PERCEPTIONS OF COMMUNITY CARE WORKERS ON THEIR ROLES AND RESPONSIBILITIES: SOSHANGUVE, PRETORIA

Tronny Mawadzwa

A research report submitted to the Faculty of Management, University of the Witwatersrand, in 50% requirement of the requirements for the degree of Master of Management (in the field of Monitoring and Evaluation)

Student Name: Tronny Mawadzwa
Student Number: 1319905
Wits School of Governance
Faculty of Commerce, Law and Management
University of the Witwatersrand
Supervisor: Marcel T. Korth & Dr Jacqui Poltera
Date: 31 March 2020

Abstract

Care workers play a pivotal role in the community affected by HIV/AIDS through regular home visits. The purpose of this research was to understand better the perceptions of care workers who provide services to HIV/AIDS home visits in the community of Soshanguve. The researcher used the qualitative research strategy because the study was concerned with collecting data about the care workers' perceptions and opinions about the services offered to HIV/AIDS-affected individuals and their families. The researcher selected a phenomenology research design for this research to help understand the perceptions and experiences of care workers, and it allowed for an in-depth analysis of the information from a single group of care workers. The researcher used semi-structured interview guides to ask questions in a focus group set up and on individuals as Key Informants' Interviews (KIIs). A sample of 9 care workers took part in the study, broken down into one focus group with 7 participants and 2 KIIs were conducted as well.

The findings from the study indicate that care workers have fragmented roles and responsibilities that are always changing. The working conditions are not safe for their health and safety. Care workers reported that they are not recognized by higher superiors and are forced to work under harsh weather conditions with tight targets to accomplish every month. Findings indicate that care workers require adequate training and psychosocial support to help them cope with emotional stress. Lastly, the remuneration of care workers has to be revised as data collected showed that the stipend they receive does not sustain their basic living conditions.

Care workers have a passion for assisting the government meet their sustainable development goals on HIV/AIDS. For care workers to effectively perform at work, roles and responsibilities have to be fixed, their working conditions improved, provide training and psychosocial support and revise their stipend.

Declaration

I declare that this report is my own, unaided work. It is submitted in partial fulfilment of the requirements of the degree of Master of Management (in the field of Monitoring and Evaluation) in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination in any other university.

TMdzwa

Tronny Mawadzwa

Dedication

To the care workers around the country, I salute you for the great work you do to support the nation in fighting the HIV/AIDS pandemic and working zealously under harsh conditions.

Acknowledgements

I am grateful to my supervisors, Mr Marcel T. Korth and Dr Jacqui Poltera for their guidance throughout the research process and the management from Thola-Ulwazi CBO to avail the care workers to be part of the interview discussions. More importantly, I give thanks to the care workers who consented to take part in the study and provided valuable information regarding the perception of care workers who provide HIV/AIDS services.

I would like to thank my wife Khukie N. Mawadzwa, for giving me support, encouragement and staying with me until late hours as well as reviewing this research report.

Table of Contents

List of abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
CBOs	Community Based Organisations
CYCW	Child and Youth Care Worker
DOH	Department of Health
DSD	Department of Social Development
ECSA-HC	East, Central and Southern African Health Community
HIV	Human Immunodeficiency Virus
HREC	Human Research Ethics Committee
HTS	HIV Testing Service
IAHSS	International Association for Healthcare Security and Safety
NGO	Non-Governmental Organisation
NPO	Non-Profit Organisation
OVC	Orphans and Vulnerable Children
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLWHIV	People Living with HIV
SACN	South African Cities Network
SDG	Sustainable Development Goal
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations International Children's Emergency Fund
USAID	United States Agency for International Development
WHO	World Health Organisation
WSG	Wits School of Governance

List of figures

List of tables

Chapter 1 Introduction

Care workers working for Community-Based Organisations (CBOs) play a vital role in bridging the gap between community members in need of services and the government in developing countries. The care workers working in CBOs are employed and paid a monthly stipend. CBOs tend to be formed by citizens concerned with helping their community. CBOs provide services such as health care, safety, well-being, environmental protection, quality of education, and access to technology (Goel, 2015). CBOs work at local levels and most of the care workers are local members with firsthand experience of community needs (Griffith, Allen, Deloney, Robinson, Lewis, Campbell, & Reischl, 2010). Care workers in CBOs can be pivotal in bringing the community together and alleviating some of the HIV/AIDS challenges that government may be hard-pressed to address or respond to (Hatzipapas, Visser, & Rensburg, 2017).

In sub-Saharan Africa, the HIV/AIDS pandemic is leaving children without parents and vulnerable to exploitation and abuse (ECSA-HC, 2011). Care workers provide support where vulnerable children and affected families can access psychosocial therapy, HIV testing and counselling, sexual reproductive rights education, and life skills (Middlemiss, 2009).

The positive outcomes of doing home visits by care workers within the HIV/AIDS context for the community are well documented (Walsh, Mulambia, Brugha, & Hanefeld, 2012; Thurman, Kidman, & Taylor, 2013). Providing care to vulnerable people is often regarded as a rewarding and unselfish action by care workers. However, the nature of care work is that it is psychologically demanding, and care workers can experience stress and depression (Makhado & Davhana-maselesele, 2015). Care workers routinely face illness, suffering, trauma and death, as well as the demands of high expectations by those they support, often in a context of low remuneration, burnout and lack of recognition (Hatzipapas et al., 2017). As such, they can experience secondary trauma and compassion fatigue (Hatzipapas et al., 2017). The remit of care workers is also broad: they offer support in child protection, drop-in-centres for children, HIV programmes, old age homes, family centres and refugee assistance services to the community (Department of Social Development, 2015).

Further, care workers also play a critical role in supporting vulnerable families by conducting regular home visits. They tend to be proactive and better positioned to offer services to communities as they understand the dynamics, culture and norms of their communities (Walsh et al., 2012). Further, community organisations typically operate with limited financial resources and recruit community care workers within their community and provide inadequate service training support (David Morton, 2013).

In South Africa, CBOs working with HIV affected or infected families have the mandate to conduct regular home visits to orphans and vulnerable families to provide psychological support as well as food parcels (O`Grady et al., 2008). There is evidence to suggest that community care workers promptly offer referral support to families when they identify potential threats to the livelihood of these families. Given the positive programme outcomes achieved by the care workers to their beneficiaries (Thurman, Kidman, & Taylor, 2013), the donors or government must channel adequate resources to care workers for them to conduct their duties effectively (Mccoskey, 2009).

This research aims to understand the perceptions of care workers who support vulnerable community members affected by HIV/AIDS. There is limited literature that looks at the perceptions of care workers and yet, care workers provide essential support services and face high levels of emotional stress, fragmented working roles and relatively low levels of stipend (Brophy, 2016). The conditions under which care workers operate are conducive to high levels of burnout and attrition rates, which adversely affect the care workers and vulnerable members of their community (Leiter, Bakker, & Maslach, 2014). The researcher applied a case study to understand the perceptions of care workers. The organisation selected by the researcher was Thola-Ulwazi Community-Based Organisation that specialises in home visits for orphans and vulnerable children (OVC) and their families in Soshanguve, north of Pretoria, South Africa.

Thola-Ulwazi was formed in 2007 with the vision of improving and empowering families to live a better and healthier lifestyle. The organisation's mission is to provide care and support to vulnerable children and their families, infected and affected by HIV/AIDS. Thola-Ulwazi has a total of 50 care workers' recruited to offer their services in the community of Soshanguve. The organisation also offers HIV/AIDS training and hospice to members of the community. Thola-Ulwazi employs care workers on short term contracts that are renewable every month.

The researcher has worked with different CBOs around Johannesburg but has never worked with those operating around the city of Tshwane. The researcher chose Thola-Ulwazi CBO to be the case study in this research to understand the perceptions of care workers in a different location as well as minimize the conflict of interest with other organisations the researcher has worked with before.

Soshanguve is one of the townships with informal settlements situated 45km North of Pretoria central business district with a 99.2% black population speaking mostly Northern Sotho 28.2% as their first language (Census, 2011). The majority of people residing in Soshanguve are immigrants within South Africa. The name of the town was derived from Sotho, Shangaan, Nguni and Venda people.

One of the characteristics of Soshanguve is the high level of vulnerability as a result of high mortality rates, morbidity or change in economic situation. The Livelihood and Poverty report revealed that more people in Soshanguve households grow their food, and the poverty rate is high (Mushongera, 2015). Soshanguve faces complex socio-economic challenges such as poverty, alcohol-related violence, child abuse, lack of employment, high numbers of HIV/AIDS pandemic, amongst others (SACN, 2017). The increase in vulnerable families has resulted in high demand for care workers.

The objective of the study

1) Explore care workers perception of providing care to HIV/AIDS affected community in Soshanguve.
2) Ascertain any challenges that care workers perceive within their working conditions.
3) Explore ways to resolve and address the challenges that care workers perceive within their working conditions.

1.1 Problem statement and purpose

Literature indicates that research has been conducted that focuses on the impact of CBOs that provide services to HIV/AIDS-affected communities. Most of the research conducted is funded by local and international donors to evaluate the impact of the programmes implemented by CBOs and not assessing care workers' perceptions. There is limited research (Schneider, Hlophe, & Van Rensburg, 2008; Makoae, 2015) which examines the perceptions of care workers in CBOs who provide HIV/AIDS services. However, literature is available on burnout and attrition of care workers (Leiter et al., 2014). Care workers can offer better quality services that are not being provided by other health facilities at the community level to their beneficiaries. Given the positive impact of care workers on the livelihoods of vulnerable families (Thurman et al., 2013), there is a need to examine the perception of care workers in relation to their work environment.

The purpose of this research is to understand better the experiences of care workers at Thola-Ulwazi Community-Based Organisation who provide HIV/AIDS home-visits in Soshanguve. Policymakers and academics can use the findings to improve the roles and responsibilities of care workers.

1.2 Research questions

The research key questions are as follows:

1. What are the perceptions of care workers at Thola-Ulwazi CBO on roles and responsibilities, and what is the effectiveness of their work and working conditions?
2. What challenges do care workers at Thola-Ulwazi CBO experience?
3. How, if at all, do these challenges affect their ability to provide care to HIV/AIDS families? What suggestions, if any, do care workers at Thola-Ulwazi CBO have to improve their perceptions and address challenges?

Chapter 2 Literature review

This chapter provides an overview of the literature on the perceptions of care workers in Community Based-Organisations who provide HIV/AIDS home visits. This chapter focused on HIV/AIDS from an international, regional to local literature. The researcher then zoomed to review literature specifically on the roles, responsibilities and scope of care workers in CBOs focused on support services for OVC and families within international, regional and local literature.

2.1 HIV/AIDS

HIV/AIDS, Tuberculosis and Malaria remain significant health threats in the world, causing deaths (UNAIDS, 2016). As a result of the consequences of human well-being, substantial financial support from international donors and governments around the world is injected to fight these diseases. Despite these efforts, communicable diseases continue to affect all countries and communities witness the negative impact of these diseases on socio-economic development (WHO, 2014).

AIDS is caused by the Human Immunodeficiency Virus (HIV)   It was firstly reported in 1981, and has caused significant national and international health and development challenges. To date, approximately 36.7 million people are living with HIV, and tens of millions have died since the first report on the disease (UNAIDS, 2017). The virus causes infected persons to be vulnerable to Tuberculosis amongst other ailments. Tuberculosis is one of the highest causes of morbidity and death in HIV positive adults in developing countries (Corbett et al., 2003). Global statistics show that countries in Eastern and Southern Africa have the highest number of people living with HIV, with approximately 19 million. The least number of people infected are in the Middle East and North Africa, with only 230 000 people living with HIV altogether. The HIV/AIDS pandemic has had a negative impact on world economic growth because people living with HIV or deaths caused by AIDS affect skilled labour, family savings and investments. For example, public investments are also being diverted from physical and human capital development to health (Ezechi, Petterson, & Byamugisha, 2012).

In response to the negative impact caused by HIV/AIDS, countries around the world have developed strategies for reduction of this pandemic through promoting dignity, equity and sustainable development. International organisations have set targets for 2020. For example, 90% of the people know their status, 90% are on treatment, and 90% have a suppressed viral load with Sustainable Development Goals (SDG) for 2030 (UNAIDS, 2011). Today many donor agencies and programs address the global pandemic The US government remains the single largest donor, despite the announcement by Donald Trump to cut development funding to Africa (*The Guardian*, 2017, 27 February).

Sub Saharan Africa has the highest number of infected people living with HIV (UNAIDS, 2017). Those infected are in the most productive age cohort of between 15-49 years. Literature indicates that new infections are high, with numbers reaching 960 000 compared to other parts of Africa despite intervention programmes implemented to capacitate people about HIV/AIDS prevention, testing and counselling programmes (UNAIDS, 2017). While intervention programmes show a positive impact, it is taking a long time for people to gain knowledge. For example, in 1999, 72% of infections were recorded in Sub Saharan Africa compared to the current rate of 46%. Knowledge about HIV has increased, but not at the expected rate. There have nonetheless been a reduction in deaths by 38%, and new infections in children by 66% between 2010 and 2015., This has been the result of the work conducted by care workers (Pustil, 2016).

Despite being the first African country in the world with PLHIV, South Africa has managed to reduce the challenges brought by HIV in the past decade, through the work of care workers at the community level. Since 2007, HIV prevalence among children aged 2-14 decreased from 5.6% to 2.5% between 2002 and 2008, and from 10.3% in 2005 to 8.6% in 2008 for youth aged 15-25 years (Shisana et al., 2009). By contrast, the HIV prevalence rate in South Africa remains high, with approximately 1000 new infections stirring daily (Johnson et al., 2016).

Awareness campaigns have been implemented by the Department of Health and NGOs using care workers that have proven to be effective in past years. The impact of these campaigns has revealed that 92.3% of the people knew areas where they could go for testing around their community and that these places are accessible (Shisana et al., 2014). Due to the aforementioned health threats and the high number of reported cases of families dying from HIV/AIDS and other infectious diseases, people have come together to assist their communities through regular home visits and the provision of psychosocial support. These communities work hand in hand with local government and international donors to fight and educate the communities about infectious diseases with a view to reducing their spread to future generations.

2.2 Community health care workers

Care workers play a critical role in communities affected by HIV/AIDS. From an international point of view, the World Health Organisation (WHO) defines community health care workers as individuals who carry out duties related to health care delivery. Care workers are trained community members who do not have formal professional or paraprofessional tertiary education or certificates in a health-related field (WHO, 2017). For care workers to effectively execute their duties, they need to have both caring and curing abilities (Borsay, 2000). Care workers have several roles and responsibilities within the community. Their scope of work includes outreach and community organisation, case management and care coordination, home visits, health education and coaching and system navigations amongst others (Findley, Matos, Hicks, Campbell & Moore, 2012).

