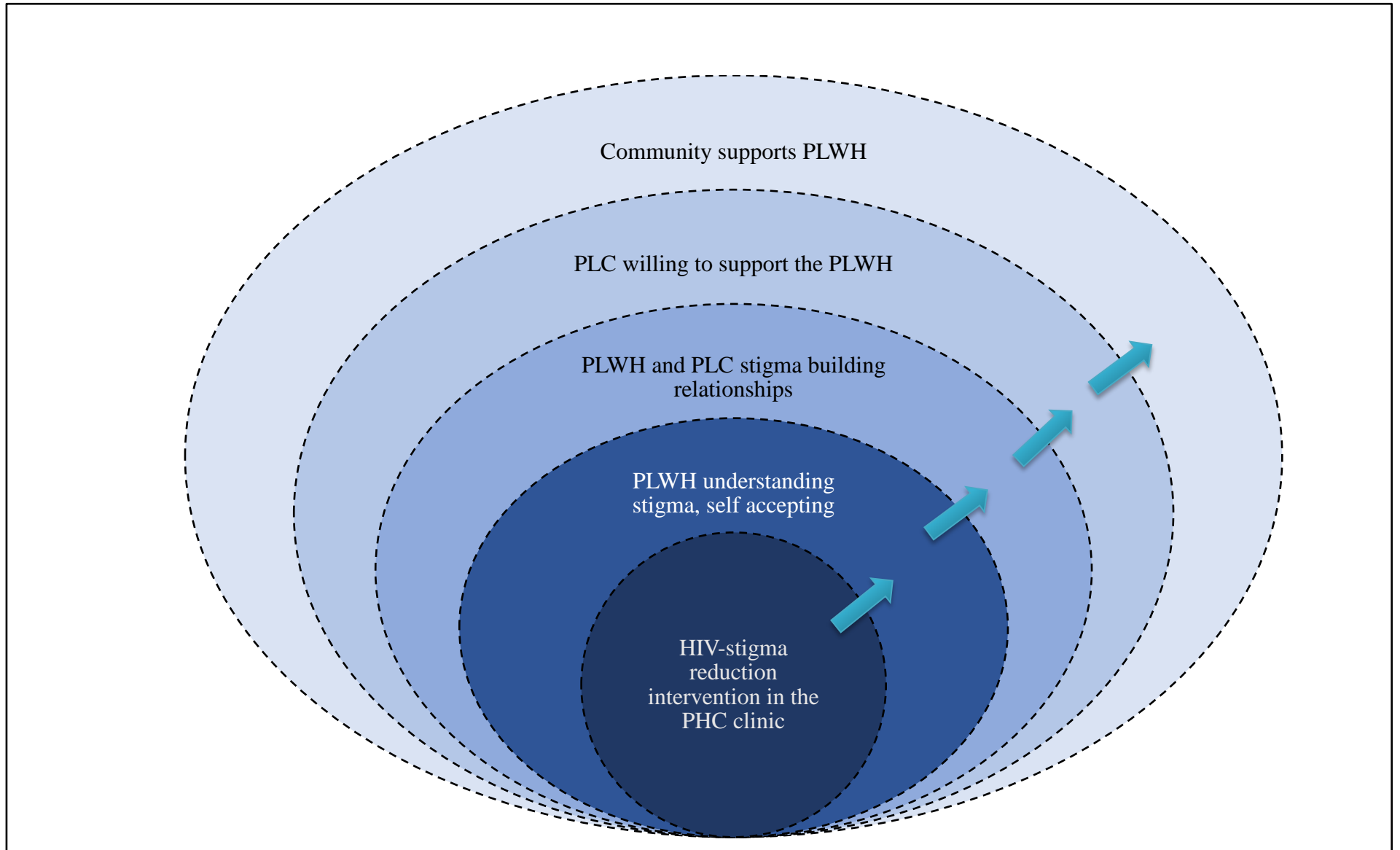
In this study each specific group experienced growth but the five groups also had a crossover effect on one another leading to reduction in HIV-stigma and responsible management of disclosure in the PHC clinics but also flowing to their personal lives and the community. The effect of the intervention can be compared to the “ripple in the pond” effect after throwing a stone, circling from the PHC clinic to the greater community.

### **Recommendations**

The PHC-based HIV-stigma reduction and responsible disclosure intervention should be formulated as a program in primary health care clinics and include the five groups mentioned in this intervention. The tenets of the intervention mentioned under 5.3.2.2.1 earlier should be respected and be the cornerstone of the program. One of the facilitators of the workshop should always be a HIV positive sero status person. The PLWH should always first be empowered and capacitated to truly understand HIV-stigma and how to disclose in a responsible manner before engaging with others in the program. The one month project empowers the various groups to become leaders and advocates for stigma reduction and should remain an essential part of the program. This program should become an everyday activity in PHC settings. The programme should link from a district, to provincial and national level. There should be a constant awareness of the various aspects of the clinic’s context that have become overt in this study, that have an effect on stigma and disclosure practices e.g. space, confidentiality etc., to be discussion points on weekly meetings. These factors contributing to stigma or the fear of disclosure should be handled in a consistent and constructive manner to ensure that stigmatisation does not occur. Ongoing scheduled in-service training, personnel support systems, clinic open day and awareness programmes focussing on HIV stigma would be beneficial. The interlinking patterns, communication and roles of the five groups (nurses, HCWs, counsellors, PLWH and PLC) during the care and management of PLWH are

important determinants to reduce or increase stigma and should be handled in a constructive manner. Multidisciplinary meetings would also be effective where PLWH and PLC are not part. Nurses, HCWs and counsellors as the major role players in these practices should become the main focus when introducing stigma reduction and disclosure management programmes and providing specific in-service training in the primary health care clinics. The dissonance in perceptions about HIV-stigma reduction and disclosure management practices between nurses, HCWs and counsellors and the relationship disconnect should be handled by: firstly, ensuring opportunities where they can regularly meet, have open discussions and build relationships through honesty and trust.

Figure 3 below demonstrates the realization of stigma reduction rippling from the clinic where there is a nurses and PLWH, PLC to PLWH to the larger community link by the HIV stigma reduction and disclosure management intervention in PHC settings.



**Figure 3: The figure depicts how stigma reduction and disclosure management intervention flows from the PHC clinics to the community**

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## **SECTION D: CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS**

### **1 INTRODUCTION**

The conclusions, limitations and recommendations in Section D are based on the findings of the two phases of this study as set out in article one and two: Phase 1: The perceptions of nurses and health care workers (HCWs) of HIV-stigma reduction and disclosure management practices in primary health care (PHC) settings; and Phase 2: The implementation of the primary health care-based HIV-stigma reduction and responsible disclosure management intervention, as well as the experiences of nurses, health care workers (HCWs), counsellors, people living with HIV (PLWH), and people living close (PLC) to PLWH of the intervention.

The study used a qualitative descriptive design to explore and describe nurses' and health care workers' (HCWs) perceptions of HIV-stigma reduction and disclosure management practices in three PHC clinics in the North West Province of South Africa. These two groups of participants were selected through purposive sampling. This was followed up by the development and implementation of a PHC-based HIV-stigma reduction and responsible disclosure management intervention in the same three PHC clinics. Thereafter followed a description of the explored experiences of nurses, HCWs, counsellors, PLWH and people living close (PLC) to PLWH involved in the repetitive interventions in the three clinics. In addition to the nurses and HCWs, counsellors and PLWH were also selected through purposive sampling, while the PLC were selected by using snowball sampling. The three tenets the intervention is built on are: 1) increasing knowledge through understanding of HIV-stigma, coping with it and responsible disclosure management; 2) equalising of relationships between the mentioned groups and 3) building leadership skills by planning and implementing a HIV-stigma reduction project by PLWH and PLC. The intervention was accomplished through a planned series of workshops in specifically PHC clinics and facilitated by the researchers and a PLWH.

## **2 CONCLUSIONS**

Conclusions are set out as separate entities for the two phases and concluded in a summative discussion.

### **2.1 Conclusions regarding perceptions of nurses and health care workers of HIV-stigma reduction and disclosure management in primary health care settings**

The findings suggest that in PHC clinics the nurses and HCWs are the parties involved in the amount of HIV-stigma reduction and disclosure management happening in the clinics. However, there seems to be a dissonance between these nurses', HCWs' and counsellors' (also present in the clinics) perceptions about HIV-stigma reduction and disclosure management practices in the PHC clinics that were in the study. There are several factors in the dissonance denoting a relationship disconnect between the nurses, HCWs and counsellors found in their distinguishable roles and their focus. It seems (in this relationship dissonance) that nurses and HCWs blame others for the absence of stigma reduction and disclosure management in the PHC clinics and take little of the blame themselves. This study reiterated the logistical challenges within the health care system itself as described by the nurses. This further confirms the-disconnect between nurses and HCWs in the PHC setting. This dissonance in the perceptions of nurses and HCWs can further be interpreted as a system disconnect which impacts negatively on HIV-stigma reduction and disclosure management in the clinics.

Nurses in this study critiqued counsellors for lack of counselling practices. They attribute the lack of stigma reduction and disclosure management in the clinics by what they perceive as the counsellors lack of skill, ineffective counselling practices and lack of trust relationship between counsellors and the PLWH. They suggest that these counsellors need to be trained to improve their counselling skills and be more professional. The HCWs, on the other hand, criticised the nurses and blamed them for not managing stigma in the clinics. They perceive them as the problem for HIV-stigma, blaming them as the cause for non-disclosure by PLWH in the clinics.

Nurses seem to be less focused on their roles in stigma reduction and become more involved with logistics, structural and organisational management. However, the nurses showed some objectivity by acknowledging certain constructive and less effective

practices of nurses in the clinics. The constructive practices of treating PLWH similar to patients with other chronic diseases and using the same queue in the clinics regardless of diagnosis were acknowledged.

The nurses and HCWs alike seemed to be less focussed on their own role in stigma reduction but in their case their focus is on criticising the nurses by referring to their lack of providing privacy and maintaining confidentiality. HCWs viewed nurses as rude and judgemental. They further also referred to logistical problems such as shortage of staff, medication and limited space in the clinic. They showed greater awareness of patients' feelings of fear, shame and experiencing rejection or being stigmatised by identification. PLWH need supportive practices that are welcoming, comfortable and that ignite open discussion between them and nurses. HCWs mentioned the need for supportive practices such as support groups for PLWH and truthful engagement.

However, concerning disclosure both nurses and HCWs mentioned the need for supportive environments like counselling that enables disclosure (nurses) and need for building a trust relationship and establishment of support groups (HCWs). Nurses outlined a supportive counselling environment that ensure privacy and provide opportunities for home visits and patient tracing. Furthermore, counsellors need to be skilled. Nurses mentioned challenges like assurances of confidentiality and non-labelling following disclosure of patients' diagnosis. Nurses also see specific benefits that disclosure offers PLWH personal benefits like freedom and accessing support in their homes, better child support and gaining knowledge through HIV-stigma education. HCWs saw that an environment enhancing the building of a trusting relationship, even with families, for support need to be developed. They were sensitive to patients' feeling fearful to disclose and their need for counselling in order to disclose. They also perceive establishment of wider support through empowerment of carers and traditional healers as important.

Both of these groups mentioned the lack of health education practices in stigma and disclosure. Nurses saw that HIV-stigma education was limited and lacked depth and could be better facilitated through media. HIV-stigma reduction and disclosure management should form part of community based health promotion through talks and radio information. The HCWs had the need for more focussed education including stigma and disclosure. Nurses need to meet regularly to discuss confidentiality, stigma and disclosure within the PHC setting translating out to the rest of the community.

The perceptions of nurses and HCWs also illuminated that PLWH suffer due to the practices mentioned. It became evident, due to these practices, stigma increases in the PHC settings and PLWH disclose less. PLWH do not access clinics and default, or poor logistics lead to PLWH having to re-visit the clinic. In general they have less support that could have been available to them and overall their quality of life then decreases.

## **2.2 Conclusions regarding the PHC-based HIV-stigma reduction and responsible disclosure management intervention in primary health care settings**

The PHC-based stigma reduction and responsible disclosure management intervention based on the workshops and HIV-stigma reduction projects were successful on all levels. This could be seen following the interviews with the five groups (nurses, HCWs, counsellors, PLWH and PLC) in the PHC clinics. All five groups gained a greater awareness and understanding of stigma, confirmed the positive effect of the intervention and felt empowered. The specific roles that the various groups have led to more specific benefits applicable to them.

*Nurses* were more aware of PLWH's experiences of stigma and that they as nurses were not trusted by PLWH. The intervention had a positive effect that led to nurses developing a greater awareness of everyone's roles and how initial negative perceptions could and have been changed. They saw how PLWH were empowered by self-acceptance that led to better self-care and access to health services. Nurses changed their behaviour towards PLWH. They saw that if stigma decreases due to several factors, disclosure increased, testing behaviour (willingness to test) increased and ART adherence improved. Consequently, they were more attuned to PLWH's negative view of them and made several changes in themselves and the clinic to reduce stigma and improve access to health care services. They moved towards a more collaborative approach.

*HCWs* noticed the discomfort of PLWH but also became much more aware of how their own conduct could stigmatize PLWH. The intervention according to them made a change in them and also the nurses. HCWs were more respectful and could see how clinic practices changed due to the changes the nurses were implementing. Support became more available to PLWH. They noticed that PLWH were much more content, had less complaints, defaulted less, self-care improved, they were happier and disclosure was done more often and openly.

The *counsellors* developed a greater awareness of how stigma impacted the everyday lives of PLWH as stigma leads to poor health care behaviour and limited disclosure. Counsellors moved from despair and unlearning their own stigmatising behaviour, therefore the intervention had a positive effect on them. They were more respectful, admitted feeling more comfortable to even touch the PLWH and will go for testing themselves. The counsellors saw how the intervention empowered PLWH to move from a prison of secrecy to freedom to disclose. Through boldness and courage their intimate relationships improved. Counsellors saw how PLWH became more supportive towards others. They felt validated and being recognised as counsellors, which have an important role to play in the provision of health care services. The counsellors experienced a greater openness from the PLWH to interact with them and join support groups as hope and friendships developed amongst counsellors and PLWH.

The *PLWH* could now recognise stigma and identify its manifestations. They could recognise how it reduces their opportunities to provide support and have effective communication. The intervention empowered them on an intra- and interpersonal level. On the intrapersonal level, knowledge replaced fear, and shame and pain were reduced. They felt that they could accept themselves, live with hope and experience less stress. On the interpersonal level PLWH in this study felt stronger to teach others, talk more freely and express their pain, as well as make friends with others. Now they expressed a greater need for support groups. As PLWH experienced more assistance, they became more comfortable to disclose. Their readiness to disclose was facilitated with humour and freedom.

The *PLC* developed an awareness of stigma on an intra-, interpersonal and community level. The intervention freed them to once again engage with PLWH which gave them courage to support PLWH. The PLWH developed a pride and satisfaction and had new hope that their loved ones were not going to die. PLC could see what causes stigma in clinics and they gained more management and leadership skills to cope with it. In general they felt that they were coping better and could handle the realities of stigma in their communities. Therefore, the intervention was effective because it could change how PLCs viewed and engaged with PLWH.

Each group experienced growth. Yet, all five groups (nurses, HCWs, counsellors, PLWH and PLC) had a ripple effect on one another, which led to HIV-stigma reduction

responsible disclosure management in the PHC clinics. This ripple effect spilled over to their personal lives and into the community, causing conducive actions for stigma reduction and disclosure management from within the PHC clinics towards the greater community.

### **3 LIMITATIONS**

The PHC clinics were understaffed and not all the nurses could participate. Reasonable steps were taken to include all those who were eligible according to the selection criteria and those nurses working directly with PLWH. Due to the intensity of the intervention, only a limited number of clinics could participate. The number of clinics selected allowed for proper research processes without interfering in the daily clinic operations.

### **4 RECOMMENDATIONS**

From the mentioned findings in phase one clear recommendations can be made to improve stigma reduction and responsible disclosure management practices in primary health care settings. Nurses, HCWs and counsellors as the major role players in these practices should become the main focus when introducing stigma reduction and disclosure management programmes and providing specific in-service training in the primary health care clinics. The dissonance in perceptions about HIV-stigma reduction and disclosure management practices between nurses, HCWs and counsellors and the relationship disconnect should be handled by: firstly, ensuring opportunities where they can regularly meet, have open discussions and build relationships through honesty and trust. Awareness should be raised on blaming behaviour and taking own responsibility for the situation as it exists in the clinics. Also, make the nurses aware of the following: *nurses* - focused on logistics and less on patient feelings, being rude, unfriendly and judgemental, sometimes breaking confidentiality leading to non-disclosure, and not providing privacy. In-service education for the nurses to strike a balance within their management and clinical role in caring for PLWH to reduce stigma. They should work on the less effective practices mentioned and build on the constructive practices they identified (treating patient the same in relationships but also in logistical issues such as allowing all patients to be in the same queues in the clinics). For *HCWs and counsellors* – becoming more aware of their own role in stigma practices (such as breaking trust and confidentiality, not having the proper skills and knowledge); criticise nurses less and work on improving their



own knowledge and skills through training to: understand stigma and - reduction; coping with stigma and responsible disclosure management; counselling skills to handle discussions about stigma with patients; to handle disclosure responsibly; and to work on trust and more meaningful relationships with HIV patients by using their strengths of being in touch with HIV patients' feelings. It is recommended that the HCWs and councillors be trained on interpersonal skills development to improve relations with nurses and PLWH, build trust relationships among themselves, nurses and PLWH..

PHC clinics as support system to patients can be improved through creating a general pleasant atmosphere in the clinics, having truthful engagements with patients, ensuring confidentiality, initiating and maintaining support groups, facilitating family support, doing home visits, and drawing in a wider support network e.g. carers and traditional healers. An effective referral system can be developed to refer patients to a broader network to fulfil all their needs. Address the general systems disconnect through an intensive audit to identify limitations address shortages of staff, limited space, privacy issues, medication dispensing practices etc.

The focus on HIV patients should specifically address stigma reduction; responsible disclosure management; their accessing primary health care clinics; improving their adherence to medication; making it easier for patients when visiting clinics due to order and well organized systems for seeing the doctor, getting their medication, receiving counselling or education in a non-stigmatising manner; providing more opportunities for support through a wider network and good referral system that could address all their needs and improve their overall health.

Well sustained and organised stigma reduction and responsible disclosure management programmes involving nurses, HCWs and counsellors in the PHC clinics through regular training and counselling sessions with patients on understanding stigma, how to reduce stigma, how to cope with stigma, and responsible disclosure management. The educational programmes can be extended to media releases, community talks and clinic activities e.g. community engagement days that could include psychodrama etc. The educational programmes should also include facilitation of access to justice and redress as well as promotion and protection of human and legal rights of PLWH.

These recommendations were incorporated in phase two during the planning of the PHC-based HIV-stigma reduction and responsible disclosure management intervention.