The duties of care workers are similar to professional health workers in that they are not fixed but are heavily dependent on context (Sokol, 2006). In the context of HIV/AIDS, care workers play a critical role by increasing the access to referrals of community members to health facilities, and this has reduced child mortality, improved maternal health and other diseases at the community level (WHO, 2017).

Africa is affected by civil wars, famines and the HIV/AIDS pandemic (Kim & Guha-Sapir, 2012). Care workers are recruited to provide support to communities affected by civil wars, famines and HIV. Evidence was reported by the UN Secretary-General statement saying (UN Secretary-General, 2017), “Inter-Agency Coordination Group on Mine and Action in collaboration with care workers are working tirelessly to protect its community members from rebels or to remove landmines and make awareness campaigns in the areas that are dangerous to community members and their livestock”. For example, in Rwanda, the civil war resulted in care workers offering socio-therapy programmes which were implemented to heal the wounds of war (Richters, 2010). Africa is also affected by famines, and care workers identify members in the community who need food parcels.

In sub-Saharan Africa, the HIV/AIDS pandemic increases vulnerability to exploitation (ECSA-HC, 2011). Families affected by the pandemic, especially children, can be exploited by their relatives and community members. Care workers play a significant role in the community, and the duties include capacity building, awareness campaigns, and the fight against gender-based violence as well as sexual abuse. Care workers also bridge the gap between the disparities of services offered to community members by health facilities in the communities (Weinstein et al., 2017). With the escalating demand for care at a community level, organisations have to take charge and voluntarily provide care and support to families affected by the HIV pandemic (Makoae, 2015). Due to the fragmented roles and responsibilities of their work, care workers can experience challenges in executing their duties effectively. Roles and responsibilities are not the only issues affecting care workers performance, but their health and social well-being are also affected. The psychological well-being of care workers will be discussed to determine any supportive mechanism to deal with the passing away of the family members that they visit regularly.

2.3 Community care workers in South Africa

The response to HIV has given rise to care workers presence in South Africa’s health system. Care workers are fulfilling critical and new service needs of home visits to HIV affected families. Care workers became well known in the mid-1990s with state support of non-governmental organizations (NGOs) employing home and community-based carers (Schneider, 2014). During that period, the care workers scope of work was to ensure that HIV patients have access to health facilities and are given Antiretrovirals (ARV), as part of a comprehensive care, management and treatment programme (Schneider et al., 2008). By 2004, approximately 40 000 care workers were employed in South Africa, which was almost equal to the number of professional nurses (43 600) working in the public sector, this resulted in the government adopting a policy framework for training and remuneration of care workers (Friedman, 2005).

The responsibilities for care workers in South Africa has increased. They have started to provide services such as counselling, social services, as well as home-based and palliative care to HIV infected and affected families (Schneider, 2014). In rural communities of South Africa, care workers offer support and community systems strengthening programmes. In South Africa, care workers form an essential component of the social and health service of human resources. Literature indicates that the South African community-based care workers use the Isibindi model of care to serve vulnerable children with the principal objective on providing support to more than 2 million children orphaned or otherwise affected by HIV and AIDS (Thurman et al., 2018).

Care workers are adopting the international donor curriculum when implementing their duties, and there is limited literature on domestic training guides for care workers in Africa. For example, in South Africa, as indicated above, the Isibindi model is one of the few curriculums that have been adopted by the Department of Social Development to train care workers. Care workers are recruited from the communities they serve and receive pre-service and ongoing training and support that enables them to work effectively with HIV affected families (Thurman et al., 2018). CBOs mostly use the international curriculum to train their care workers. The challenge with international donor curriculums for care workers is that it does not take into consideration cultural dynamics. Developing countries invest less in training HIV/AIDS care workers because the continent is comprised of nations falling within the low and middle-income class cohorts (Galárraga, Wirtz, Santa-Ana-Tellez, & Korenromp, 2013).

2.4 Scope of work for care workers

Dependence on Care workers to support HIV/AIDS patients continues to increase, especially in middle and low-income communities. The advantages of engaging this cadre of community health care workers include their familiarity with local issues, good communication with community members, and lower human resource costs (Torpey, Kabaso, Mutale, Kamanga, & Mwango, 2008). The last mentioned is often a reason for task shifting, where roles and responsibilities that previously were seen to require clinical skills have been transferred to lay personnel who are often volunteers, freeing up more expensive and higher-level staff (Busza et al., 2018). Additionally, care workers provide crucial support where human personnel remain scarce (Masquillier, Wouters, Mortelmans, & Wyk, 2016).

Care workers' roles and responsibilities are fragmented, and they do multiple functions in HIV programmes. Their activities include referral process of community members for HIV testing, linking them to health facilities, accompanying them to clinic appointments, providing psychosocial support and making referrals to other services (Busza et al., 2018).

2.4.1 HIV Testing Services

HIV testing services (HTS) encompass the full package of services that should be offered collectively with HIV testing. These services include counselling (pre-test information and post-test counselling), linkage to appropriate HIV prevention, treatment and care services and other clinical and support services; and coordination with laboratory services to support quality assurance and the delivery of correct results (Department of Health, 2015). There is a global initiative to accelerate universal access to HIV prevention, treatment, care and support services for people living with HIV and AIDS (PLWHA). The main entry point for the HIV continuum of care is through HIV Testing Services (HTS), which has become increasingly available. South Africa has more than 4 000 public health facilities offering HTS services. HTS is also available through nonmedical sites and the private sector. The nonmedical areas include the community-based organisations that recruit care workers to offer campaigns on HTS using gazebos.

Care workers offer HTS on a mobile basis or at stand-alone CBOs that are similar to services provided from the existing public health facilities. Mobile services are offered from a mobile van and ‘pop-up’ tents, set up in public spaces. Stand-alone centres are fixed premises, but not attached to a health facility, like Thola-Ulwazi. Both mobile and stand-alone centres only provide HIV testing and related health services (Maheswaran, Thulare,&Stanistreet, 2014). Mobile services offered by care workers reach different populations compared to fixed public health facility-based services (Meehan, Naidoo, Claassens, Lombard, & Beyers, 2014). The work of care workers has improved the uptake of HIV services and treatment adherence. These cadres work in communities visiting patients to educate them about taking medication and knowing their status (Masquillier, 2016).

Literature reveals that HIV testing is a process, and several steps have to be taken when testing. In communities where care workers conduct HIV testing, people can request a test. There are three types of HIV testing options, nominal, non-nominal and anonymous testing (CATIE, 2020). In all instances, a person must give the care worker consent before having the HIV test. During the consent process, a person should be given information or counselling about HIV before the test.

The care workers make referral process to the health facilities when the testing is completed, and the results have been shared with the patient. As for those who are negative, the care workers advise them to keep protecting themselves by using a condom during sexual intercourse.

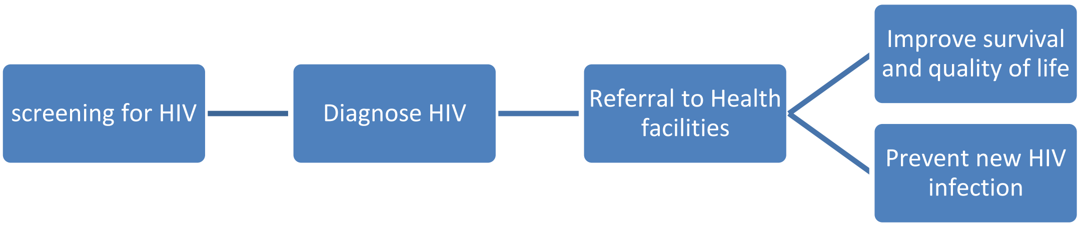
2.4.2 Referral Process

Care workers have the task of making a referral to their patients to health facilities. Referral to care is an important first step in successful HIV management. Literature defined referral as the fulfilment of a first health facility visit after HIV prognosis (Dombrowski, 2020). Referral to health facilities plays a significant role in the HIV treatment—it is a necessary forerunner to ART therapy inception and suppression of the viral load. The literature indicates that ART treatment momentously reduces the risk of developing HIV-related complications (Mugavero, Amico, & Horn, 2013). Besides, ART treatment reduces HIV transmission to other people.

The referral process conducted by care workers is done promptly. Without timely referral by care workers, patients with HIV miss a chance to benefit from ART treatment at the earliest possible stage. The rapid referral process done by care workers for the initiation of ART after HIV prognosis is a crucial pillar of the South African national health initiative for ending the HIV Pandemic.

On the other hand, delayed referral to health facilities is a barrier to "treatment as prevention" to reduce HIV transmission rates in South Africa. Identifying persons with HIV and successfully referring them to clinics, thus plays an essential role in the overall HIV epidemic, both from a treatment and a prevention standpoint. The figure 1 below outlines the main goals of making the referral process to HIV diagnosed patients.

Figure 1 Referral goals



Source: Linkage to care

When care workers are conducting their HIV testing services, they start by screening individuals followed by counselling before testing. When the individual has consented, a test is then done. If the person is diagnosed with HIV, the care workers make a referral to a close local clinic for further testing by a professional nurse or doctor. As outlined in figure 1 above, the objective of referral is to ensure that as soon as a person is diagnosed with HIV, immediate action is taken and he/she starts taking medication to improve survival and quality of life as well as to prevent new infections.

2.4.3 Awareness campaigns

Awareness campaigns involve educating the community about specific issues that might affect their social life Building awareness with the general public is, therefore, an essential first step. People in the communities are unaware of the extent and complexity of the HIV pandemic. When care workers are doing their awareness campaigns, their target audience consists of the general public at the shopping malls. In many cases, HIV affected families experience heavy financial and psychosocial burdens associated with the caring of HIV affected individuals. Provision of palliative care to a community member in South Africa is through community participation, which can be achieved by improving the awareness of the people about HIV/AIDS (Adinarayanan, Ankit, & Balajee, 2016).

Awareness campaigns are the most efficient and effective means of information communication to the general public. Still, not all means of communication used by care workers are useful in terms of influencing the community’s beliefs and changing their behaviour. The main challenge faced by care workers to effectively implement successful campaigns is because of their low levels of literacy (Masiulien, Looney, & Aertgeerts, 2017). Therefore, to set up and undertake a successful awareness campaign for low literacy amongst community care workers, it is crucial to know the characteristics of successful campaigns. The table 1 below outlines the elements of successful campaigns that can be used by care workers when planning their HIV campaigns in the community.

Table 1: Elements of successful awareness campaigns

Elements of awareness-raising	**Success factors identified in the health field**	**A brief comment**
1. Planning and monitoring	Defining the goal, current situation and the gap that needs to be closed.	Conducted at the very beginning of the the campaign, it should help to clarify at least the following aspects: Issues target group(s) faces; Needs of the target group(s); The best channels and ways to communicate and spread the message to the target group.
2. Goal setting	Clear goals	- SMART(specific, measurable, achievable, realistic, time-bound); - Short term and long term;
3. Target audience	Target group(s)	Target audience helps to identify the needs of the target group and, respectively, identify clear goals and prepare a campaign's contents more specific and influential, suitable for the community.
4. Message	Tailored messages	Should be developed in a way to capture target audience attention, suggest an

		acceptable solution to solve the problem and motivate community members for social change.
5. Stakeholder engagement	Expertise, Engagement of various stakeholders and vital networking with health departments	Campaign developers should plan how to and involve multiple relevant stakeholders in the campaign: Policymakers; Trainers; Representatives of media; Other relevant groups.
6. Staff motivation	Loyalty to the message	Motivated staff and engaged stakeholders contribute to the campaign's sustainability and success.
7. Communication channels	Proper communication channels to spread the message	Communication channels would help to achieve the target group at maximum.
8. Resource management	Accessibility, sustainability and continuation	Resource management involves planned and proper management of human and financial resources; Prepared strategies/plans to collect additional funding; Wide outreach of services; Continuous monitoring and evaluation of the campaign to make it renewable and cost-effective.
9. Multisectoral collaboration	Contribution to broader strategies	Harmony in campaigns and national/ international goals is

	and policies	helpful and may be beneficial in terms of increasing the campaign’s visibility and influence, finding new funding opportunities, supporters and partners, etc.

Source: European Literacy Policy Network

Motivating and encouraging community participation in HIV/AIDS health-related activities has remained a challenge for health programs around the country of South Africa. High levels of awareness of the need and motivation among community care workers for providing HIV/AIDS campaigns are therefore required. The community still needs to be educated about HIV/AIDS as they have limited knowledge as witnessed by the high levels of discrimination and stigma on people with HIV and their families (Adinarayanan, *et al*.,2016). Health awareness campaigns at the community levels may be made possible through using various methods of health education such as short films, street plays and hand-outs.

2.4.4 Provision of psychosocial support

Care workers have a big responsibility to provide psychosocial support to their clients, and this support addresses the ongoing psychological and social problems of HIV infected individuals and their families (WHO, 2020). The care workers have an important role to play in the management of HIV patients. The well-being of care workers is crucial because the impairment of their physical or mental health could impact negatively on the management of their HIV-positive family member (Van Deventer & Wright, 2017).

The lives of patients with HIV are affected physically, psychologically, socially, and spiritually   Social support and counselling can assist them, and the care workers can cope more effectively with each stage of the infection and enhance the quality of life can be enhanced. With appropriate support, people living with HIV are more likely to be able to respond to the stress of being infected and are less likely to develop serious mental health problems

(Robert & Peter, 1997). It is the responsibility of care workers to offer psychosocial support services to HIV affected patients and their families. Psychologically HIV infection often results in stigma and fear for those living with the infection as well as those caring for them. Care workers visit these affected families to offer them ongoing counselling and encouraging the patients on the importance of treatment adherence.

The level of literacy amongst care workers is low, and literature reveals that the challenges in offering HIV services are related to the knowledge gap and lack of counselling skills (Rujumba, & Mbasaalaki-Mwaka, 2010). The need to train care workers in counselling skills has been identified, including matters such as disclosure, sexual abuse, sexuality and how to handle fears related to death. The other challenges faced by care workers are the failure to cope with the knowledge demand, difficulty in facilitating disclosure, a heavy workload and lack of other support services (UNAIDS, 2000). Maternal deaths caused by HIV result in care workers taking the role of caregivers for orphaned children or single-headed households., This role can adversely affect the care workers psychological health (Lentoor, 2017).

2.5 Conclusion

Literature indicates that several studies are conducted about HIV/AIDS, its impact on affected families as well as the economy at large. Results revealed that HIV/AIDS hurts affected families as it leaves them vulnerable psychologically and financially. Also, in terms of the economic status at the national level, it negatively impacts the production system of the country as resources are being channelled to health facilities.