Following the intervention in the three PHC clinics the following recommendations were made: The PHC-based HIV-stigma reduction and responsible disclosure intervention should be formulated as a program in primary health care clinics and include the five groups mentioned in this intervention. The tenets of the intervention mentioned earlier should be respected and be the cornerstone of the program. One of the facilitators of the workshop should always be a person with an HIV positive status. The PLWH should firstly be empowered and capacitated to truly understand HIV-stigma and how to disclose in a responsible manner before engaging with others in the program. The one month project empowers the various groups to become leaders and advocates for stigma reduction and should remain an essential part of the program. This program should become an everyday activity in PHC settings. There should be a constant awareness of the various aspects of the clinic's context effecting HIV-stigma and disclosure practices e.g. space, confidentiality etc. These factors contributing to stigma or the fear of disclosure should be handled in a consistent and constructive manner to ensure that stigmatisation does not occur. The interlinking patterns, communication and roles of the five relevant groups (nurses, HCWs, counsellors, PLWH and PLC) during the care and management of PLWH are important determinants to reduce or increase stigma and should be handled in a constructive manner.

## **5 IN SUMMARY**

Phase one suggested a dissonance between the nurses, HCWs and counsellors (also present in the clinics) and a disconnection in their relationship, which was resolved by providing all with the necessary knowledge and including all of them as equal participants in the intervention. This disconnect improved by including PLWH and PLC. The open discussions allowed for a common understanding to develop among them. Nurses became aware of their focus on logistics and not really being aware of patients and how they influence the atmosphere in the clinic. The details mentioned as recommendations in phase one are necessary for an understanding about the changes to be brought about in clinics. HCWs also realized what nurses blamed them and that they needed more counselling skills and specific knowledge on stigma and disclosure. Both groups worked on a supportive environment. Nurses changed the clinic logistics and payed attention to how they handled patients. HCWs felt validated as they became more knowledgeable, skilled and supportive to PLWH. Support groups were revived or new ones initiated. Patient experienced a general behavioural change, being were more willing to access

health services, disclosing or getting tested. This behavioural change gave them the opportunity to use the health services in full, to gain support and the opportunity to improve their overall quality of life. The PLC to PLWH gained more control of their lives and felt stronger to face the community and the problems they had instead of just isolating themselves from their communities. They felt encouraged to support their communities. The mentioned crossover effect of the various groups on one another strengthened the changes made in the clinics leading to stigma reduction truly happening and PLWH being freer to disclose. The various experiences indicate that the PHC-based HIV-stigma reduction and responsible disclosure management intervention was successful. Over and above the implementation of the mentioned program, in-service training regular meetings, open discussions and building relationships thorough honesty and trust could be implemented to facilitate general change. PHC clinics should realise the absence of HIV-stigma reduction and disclosure management practices and should provide well sustained and organised HIV-stigma reduction and responsible disclosure management programs. These programs should integrate into the everyday activities of the PHC clinics. The already identified constructive practices that focus on atmosphere, truthful engagements, better confidentiality management, and support in general and linking wider networks could be implemented followed by regular audit not to fall back in existing practices.

## ADDENDUM A: ETHICS APPROVAL GRANTED



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South Africa 2520

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Web: <http://www.nwu.ac.za>

To whom it may concern

**Faculty of Health Sciences**  
Tel: 018 299-2095  
Fax: 018 299-2068  
Email: [Annamarie.Kruger@nwu.ac.za](mailto:Annamarie.Kruger@nwu.ac.za)

4 March 2014

Dear Prof. Greeff

**Ethics application: NWU-00008-14-S1**

**"HIV-stigma reduction and responsible disclosure management in a Primary Health Care setting"**

Thank you for the amendments made to your application. All ethical concerns have now been addressed and ethical approval is granted.

Yours sincerely



Prof. Annamarie Kruger  
Ethics Committee - Humans Vice Chairperson

Original de: Prof. Annamarie Kruger (0062416) C:\Users\13210572\Documents\ETIEK2014\ETHICS\NWU-00008-14-S1.docx  
4 March 2014

File reference: NWU-00008-14-S1

**ADDENDUM B: APPROVAL NORTH WEST PROVINCIAL DEPARTMENT OF HEALTH**



**health**

Department of  
Health  
North West Province  
REPUBLIC OF SOUTH AFRICA

3801 First Street  
New Office park  
Mafikeng, 2745  
Private Bag X2068  
MMABATHO, 2735

Tel: (018) 391 4504  
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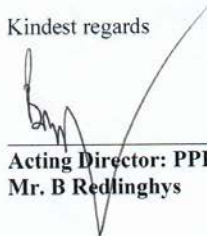
**POLICY, PLANNING, RESEARCH, MONITORING & EVALUATION**

**To : Ms M Hlahane**  
**From : Policy, Planning, Research, Monitoring & Evaluation**  
**Subject : Approval Letter- HIV stigma reduction and responsible disclosure management in a primary health care setting.**

To inform the researcher that permission to undertake the above mentioned study has been granted by the North West Department of Health. The researcher is expected to arrange in advance with the chosen districts or facilities, and issue this letter as prove that permission has been granted by the provincial office.

Upon completion, the department expects to receive a final research report from the researcher.

Kindest regards

  
Acting Director: PPRM&E  
Mr. B Redlinghys

  
Date



Healthy Living for All

## **ADDENDUM C1: INFORMED CONSENT FOR NURSES**



### **HIV-stigma reduction and disclosure management CONSENT TO BE A RESEARCH PARTICIPANT**

*I am a student at North West University working on HIV-stigma reduction and disclosure management. We would like to invite you to participate in this study. Here is some more information about the study to tell you what you need to know before giving consent.*

#### **1. PURPOSE OF THE STUDY**

The aim of this study is to understand the perceptions and experiences of nurses and health care workers of how HIV-stigma might be reduced and how people who are newly diagnosed with HIV can manage their disclosures. The findings will be used to develop, implement and evaluate an intervention programme for people living with HIV. The research will be done in three clinics in the Dr. Kenneth Kaunda district (North-West province), South Africa. You are being asked to participate in this study because you are a nurse working with people living with HIV (PLWH) and we want to hear your views on HIV-stigma reduction and disclosure management and your experiences working with PLWH.

#### **2. PROCEDURE**

If you agree to be in this study you will be expected to do the following:

- Take part in a semi-structured interview where the researcher will ask you questions about your understanding of HIV-stigma and the needs of PLWH regarding HIV-stigma reduction and disclosure management. It will take about an hour and it will be digitally recorded.
- Take part in a one day workshop about HIV-stigma and disclosure management with PLWH and health care workers.
- Attend a project evaluation session where you will hear feedback from the different projects you were involved in.
- Take part in an in-depth interview where the researcher will ask you questions about how you experienced the intervention as a whole. It will take about an hour and it will be digitally recorded.

#### **3. RISKS/DISCOMFORTS**

Sharing your views and experiences could be painful and difficult. Should you have any discomfort during the interviews, you will have access to a counselor. Some of your privacy might be lost during this study due to the fact that the researcher, HCW, PLWH and PLC will know your name but your name will never be made known outside of the group of participants. No individuals' identifiers (name, address etc.) will be used in any publications resulting from this study and only the researcher, promoter, co-promoter and research assistants will work with the information that you shared. All information will be protected by locking it up and storing it on a password protected computer at the University for 7 years.

#### **4. BENEFITS**

By being involved in this research project you will help the researchers to better understand HIV-stigma and the needs of the PLWH regarding HIV-stigma reduction and disclosure management. You might also be empowered during the HIV-stigma reduction and disclosure management workshop.

#### **5. COSTS**

There will be no cost to you as a result of your participation in this study.

#### **6. PAYMENT**

You will receive no payment for participating.

**7. QUESTIONS**

You are welcome to ask any questions to the researcher, Salamina Hlahane, before you decide to give consent. You are also welcome to contact Poncho (018 299 4289) if you have any further questions concerning you consent.

**8. FEEDBACK OF FINDINGS**

The findings of the research will be shared with you if you are interested. You are welcome to contact us regarding the findings of the research. We will be sharing the findings with you as soon as it is available.

**CONSENT FORM**

**PARTICIPATION IN THIS RESEARCH IS VOLUNTARY.**

You are free to decline to be in this study, or to withdraw at any point even after you have signed the form to give consent without any consequences.

Should you be willing to participate you are requested to sign below:

I \_\_\_\_\_ hereby voluntarily consent to participate in the above mentioned study. I am not coerced in any way to participate and I understand that I can withdraw at any time should I feel uncomfortable during the study. I also understand that my name will not be disclosed to anybody who is not part of the study and that the information will be kept confidential and not linked to my name at any stage. I also understand what I might benefit from participation as well as what might be the possible risks and should I need further conversations someone will be available.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of the participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of the person obtaining consent

## **ADDENDUM C2: INFORMED CONSENT FOR HEALTH CARE WORKERS AND COUNSELLORS**



### **HIV-stigma reduction and disclosure management CONSENT TO BE A RESEARCH PARTICIPANT**

*I am a student at North West University working on HIV-stigma reduction and disclosure management. We would like to invite you to participate in this study. Here is some more information about the study to tell you what you need to know before giving consent.*

#### **1. PURPOSE OF THE STUDY**

The aim of this study is to understand the perceptions and experiences of nurses and health care workers of how HIV-stigma might be reduced and how people who are newly diagnosed with HIV can manage their disclosures. The findings will be used to develop, implement and evaluate an intervention programme for people living with HIV. The research will be done in three clinics in the Dr. Kenneth Kaunda district (North-West province), South Africa. You are being asked to participate in this study because you are a person working with people living with HIV (PLWH) and we want to hear your views on HIV-stigma reduction and disclosure management and your experiences working with PLWH.

#### **2. PROCEDURE**

If you agree to be in this study you will be expected to do the following:

- Take part in a semi-structured interview where the researcher will ask you questions about your understanding of HIV-stigma and the needs of PLWH regarding HIV-stigma reduction and disclosure management. It will take about an hour and it will be digitally recorded.
- Take part in a one day workshop about HIV-stigma and disclosure management with PLWH and nurses.
- Attend a project evaluation session where you will hear feedback from the different projects you were involved in.
- Take part in an in-depth interview where the researcher will ask you questions about how you experienced the intervention as a whole. It will take about an hour and it will be digitally recorded.

#### **3. RISKS/DISCOMFORTS**

Sharing your views and experiences could be painful and difficult. Should you have any discomfort during the interviews, you will have access to a counselor. Some of your privacy might be lost during this study due to the fact that the researcher, HCW, PLWH and PLC will know your name but your name will never be made known outside of the group of participants. No individuals' identifiers (name, address etc.) will be used in any publications resulting from this study and only the researcher, promoter, co-promoter and research assistants will work with the information that you shared. All information will be protected by locking it up and storing it on a password protected computer at the University for 7 years.

#### **4. BENEFITS**

By being involved in this research project you will help the researchers to better understand HIV-stigma and the needs of the PLWH regarding HIV-stigma reduction and disclosure management. You might also be empowered during the HIV-stigma reduction and disclosure management workshop.



**5. COSTS**

There will be no cost to you as a result of your participation in this study.

**6. PAYMENT**

You will receive no payment for participation.

**7. QUESTIONS**

You are welcome to ask any questions to the researcher, Salamina Hlahane, before you decide to give consent. You are also welcome to contact Poncho (018 299 4289) if you have any further questions concerning you consent.

**8. FEEDBACK OF FINDINGS**

The findings of the research will be shared with you if you are interested. You are welcome to contact us regarding the findings of the research. We will be sharing the findings with you as soon as it is available.

**CONSENT FORM**

**PARTICIPATION IN THIS RESEARCH IS VOLUNTARY.**

You are free to decline to be in this study, or to withdraw at any point even after you have signed the form to give consent without any consequences.

Should you be willing to participate you are requested to sign below:

I \_\_\_\_\_ hereby voluntarily consent to participate in the above mentioned study. I am not coerced in any way to participate and I understand that I can withdraw at any time should I feel uncomfortable during the study. I also understand that my name will not be disclosed to anybody who is not part of the study and that the information will be kept confidential and not linked to my name at any stage. I also understand what I might benefit from participation as well as what might be the possible risks and should I need further discussions someone will be available.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of the participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of the person obtaining consent

## **ADDENDUM C3: INFORMED CONSENT FOR PEOPLE LIVING WITH HIV (PLWH)**



### **HIV-stigma reduction and disclosure management CONSENT TO BE A RESEARCH PARTICIPANT**

*I am a student at North West University working on HIV-stigma reduction and disclosure management. We would like to invite you to participate in this study. Here is some more information about the study to tell you what you need to know before giving consent.*

#### **1. PURPOSE OF THE STUDY**

The aim of this study is to understand the how people think and feel about HIV-stigma reduction and how people who are newly diagnosed with HIV can manage their disclosures. The findings will be used to develop, implement and evaluate an intervention programme for people living with HIV. The research will be done in Dr Kenneth Kaunda district (North-West province) South Africa. You are being asked to participate in this study because you are a person living with HIV and we want to hear your views on HIV-stigma reduction and disclosure management as well as your experiences.

#### **2. PROCEDURE**

If you agree to be in this study you will expected to do the following:

- Take part in a semi-structured interview where the researcher will ask you questions about your understanding of HIV-stigma and the needs of PLWH regarding HIV-stigma reduction and disclosure management. It will take about an hour and it will be digitally recorded.
- Take part in a two day workshop about HIV-stigma and disclosure management with other people living with HIV and people living close to them and also health care workers.
- Attend a project evaluation session where you will hear feedback from the different projects you were involved in.
- Take part in an in-depth interview where the researcher will ask you questions about how you experienced the intervention as a whole. It will take about an hour and it will be digitally recorded.

#### **3. RISKS/DISCOMFORTS**

We understand that sharing your views and experiences could be painful and therefore a counselor will be available for you if you have any discomfort during the interviews. There is also a possibility that disclosing your HIV status during the workshop might make you emotional. Some of your privacy and confidentiality might be lost during this study due to the fact that the researcher, PLC and other participants in the research will know your name but your name will never be made known and your data will be handled as confidential as possible. No individuals' identifiers will be used in any publications resulting from this study and only the researcher, promoter, co-promoter and research assistants will work with the information that you shared. All sensitive information will be protected by locking it up and storing it on a password protected computer.

#### **4. BENEFITS**

By being involved in this research project you will help the researchers to better understand HIV-stigma and the needs of the PLWH regarding HIV-stigma reduction and disclosure management. You will benefit through gaining knowledge about HIV-stigma reduction and disclosure management, learning skills to handle HIV-stigma and disclosure management, as well as being empowered in project planning and implementation including possibilities of improved relations.

**5. COSTS**

There will be no cost to you as a result of your participation in this study.

**6. PAYMENT**

You will receive no payment for participation. You will receive refreshments every time you spend time with the research team. Transportation or money for transport will be provided if necessary.

**7. QUESTIONS**

You are welcome to ask any questions to the researcher, Salamina Hlahane, before you decide to give consent. You are also welcome to contact Poncho (018 299 4289) if you have any further questions concerning you consent.

**8. FEEDBACK OF FINDINGS**

The findings of the research will be shared with you if you are interested. You are welcome to contact us regarding the findings of the research. We will be sharing the findings with you as soon as it is available.

**CONSENT FORM**  
PARTICIPATION IN THIS RESEARCH IS VOLUNTARY

You are free to decline to be in this study, or to withdraw at any point even after you have signed the form to give consent without any consequences.

Should you be willing to participate you are requested to sign below:

I \_\_\_\_\_ hereby voluntarily consent to participate in the above mentioned study. I am not coerced in any way to participate and I understand that I can withdraw at any time should I feel uncomfortable during the study. I also understand that my name will not be disclosed to anybody who is not part of the study and that the information will be kept confidential and not linked to my name at any stage. I also understand what I might benefit from participation as well as what might be the possible risks and should I need counseling someone will be available.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of the participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of the person obtaining consent

## **ADDENDUM C4: INFORMED CONSENT FOR PEOPLE LIVING PLC (PLC)**



NORTH-WEST UNIVERSITY<sup>®</sup>  
YUNIBESITHI YA BOKONE-BOPHIRIMA  
NOORDWES-UNIVERSITEIT  
POTCHEFSTROOM CAMPUS

### **HIV-stigma reduction and disclosure management CONSENT TO BE A RESEARCH PARTICIPANT**

*I am a student at North West University working on HIV-stigma reduction and disclosure management. We would like to invite you to participate in this study. Here is some more information about the study to tell you what you need to know before giving consent.*

#### **1. PURPOSE OF THE STUDY**

The aim of this study is to understand the how people think and feel about HIV-stigma reduction and how people who are newly diagnosed with HIV can manage their disclosures. The findings will be used to develop, implement and evaluate an intervention programme for people living with HIV. The research will be done in Dr Kenneth Kaunda district (North-West province) South Africa. You are being asked to participate in this study because you are a person living close to a person with HIV and we want to hear your views on HIV-stigma reduction and disclosure management and your experiences living with PLWH.

#### **2. PROCEDURE**

If you agree to be in this study you will expected to do the following:

- Share your experiences of HIV-stigma and disclosure management during an in-depth interview that will be conducted with you by the researcher. It will take about an hour and it will be digitally recorded.
- Take part in a two day workshop with PLWH on understanding HIV-stigma and coping with it. During this workshop you will also plan and implement a workshop involving more people.
- Take part in an in-depth interview where the researcher will ask you questions about how you experienced the intervention as a whole. It will take about an hour and it will be digitally recorded.

#### **3. RISKS/DISCOMFORTS**

Sharing your views and experiences could be painful and difficult. Should you have any discomfort during the interviews, you will have access to a counselor. Some of you privacy might be lost during this study due to the fact that the researcher, HCW, PLWH and PLC will know your name but your name will never be made known outside of the group of participants. No individuals' identifiers (name, address etc.) will be used in any publications resulting from this study and only the researcher, promoter, co-promoter and research assistants will work with the information that you shared. All information will be protected by locking it up and storing it on a password protected computer at the University for 7 years.

#### **4. BENEFITS**

By being involved in this research project you will help the researchers to better understand HIV-stigma and the needs of the PLWH regarding HIV-stigma reduction and disclosure management. You might also be empowered during the HIV-stigma reduction and disclosure management workshop.

**5. COSTS**

There will be no cost to you as a result of your participation in this study.

**6. PAYMENT**

You will receive no payment for participation.

**7. QUESTIONS**

You are welcome to ask any questions to the researcher, Salamina Hlahane, before you decide to give consent. You are also welcome to contact Poncho (018 299 4289) if you have any further questions concerning you consent.

**8. FEEDBACK OF FINDINGS**

The findings of the research will be shared with you if you are interested. You are welcome to contact us regarding the findings of the research. We will be sharing the findings with you as soon as it is available.

**CONSENT FORM**

**PARTICIPATION IN THIS RESEARCH IS VOLUNTARY**

You are free to decline to be in this study, or to withdraw at any point even after you have signed the form to give consent without any consequences.