The analysis of the literature shows how care workers play an essential role in communities when addressing the HIV/AIDS pandemic (Walsh et al., 2012). With limited studies conducted to examine the perceptions of care workers who provide services to HIV/AIDS. This study was interested in exploring the perceptions of care workers working for a community-based organisation providing HIV/AIDS services. Care workers not only do home visits to HIV affected/infected families when they are on-site, but they also offer referral services, psychosocial support, management and care, counselling, and many other services. The literature has shown that the care worker programme is associated with positive outcomes for HIV affected families, including increased access to social services. However, these results may come at a high personal cost to care workers, because in their work, they experience work-related stress, burnout, difficult working conditions amongst others (Thurman et al., 2018). The study, therefore, examined the perceptions of care workers through a case study approach from a community-based organisation in Soshanguve.

Chapter 3 Research Methodology

This chapter describes the researcher's data collection methods, the research strategy, research design, procedures and processes, as well as limitations.

3.1 Research strategy

The most appropriate research strategy to examine the perceptions of care workers was the qualitative research strategy. Babbie (2014, p.382) defines qualitative research strategy as "a non-numerical examination of findings to discover the meanings and relationships of the variables". Qualitative research is concerned with non-statistical methods and small samples and deals with people's perceptions, behaviour, emotions and feelings. It often attempts to understand the meaning of perceptions of persons with problems by explaining social phenomena from the perspective of participants (Bryman, 2012, p. 36). This study adopted qualitative research since it was concerned with individual perceptions and opinions rather than statistics. The research strategy chosen in this thesis applied to a small sample and gathered an in-depth understanding of care workers perceptions.

3.2 Research design

The researcher used a phenomenological research design in this study because it helped to identify some shared phenomena and experiences of care workers as they offer their services to HIV/AIDS families (Neuman, 2014, p.42; Wanger, Kawulich, & Garner, 2012). Phenomenology allowed for an in-depth analysis of information from a single group of Thola-Ulwazi Care workers in Soshanguve (Neuman, 2014, p.42). The design begins with the experience of a single care worker then moves to a group to understand their shared perceptions at work (Wanger et al., 2012). The design helped to generate data that was detailed, varied and sufficient to assess and understand the perceptions of care workers.

3.3 Research Procedure and Methods

The following sections outlined the procedures and methods that were used in this research to sample, collect data, process and analyse data collected from the target audience.

3.3.1 Data collection instruments

This study used a semi-structured interview guide when asking questions in a focus group discussion and Key Informant Interviews. A pre-formulated semi-structured interview schedule enabled the interview to flow naturally, and participants were encouraged to talk about their views and perceptions (Walsh et al., 2012). The researcher had the opportunity to probe for more answers during data collection when responses were ambiguous.

3.3.2 Target population and sampling of respondents

The target population is defined as a "specified large group of many units from which a researcher draws a sample and to which results from a sample are generalised" (Neuman, 2014, p.252). The researcher selected the sample from a target population of 50 care workers of Thola-Ulwazi CBO in Soshanguve. The sampling technique used was non-probability sampling using a purposive sampling approach. A total of 9 care workers (7 for a focus group and 2 for KII) took part in the study. The objective of a purposive sample was to produce results that can be assumed to be representative of the care workers of Thola-Ulwazi. From the total number of care workers at Thola-Ulwazi, the researcher purposively selected participants according to their availability. The researcher conducted the interviews during working hours. As such, not all care workers could contribute. Thola-Ulwazi had a limited number of male care workers. Only one male agreed to take part in the study.

3.3.3 Ethical considerations during the research process

It was the responsibility of the researcher to ensure the research is ethical and does not cause harm to respondents. Ethics are there to protect both the respondent and the researcher in the event of a misunderstanding. The researcher will safeguard the confidentiality of collected data, personallyidentifying information from consent forms were kept separate from the transcriptions. The researcher used only coded identifiers when transcribing the data. This may not ensure the privacy of respondents, but it may help with confidentiality. The files were password-protected, and the computer hosting such files had password protection to prevent access by unauthorised users.

The researcher read the information sheet form and informed consent signed by participants before the commencement of the discussion. The information sheet outlined the issue of confidentiality, privacy, voluntary participation, any risk if available, of taking part in the study, benefits, and reporting of findings.

The Wits School of Governance Human Research Ethics Committee (WSG HREC) issued an ethical clearance certificate before data collection began. Upon receiving the ethical certificate from WSG HREC, the researcher presented the document to Thola-Ulwazi, and verbal consent was given to interview the care workers.

3.3.4 Data collection process and storage

Data collection involved gathering data from sampled eligible participants (Bryman, 2012, p.12), the researcher used focus group discussion and key informant interviews to collect data with care workers from Thola-Ulwazi CBO. The group discussion answered why and how questions in a focus group and spelt out the relationship between care workers and the community in which they operate. The focus group discussion was useful to obtain detailed information about care workers group feelings, perceptions and opinions about their services offered to the HIV/AIDS affected community in Soshanguve. On the other hand, the key informant interviews with care workers enabled the researcher to gather additional information on questions which might have been difficult or omitted during the group discussion as they might have perceived them sensitive.

The researcher conducted a focus group discussion with care workers within the organisation of Thola-Ulwazi. The focus group had a maximum of 7 participants, and other 2 care workers were interviewed as key informants within the organisation. The rationale of including key informant interviews was used to support or oppose the findings from the focus group discussion and results were triangulated during the analysis phase. The researcher recorded the conversations. Recording the interview allowed the researcher to capture all the information shared by respondents, and after the interview, the recording was downloaded into a computer for transcribing.

3.3.5 Data processing and analysis

When data was captured or recorded, it was raw and difficult to analyse, so the researcher conducted data processing before the analysis began. Qualitative data involved transcribing the recordings from audio to text verbatim. The data gathered was transcribed word for word, and transcriptions were then translated from local languages to English as some of the respondents used vernacular in answering the questions. Empirical data from care workers were analysed using thematic analysis. Thematic analysis was more appropriate for the study because it gave a better understanding of care workers personnel knowledge, attitude and perceptions and understanding the sequences of events during the time they have been working in the organisation (Bryman, 2012, p.491). In this study, the researcher derived themes from the respondents' answers to questions about their perceptions of activities, roles and responsibilities, working conditions, training, support structures, challenges, experiences, opportunities amongst others. Concerning the phenomenological analysis, the identified themes shared phenomenon and the description of shared experiences of care workers'. Amongst other questions, what and how questions on experiences of care workers' duties were asked (Wanger et al., 2012).

3.4 Limitations

The researcher experienced several limitations during data collection and processing. The interview focused only on one group of care workers; this limited the findings to the respondents' perceptions, without having the view of beneficiaries and other care workers in different locations. The beneficiaries understand better the challenges that care workers experience when visiting them because care workers disclose to them problems regarding their work.

During the inception stage of data collection, the researcher made three appointments to meet with management to request permission to talk to the care workers. The director for the organisation was not available but instructed the management to allow the researcher to speak to the care workers. The care workers agreed to take part in the study after the researcher had addressed them.

Care workers availability was a challenge; the researcher met with respondents after working hours when they had returned from patients. This was a limitation because care workers were tired. Morning appointments with care workers were not possible because they were rushing to see their patients.

The time frame to complete the research was short for it to include more than one CBO to make a comparative analysis of HIV/AIDS provision organisations versus those who do not offer HIV/AIDS services. The research, therefore, focused on one CBO, and it was possible to complete within the available time frame.

Limitation in terms of generalisation of findings because the researcher conducted the study in Soshanguve, and the results may differ in other areas. Each site bears unique characteristics such that findings on care workers' perceptions from one place cannot be generalized or applied to other sites and care workers.

Chapter 4: Presentation of findings

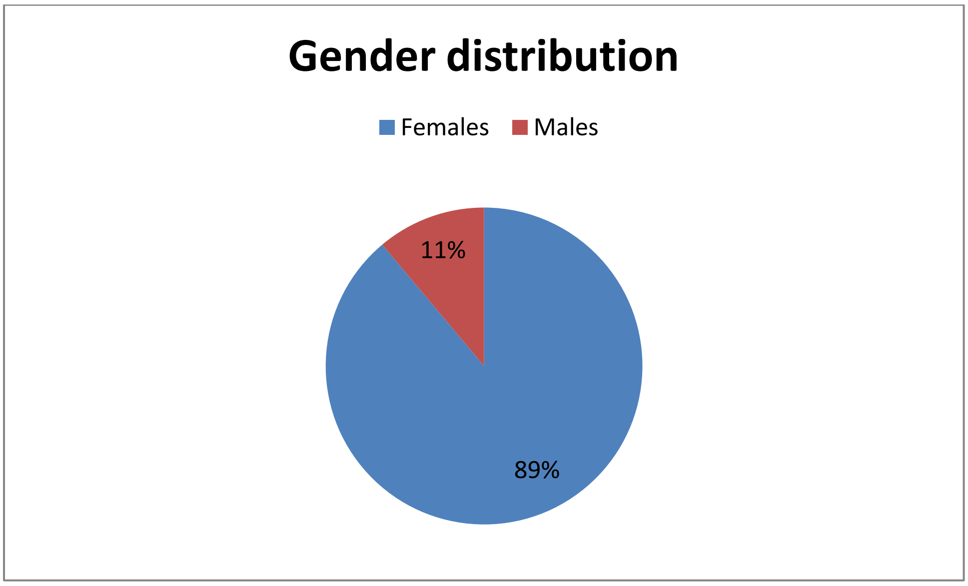
This study aimed to understand the perceptions of care workers who support vulnerable community members affected by HIV/AIDS. Based on the findings, the study identified some of the significant issues of concern. In this chapter, the researcher presents empirical findings as voices of participants by highlighting major issues which emerged from data. The demographic profile of the participants is presented first, followed by roles and responsibilities, working conditions, support structures, the outcome on work performance, effectiveness and challenges.

4.1 Demographics

Of the nine study participants, eight were female, and one was a male. During the discussions with care workers, each of them indicated that they have at least one child and stay with their families. During the information session of the study at Thola-Ulwazi with all the care workers, the researcher discovered that the majority of staff are females, with only two staff members being males.

Figure 2 below shows the diagrammatical distribution of the sample. The findings are well supported by the evidence gathered during the sensitisation study with all care workers at Thola-Ulwazi.

Figure 2: Gender distribution



Data shows that the age range of the participants was between 25 and 45 years old; this is a group that typically has families to support. The level of education amongst care workers is standard 8, which is equivalent to grade 10, and the respondents indicated that their employment contract is renewable every month.

4.2 Roles and responsibilities

Care workers in the community of Soshanguve provide many services to HIV/AIDS patients[1], and their roles and responsibilities include tracing of defaulters, treatment adherence and management support of patients.

4.2.1 Tracing defaulters

The care workers are given a list of HIV patients who have missed their appointments at the clinic as well as those who are no longer collecting their medication. Care workers indicate that they trace all the defaulters.

"We do track and trace the defaulters of HIV/AIDS that's what we do daily, and we receive the list from local clinics around Soshanguve" (CW_KII_Female).

Care workers are given a list of patients who have stopped collecting their medication at the clinics. Care workers reported that they are given a list of approximately 20 names to trace and track. Care workers manage to find the patients they are tracking. Data shows that care workers provide management support to patients and educate them about the importance of treatment adherence.

"Services that we provide include retention of defaulters, adherence treatment and management of HIV/AIDS patients" (CW_KII_Male: Supervisor).

---

[1] In this report, the researcher used the words client, beneficiary and patient interchangeably.

Care workers ensure that after their visit, the retention rate increases amongst HIV patients because of the adherence support management offered to their clients. Care workers reported that tracing and tracking done helps health facilities by bringing the patients back to the clinic to continue taking their medication.

4.2.2 Home visits

The care workers conduct door-to-door visits as part of their daily duties, and this involves walking from one patient to the next. The door-to-door campaigns have proven to be effective because the data indicates that patients open up to care, workers, when discussing reasons why they are no longer taking their medication or going to the clinic.

"In the community of Soshanguve, the things that we do is door to door. The home visit is done to locate the patients who have defaulted and who are no longer coming to collect medication as well as offer HIV/AIDS counselling" (CW_KII_Female).

The participants of the focus group discussion indicated that door-to-door activities are part of the roles and responsibilities to their clients. The duties of conducting home visits are paramount essential for care workers.

"We offer psychosocial support during home visits; we talk about social matters that affect their well-being as patients" (CW4_FGD_Female)

This strategy enables them to meet with patients at their homes. Care workers have enough time to discuss challenges experienced by HIV affected families as well as HIV positive patients. Care workers highlighted that HIV/AIDS patients have challenges with their social life. Home visits enable them to have a one-on-one session to understand their lifestyle better.

"As care workers, we visit patients in their homes on an individual basis since each person works alone. We clean the house of our patients if it is a duty" (CW_KII_Male: Supervisor)

Care workers reported doing laundry for their patients, especially when they are bedridden and are unable to do their chores. At patients' homes, care workers indicated that they help children with their homework and even play games.

4.2.3 Educational talks

As part of their home visits, the care workers also provide educational talks with their patients. The focus group highlighted that educational talks enable the patients to understand in-depth the dangers of defaulting or not taking medication as instructed at the clinic. These talks allow the patients to ask questions which are not answered at the clinics.

"We do track and [trace] defaulters. If we find them, we educate them about the dangers of defaulting and encourage them to continue with their medication. We find them daily. For example, today, we are from door-to-door visiting them." (CW2_FGD_Female)

Taking medication is the key topic that care workers educate their HIV positive patients. They ensure that the patients understand the dangers of discontinuing ART.

"We also educate our patients on financial management. This involves saving money and starting a home garden so that they can eat fresh vegetables" (CW_KII_Male: Supervisor)

The educational talks also cover issues on social and economic matters that affect the family. Care workers highlighted that most families face challenges on financial matters. Care workers, therefore, indicated that they train patients and their families on economic strengthening programmes.

"Education on condom use, risk of multiple partners, and prevention of TB are some of the topics we cover with our patients as well in the community around Soshanguve" (CW1_FGD_Female)

Study participants expressed their views that this process of talking to patients makes them feel valued and appreciate that there are people who still care about them regardless of their status.

4.2.4 Follow-up calls

Phoning the patients is part of the roles and responsibilities of care workers to remind them about the date for collection of their medication at the health facilities.

"As care workers, we have the responsibility to call our clients and check on them as well as reminding them about taking medication and their date for clinic visits" (CW5_FGD_Female)

Other than reminding the patients about clinic dates, care workers also check on the well-being of their clients and ask if they need any support.