Should you be willing to participate you are requested to sign below:

I \_\_\_\_\_ hereby voluntarily consent to participate in the above mentioned study. I am not coerced in any way to participate and I understand that I can withdraw at any time should I feel uncomfortable during the study. I also understand that my name will not be disclosed to anybody who is not part of the study and that the information will be kept confidential and not linked to my name at any stage. I also understand what I might benefit from participation as well as what might be the possible risks and should I need further discussions someone will be available.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of the participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of the person obtaining consent

## ADDENDUM D: EXCERPT FROM A TRANSCRIPT

**Interviewer** Before we continue with the interview, do you have any questions that you want to ask me?

**Participant** No, I am ok.

**Interviewer** Ok. I am going to read the question we are going to discuss in English then from there I will translate it in Setswana. Some health care workers, nurses and counselors have undergone a workshop on understanding HIV-stigma reduction and responsible disclosure management. A project was also conducted by people living with HIV and people living close to them in this primary health care clinic. Tell me about your experience of being involved in this HIV-stigma reduction intervention in this primary health care clinic.

**Participant** In this project of stigma I liked it when they did a drama it showed people that people with this disease we shouldn't push them aside (3.1). We are supposed to give them the warmth of love and support them because they are people just like us (1.1). And when you have this disease don't drink alcohol you are supposed to drink your pills for you to be healed. Eat healthy foods like spinach, vegetables. And a person who has this disease we shouldn't be disgusted of her, sometimes you find when she enters the clinic we put her aside whereas she doesn't have TB (1.1). So like we close them out and we give them names saying they stepped on cables and then even at home we close them out, they sleep at the shack alone (1.5). We don't care about them, when we give them food we give them as if we are giving it to dogs. Even at church, we close them in the house they can't even be taken to church. They are not taken care of and it is not good like we abuse them physically. And in the bible we are not supposed to do that to people, we are supposed to treat them the same, and take care of them because they are people just like us. If we take care of them these people will be able to live well and be healed (1.1), HIV can be healed if you take care of yourself and drink your pills. Pills are there at the clinic for free, other people are afraid to drink pills when they are with their friends because they will stigmatize them for drinking HIV pills, of 'three numbers' (1.5). Now that is why our people are not able to drink treatment it is because of us, our words to them (1.5). So what I can say is I like the way your group works, they make people realize that they are people too (3.1). They go around being hurt even in the clinic but what I liked is now it has changed in the clinic. It doesn't show anymore that, that room is for HIV people we are treating them the same (1.5). All we need to do is support them, so they drink their pills and treat them well, we shouldn't laugh at them, we should love them it is our people (2.1). You can live many years with this disease if you just accept yourself (1.2).

**Interviewer** Yes, continue.

**Participant** I am going to do an example with me, this disease I also have it. I found out 2004 that is when I had this disease, where I had a child 1999. After I had a child I got sick and tested and I was HIV and I started drinking ARV's 2006, and now I am still drinking those pills, I am living well a normal life. And I haven't been pointed at that I have HIV, I got support from home. I went for counseling at PUKKE, I was counseled by XXX so I went to that counseling. The doctor I was working for brought me to the hospice in Promosa and I met with people who have this disease until I accepted myself and went around telling people this disease. Even now I am still alive, I am alright, I am healthy, I live a normal life, I eat, I enjoy life to the fullest. I take care of myself I condomize, even after that one child I have never thought to have another child, this year I am 50years, so I have many years with this disease. And now I am a community health worker in Promosa clinic and I am proud of what I am. And I also support people, they are there people who I have helped and now they are healed and have other children. Others didn't care and they died so I am still like that and when you see me you won't say I have the disease. God just shook me to see if I forgot myself but here I am I am still here and I have even raised two of my siblings who are orphans. The other one come

to stay with me at four months the other one at four years, the four years one now has twenty years and it is her second year at PUKKE. The second one came four months, she is doing grade eleven she has passed she is going to do grade twelve at Tegnies. I thank God for preserving me in my sickness but I was sick and still going to work at the doctor. Those children now I am their guardian mother, so I thank God for giving me this opportunity. When you pray and say Father God I am your child, I want these children to go to school, they listened to me and went to school. They are good children these two girls, they didn't make me ashamed and now they still listen to me and they don't control me, I always guide them and say don't fall in where I fell. Please go to school because education that no one can take from you if tomorrow God misses me, if it happens then at least you would have finished school. Then I will be satisfied and sleep a good sleep. All I cry for is your education and the respect you have is all I want. It is only the work of God, He can hear us, and what is important is that you should lean on church, read your bible, go on your knees and ask God, He listens to us all, we are His children. He does not segregate and he does not slumber.

**(The above response was about the participant's own experience and not related to the research question)**

**Interviewer** You spoke about we started you like the drama a lot.

**Participant** I like the drama it taught many that in the drama you are supposed to give a person support when they have this sickness (3.1). We are supposed to rebuke you for alcohol, drink your treatment and live a normal life (2.2). And we shouldn't criticize you giving you names of stigma and saying you stepped on a cable, those bad saying we say like three numbers. It is not the right words when you have this disease we are supposed to support you and give you the warmth of love (1.5) . Eat well, we shouldn't set you aside, sometimes we are afraid to drink pills because of peoples words. I am afraid to drink pills because my friend is going to see me that I am drinking pills and on the other side I default. And when you start being sick go to the clinic to test and when you find out that you are HIV positive go to the clinic and drink your treatment. If anyone laughs at you it is for themselves because you are better you know your status, you can live a very long life. So those who laugh at you, they are the ones you are going to bury and you continue to live a normal life because they hide themselves.

## **ADDENDUM E: EXCERPTS FROM NAÏVE SKETCHES**

### **NURSE'S EVALUATION OF THE WORKSHOP**

#### **I have experienced this day of the workshop as:**

To treat people equally. To support and encourage PLHA to take their treatment not to ask PLHA many questions, not to judge people living with HIV/AIDS. I now have the knowledge of what HIV-stigma can do to a person. I now understand the decision of a PLHA when or where to disclose. I believe that together we can make a difference in our community to reduce HIV-stigma.

**I FEEL:** People can be taught about HIV-stigma, and it can be done every day at the clinic because the community will realise that HIV doesn't kill is the stigma that kills. Treat others the way you want to be treated when you are sick. Thank you.

### **HEALTH CARE WORKER'S EVALUATION OF THE WORKSHOP**

#### **I have experienced this day of the workshop as:**

The workshop was excellent, I learnt more things. I hear you disclose when you are ready, not people to disclose for you. Not to discriminate the people who are HIV positive. I must support them or encourage them to drink their medication, other people give them names, they hide them. They gossip about them, they don't want to eat with their plate, they think others will also be HIV positive like them. As a community health worker I am going to teach the community and support them, not to gossip or laugh them. We must teach their families to support and love them.

**I feel:** I am happy to be in this workshop

### **COUNSELLOR'S EVALUATION OF THE WORKSHOP**

#### **I have experienced this day of the workshop as:**

As a counsellor, I've learned a lot of things about stigma and diagnosis of HIV. I've got a lot of information from the workshop, am going to give this information to the clinic, my colleague and community. I learnt different stigmas, how does it works as a counsellor. As clinics we have to help others out there, to make them live good life, especially to those who had HIV, we both are saying and no one's perfect. Know how to deal with the person with stigma from today and we'll do all the best to make them happy.

**I feel:** I feel so happy because I've got a lot of information today and I'm glad too because I know everything about stigma today.

### **PLC EVALUATION OF WORKSHOP**

#### **I have experience this day of the workshop as:**

I have experienced that we must treat people living with HIV because if we don't they going to get sick and not believe on themselves

We must support them throughout and be with them no matter how difficult it is

I have learned that the stigma is yourself and you must deal with it

Also learned that we must teach the nurses how to treat people living with HIV

We must do the support groups to help people living with HIV

We must not abuse them in anyway or neglect them.

Learned that the talks we talk as families and communities they lower – self esteem or stigmatise of people with HIV

**I FEEL:** I felt so grateful to have this opportunity to have knowledge about the stigma of people having or living with HIV I will treat them well and watch my talking



## **PLC'S EVALUATION OF WORKSHOP**

### **I have experience this day of the workshop as:**

I have learned a lot today about HIV and AIDS; stigma is the new name that people can use in the place of HIV

Stigma is like a paint brush which comes in different colours, e.g. red, yellow. There are three balls in our lives,

If you hide yourself then your skin changes colour and it will beat you.

Self stigma; it is when you self trigger about stigma and when people gossip about you; behaviours, when people talk good about you.

Received stigma; when people do not want to help you, at all. The sister does not want people to even cough before them. People must focus on our problems. I learnt a lot how to talk with other people. I learnt actively so much. Self-trust.

## **ADDENDUM F: EXCERPT FROM FIELD NOTES**

### **OBSERVATIONAL NOTES**

The group of participants are ferried to the venue for the interviews by a taxi facilitated by the research assistance to ensure proper coordination and avoid any inconveniences.

The venue is in the one of the boardrooms of the Department of Health offices. The room was big well ventilated with good lighting and minimal noise and disruptions

A group of fourteen (14) participants sat attentively as if they were not sure why they were part of the training session. A session for self-introduction was done by all. The facilitator of the session gave a brief background of the project and also indicated that she is participated in many other studied like the current one with a team of researchers from five African countries. They [researchers] started with the HIV-stigma and the individual moved to the community and now the current study focuses on Primary Health Care Clinics hence they have been nominated by the North West Department of Health to participate in this study as people with the required experience.

There were fourteen (14) participants consisted a professional nurse (working in a PHC clinics for 4 years), health care workers (HCWs) and lay counsellors (working experience ranged from 2 to 15 years). The group consisted of both males and females. They were informed that they have a right to withdraw if they are uncomfortable or so wish without any form of penalties. What was interesting was that all of the participants were currently involved in the process of PHC Reengineering.

After one of the field workers disclosed "personal" HIV status they were more comfortable to talk. The participants were offered refreshments and after lunch, 3 were sleepy, the rest stayed wide awake with interest.

The session was an active participation where the participants had to respond to questions in groups and nominate a representative to present their responses.

### **PERSONAL NOTES**

There is a personal realization that HIV-stigma persists despite intervention measures in place with special noting of the PHC clinics context. The venue was warm far from destructions. I was personally not very sure of how the process would unfold but I was at ease as: the facilitator continued with the explanations and the session unfolded and the participants seemed more relaxed. The session was really meaningful for me and I also realised that HIV-stigma still exists and it is confirmed in the PHC clinics by the participants.

### **METHODOLOGICAL NOTES**

All research documentation (approval by the North West University, North West Department of Health Ethics, and NWU Ethics Committee) are all available. The participants were identified by North West Department of Health and followed up by the field workers for finer details of the project and to get all of them on time for the sessions as scheduled. The session was facilitated by an experienced researcher who could meander along with the participants' engagement or non responsiveness at some point.

Ground rules were agreed upon and lay out of the session given. The power point presentation, facilitators manual as well as lecture notes are available for the training session of nurses and health care workers on HIV-stigma reduction and disclosure management.

After lunch the facilitator made the training session to be highly interactive. Questions were posed and the groups responded through presentations.

### **THEORETICAL NOTES**

Training manual and power point presentations were available. One participant looked on with pitiful eyes after noting disclosure of positive HIV status by one of the field workers. The HIV-stigma session meant a lot to the participants as it gave a deeper understanding of HIV-stigma as noted from their comments.

The disclosure session was like an eye opener to the participants as most verbalised they were now empowered in assisting PLWH to disclose their positive HIV status.

Some had this to say:

“I learned a lot about the process of disclosure

“I did not know much about HIV-stigma and disclosure and will be able to do my work better’

“Trust is critical”

“I did not really give a lot of focus on HIV-stigma and disclosure but from today I will”

“I do not have to force people to disclose but to encourage them”

“HIV-stigma is high in the clinics”

In closure all participants were happy to be part of this project. They had tea and ferried back to their homes.

**ADDENDUM G: DETAILED THEMES, CATEGORIES AND SUBCATEGORIES OF THE EXPERIENCES OF NURSES, HCWS, COUNSELLORS, PLWH AND PLC OF THE HIV-STIGMA REDUCTION AND RESPONSIBLE DISCLOSURE MANAGEMENT INTERVENTION IN PRIMARY HEALTH CARE SETTINGS**

THEMES	NURSES	HCWs	COUNSELLORS	PLWH	PLC
<b>SIMILARITIES FOR THE NURSES, HCWS, COUNSELLORS, PLWH AND PLC</b>					
<b>Awareness and understanding of HIV-stigma</b>	<p><b>IMPROVED UNDERSTANDING HIV-STIGMA:</b></p> <ul style="list-style-type: none"> <li>• PLC sometimes emotionally abuse PLWH</li> <li>• Greater awareness for patients' expressed feelings of loneliness and little support</li> <li>• Inhibited health promotion due to distrust staff and HCW</li> <li>• Stigmatization causes wrongful usage of medication</li> </ul>	<p><b>CRITICAL AWARENESS OF STIGMATISATION:</b></p> <p><b>HIV-stigmatization causes discomfort for PLWH:</b></p> <ul style="list-style-type: none"> <li>• Fear of rejection and hurt</li> <li>• Fear of being infected with HIV</li> <li>• Inhibited participation in relational negotiation</li> <li>• Inhibited participation in health care services</li> <li>• Emotional abuse by community members</li> </ul> <p><b>Awareness of own stigmatizing behaviour as HCW:</b></p>	<p><b>HEIGHTENED AWARENESS OF STIGMA:</b></p> <p><b>Improved understanding the meaning of stigma:</b></p> <ul style="list-style-type: none"> <li>• Stigma is real, serious, everyday occurrence</li> <li>• Stigma is unnecessary occurrence</li> <li>• Focused on others</li> <li>• Focused on self</li> </ul> <p><b>Negative impact of stigma:</b></p> <ul style="list-style-type: none"> <li>• People left to deal with own negative experiences</li> <li>• People become physically or mentally sick</li> </ul>	<p><b>A BETTER UNDERSTANDING OF STIGMA:</b></p> <p><b>Stigma awareness gained:</b></p> <ul style="list-style-type: none"> <li>• Enjoyed the workshop and gained excellent stigma knowledge</li> <li>• Greater awareness of what behaviour is stigmatising</li> <li>• Understanding how stigma hurts community</li> <li>• Reduces community support and inhibits good communication</li> </ul>	<p><b>IMPROVED UNDERSTANDING OF STIGMATISATION:</b></p> <p><b>On intrapersonal level:</b></p> <ul style="list-style-type: none"> <li>• Non-disclosure decreases health</li> <li>• Leads to unhealthy behaviour</li> </ul> <p><b>On interpersonal level:</b></p> <ul style="list-style-type: none"> <li>• Stand in judgement of others</li> <li>• Avoid association with PLWH</li> </ul> <p><b>In the community:</b></p> <ul style="list-style-type: none"> <li>• Stigma cannot be ignored and needs to be dealt with sensitively and responsibly</li> <li>• Openness to differences in</li> </ul>

		<ul style="list-style-type: none"> <li>Continued stigmatising practices by HCW</li> <li>Other specific stigmatising practices</li> <li>Accuse patients of default to receive a grant</li> <li>Patients' complaints and concerns not taken serious</li> </ul>	<ul style="list-style-type: none"> <li>Stigma impacts negatively on PLWHs' health care behaviour:</li> <li>Perception of HIV being a death sentence</li> </ul> <p><b>Disclosure deeply feared because of stigma:</b></p> <ul style="list-style-type: none"> <li>General fear of disclosure</li> <li>Accidental disclosure feared</li> <li>Health care practices of forced disclosure</li> </ul>		<p>people (receive different kinds of patience and understanding.)</p> <ul style="list-style-type: none"> <li>People are equal and should be treated equally</li> </ul>
<p><b>Positive effects and empowerment following the intervention</b></p>	<p><b>POSITIVE EFFECTS OF THE INTERVENTION:</b></p> <ul style="list-style-type: none"> <li>Relevance and inclusiveness of the workshop and project:</li> <li>Ample opportunity to learn about stigma</li> <li>Inclusiveness of all categories</li> </ul>	<p><b>POSITIVE EFFECTS OF THE INTERVENTION:</b></p> <p><b>Changed positive attitudes of nurses and HCWs:</b></p> <ul style="list-style-type: none"> <li>Behaviour respectful and welcoming</li> <li>Safer emotional atmosphere in the clinic</li> </ul>	<p><b>EVIDENCE OF EMOTIONAL STRENGTH AFTER THE INTERVENTION:</b></p> <p><b>From fear to coping with stigma:</b></p> <ul style="list-style-type: none"> <li>Clarity in peoples' understanding of stigma</li> <li>Greater freedom</li> <li>Displaying a new boldness</li> </ul>	<p><b>EMPOWERMENT THROUGH THE INTERVENTION :</b></p> <p><b>Enhanced intrapersonal strength for PLWH:</b></p> <ul style="list-style-type: none"> <li>Knowledge replacing the fear and problems of stigma</li> <li>Reduced inner pain and shame</li> </ul>	<p><b>ENHANCED POSITIVE EXPERIENCES:</b></p> <ul style="list-style-type: none"> <li>Feeling of courage</li> <li>Feeling of freedom</li> <li>Feeling of hope</li> <li>Feeling of pride and satisfaction</li> </ul>