"The money for airtime given to us by management to make follow up calls to our clients is only R50 per month" (CW_KII_Female)

"The money for airtime is not enough to call 32 beneficiaries per month. The office said we have to use the office phone, but we are not given the password, and we have to ask from the management every time we want to follow up with our patients" (CW_KII_Male: Supervisor)

Care workers indicated that this role of calling the patients is costly as they are only given R50 for airtime for the whole month. The care workers end up using their own money to do follow-ups as the money is not enough to call their target of 32 patients per month. The constant communication with the patients strengthens the relationship with them and allows care workers to know their patients better.

4.2.5 Accompanying patients to the clinic and hygiene practice

Care workers reported that many HIV patients do not frequently visit their local clinic for medication because of fear of being discriminated when people in the community see them collecting ART medication. The results in HIV affected patients not going to the clinic.

"Many of our patients stop going to the clinic because it's far or they do not like the way nurses treat them" (CW_KII_Female)

Care workers duties include taking the defaulters to a clinic and assisting them with transport. As their role, care workers responsibilities of taking the patients to the health facilities ensures that they are supported and have people who care about their health and well-being.

Care workers revealed that upon arriving at the household, they start by cleaning up the room to make sure that the environment is clean, especially when the client is bedridden. The quote below shows that care workers do have multiple roles in their line of work:

"I have to provide services to the patient; I start by cleaning up the room to make sure the environment is clean. When I get there I knock, and they will say come in, they already know it is the care worker, upon arriving in the house, there are dishes, you open windows, the patient hasn't bathed since morning, you have to make sure that the house is clean, patients eat before they take their medication, you provide services like cleaning for them, washing dishes, you make the bed and bath the patient." (CW_KII_Male: Supervisor)

Care workers practice hygiene. They informed the researcher that they value the lives of their patients. Care workers are trained to ensure that the surroundings of their patients are always clean. Hygiene is associated with a healthy lifestyle, and care workers lead the process by showing the patients that they always need to eat healthy food. Even when they go to the clinic to collect their medication, they should always eat and bath because sometimes the patients spend the whole day at the clinic.

4.2.6 Awareness campaigns

In Soshanguve, there is a limited number of campaigns done in the community to educate people about HIV/AIDS; therefore, the care workers at Thola-Ulwazi do campaigns in their community as part of their services.

"We do door-to-door awareness campaigns in the communities around Soshanguve" (CW6_FGD_Female)

Care workers do door-to-door awareness campaigns that involve visiting community members on an individual basis. During the visits, the community is educated about HIV/AIDS and the need to use protection.

"We educate the community about HIV/AIDS, and this enables people in the community to practice safe sex" (CW_KII_Male: Supervisor)

Care workers highlighted that the approach of door-to-door campaigns has proved to be effective because patients are free to express their health concerns.

Another form of the campaign done by care workers involves community campaigns at shopping centres. People in the shopping malls welcomed the approach and loved to be tested at the gazebo because there is privacy, and they do not stay for long waiting for the service.

"As care workers, we are tasked to do community campaigns at the taxi rank and shopping complex. We distribute condoms and test people for HIV" (CW_KII_Female)

Group campaigns involve mobilizing the community into one place and educating them about HIV/AIDS and condom use. During the group campaigns, gazebos are put in place to allow those willing to be tested to come through rather than going to the clinic.

"Our campaigns are meant to support those living with HIV and their families as well as the community at large. We educate people on dangers of drug abuse, and it's relation to unsafe sex." (CW_KII_Male: Supervisor)

Care workers campaigns also involve gender-based violence. Tribute is paid to those who have lost their lives to HIV and AIDS. Data revealed that care workers campaigns help to motivate, support and teach youth on sexual and reproductive health and rights and HIV, as well as to reduce the stigma and discrimination towards young key populations.

4.2.7 HIV testing and counselling

Counselling is offered by care workers to a person who voluntarily agrees to be tested. Consent forms are signed when he/she agrees.

"In my experience, I did HIV counselling and testing, I did ancillary and testing and counselling, but I did not do them here at Thola-Ulwazi, I went to school for those, and we offer these services to people." (CW_KII_Female)

People who voluntarily agree to be tested sometimes invite the care workers to come to their household to do the testing. Care workers reported that they visit these households with a test kit to conduct the testing.

"When you qualify to do testing as a care worker we can come to your house with a test kit." (CW_KII_Male: Supervisor)

Care workers reported that the Department of Health sometimes invites them when doing HIV testing in their communities. The professional nurses go with care workers to demonstrate and teach them how to conduct HIV tests. Within the organisation of Thola-Ulwazi, there is a specific department for HTS and care workers are invited to come along with them so that they can collect contact details of those who consent to be visited for further counselling. The care workers reported that after counselling, they encourage people to go to the clinics for further testing, which involves the drawing of blood to check the CD4 count and the Viral load. The patient is then informed that only the health facilities are authorized to give out Antiretroviral (ARV) drugs. As part of the counselling process, patients are informed about the side effects of taking the ARV for the first time. Care workers advise patients that ARV side effects fade away as they continue with the medication because the body will be adjusting to the treatment. They are hence advised not to stop but to continue as it is suitable for their health.

"We counsel and encourage them to go to the clinic because we don't give those pills, and we do not test them either., We only ask clients to go to the clinic so they can get help and treatment, so they can be healthy." (CW7_FGD_Female)

HIV testing and counselling at the community level occurs in the non-clinical set-up. Community HIV testing and counselling programmes are typically combined with teaching and outreach activities such as health fairs. Health facilities may partner with community-based organizations to provide testing resources, including test kits and professional nurse to accompany care workers.

HIV testing in community surroundings can help a large number of people who are under threat and who may be less likely to visit a clinic for a test. Care workers apply this approach of HIV testing and counselling by going directly to places where people live and work.

4.2.8 Administration services

The roles of care workers are not only limited to tracking, tracing, management support, or campaigns. All the activities that care workers do in the field have to be reported to management. This reporting involves completing the service forms upon arriving at the patient's home. Care workers indicated that they complete wellness screening forms when they do their home visits to patients. The form is submitted at the office, and it comprises of questions that will enable the care worker to determine if the patient has to visit the health facility or not. One of the care workers during the discussion mentioned some of the questions asked.

"On wellness screening, you ask a question like "do you cough at night"? If he/she says NO, then you tick, "Do you sweat at night?". If he/she says NO, then you tick. It is the one that shows that a person has TB or not, HIV or not. (CW7_FGD_Female)

Completing the service forms is part of the roles and responsibilities of care workers and enables the management to monitor their performance in the field. At the clinics care workers are given confirmation slip forms that are signed by the professional nurse to indicate that he/she performed his/her duties of tracing the patients allocated to them.

"The forms that we fill there are many and include the participant form, counselling form, wellness form, and confirmation slip form. There are a lot of forms that we complete and nurses have to sign them. Sometimes the nurses refuse to sign and stamp the forms." (CW_KII_Female)

It is important to document the results collected by care workers daily for submission to management. In summary, care workers indicated that the following statistics are submitted daily; the number of families served; the number of children accessing the services; the number of clients served; and the number of people taking medication amongst other statistics.

4.2.9 Psychosocial support services

Care workers scope of work involves offering psychosocial support services to their patients. Care workers reported that most of their patients suffer from depression. The role of the Care worker is, therefore, to provide counselling.

"Our patients are stressed, and some of them report that their relatives have abandoned them because of their status" (CW_KII_Male: Supervisor)

Care workers mentioned that when they visit their patients to offer psychosocial services, the patients feel relieved after sharing their problems. The one-on-one sessions with HIV patients have been fruitful as care workers highlighted that the behaviour of their clients' changes. Care workers reported that they receive calls from their patients, thanking them for the words of wisdom.

Another form of psychosocial support offered to patients by care workers is the support group. HIV patients are invited to come together and share their successes and challenges dealing with the pandemic.

"support group programmes have been added to our duties. A support group is when three or more HIV positive people come together with a view to supporting one another. They talk about their experiences on how they got HIV. If there is someone who struggles to disclose their status, the group assists him/her to open up." (CW_KII_Female)

In a group set-up, people are free to share their challenges, especially when everyone within the group shares the same characteristics and problems. Care workers reported that the support groups started by their organisation have made their patients realise that more people are HIV positive and have similar issues like them. This has resulted in people within the group sharing openly on how to fight the problems of disclosure, discrimination and stigma.

4.2.10 Referral process

Care workers act as advocates for their clients. As part of their responsibilities, they make referrals to different government departments; for example, patients without national documents are referred to the Department of Home Affairs and the Department of Social Development. If within the community, their patients have challenges with water or electricity, the care workers are responsible for reporting the matter to the auxiliary social workers who then forward the problem to respective institutions or municipality.

“If our client needs an ID, we do refer them to Home Affairs, and if they have a problem with a leaking tap or electricity, we report that to the relevant department. If an HIV/AIDS patient has a problem with running water in their yard, it will compromise their immune system. Stagnant water will form algae and algae is a bacteria which is not good for health as it will compromise the immune system of a person who is HIV positive. We deal with the social issues that affect the patients. A person living with HIV/AIDS is not only about taking medication, or nutrition but the environment surrounding them has to be clean” (CW_KII_Male: Supervisor)

Care workers reported that all matters that affect the social status and health life of their clients have to be reported because they are responsible for keeping their clients alive and in good health.

“We do not only focus on the referral of HIV patients, but we also report cases of abuse and advise our clients to report the cases to the police.” (CW_KII_Female)

Gender-based violence is common in the community of Soshanguve, and care workers reported that people approach them when walking around to report such cases. The care workers will then make referrals to the police as well as to social workers.

4.3 Working conditions

The researcher asked the respondents about their working conditions, and they reported that they felt unsafe while doing their job. Care workers said that the community in which they operate is not safe and most of the patients whom they visit are located in informal settlement sections around Soshanguve.

The crime rate is high in informal settlements. Female care workers are exposed to the dangers of rape and robbery. Care workers indicated that the high unemployment rate in informal settlements contributes to these areas not being safe for care workers and members of the community

Looking after HIV patients requires that a person takes precautionary measures and not have contact with the blood of the infected person. Care workers reported that in their line of duty, there is no provision for safety or protective clothing provided to them by the organisation.

"The organisation does not provide us with protective clothing that is suitable for working with HIV patients. We buy uniforms using our own money including masks and gloves" (CW1_FGD_Female)

Respondents in a focus group discussion indicated that they have to buy their gloves so that they can use when the patient needs to be bathed or for those who are bedridden. Literature also suggests that HIV positive people stand a high risk of being infected with TB when their immune system is weak. TB is an air-bone disease, and without protective mask or clothing, care workers face the risk of being infected.

"We don't have the mask, and we don't have gloves, we don't have anything. We visit patients without protective clothing. Sometimes we see someone who is very sick, and we have to touch, clean and bath them." (CW3_FGD_Female)

The care workers report that they walk long distances from one patient to the other when tracking defaulters. They walk from one section or block to another. For example, the distance from block BB Soshanguve to Mabopane is approximately 7.5kms. Figure 3 shows the distribution map of communities around Soshanguve and where the care workers operate.

Figure 3: Soshanguve Map

Source: Google maps

Care workers reported that they walk from Block KK to trace clients who are residing in Soshanguve south and back to Block T (see map above). The care workers also mentioned that HIV positive patients do not go to a nearby clinic close to where they stay because they fear that people will know that they are taking ARVs. Hence, they look for a clinic which is far and a place where they are not known. Care workers have to walk long distances when tracking defaulters.

"I walk from block DD coming from block XX fine I don't care about the area or saving because I chose to be here, then I come to block BB I have to go back halfway to block XX from block L walking and by 3 O'clock I have to be at the office, you expect me to see five people a day how do I do that?". (CW_KII_Male: Supervisor)

The time care workers spend walking affects their performance when they arrived at the patient because they will be tired—fatigue from walking results in care workers spending a short time with patients.

“You work from 9 am to 4 pm every day from Monday to Friday. The distance we walk during the week is too much and having the only weekend to rest is not enough as our feet will be still painful.” (CW3_FGD_Female)

Care workers reported that the targets given to them per day are too much, and this results in them not spending enough time with the patient and doing a sloppy job. When care workers were asked about their target per month, they indicated 32 patients.

“The number has been increased from November the management wants 16 clients on top of the 32 clients. These additional clients are for support group” (CW_KII_Female)

Care workers indicated that an additional number of clients compromises the time spent with patients. The management had not consulted with them for suggestions, and if it will not be feasible.

The critical observations around the care workers working conditions are not only linked to high targets and having to walk long distances. Participants reported that management does not support them morally nor appreciate the deliverables they provide by the end of the month. Data collected indicates that there is an element of disrespect perceived to be coming from management. The manner of communication used is reported to be unprofessional.

During their regular meetings, one of the participants reported that their contributions are not given attention and that communication is only one way. The feeling is that leadership is autocratic. She stated:

“Our superiors are disrespectful. They don’t appreciate us or the efforts we make to reach monthly targets. They are disrespectful” (CW7_FGD_Female)

When probed by the researcher to give scenarios about disrespect, one of the participants indicated that they are afraid to raise important issues that affect their performance in the field. As she said:

“They always threaten to fire us if we raise issues that affect us in our field of work” (CW4_FGD_Female)

The Care workers job is dominated by females. Some participants reported challenges around walking long distances whilst in their menstrual cycle. The care workers also noted that the number of maternity leave days is insufficient for those who give birth.

“They don’t put our needs first; for example, you can give birth today and be expected to come back to work after three days. You can’t even walk, and you must come back to work; it doesn’t make sense.” (CW2_FGD_Female)

The researcher reported that participants in a group discussion highlighted that management always reminds them that care workers can be replaced at any time if they do not perform and reach their targets

“We are treated like street maids, and it is like they are doing us a favour” (CW5_FGD_Female)

Weather conditions do not stop care workers to do their daily duties. Care workers reported that they are expected to conduct their assignments daily in the heat and the rain. One of the care workers reported that they walk long distances, often in hot, sunny conditions, and this affects their performance upon arriving at the client’s house.

Care workers work hand in hand with professional nurses, but participants complained that at health facilities, they are made to join the line when they come with patients, which results in patients complaining to care workers.

“Nurses are slow to attend to patients that we bring into the clinic. On top of that nurses are the ones that give us the list of defaulters to bring to the clinic, and now the nurse doesn’t even schedule the client or help fast enough so that the client doesn’t default again.” (CW_KII_Female)

The passion that care workers show in working for their community is adversely affected by the unpleasant working conditions that were reported during the study. Care workers are not happy with the treatment they receive from senior management and the lack of support from the Department of Labour as well as Social Development.