	<ul style="list-style-type: none"> <li>• Sparked a change in how patients and staff view each other</li> <li>• Everybody to be exposed to the intervention</li> <li>• Improvement in community involvement</li> <li>• Improved self-acceptance by PLHA:</li> <li>• Positive changes in personal health care</li> <li>• Courage to seek support</li> </ul>	<p><b>Changed clinic practices:</b></p> <ul style="list-style-type: none"> <li>• Removed HIV specific medicine packaging</li> <li>• Removed stigmatizing signs on doors</li> <li>• Effort to address long queues</li> <li>• Accommodating patients to visit the clinics after work</li> <li>• Allowed to send someone else to fetch prescribed medication.</li> </ul> <p><b>Contentment of patients increased:</b></p> <ul style="list-style-type: none"> <li>• Happier to attend the clinic</li> <li>• Fewer complaints about the service</li> <li>• Fewer defaulting patients</li> </ul> <p><b>Positive intra-personal changes in PLWH:</b></p>	<ul style="list-style-type: none"> <li>• Gained courage to stand up for themselves</li> <li>• PLWH talked about recognition of self-stigmatisation</li> </ul> <p><b>From a prison of secrecy to freedom of disclosure:</b></p> <ul style="list-style-type: none"> <li>• Freedom to live unashamedly</li> <li>• Freedom to enjoy romantic relationships</li> <li>• Increased self-confidence to disclose status</li> <li>• Lost fear of gossip</li> </ul> <p><b>From despair to courageous unlearning of stigmatisation behaviour by counsellors:</b></p> <ul style="list-style-type: none"> <li>• Not to be ashamed of associating with PLWH</li> <li>• Becoming free enough to touch</li> </ul>	<ul style="list-style-type: none"> <li>• Learnt self-acceptance and belief in self</li> <li>• Encouraged to live positively and with hope</li> <li>• No stress anymore, taught us not to allow people to put us down</li> </ul> <p><b>Enhanced interpersonal strength:</b></p> <ul style="list-style-type: none"> <li>• Gave courage to go forward and teach others about stigma.</li> <li>• Opened up communication about HIV matters, to talk and share</li> <li>• We learnt words to express the pain of stigma.</li> <li>• Made new friends and found a new family</li> </ul>	
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		<ul style="list-style-type: none"> <li>• Happier in themselves</li> <li>• Improved self-care and self-acceptance.</li> <li>• Feeling less stigmatized</li> </ul> <p><b>Positive interpersonal changes in PLWH after the intervention:</b></p> <ul style="list-style-type: none"> <li>• Freedom within relationships</li> <li>• Enhanced relationships with PLC</li> <li>• Enhanced romantic relationships</li> <li>• Greater freedom to interact with others</li> </ul> <p><b>Greater understanding of disclosure:</b></p> <ul style="list-style-type: none"> <li>• Increase of disclosure practices by PLWH</li> <li>• Better understanding of the HIV disclosure process and facilitation by HCW</li> </ul>	<p>PLWH in a normal way</p> <ul style="list-style-type: none"> <li>• Greater openness for testing</li> <li>• Encourage PLWH to be self-accepting</li> <li>• Greater awareness of respectful behaviour</li> <li>• Becoming more supportive towards others</li> </ul>		
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		<p><b>Observed changed behaviour of PLWH in support:</b></p> <ul style="list-style-type: none"> <li>• Greater need for support in the community</li> <li>• Giving support rather than gossip and stigmatization in the community</li> <li>• Invite others to existing support groups</li> <li>• Initiate more support groups</li> <li>• Facilitate door to door visitation by HCW to community members</li> </ul>			
<b>SIMILARITIES COUNSELLORS AND PLWH</b>					
<p><b>Renewed confirmation, interest and need of counselling and support</b></p>			<p><b>RENEWED CONFIRMATION OF COUNSELLING AND SUPPORT:</b></p> <p><b>Counselling validated after the intervention:</b></p> <ul style="list-style-type: none"> <li>• Recognized as necessary function and more utilized than before</li> </ul>	<p><b>RENEWED INTEREST AND NEED FOR SUPPORT GROUPS:</b></p> <ul style="list-style-type: none"> <li>• Greater need for support groups in the community</li> <li>• New interest in joining support groups</li> </ul>	



			<ul style="list-style-type: none"> <li>• Appreciation of knowledge and skills</li> <li>• Greater openness to interact with counsellors</li> <li>• Counselling progressed beyond emotional pain</li> <li>• Emotional burden was lessened</li> <li>• Available resources gained value</li> </ul> <p><b>Support groups revived and initialized since intervention:</b></p> <ul style="list-style-type: none"> <li>• New and existing support groups utilized without fear of stigmatization</li> <li>• Increased opportunity to share and support</li> <li>• Stronger message of hope and friendships</li> <li>• The psychodrama enlightened the</li> </ul>	<ul style="list-style-type: none"> <li>• Support groups valuable</li> </ul>	
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			understanding of the illiterate		
SIMILARITIES FOR NURSES, PLWH AND PLC					
<b>Changes in patient behaviour, assistance to disclose and coping strategies</b>	<b>OBSERVED CHANGES IN PATIENT BEHAVIOUR:</b>  <b>Increased disclosure practices:</b> <ul style="list-style-type: none"> <li>• Less stigma improved disclosure</li> <li>• Greater understanding of disclosure increased disclosure practice</li> </ul> <b>Positive changes in patient behaviour:</b> <ul style="list-style-type: none"> <li>• Reduced stigma freed people to openly speak</li> <li>• Increased individual and couple testing</li> <li>• Increased numbers visiting the clinic</li> </ul>			<b>OFFERED PLWH ASSISTANCE TO DISCLOSE:</b> <ul style="list-style-type: none"> <li>• The intervention brought comfort to risk disclosure</li> <li>• Created an opportunity where others also disclosed their status</li> <li>• Psychodrama facilitated humour and freedom</li> <li>• Gave PLWH strength to disclose</li> <li>• Enhanced access to health care services</li> </ul>	<b>IMPROVED COPING STRATEGIES FOR STIGMA REDUCTION.</b> <ul style="list-style-type: none"> <li>• Improve an understanding of</li> <li>• Rely on God</li> <li>• Learn to handle realities and act positively</li> <li>• Get involved and participate in community projects</li> <li>• Learn to be positive about change</li> <li>• Improve and acknowledge personal coping strategies and skills</li> </ul>

UNIQUE FINDINGS FOR NURSES AND PLC					
<p><b>Awareness of patients' negative view of staff and greater need for service improvement</b></p>	<p><b>AWARENESS OF PATIENTS' NEGATIVE VIEW OF STAFF:</b></p> <ul style="list-style-type: none"> <li>• Staff are observed as stigmatizing</li> <li>• Lack of confidentiality by staff leads to distrust</li> </ul>				
	<p><b>GREATER AWARENESS OF NEED FOR IMPROVEMENT OF SERVICES:</b></p> <ul style="list-style-type: none"> <li>• HIV-stigmatisation affects the quality of service</li> <li>• Patients and staff both contribute to stigma and stigmatisation</li> <li>• An improved collaborative approach is needed</li> </ul>				
<p><b>Environmental stumbling blocks and empowerment in project management and leadership</b></p>					<p><b>ENVIRONMENTAL STUMBLING BLOCKS FOR EFFECTIVE HIV AND CARE:</b></p>

					<p><b>Stigma still high in clinics:</b></p> <ul style="list-style-type: none"> <li>• Lack of positive attitude</li> <li>• Lack of support</li> <li>• Lack of understanding for painful or difficult experiences</li> <li>• Lack of confidentiality impacts on trust</li> </ul>
					<p><b>EMPOWERMENT IN PROJECT MANAGEMENT AND PERSONAL LEADERSHIP:</b></p> <p><b>New insight into community project management:</b></p> <ul style="list-style-type: none"> <li>• Felt accepted by project facilitators</li> <li>• Projects helpful</li> <li>• Projects can be target specific</li> <li>• Projects can encourage disclosure</li> </ul>

					<p><b>Enhanced personal leadership skills:</b></p> <ul style="list-style-type: none"><li>• Becoming leaders in stigma reduction</li><li>• Personal coping and facilitating coping in others</li><li>• Enhanced communication skills</li><li>• Ability to motivate others</li><li>• Trusting self</li><li>• Changed attitude</li><li>• Seek Gods help</li></ul>
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## **ADDENDUM H: AUTHOR GUIDELINES FOR THE JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE (JANAC)**

The journal of the Association of Nurses in AIDS Care (JANAC) is the official journal of Association of Nurses in AIDS Care (ANAC). JANAC's mission is to support nursing practice, research, and education through the dissemination of scholarly, cutting-edge knowledge and practice standards. JANAC provides a forum for interdisciplinary discussions about clinical practice, education, research, prevention, public health, health administration, international health, legal-ethical issues, social issues, and public policy related to all aspects of the HIV epidemic. JANAC invites original articles that focus on a broad spectrum of issues related to HIV, from the perspectives of nursing, public health, clinical care, research, mental health, behavioural health, and medicine.

**Manuscript submission:** JANAC reviews manuscripts with the understanding that they were never submitted for publication to any other journal. It is unethical to submit a manuscript to more than one journal at a time. A manuscript must be rejected or formally withdrawn by the author from one journal before it can be submitted to another journal.

JANAC allows manuscripts (maximum 24 pages); research, practice or brief (8-10 pages); case studies (8-10 pages); topical columns and comments (6-8 pages) and media and book reviews (8-10 pages) including letters to the editors.

JANAC uses an online manuscript submission and review system. Please visit <http://ees.elsevier.com/janac> to submit a manuscript electronically. The Web site guides authors through the initial registration process, including uploading requisite files. A tutorial is available at the site for authors. All correspondence, including notification of the Editor's decision and request for revision, takes place by e-mail. The system automatically converts source files to a single PDF file of the article, which is used in the peer-review process. Please note that through manuscript source files are converted to PDF files at submission for the review process, the source files (in a Word document) are needed for further processing during the revision process.

JANAC uses iThenticate to detect similarities between submitted papers and information on the internet. We will not review submissions with excessive similarities to other publications. Please submit your article via <http://ees.elsevier.com/janac>

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**Peer review:** Every submission for a featured manuscript is evaluated by at least two members of the review panel to determine the paper's relevance and significance, the degree to which it advances knowledge, the quality of scholarly presentation, the integrity of research methods, and clinical content relevant to nursing practice and HIV care. Authors may be requested to make corrections as advised by the review panel to comply with JANAC style.

**Manuscript preparation:** Submission for feature articles should have the following components: (a) title page, submitted in a separate file (see the sample title page in the JANAC Style Guide); (b) manuscript body, including abstract and 3-6 key words (on first page), title, manuscript text, references, and tables, if applicable, and key considerations (see the JANAC Style Guide); and (c) figures, if applicable. Feature articles may be up to 28 pages on initial submission, not including the Title Page or Key Considerations. We accept a combined total of up to 5 tables and figures in feature manuscript submissions.