The communities in which care workers render their services are not safe to be walking alone as they are prone to sexual abuse and robbery. Care workers are also in danger of being infected by TB as they are not provided with protective clothing when in the field. Data showed that care workers walk long distances when tracing the defaulters because patients tend to choose a far-away clinic to collect medication as they fear to be discriminated against by people they know.

4.4 Support structures

Care workers work hard to achieve and meet their daily targets and face difficulties when dealing with HIV/AIDS patients, especially those who default and those who are being abused by their partners. Support structures have, therefore to be put in place to help care workers de-stress after long working hours. They also need to be given adequate training on how to deal with different scenarios concerning patients. We acknowledge that some of the care workers have enough training and experience when dealing with HIV/AIDS patients.

“I did training in adherence counselling, peer education, HTS, rapid testing and quality improvement initiative programmes, counselling and testing. Counselling and testing encompass everything about people’s lives. Immediately we start talking about counselling we want to touch base on the spirituality and psychology of the person. We have to be there for the

patients psychologically. Psychosocial support is provided to our patients. As care workers we only receive the basic training because we deal with people in the community; hence, we are told to have the basic to know-how to identify somebody who is not psychologically well" (CW_KII_Male: Supervisor)

On the other hand, data revealed that upon recruitment, care workers are not given adequate training but are instructed to go and work. They only receive basic training and do not go in-depth on how to deal with the challenges experienced in the field. Recently, the care workers of Thola-Ulwazi reported that there was a new programme introduced by its organisation called Support Group. Care workers felt that it was unprofessional to be told to go and form support groups without being trained on how to run the group. Care workers indicated that no training was offered to them on how to manage a support group programme. As one participant stated:

"I cannot explain what a Support Group is since I don't have any experience of what it is and have no training of it either" (CW_KII_Female)

When organisations recruit care workers, they assess their ability to write and read before being offered a job. The matriculants' results are not taken into consideration. Care workers have therefore reported that without adequate training on the job they do, they find it difficult to offer professional counselling to their patients, especially those that are stressed. Psychology training is important to care workers, as it helps them to manage patients who need psychosocial support because of the stress being caused by their status. One participant expressed her concern:

"We have not received any training on the job we do, especially psychological training on how to deal with stressed patients." (CW_All_FGD_Female)

During the group discussion with care workers, one of them reported that they only receive one-day training and after that, they are ready to visit patients. Care workers also mentioned that when new donors approach the CBOs, they are not consulted by the management on how they can help achieve the goals of the donor. Additional assignments with new targets are given to care workers without consultation. Care workers reported that no managerial support is given to them when they are in the field. Supervision by their superiors during fieldwork is not promoted amongst care workers as they reported that management uses an autocratic style of leadership. Care workers are told to go into the field and bring results. The Care workers reported that they need their managers also to join them in the field so that they can support them and see the challenges they experience when doing their daily activities.

Other than training and supervision support, the care workers who were interviewed highlighted that they need to be supported psychologically and emotionally because their work is stressful.

"This work is stressing, and the organisations do not value the work we do. They are only concerned with numbers/ targets. If we share with them the challenges we experience in the field, they do not address them." (CW4_FGD_Female)

The work done is demanding, and care workers reported that it affects them psychologically and that the stress from work affects their family happiness. They note that the workload is too much and the time to accomplish it is limited, resulting in experiences of burnout. Data revealed that care workers require support within their organisation and are allowed to see a psychologist. Care workers listen to the patients' problems and try to support them so that their patients can overcome the challenges. Every patient visited by care workers shares different problems about their life. The care workers take a significant burden themselves.

Organisations need to value the work that care workers do and appreciate the effort they make to help HIV affected families by putting their own lives at risk. The communities in which care workers conduct their daily home visits have high crime rates, and as females, they do not always feel safe walking alone.

"Some of the communities we work in are not safe, and we work long hours without being allowed to take sick leave. When we miss working for two days, we will find that someone has replaced us." (CW5_FGD_Female)

Care workers reported that the government does not support them, particularly the Departments of Health and Social Development.

"This is a coordinated programme via the Department of Health and the Department of Social Development. These departments are failing us as care workers. Thola-Ulwazi has not come up with a programme. The programmes originate from the DoH who then appoint the organisations like Thola-Ulwazi" (CW_KII_Male: Supervisor)

Community-based organisations are non-profit organisations, and their funding depends on donors. Therefore, as reported by the care workers during the group discussions, it is the responsibility of government departments to support the care workers and to ensure that there is job security. As the prime donors for CBOs, care workers need to be protected and be recognized by labour laws in the country.

As one participant pointed out:

"For me to do this work today at this age, it takes dedication, the passion you can't just wake up in the morning and say I'm going to run around the storms, rain and sun you understand it takes passion, it takes dedication, but the managers are failing us, our institutions are failing us, the organisations are failing us, you understand they don't see our worth we are only needed when it's time for statistics you understand, the numbers that's what they care about but not your wellbeing." (CW_KII_Male: Supervisor)

Care workers often pointed out that it is the passion that drives them to work in the community so that they can help families affected by the HIV/AIDS pandemic to live a healthier lifestyle. Bad weather conditions do not prohibit them from conducting their daily duties, and they ensure that if they are given the list of beneficiaries to track, they go all out to find those patients and educate them about the importance of taking medication. As indicated during the discussion, institutions such as the Department of Labour, DoH, DSD amongst others do recognize the positive impact done by care workers in reducing the spread of HIV/AIDS in their communities. These institutions are failing to support them in terms of job security, safety, psychological support, and adequate training. They have also failed to assist them in negotiating better salaries.

4.5 Outcome of work performance

The time spent by care workers on the road walking from door-to-door affects their performance. Care workers indicated that upon arriving at the patient's house, they do a sloppy job because of fatigue. The other reason that results in care workers not applying enough commitment to their work is the targets that organisations give, which are sometimes not reachable.

"I leave the office at 9 am, and the first person I see will be at block L where I will arrive at around 11 am; the second person will be seen after an hour or so. Due to high targets given to us and the time spent on the road walking, we arrive at the tired [which] results in us doing a sloppy job. When we arrive at the, we do touch-ups here and there and not offer good services." (CW_KII_Male: Supervisor)

The responsibility of care workers is to listen to patients upon arriving at their homes. Care workers reported that they have to offer their time to patients irrespective of taking them to the clinic. The challenge faced by care workers is that they have to rush the service so that they visit another patient. The short time spent at patients' homes results in care workers offering poor service delivery.

On the other hand, care workers reported that for them to reach their targets, they end up spending their money on public transport so they can spend less time walking but more time with the patients. Care workers indicated that when the patients do not have money for transport to go to the clinic, care workers use their own money to pay for their transportation. For example, this participant explains:

"I use my transport money if a client doesn't have money, I have to pay for him/her because we have a target and I have to increase my numbers by paying for the client to go the clinic. (CW_KII_Female)

The targets for care workers are not fixed; they change with every donor funding the organisation. Care workers reported that currently, their organisation had set the target to 5 patients per day. Care workers reported that even if they mention to their superiors that the target is high and it compromises their quality of work, they are not listened to:

"They are interested in reaching the target, and our target is 5 patients per day" (CW5_FGD_Female)

The outcome performance of care workers is adversely affected by the time they spend walking in the field tracking the patients. Spending more time walking has negatively affected the quality of services offered to the clients in their community. Care workers also highlighted that organisations are only interested in numbers but not quality services. The targets affect their performance upon arriving at their clients as they do not spend enough time to listen to the challenges or problems that affect clients and the reasons for stopping their medication.

4.6 Challenges

Several challenges have been raised by care workers when performing their duties. Amongst others, care workers highlighted the issue of safety when they visit HIV affected families as well as the patients and walking long distances contributes to the negative outcome of their services to their clients. Safety in terms of their health is compromised when they offer services to bedridden patients.

Lack of recognition is the other challenges that care workers experience in the community as well by the government:

"Main challenges of being a care worker include not being recognized, and the value that one adds in the community not being appreciated because being a volunteer or a care worker in the community for is about saving lives. Unfortunately, this worth is not valued." (CW_KII_Male: Supervisor)

There is still an element of discrimination and stigma; hence, some of the patients we meet do not want to disclose their status. This discrimination is a challenge as it hinders the ability to reach everyone in the community. After campaigns, people are tested, and those who test positive find it difficult to accept the result and refuse to go to the clinic to start treatment because they are afraid of the side effects of the ART. As one participant indicates:

"Side effects of pills are the ones that make people not to go to the clinic because they are scared that they will have a rash., That makes them reluctant to go to the clinic." (CW3_FGD_Female)

When other service providers approach our organisation, there is no communication with the care workers to find out how they can be assisted in achieving their objectives. Care workers reported that they are given additional work without consultation. Evidence from participants indicates that extra work is given to care workers without other incentives:

"For example, Wits will give care workers a certain amount, but just because they are on a payroll already, they will not know about the funding from Wits. They will not know about the extra money for additional work. The organisation will tell them to multi-task, and they will receive nothing for

additional work. They will only receive the stipend for what they have been appointed to do, that is being a care worker." (CW_KII_Male: Supervisor)

Transportation of HIV patients is a challenge, and care workers reported that the money given to them is not enough to pay for their clients. For example, the health facilities provide them with a list of defaulters to track and trace as well as bring them to the clinic for medication, but they are not given money to pay for their transport. Data collected revealed that care workers are only given R150 for the whole month to pay for patients transport, and they are expected to track and trace 36 defaulters. The money they receive is not sustainable for the target number of patients per month, but because of the passion they have for their work, they end up paying for their clients using their own money.

As participants report:

"Sometimes when we visit the client, and he/she doesn't have the money, we have to pay for their transport fee" (CW2_FGD_Female). "[The money] is for my transport even though it's mine but if a client doesn't have money I have to pay for him/her because we have a target so I have to increase my stats so I will pay for the client as well" (CW_KII_Female)

The transport money for care workers is not enough to transport 25 clients per week. Care workers reported that they have to accompany their clients to the clinic because if they give them money, some of them use the money for other things and do not go to the clinic. The care workers, therefore, have to pay for the transport of the patients with the same money given by the organisation.

Care workers acknowledged that they are in this industry because of their passion in helping the HIV positive patients to live a longer life, but they end up being de-motivated due to little stipend they receive at the end of the month. As volunteers, they propose to be recognized and paid enough stipends to keep them motivated and be able to support their families. The stipends paid to care workers are not yet regulated and largely depend on the funders as reported during the group discussion.

"Our stipend depends on funders within our organization. Some care workers are given R2000 and others R3500 depending on their programme. For example, those working on CAB are given R2000 per month while those working with HIV/AIDS clients we are given R3500" (CW5_FGD_Female)

Job security is a challenge amongst care workers as their contracts are short term and renewed every month. Care workers reported that they are always afraid that their contracts will not be renewed at the end of every month.

"Our stipend is R3 500, and our contract is a short term" (CW1_FGD_Female)

The male care worker revealed that the salaries paid to them are not adequate to support the family or meet their needs. He also indicated that males are not consulted in decision making, and their contributions during the meetings are not considered by management.

"For our organisation, I wish that our contracts would be renewed because there are a lot of people who need jobs. Although we are getting tired, there's nothing we can do because there is no one who can come and give us R3 500. We are supposed to work for it." (CW_KII_Female)

Burn out affects care workers performance both at work and at home. Care workers become anti-social when they knock off because they will be tired and stressed from listening to patients' problems and challenges. Participants indicated that when they get home, they do not have time to spend with their families.

"So in terms of burn out, it doesn't work in this field, you cannot complain and say you are tired., We push ourselves beyond our abilities, beyond our

reserved energy for our families at home after knocking off from work." (CW_KII_Male: Supervisor)

"We walk for long distances from the office to our clients. Another exhausting thing is these forms we complete daily." (CW_KII_Female)

The challenges highlighted by care workers during data collection adversely affect their work performance. Care workers reported that they would appreciate if their organisation as well as other funders revise their working conditions and listen to their challenges experienced when working with HIV/AIDS patients in their community.

Burnout affects care workers psychosocially; they reported that their leave days are not enough for resting. The daily rate is used to calculate salaries, and missing a day at work means reduced stipend. Care workers reported that the workload makes them go the extra mile to reach targets. When care workers are sick, they are afraid of missing a day at work because of the fear of replacement.

4.7 Conclusion

Data demonstrated that care workers are responsible for tracking and tracing patients who default on their medication. Community-based organisations like Thola-Ulwazi work with clinics around the community of Soshanguve and the care workers are given the list of defaulters to track. Upon finding the patients, care workers provide counselling services to patients and educate them about the importance of continuing with taking medication. Care workers reported recruiting new patients who are HIV positive using a process called indexing. The indexing method is used when an HIV positive person links the care workers with their recent partners. It will then be the responsibility of the care worker to follow up and convince the other person to get tested.

Care workers revealed that they provide adherence and management support services to HIV/AIDS patients in their community. They support the patients and motivate them to continue taking their medication. They give them health talks about eating nutritious foods so that their immune system is not compromised.

Data also indicated that care workers take the lead on awareness campaigns in educating the community about HIV/AIDS as well as staying negative by practicing safe sex. During the campaigns, they also advise those that are positive to always to use a condom when having sex to prevent re-infection.

The communities in which care workers work are not safe, and a high number of people use drugs. Crime and drug abuse compromised the work of care workers because they cannot go alone, but they have to go in pairs. Data shows that care workers walk long distances when conducting door-to-door tracking and tracing defaulters. The time spent walking results in care workers not being more useful when they find a patient because they will be tired and also thinking about their set daily targets. Care workers reported that they are given a target of 5 patients per day, and they have to report the numbers at the clinics and to their management. The targets given to care workers are too high, and participants highlighted that for them to meet the target, it compromises the quality of services provided to patients.

Care workers are given training, but data revealed that the practice is not enough because sometimes they find it challenging to offer to counsel the patients. Their training is only for one day, and they feel that sometimes they are not ready to go into the field and support or recruit people, especially when people are afraid of stigma and discrimination. The outcomes or quality of services provided to patients is affected.

Lack of recognition by the organisation and undermining the services they offer in the communities is a challenge to care workers. The organisations do not respect them and make them work long hours without giving them incentives. Care workers highlighted that the salaries they receive at the end of the month are not enough to support their families.

Care workers highlighted burnout as it affects their work performance. Care workers reported that the organisation gives them too much work to report daily. The targets are too high and force them to work hard and not take lunch or break to gain energy for the next visits. Care workers reported that tracking and tracing, walking long distances, high targets, support group programmes, amongst other roles and responsibilities, make them feel tired and burnt-out with the work they do.

.

Chapter 5 Analysis of findings

In this chapter, a critical analysis of findings is presented based on the researcher's understanding and knowledge on the perceptions of care workers who provide HIV/AIDS services. The researcher did triangulation of research findings with the literature review under the following subheadings, roles and responsibilities, working conditions, support structure, the outcome on the work and challenges.

5.1 Community care workers

Literature has revealed that care workers play a pivotal role in the community by visiting HIV patients (Thurman et al., 2013). The scope of work for care workers includes home visits, adherence support, HIV testing and counselling, referral process, and support group management amongst others. The literature and data collected revealed that the scope of work for care workers had not changed much ever since the HIV pandemic started and the formation of care workers to look after the HIV affected families.

When the HIV outbreak began in the early 1980s, it had already spread to five continents, that was, North America, South America, Europe, Africa and Australia. In that period, between 100,000 and 300,000 people had already been infected (Avert, 2016). As a result, the workload for professional nurses and doctors increased and as literature indicated that professionals were stationed at a fixed place/structure (Meehan et al., 2014). People in communities realised that a lot of people were dying because of lack of attention from professional nurses. Due to this realization, they decided to form voluntary organisations and train community members to become care workers to do the job that was not done by nurses of visiting HIV infected patients in their homes. As indicated by the literature, the care workers job was to provide palliative care to HIV patients and data collected shows that even now care workers are providing care to HIV patients through home visits.

The literature revealed that there is a gap in terms of services offered by health facilities to HIV patients after they have collected their medication

(Masquillier, 2016). Data collected indicated that the presence of care workers in the communities is to bridge the gap of close monitoring the patients and ensure that they are taking their treatment and eating healthy food. As a researcher and with the experience gathered during data collection with care workers, I have realised that care workers are making a difference in the community they operate by ensuring that HIV patients and the community are educated about medication adherence. Care workers bring the community together and do awareness campaigns about discrimination and the stigma of HIV affected families. Other than educating the community, the workload of care workers is always increasing because donors target community-based organisations to implement HIV programmes. Care workers are overwhelmed with work, and they reported that sometimes the targets given to them are unreasonable and difficult to reach.

Care workers directly work with the community and HIV affected families; they, therefore, understand better the culture and social aspect of people living around the area. Data collected revealed that when donors approach the CBOs, no consultation is done with care workers to ask about the challenges they experience in the field. Care workers reported that management does not involve them during such meetings, and they are told about the additional work for them. Care workers receive additional workload without having an increase in their stipends. International and local donors bring their policies that are not compatible with South African beliefs; hence, care workers reported that their work performance is adversely affected.

Care workers services are still needed in the communities as they take the responsibility of looking after families affected by HIV. Literature shows that children left behind by parents who died because of HIV are vulnerable to abuse, so care workers support and look after these orphans by the provision of regular home visits.

5.2. Analysis of care workers scope of work

The scope of work for care workers has shifted from offering palliative care to HIV infected patients to tracking and tracing, psychosocial support services, HIV testing services, awareness campaigns, adherence support, amongst other roles and responsibilities. This subsection will critically analyse the scope of work for care workers with literature.

5.2.1. Roles and responsibilities

Community care workers are well known in South Africa, and most people can easily identify them with their navy blue uniforms when walking around the community. People in the community associate them with HIV/AIDS because they started being more influential when HIV/AIDS was at its peak, taking people’s lives and leaving the community and families devastated and children orphaned. Hence, the roles and responsibilities of care workers are to conduct home visits to affected or infected families. In South Africa, care workers working with HIV affected or infected families have the mandate to conduct regular home visits to orphans and vulnerable families to provide psychosocial support as well as give out food parcels (O`Grady et al., 2008).

5.2.1.1. Home visits

Literature indicated that the care workers role in conducting home visits that were applied during the beginning stages of HIV pledge is still being used to help the affected patients (Brophy, 2016). Care workers reported that they do home visits to all patients that they receive from the clinic. During the home visits, care workers reported that they look after the patients and ensure that they attend to all the problems they experience regarding their health. Care workers are still offering palliative care. Respondents reported that upon arriving at the patient’s home, they clean the house, do laundry, cook for them and ensure that they have eaten before giving them their medication.

The role of home visits is fruitful because the care workers do regular monitoring and establish a good relationship with their patients. The quality of services offered by care workers has improved since the 1980s as most trainings are done by the donors of different programmes on how to deal with

HIV positive patients. Regular home visits have to continue in our communities, as this helps to fight discrimination and stigma from members of the community and family members. As for HIV positive patients, the home visits encourage them to take their medication and makes them feel cared for by other people. This approach of home visits done by care workers has a positive impact on HIV infected patients as it supports the patients to live a better and healthier lifestyle. The government and international donors have to continue supporting and funding this approach of home visits by care workers so that new infections can be reduced and the levels of discrimination and stigma are decreased.

5.2.1.2 Tracking and tracing

The services of home visits continue today, even though HIV/AIDS is now manageable. Care workers reported that they now focus more on tracking and tracing defaulters. Tracking and tracing is the responsibility of care workers to conduct door-to-door and look for patients who have stopped coming to the health facilities to collect their medication. Health facilities do not follow up with their HIV patients to see if they are taking their medication; therefore, care workers have been given extra work to trace these patients. Care workers reported that their CBO work is with local clinics, and they receive the list form the health facilities.

Tracking of defaulters involves walking long distances, and care workers are given a scattered list of addresses, and this entails them spending more time on the road than educating the community about HIV/AIDS. This process of tracking defaulters was not available when HIV started to kill people as has been indicated by our literature. Also, people were not aware that the viral load could be suppressed by taking medication. Care workers who participated during the group discussion reported that the number of defaulters is relatively high.

The local clinics do not follow up with defaulters of HIV medication; care workers are given the list to conduct door-to-door visits. Research reveals that upon arriving at the patient’s house, care workers ask them why they have stopped going to the clinic and taking their medication. The response they receive from patients was that the poor services offered at the clinics discouraged them from going back. Others respond that they are now taking traditional medicine. Care workers reported that they educate the patients on the importance of taking their medication.

Tracking and tracing have helped reduce the number of defaulters and care workers are doing a great job searching for patients who have stopped taking their medication. From the researcher's point of view, I believe that care workers need to be provided with enough resources when tracking the patients, for example, money for transport to respective households or transportation in the form of bicycles.

5.2.1.3. HIV testing services

As has been indicated by literature, care workers responsibility was to provide home visits and offer palliative care (Walsh et al., 2012). It was the responsibility of health facilities to conduct HIV testing, but due to the workload at the clinics, the government introduced nonmedical sites to offer HTS in the communities (Schneider et al., 2008). The nonmedical areas include community-based organisations that recruit care workers to provide campaigns with HTS using gazebos.

The care workers adopted the approach that is applied to the clinics by offering pre-test and post-test counselling. Care workers offer to counsel individuals on the importance of knowing their status and how to deal with the viral load. The process of counselling helps to prepare patients not to think that they are dying but to encourage them to know that there is still a healthy life after infection.

The findings from other studies indicate that males usually do not like going to clinics and have their status checked (Meehan et al., 2014). The introduction of mobile clinics and gazebos that are operated by care workers in their communities has thereby increased the uptake of people reaching out for testing. As reported by care workers interviewed during the data collection, the community males and youth come to their gazebo for testing and ask for condoms.

Literature shows that there are three main types of HIV tests: CD4 tests, viral load tests, and a combination test that detects both antibodies and a viral protein called p24 (antibody-antigen test, or HIV Ab-Ag test) (Gonzalez, 2020). The tests mentioned above are not done by care workers, at the community level, care workers only do a needle prick method of testing. After testing with the care workers, if the results are positive, then the person is referred to the clinic or hospital for further advanced testing and treatment.

5.2.1.4 Awareness campaigns

Campaigns in the communities are another responsibility for care workers. In the community of Soshanguve, we see gazebos at business centres with care workers conducting HIV awareness campaigns. Individuals are allowed to get free counselling and testing at the gazebos. The care workers also do home visit testing upon request by the community and when they are doing door-to-door campaigns. In Soshanguve, Thola-Ulwazi care workers are being overwhelmed with work because of the limited number of care workers working around the community. Data shows that care workers have to walk long distances to cover Soshanguve so they can offer their services to everyone, and this strains the care workers as well as negatively affecting their performance.

Campaigns at the busy community centres have proved to be most effective for care workers because they give full attention to community members, and data from the research revealed that there is less fatigue as they will be stationed in one place.

The awareness campaigns offered by community care workers are different from the ones done by the national Department of Health. Literature shows that the Department of Health usually does its awareness campaigns on national television and radios with less contact with community members directly. On the other hand, care workers reported that they spend time talking to people in the community face-to-face and responding to their questions when doing awareness campaigns. The respondents who participated in the group discussions requested the government to provide them with educational resources. Care workers will use the resources when doing HIV campaigns and this makes their job to be effective and enables them to help the community as they spend more time with them. Data collected shows that care workers have limited knowledge on educating the community about adherence to medication and encouraging them to take ART and not default.

5.2.1.5 Referral process

There is evidence to suggest that care workers promptly offer referral support to HIV affected families when they identify potential threats (Thurman et al., 2013). Care workers do referral to Home Affairs, Social Development, and local municipalities, amongst others to their HIV patients. Data shows that care workers act as advocates for community members, especially on matters that compromise the health and nutrition of their beneficiaries.

Care workers do not only stop at referrals. Still, they do follow-ups with respective organisations in which they have referred their clients and also made phone calls or visited the client to get the feedback regarding the services offered. The referral process offered by community care workers is more effective, and the community feels valued and cared for by these folk. Literature shows that when health departments do their referral process from clinic to hospital level, no follow up is done by the respective person but they only wait for the patient to come back and give them the feedback (Give et al., 2019).

Care workers go an extra mile walking in the communities conducting door-to-door services and tracking the defaulters. Upon arriving at the household, the care workers educate the patients on the importance of taking their medication. When the patient is bedridden, the care workers help with cleaning the house, bathing the patient, cooking and ensuring that by the time they leave the house, their client is happy with the services offered.

5.2.1.6 Psychosocial support

South Africa is home to an estimated 5.7 million people living with HIV, more than any other country in the world. At least 4 million South African children are HIV positive, have a positive parent, or have lost a parent to HIV and AIDS. These HIV patients are at disproportionate risk for illness, food insecurity, psychological distress, stigmatization, abuse and neglect (Thurman, Yu, & Taylor, 2009). The care workers have the responsibility to assist with psychosocial support to children and families affected by the HIV pandemic. Pre-service and in-service training in psychosocial support is crucial for nurses and other health care personnel. Care provided by care workers can be bolstered with the training of volunteers and others to assist HIV infected individuals and their families in the neighbourhood setting (WHO, 2020).

Evidence from data collected indicates that care workers offer psychosocial support to their beneficiaries and family members. HIV patients usually suffer from depression and psychological distress, thinking that they are going to die. Patients are discriminated against when people around them know that they are HIV positive. Care workers, therefore, visit them and their families to offer to counsel. Data indicated that the level of counselling offered by care workers is not the best because of limited training on psychosocial support. Care workers only touch the basics of counselling and encourage the beneficiaries to take their treatment regularly.

To improve on the psychosocial support offered to HIV patients and their families, care workers from Thola-Ulwazi has started support group programmes. These programmes are the additional responsibility for care workers with the mandate to support HIV affected people to disclose their status as well as fight discrimination. Care workers facilitate support groups. They meet regularly with their patients and conduct discussions amongst themselves on how each person has managed to disclose his/her status and to stay healthy all the time. Research shows that these groups help to support others and motivate them to take their medication.

Care workers expressed that while great strides have been made in raising access to HIV medicinal treatment and care in the community, there has been a deficiency in acknowledging and supporting the care workers' well-being. Care workers reported that collective efforts are required to tackle the individuals, particularly their psychosocial needs holistically.

Evidence from this study indicates that the scope of work for care workers who provide HIV/AIDS services includes tracking and tracing, adherence support, referrals and support groups programmes have managed the patients' health and their wellbeing psychologically. Care workers reported that tracking and tracing, adherence support and HIV testing activities offered to HIV patients and community members are supporting and contributing to the achievement of UNAIDS 90-90-90 target[2] as well as the South African National Development Plan. These foot soldiers (care workers) are visiting the communities and educating people to get tested, take their medication and eat healthy so that they can suppress their viral load and increase the CD4 count.

5.3 Working conditions

5.3.1 Care workers safety in the field

The high number of HIV defaulters means more care workers are needed to track and trace, and this entails being sent into strangers' homes, leaving them vulnerable and unprotected. Although sometimes the patients themselves pose a risk, the dangers for care workers come in many forms: dangerous neighbourhoods and high-strung friends and family of the ailing patient. The hazards that care workers face are numerous, and they stem from the same source, that is, the community (HomeCare, 2018).

In Soshanguve specifically, the community in which care workers operate is not safe, and most of the patients they visit are located in informal settlement sections around Soshanguve. High poverty areas are around the informal settlement, and this correlates to high rates of HIV infection due to practicing

---

[2] 90-90-90 target: diagnose 90% of all HIV-positive persons, provide antiretroviral treatment(ARV) for 90% of those diagnosed, and achieve viral suppression for 90%

unsafe sex because most people staying in these communities spend their time drinking alcohol and taking drugs (Tsodzo, 2007). Care workers lives are compromised, and they end up not visiting other communities or performing their duties effectively. For example, in the Wintervelt community of Soshanguve, there is a high rate of crime and care workers do not go in those areas to track and trace defaulters. It is not safe to conduct door-to-door campaigns in such communities because they are mandated to visit patients on an individual basis.

The report on the International Association for Healthcare Security and Safety (IAHSS) survey indicates that 61% of community care workers have experienced some form of workplace violence (Hanson, Perrin, Moss, & Laharnar, 2015). Workplace violence is one of the major catalysts of the industry's mounting crisis. While the need for home care workers is proliferating, the supply of care workers is dwindling. In South Africa, the records of violence amongst care workers are not documented; hence, we lack the records. During data collection amongst care workers, they reported that there are no unions or associations registered for care workers to report their grievances and challenges at the workplace.

5.3.2 Care workers health and safety

Care workers face a wide range of hazards on the job, including sharp injuries, harmful exposures to chemicals and hazardous drugs, back injuries, latex allergy, violence, and stress (CDC, 2019). Although it is possible to prevent or reduce care worker exposure to these hazards, care workers continue to experience injuries and illnesses in the workplace. Evidence from the data collected during the study indicates that health issues affect care workers working conditions. Care workers complained that they are not provided with enough equipment to protect themselves when working with ailing patients who are bedridden. Data shows that they need gloves and masks to protect themselves when nursing a patient so that they can minimize the risk of being contaminated with infectious diseases. As a researcher, I observed that some of the care workers spoken to during data collection were wearing torn uniforms. A torn uniform portrays a gloomy picture either to the government or organisation and adversely affects care workers performance as well as trust by patients. People in the community look at one's appearance and dressing for them to pay attention to what you are educating them about fully. For care workers to be effective, they need to be presentable and be provided with necessary outfits and equipment.