**Other submissions:** Submissions are accepted for research, practice, or program briefs; topical columns and commentaries; guest editorials; media reviews; and letters to the editors. The editor reviews these submission and determines whether input is needed from additional reviewers. These submissions should have the following components: (a) title page, submitted in a separate file (see the sample title page in the JANAC Style Guide); (b) manuscript body, including title, text, references, and tables, if applicable; and (c) figures, if applicable. Papers in this category may be up to 10 pages on initial submission. Please limit these submissions to a total of 2 tables and/or figures per manuscript. Abstracts and keys considerations are not required.

**Title page:** The title page should include each author's credentials, title/position, affiliation and location (city and state and/or country), and corresponding author and her/his e-mail address. The title page should be submitted as a separate document to blind our reviewers to information about the authors. See sample title page in the JANAC Style Guide.

**Conflict of interest:** Authors are required to provide full disclosure of actual or potential conflicts of interest relevant to the subject matter of the manuscript that have occurred over the previous 2 years, during the research being reported on, and/or that

can reasonably be expected to occur in the foreseeable future. Disclosures may include, but are not limited to, grants and funding, employment, affiliations, honoraria, consultancies, board positions, royalties, stock options and ownership, or expert testimony. Unless determined to be important to the review process, disclosures are held confidential until an article is accepted for publication. Disclosure statements appear with all articles published in JANAC. Authors should contact the Managing Editor with questions or concerns, but should err on the side of inclusion when in doubt. Please see the full Conflict of Interest on our web site at <http://www.nursesinaidscarejournal.org/webfiles/images/journals/jana/conflict.pdf>

If the author(s) has no conflict of interest to declare (including relationships with pharmaceutical companies, biomedical device manufactures, grantors, or other entities whose products or services are related topics covered in this manuscript) this must be stated. In this case, please use the following statement:

- The author(s) report(s) no real or perceived vested interest that relate to this article that could be construed as a conflict of interest.

The following is a sample text for disclosure of a real or perceived conflict of interest.

- This study was funded in part by ABC Corporation and grant #1=234-5678 from DEF Foundation. Kyle smith reports having received lecture fees from XYZ Laboratories. Chris Gallegos disclosed consulting fees from 123 Inc. Pat Jones reports no financial interest or potential conflicts of interest.

**Acknowledgements:** Please acknowledge all sources of funding in an Acknowledgement Statement on the title page of the manuscript. This is also an appropriate place to acknowledge assistance from non-author colleagues in the development and production of a manuscript.

**Abstract:** Abstracts may contain up to 150 words, and should appear immediately above the body of the manuscript on page 1. Authors will so be asked to provide the abstract as part of the submission process. You may cut and paste your abstract into the submission box. Abstracts are required for all feature articles but not for other submissions.

Please provide at least 3 and no more than 6 key words. Key words related to the content of the manuscript should be listed in alphabetical order and separated by commas. For feature articles, place key words after the abstract on the first page of the manuscript. For other submissions, please place the key words on the title page.

**Manuscript body:** Manuscript body manuscript pages should be numbered consecutively; running heads are not recommended. A clear and concise writing style is required.



**References:** The reference section should start on a new page after the end of the body of the paper. The list should represent current literature and appropriate historical references that have been used in the body of the paper as citations or referenced in the tables and/or figures. References should be limited to about 30 for research manuscripts; review manuscripts may use more references, but with restraint; brief submissions should limit references to 10-15.

**Key considerations:** All feature manuscripts should include 3-6 key points from the article, with a focus on clinical applications. Points should be presented in a bulleted list and focus on pertinent concepts that can be reasonably derived from the manuscript and how they apply to the care of people living with HIV infection. This list should start on a new page following the reference list.

**Tables and figures:** Tables are encouraged if they will help the reader better understand the text. Tables should be self-explanatory and enhance, not duplicate, the text. Tables should be numbered, titled and referenced in the most appropriate section of the manuscript text. Tables should be placed as close as possible to the table reference in the sequentially as they appear in paper. Figures, including photographs, are encouraged if they will help the reader better understand the text. Figures should be self-explanatory and enhance, not duplicate, the text. Figures can be imbedded in the manuscript as long as they remain clear and easy to read. Otherwise, submit them as separate files.

**Revised submissions:** When we ask for revisions, we will also ask that you provide JANAC with editable source files in Word documents: 1 file for the title page; 1 file for the text, tables, and key considerations; and 1 file for each figure. For best publication quality, figure files should be 300 dpi and in jpeg, EPS, or TIFF format. Figures should be numbered, titled and referenced in the most appropriate section of the manuscript text. See the copyright section.

## **ADDENDUM I: AUTHOR GUIDELINES FOR THE JOURNAL OF SOCIAL ASPECTS OF HIV AND AIDS (SAHARA)**

Publication details, including instructions for authors and subscription information: <http://www.tandfonline.com/loi/rsah20>

The journal publishes contributions in English and French from all fields of social aspects of HIV/AIDS (care, support, behavioural surveillance, counselling, impact, mitigation, stigma, discrimination, prevention, treatment, adherence, culture, faith-based approaches, evidence-based intervention, health communication, structural and environmental intervention, financing, policy, media, etc.). While the emphasis is on empirical research (qualitative and quantitative), the journal also accepts theoretical and methodological papers, and review articles, which should not be longer than 8000 to 10000 words, as well as short communications, letters, commentaries and book reviews. Priority is given to articles which are relevant to Africa and the developing world and which address social issues related to HIV and AIDS. Special issues may deal with a specific topic, region or country. Submission of papers presented at the biannual international conferences of HIV/AIDS and STI in Africa and biannual Social Aspects of HIV/AIDS Research Alliance (SAHARA) conferences are especially invited.

Authors are requested to submit their original manuscript and figures with two copies and a matching disk to the Editor: Professor Karl Peltzer, Social Aspects of HIV/AIDS and Health, Human Sciences Research Council, Private Bag X9182, Cape Town 8000, South Africa. Manuscripts can also be submitted by e-mail. Please create one folder (with the name of the corresponding author) for all word and figure files, and e-mail this to the editor at [KPeltzer@hsrc.ac.za](mailto:KPeltzer@hsrc.ac.za)

Submissions will be considered on the understanding that they comprise original unpublished material and are not under consideration for publication elsewhere (all authors are to sign on submission of the article), and the study (ies) on which they have been subject to appropriate ethical review.

All submissions may be subject to initial assessment by the editor or appropriate Editorial Board members to determine their suitability for consideration by the Journal of Social Aspects of HIV/AIDS. Papers accepted for formal review will be sent anonymously to at least two independent referees.

Short biographic details of not more than 10 lines should be provided at acceptance of the paper for publication.

### **Manuscript preparation**

**General:** Manuscripts must be typewritten, double-spaced with wide margins, on one side of white paper. Good quality print-outs with a font size of 12 are required. The corresponding author should be identified (include a fax number and e-mail address).

The reference style should follow APA guidelines: <http://humanities.byu.edu/linguistics/Henrichsen/APA/APA01.html>

**Abstract and keywords:** Supply an abstract (without subheadings) of up to 300 words and up to six keywords.

**Text:** Follow this order when typing manuscripts:

- On the covering page – author, affiliation, full postal address, fax number and e-mail address, names and affiliations of co-authors should be clearly indicated. Please, ensure that these details are printed on the cover page only and do not appear on any other separate sheets.
- References
- Appendix
- Figure captions
- Tables and figures. Do not import figures or tables into the main text. Footnotes are to be listed separately at the end of the text and not at the bottom of each page.

**References:** All publications cited in the text should be presented in a list of references following the text of the manuscript. In the text refer to the author's name (without initials) and year of publication (e.g. 'Since Shisana and Simbayi (2002) have shown that...' or 'This is an agreement with results obtained later (Uys, 2002)'). For 2-6 authors all authors are to be listed at first citation, with '&' separating the last the authors, for more than six authors, use the first six authors followed by 'et al'. . In subsequent citations for three or more authors use 'et al'. in the text. The references should be arranged alphabetically by authors' names. The manuscript should be carefully checked to ensure that the spelling of authors names and dates are exactly the same in the text as in the reference list. References should be given in the following form: Shisana, O., & Simbayi, L. (2002) Nelson Mandela/HSRC study of HIV/AIDS: South African national HIV prevalence, behavioural risks and mass media household survey 2002. Cape Town: Human Science Research Council Publishers. (full text: [www.sahara.org.za](http://www.sahara.org.za)); Streefland, P.H. (2003). Introduction of HIV vaccine in developing countries: social and cultural dimensions. *Vaccine*, 21 (13-14), 1303-1309.

## ADDENDUM J: DECLARATION FROM LANGUAGE EDITORS

DR AMANDA VAN DER MERWE

(DLitt et Phil)

ACCREDITED LANGUAGE PRACTITIONER • GEAKKREDITEERDE TAALPRAKTIKSYN

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28 March 2017

Ms S Hlahane  
Author  
North-West University  
Potchefstroom Campus

Dear Ms Hlahane

### Language editing

This is to confirm that I edited chapters 1 and 2 of your thesis *HIV stigma reduction and responsible disclosure management in primary health care settings* and that I indicated the necessary grammatical corrections.

Please contact me if there are any queries or if I can be of further assistance.

Yours sincerely



A van der Merwe



■ Language Matters Pty Ltd  
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To whom it may concern,

This document certifies that the manuscript listed below was edited for proper English language, grammar, punctuation, spelling, and overall style by one or more qualified text editor(s) at Language Matters.

Manuscript title: HIV-stigma reduction and responsible disclosure management in a primary health care setting

Author(s): Ms. MSM Hlahane

Date Issued: 26 November 2018

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