Leave days for care workers is a challenge; data collected revealed that after giving birth, care workers are only given three days to recover and come back to work. The few numbers of leave days compromise the health of care workers because three days is not enough for someone who is coming from labour to be at work. Care workers spend most of their time walking in the field to trace patients. More data collected shows that when care workers miss a day of work, they are supposed to come with a doctor's letter, and this is a challenge because some of the illnesses do not need a visit to the doctor.

5.3.3 Care workers work targets

Care workers reported being given high targets which are a challenge to achieve daily. The care workers indicated a target of 32 patients per month has to be tracked. High targets have resulted in care workers not offering best services to HIV defaulting patients because they will be chasing after the target. Other than high targets set for them, care workers reported walking long distances and tracing defaulters under harsh weather conditions. Literature supports this; care workers are affected by high levels of burnout as well as attrition rates because of overstretching themselves to achieve their targets (Leiter et al., 2014).

The industry of community care workers is dominated by women, and females represent nearly 80% of the healthcare workforce (CDC, 2019). The high number of female care workers is supported by data collected, revealing that 88% of respondents interviewed were females, and only 11% were males. The treatment care workers receive from this sector is not appreciated by females; for example, as shown in the findings, they are not given enough maternity leave days. When they are not feeling well, they are forced to come to work and failure to be present results to dismissal. The institutions/organisations are more interested in targets more than the health and welfare of their employees. Care workers need respect and recognition in this industry. Care workers require unions to represent their rights and working conditions. Data collected showed that management always threatens to fire them when they become vocal because they are easily replaceable. The reason why they are easily replaceable is that when recruiting care workers, organisations do not look at their qualifications but their ability to read and write as well as their ability to walk from one point to the other.

5.4 Support structures

Findings from the study revealed that care workers are reporting insufficient support in their work. The work of looking after a sick patient is stressing and requires the care workers to undergo regular debriefing sessions to distress and download other people's problems. Care of carers is a support structure that is not available amongst care workers. Care of carers is when care workers are given an opportunity of talking to a professional psychologist and share their challenges and problems. Care of carers programme allows care workers to download any matters that affect them at work. If care workers undergo such a programme, they will feel relieved and motivated to continue with their duties. It will also make them feel recognized in this industry.

A one-day training session of care workers is not enough for them to start working with ailing patients. Data revealed that sometimes care workers feel as if they are not ready to start visiting patients because of inadequate knowledge about the work. They cannot support HIV affected families psychologically or emotionally or even make the person open up to them on the reason of defaulting because they will be strangers to them on their first visit. Table 2 below outlines the criteria proposed by the WHO for the training of community care workers for them to be more effective in their work.

Table 2: Criteria for successful Care worker programmes

Basic essential conditions	**Description**
Selection and motivation	Care workers need to understand the community in which they work and be trusted. Formal education is less important than motivation to work in the community
Initial training	Training content and length should be based on existing knowledge and experience should be participatory and should focus on practical skills and problem-solving Communication and counselling should be emphasized
Simple guidelines and standardized protocols	Materials should ensure care workers cover all areas in which they have been trained Manuals prevent care workers' feeling overwhelmed by multiple tasks Can be used as a basis for supportive supervision
Supervision and support	Regular mentoring and refresher training maintain motivation Structured and constructive supervision maintains programme quality
Adequate remuneration/career structure	Remuneration in some form is crucial for care workers to feel valued Compensation increases care workers commitment and reduce drop-out
Required for scale-up Political support Alignment with health system strengthening	The formal role of care workers' needs to be defined over time and regulated within the broader health system Functioning health systems are required for care workers to function effectively Care workers should make referrals to the comprehensive constellation of services
Flexibility and dynamism	Programmes should evolve and adapt as social and health conditions change
Specific to ART support Using the experience of people living with HIV Focus on chronic care, retention and adherence	Care workers living with HIV offer hope and inspiration and can lead by example. Self-management and sustainability of care key issues to address by care workers Care workers should emphasize skills for long-term retention in care and adherence

Source: WHO guideline on health policy and system support to optimize community health worker programmes

Community-based organisations need to apply the basic selection criteria when selecting the care workers and offer those mentioned above primary essential conditions. The critical training support for care workers has to be on psychosocial issues on how to deal with patients, and such support structures have to be established by the government. The government has to ensure that every CBO that deals with HIV/AIDS patients provides training for its care workers on psychosocial knowledge. Given the positive programme outcomes achieved by care workers to their beneficiaries (Thurman et al., 2013), adequate support structures and resources must be channelled to care workers to conduct their duties effectively (Mccoskey, 2009).

5.5 Outcome of work performance

Literature has shown that care workers are the foot soldiers and are doing a great job in fighting the HIV pandemic by educating the community and defaulters on the importance of practicing safe sex and taking medication. Data collected revealed that care workers always take extra steps to reach their targets, especially tracing the defaulters and ensuring that they continue with their treatment. Performance of care workers are adversely affected because of walking long distances in the field, too much paperwork and high daily targets. One of the respondents during data collection highlighted the following:

"It takes us an hour or so to talk to patients and give them our full attention to educate them, but due to the pressure we get from the office we end up spending 10 to 20 minutes only"(CW_KII_Male: Supervisor)

The little time spent with the patients affects the outcome because less information is shared, and there will be a high probability that she/he will default again; hence, the high numbers are given to track and trace, negatively affect their work performance.

Other than having the passion for doing the care working job, care workers' remuneration cannot sustain their living standards. Data shows that they receive R3500 per month and some use this money to pay for patients transport so that they meet their monthly targets. Low remuneration affects the performance of everyone in any industry, especially when there is a lack of monitoring and supervision. Care workers, therefore, tend to slow down in their duties and do not deliver effectively.

5.6 Challenges

Care workers daily experience several challenges, as confirmed by the data collected. Care workers work long hours and are not transported from one household to the other but walk around the community when performing their duties. The communities in which care workers conduct their tracing of defaulters is not safe, and this has resulted in them communicating amongst each other to know the whereabouts of other colleagues. Care workers are given high targets to meet, and this makes it difficult to accompany each other or to work in pairs. Therefore, it puts their life at risk when they work alone to meet the monthly targets.

The roles and responsibilities of care workers are not fixed and do not correlate with their remuneration. The increase in workload affects work performance negatively. Care workers reported that burnout affects them because of too much pressure from work, and results in them not having enough family or social life. The workload and walking long distances visiting patients adversely impacts on the mental well-being of care workers. The data collected is also supported by literature in that care workers face high levels of emotional stress, fragmented working roles and relatively low levels of pay (Brophy, 2016). If the CBO receive donor funding to perform a specific task, the responsibility is channelled to care workers as long it has to do with HIV patients or the community. During data collection, respondents reported being given additional tasks through the provision of support groups for HIV positive patients on top of their daily duties of tracing and tracking as well as educating the community on adherence. The challenge experienced by care workers is that when the organisations introduce new roles, they are not given adequate training, and that compromises their performance within the group.

Health safety of care workers is a challenge. Participants reported that they are not given protective clothing when working with bedridden patients, and this is risky. Care workers need to have their small medical kit when visiting beneficiaries so that they can use them when it is necessary. Supply of proper uniforms has to be provided to them so that they can portray a positive picture in the community as well as their representatives.

Lack of recognition by the superiors is a challenge to care workers. Data shows that they are undermined because of lack of education. CBOs treat care workers disrespectfully and use harsh words when communicating with them, particularly when they raise their grievances about work challenges. Female care workers are afraid to ask for leave days, as evidenced in the data. When they miss 2 or 3 days of work, management replaces them. Lack of recognition and support from the superiors adversely affects care workers' performance and the vulnerable members of the community because they leave the organisation and look for better jobs (Leiter et al., 2014). The attrition rate of care workers is increasing at CBOs, and they keep on looking for personnel to do the care working duties.

Care workers are responsible for taking the patients to the clinic for the collection of their medication. Data shows that care workers use the little money given to them by the organisation to pay for patient's transport and take them to health facilities. The study revealed that care workers are given R150 per month to transport at least 32 patients. Evidence indicates that most defaulters reported they did not have money to go to the clinic, and the long queues were a deterrent. Care workers revealed that they assist beneficiaries by paying for their transport so that the patient does not have an excuse of not going to the clinic.

5.7 Conclusion

Care workers are of paramount importance in the continued fight against the HIV/AIDS pandemic in the country. As evidenced in this study, professional nurses cannot perform the duties and responsibilities of going from door-to-door to look for HIV/AIDS defaulters because nurses are stationed at health facilities. Care workers are given the list of defaulters and walk under harsh weather conditions to the homes of the patients to educate them about the importance of taking medication and adherence. The mobile clinics are not effective in Soshanguve, so care workers use gazebos at the community centres when conducting awareness campaigns and HTS.

The fragmented roles and responsibilities of care workers negatively impact on their work performance. Data revealed that high targets resulted in insufficient time being spent with defaulters educating them about the importance of healthy nutrition and taking their medication diligently. HIV/AIDS patients need sufficient time when home visits are done as they know their rights as patients. They are aware that they have to be heard and should not be discriminated against due to their status.

Evidence in this study shows that monitoring or supervision of care workers is lacking. The management appears to be interested primarily in the numbers provided by care workers. Management does not go with them to see the challenges they experience when performing their duties in the field. Other than lack of management supervision, care workers report a lack of concern by management when communicating t their grievances and are not heard when they report their challenges.

Remuneration for care workers does not correlate with their roles and responsibilities, and evidence shows that they receive R2000-R3500 per month. Another challenge faced by care worker is that the CBOs often delay the payment of care workers and no communication is done regarding that, indicating that they are not valued within the organisation.

The Health and safety of care workers is compromised when they are not given protective clothing to use when they visit HIV affected patients. In some instances, care workers come across a bedridden patient, and they have to clean the home of that person, cook for them, as well as bath them before taking them to the clinic or administering their medication.

Another challenge experienced by care workers is security when walking about the community conducting the door-to-door visits. Since the field of community care working is dominated by females, they are prone to sexual abuse, especially when they visit the homes of strangers alone.

Chapter 6 Conclusion and Recommendations

This chapter concludes the study by presenting the conclusion and recommendations based on the research question findings. The recommendations by the researcher are meant to guide policymakers at all levels of government and community-based organisations that employ community care workers.

6.1 Conclusion

Care workers are the foot soldiers for the health and social development sectors. The services offered to HIV patients and their families have shown a positive impact on the social-economic and healthy lifestyle in their survival.
Care workers play an important role in the community affected by HIV, as highlighted by their roles and responsibilities. Irrespective of changing roles and responsibilities, care workers ensure that they deliver because of the passion they have in assisting their community. The research affirmed that care workers' roles and responsibilities are fragmented and regularly change. Literature and findings from the study support the fragmentation of care workers' roles, and this poses a challenge in effectively performing their duties. Tracking, tracing, support groups, adherence support, campaigns, testing, and counselling are all part of management support services offered by care workers to HIV patients and their families in the community of Soshanguve. The other role which care workers do include referral services of their clients to different institutions like health facilities, Home Affairs, social workers at DSD and even the police when the cases involve gender-based violence and rape.

Work burnout has been raised as a challenge by care workers because they reported walking long distances when visiting ailing patients and their families. High targets given to care workers compromise the service output given to patients. The research revealed that burnout has a negative impact on care workers performances because when they are tired, they do not offer quality services to patients. Care workers also face a wide range of psychosocial stressors; they face a high risk of developing burnout syndrome, which in turn affects outcomes such as the quality and safety of care provided. Due to psychosocial stress that affects care workers, they are needed to offer care to carers so that they can debrief with professionals. This study showed the importance for CBO managers to carry out management practices that promote job control and provide care workers with job resources, to reduce the burnout risk.

Care workers reported that they lack support systems from the various institutions from NGOs, the community, management organisations and international and government funders. Care workers indicated that they feel that they are not respected and are not given moral support by the management. The manner which the managers communicate with the care workers does not show respect, and hence, the care workers feel they are not valued. The care workers indicated that their contributions are not listened to by management. Thus, there is a one-way communication from the top to the bottom. The results of the study indicated that with support systems from the relevant institutions, care workers carry their work obligations efficiently and effectively.

The study set out to find out the perceptions of care workers who provide services to HIV or AIDS patients in Soshanguve, South Africa. There were factors relating to the working conditions, roles and responsibilities, the health and physical aspects of the care workers. The participants experienced a range of sentiments from anxiety, a feeling of impotence and despondency, distress and misery to feeling submerged. Still, some had hope for the recovery of patients under their care. However, some of the respondents seemed to be at the end of their tether. It is an attestation to the pliability of care workers that all of them were coping with their strenuous role, with very little social and management support. The researcher carried out the study in the hope that the findings would clarify the perceptions of care workers who provide services to HIV patients and their families.

6.2 Recommendations

Roles and responsibilities

Care workers roles and responsibilities have to be well articulated. Care workers highlighted that they need their roles and responsibilities to be written down and to ensure that a comprehensive contract is ready for signing before the commencement of the contract. Data shows that their contracts are not fixed and change regularly depending on funding received by the organisation. Community-based organisations tend to add tasks to care for workers that are not part of their job description.

Working Conditions

Care workers have to be allowed to air their views and the challenges they experience in their field of work. The care workers' challenges have to be addressed. The representatives of the care workers have to do follow up regarding their grievances and render support.

Well recognized institutions have to provide care working courses for those people who have a passion for their work. The courses offered should be accessible to individuals who have not passed their matric but have a passion for assisting the government fight HIV pandemic in the country and supporting the 90-90-90 goal.

The researcher recommends the provision of bicycles to care workers to use when conducting door-to-door so that they are mobile, and this will eliminate the issue of the fatigue that affects their performance. The government may also include transportation budgets for care workers that will be used when conducting their field services.

Working in pairs as care workers will minimize the risk of sexual assaults. They will also be able to support each other when visiting HIV affected families.

Support structures

The researcher recommends training on psychosocial support to be implemented to all care workers and should be part of their courses. HIV/AIDS care workers deal with stressing and emotional matters when visiting affected families, and this will require someone who can handle problems and challenges shared to them as well as give advice.

The researcher recommends care of carers programme to be implemented to all the CBOs that offer services to HIV/AIDS-affected communities. The programme will allow the care workers to debrief and download all the problems and challenges shared to them by their beneficiaries.

Job security

Job security is not guaranteed if one is a care worker. The Department of Social Development and the Department of Health need to put in place support structures for care workers to enhance their job security. Care workers need to be recognized in the industry by their organisations.

Appendix A: Information sheet

Wits School of Governance,
2st David’s Place, Parktown
Johannesburg

Dear Sir / Madam

My name is Tronny Mawadzwa, and I am a Masters student in Management in the field of Public and Development sector Monitoring and Evaluation at the University of the Witwatersrand in Johannesburg. As part of my studies, I have undertaken a research project, where I am investigating the perceptions of care workers. This research project aims to explore the perceptions of care workers who provide HIV/AIDS home visits.

As part of this project, I would like to invite you to take part in a focus group discussion. This activity will involve answering questions and will take around 60 minutes. With your permission, I would also like to record the interview using an Olympus digital device.

You will not receive any direct benefits from participating in this research, and there are no disadvantages or penalties for not participating. You may withdraw at any time or not answer any question if you do not want to. The discussion will be completely confidential and anonymous as I will not be asking for your name or any identifying information, and the information you give to me will be held securely and not disclosed to anyone else. I will be using a pseudonym (false name) to represent your participation in my final research report. If you experience any distress or discomfort at any point in this process, we will stop the discussion or resume another time.

If you have any questions during or afterwards about this research, feel free to contact me or my supervisor on the details listed below. This study will be written up as a research report which will be available online through the university library website. If you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email Shaun.Schoeman@wits.ac.za

Yours sincerely,
Tronny Mawadzwa

Researcher name: Tronny Mawadzwa
Email: 1319905@students.wits.ac.za
Phone number: 083 481 3035

Supervisor name: Dr Jacqui Poltera
Email: Jacqui.poltera@wits.ac.za

Supervisor name: Mr Marcel Korth
Email: Marcel.Korth@wits.ac.za

Appendix B: Consent form

Title of the research project: Examining perceptions of care workers who provide HIV and AIDS services.
Name of principal researcher: Tronny Mawadzwa

I …………………………………….. agree to participate in this research project. The research has been explained to me and I understand what my participation will involve.

	(Please circle)
I agree that my participation will remain anonymous	YES NO
I agree that the researcher may use anonymous quotes in his research report	YES NO
I agree that the interview may be audio recorded	YES NO
I agree that the information I provide may be used anonymously by other researchers following this study	YES NO

Name of participant: ....
Signature: ....
Date: ....

Appendix C: Data collection schedules

Interview Schedule questions: FDG guide for Care Workers

1. Could you please tell me about the activities you provide as HIV/AIDS care workers in the community of Soshanguve?

   Probe: How have the care workers of Thola-Ulwazi CBO been supporting OVC, their families and people living with HIV and AIDS in Soshanguve?
2. What support mechanisms have been established to provide care and support to OVC and PLWHA?

   Probe: Training and psychosocial support
3. What are your perceptions of being a care worker at Thola-Ulwazi CBO when conducting your duties in the community?
4. What are the main challenges involved in being a care worker?
5. What are the opportunities and benefits of being a care worker?
6. In your experience as a care worker, what systems and processes have Thola-Ulwazi put in place to within your working environment?

   Probe: reporting of activities, recruitment of beneficiaries, and referral process of beneficiaries to health facilities or social development amongst others.
7. Evidence from literature highlights high rates of burnout associated with care workers. What is your perception of burnout amongst care workers in this community?

   Probe: Does this organisation provide counselling for care workers, and what places are available to care workers to obtain support and counselling?
8. What do you think could be done to support you for the effectiveness and efficiency of your services to the community?

   Probe: Are there any other input/things you think I need to consider?

Semi-structured interview guide for key informant: Care Workers

1. Could you please tell me about the activities you provide as HIV/AIDS care workers in the community of Soshanguve?

   Probe: How have the care workers of Thola-Ulwazi CBO been supporting OVC, their families and people living with HIV and AIDS in Soshanguve?
2. What support mechanisms have been established to provide care and support to OVC and PLWHA?

   Probe: Training and psychosocial support
3. What are your perceptions of being a care worker at Thola-Ulwazi CBO when conducting your duties in the community?
4. What are the main challenges involved in being a care worker?
5. What are the opportunities and benefits of being a care worker?
6. In your experience as a care worker, what systems and processes have Thola-Ulwazi put in place to within your working environment?

   Probe: reporting of activities, recruitment of beneficiaries, and referral process of beneficiaries to health facilities or social development amongst others.
7. Evidence from literature highlights high rates of burnout associated with care workers. What is your perception of burnout amongst care workers in this community?

   Probe: Does this organisation provide counselling for care workers, and what places are available to care workers to obtain support and counselling?
8. What do you think could be done to support you for the effectiveness and efficiency of your services to the community?

   Probe: Are there any other input/things you think I need to consider?

List of References

Avert. (2016). Funding for HIV and AIDS. Global information and education on HIV and AIDS. Retrieved from http://www.avert.org/professionals/hiv-around-world/global-response/funding

Borsay, A. (1994). Coordinating Community Care: Multidisciplinary Teams and Care Management, Open University Press, Buckingham.

Brophy, M. C. (2016). Challenges Facing Home Care Workers and Assessment of Experiences of Support and Supervision. Dublin: DBS School of Arts.

Bryman, A. (2012). *Social research methods* (4th ed.). New York: Oxford university press.

Busza, J., Dauya, E., Bandason, T., Simms, V., Chikwari, C. D., Makamba, M., Ferrand, R. A. (2018). The role of community health workers in improving HIV treatment outcomes in children : lessons learned from the ZENITH trial in Zimbabwe. *Health Policy and Planning*, 328–334.

CATIE. (2020). The HIV testing process. *Canada's Source for HIV and Hepatitis C Information*. Retrieved from https://www.catie.ca/en/fact-sheets/testing/hiv-testing-process

Centres for Disease Control and Prevention. (2019). Workplace Safety and Health. Retrieved from https://www.cdc.gov/niosh/topics/healthcare/default.html

Chandra, A., Sarkar, S., Adinarayana, S. & Balajee, K. L. (2016). Impact of Health Awareness Campaign in Improving the Perception of the Community about Palliative Care: A Pre- and Post-intervention Study in Rural Tamil Nadu. *Indian Journal of Palliative Care*, *22*(4), 467–476.

Corbett, E. L., Watt, C. J., Walker, N., Maher, D., Williams, B. G., Raviglione, M. C., & Dye, C. (2003). The Growing Burden of Tuberculosis. *Archives of Internal Medicine*, *163*(9), 1009.

Department of Health. (July 2015). National HIV Testing Services: Policy and Guidelines. Pretoria.

Department of Social Development. (March 2015). State of South African Registered Non-Profit Organisations 2014-2015. Retrieved from http://www.dsd.gov.za/npo/index2.php?option=com_docman&task=doc_view&gid=183&Itemid=116

Dombrowski, J. (2020). Linkage to HIV Care Process for Estimating and Monitoring Linkage to Care, 1–22.

ECSA-HC. (2011). *Child Sexual Abuse in Sub- Saharan Africa*.East, Central and Southern Health Community. Arusha, Tanzania.

Ezechi, O., Petterson, K., & Byamugisha, J. (2012). HIV/AIDS, tuberculosis, and malaria in pregnancy. *Journal of Pregnancy*, *2012*, 10–12. https://doi.org/10.1155/2012/140826

Findley, S. E., Matos, S., Hicks, A. L., Campbell, A., Moore, A., & Diaz, D. (2012). Building a consensus on community health workers' scope of practice: lessons from New York. *American journal of public health*, *102*(10), 1981–1987. https://doi.org/10.2105/AJPH.2011.300566

Friedman, I. (2005). South African Health Review 2017. *Sabinet*, *1*, 176-188 (13).

Galárraga, O., Wirtz, V. J., Santa-Ana-Tellez, Y., & Korenromp, E. L. (2013). Financing HIV Programming: How Much Should Low- And Middle-Income Countries and their Donors Pay? *PLoS ONE*, *8*(7). https://doi.org/10.1371/journal.pone.0067565

Give, C., Ndima, S., Steege, R., Ormel, H., Mccollum, R., Theobald, S., & Sidat, M. (2019). Strengthening referral systems in community health programs : a qualitative study in two rural districts of Maputo Province, Mozambique. *BMC Health Services Research*, (702), 1–11.

Goel, K. (2015). Community-Based Organisations : Role in Settling Immigrants Community-Based Organisations. ResearchGate. University of South Australia. Australia.

Gonzalez, G. S. (2020). HIV Testing. Retrieved from https://www.medicinenet.com/hiv_testing/article.htm

Griffith, D. M., Allen, J. O., Deloney, E. H., Robinson, K., Lewis, E. Y., Campbell, B., & Reischl, T. (2010). Community-based organizational capacity building as a strategy to reduce racial health disparities. *Journal of Primary Prevention*, *31*(1–2), 31–39. https://doi.org/10.1007/s10935-010-0202-z

Hanson, G. C., Perrin, N. A., Moss, M., & Laharnar, N. G. (2015). Workplace violence against homecare workers and its relationship with workers health outcomes: a cross-sectional study. *BMC Public Health*, *15*(11).

Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4308913/

Hatzipapas, I., Visser, M. J., & Rensburg, E. J. Van. (2017). Laughter therapy as an intervention to promote psychological well-being of volunteer community care workers working with HIV-affected families. *Journal of Social Aspects of HIV/AIDS*, *14*(1), 202–212. https://doi.org/10.1080/17290376.2017.1402696

HomeCare. (2018). Addressing the Dangers Faced by Caregivers in the Field. Retrieved from https://www.homecaremag.com/december-2018/lone-worker-monitoring

Johnson, L. F., Chiu, C., Myer, L., Davies, M. A., Dorrington, R. E., Bekker, L. G., & Meyer-Rath, G. (2016). Prospects for HIV control in South Africa: a model-based analysis. *Global Health Action*, *9*(June), 30314. https://doi.org/10.3402/gha.v9.30314

Joint United Nations Programme on HIV/AIDS UNAIDS. (2016). Fact sheet, People living with HIV, HIV, antiretroviral therapy, new HIV infections, AIDS, tuberculosis, facts. *Fact Sheet*, (NOVEMBER), 1–8. Retrieved from http://www.unaids.org/sites/default/files/media_asset/UNAIDS

Kim, J. J., & Guha-Sapir, D. (2012). Famines in Africa: Is early warning early enough? *Global Health Action*, *5*(1), 3–5.

Leiter, M. P., Bakker, A. B., & Maslach, C. (2014). Burnout at work: A psychological perspective. *Psychology Press*.

Lentoor, A. G. (2017). Psychosocial Challenges Associated with Caregiving in the Context of Pediatric HIV in Rural Eastern Cape. *Frontiers in Public Health*, *5*(127).

Maheswaran, H., Thulare, H., & Stanistreet, D. (2014). Starting a Home and Mobile HIV Testing Service in a Rural Area of South Africa., *59*(674), 1–8. Retrieved https://doi.org/10.1097/QAI.0b013e3182414ed7.Starting

Makhado, L., & Davhana-maselesele, M. (2015). Knowledge and psychosocial wellbeing of nurses caring for people living with HIV / AIDS (PLWH), *1*, 1–10. https://doi.org/10.1016/j.hsag.2015.10.003

Makoae, M. G. (2015). Experiences of caregivers implementing HIV and AIDS services within Community-Based Organisations in rural Maseru. Unpublished Master's Thesis, University of Free State. Bloemfontein, South Africa.

Masiulien, L., Looney, J., & Aertgeerts, H. (2017). The key features of successful awareness-raising campaigns, 1–13.

Masquillier, C. (2016). Bridging the gap : The intermediate role of the household in community-based support for people living with HIV / AIDS in South Africa. University of Antwerp. Belgium.

Masquillier, C., Wouters, E., Mortelmans, D., & Wyk, B. Van. (2016). HIV / AIDS Competent Households : Interaction between a Health-Enabling Environment and Community-Based Treatment Adherence Support for People Living with HIV / AIDS in South Africa, 1–19. https://doi.org/10.1371/journal.pone.0151379

Mccoskey, S. (2009). NGOs in the Aid Community: Do Funding Source or Economic Conditioning Matter to Decisions of Country or Activity Involvement? Retrieved from https://sites.tufts.edu/jha/archives/381

Meehan, S., Naidoo, P., Claassens, M. M., Lombard, C., & Beyers, N. (2014). Characteristics of clients who access mobile compared to clinic HIV counselling and testing services : a matched study from Cape Town, South Africa, 1–8.

Middlemiss, L. (2009). The role of community-based organisations in stimulating sustainability practices among participants. *PhD Thesis*, The University of Leeds, Leeds, USA.

Morton, D., Mayekiso, T., & Cunningham, C. (2013). Support for volunteer caregivers and its influence on the quality of community home-based care in the Eastern Cape, South Africa. *Psychology in Africa*, *23*, 104–109.

Mugavero, M. J., Amico, K. R., Horn, T., & Thompson, M. A. (2013). The state of engagement in HIV care in the United States: from cascade to continuum to control. *Clinical infectious diseases: an official publication of the Infectious Diseases Society of America*, *57*(8), 1164–1171. https://doi.org/10.1093/cid/cit420

Mushongera, D. (2015). Livelihoods and Poverty. *Climate Change 2014 Impacts, Adaptation, and Vulnerability*, 793–832. https://doi.org/10.1017/CBO9781107415379.018

Neuman, W. L. (2014). *Social Research: Qualitative and Quantitative Approaches. Social Research Methods: Qualitative and Quantitative*

Approaches. Pearson. https://doi.org/10.1234/12345678

O`Grady, M., Njaramba, P., Sebastian, B., Chung'andu, A., Oti, S., Selvaggio, M., & Thurman, T. R. (2008). OVC Programmes in South Africa Funded by the U.S. President's Emergency Plan for AIDS Relief. Summary Report for 32 Case Studies. *Khuilsa Management Services*. Retrieved from http://www.cpc.unc.edu/measure/program-areas/ovc/ovc-program-case-studies/ovc-case-studies-sa/Summary-SR0842-SUM-v2.pdf

Pustil, R. (2016). Global AIDS. *UNAIDS*, *17 Suppl 4*, S3-11. https://doi.org/10.1073/pnas.86.15.5781

Richters, A.J. (2010). Suffering And Healing In The Aftermath Of War And Genocide In Rwanda: Mediations Through Community-Based Sociotherapy.

Robert, B., & Peter, D. P. (1997). The impact of HIV/AIDS on families: An overview of recent research. *Families, Systems, & Health*, *15*(4), 413–427. Retrieved from https://doi.org/10.1037/h0089837

Rujumba, J., Mbasaalaki-Mwaka, C. L., & Ndeezi, G. (2010). Challenges faced by health workers in providing counselling services to HIV-positive children in Uganda: a descriptive study. *Journal of the International AIDS Society*, *13*, 9. https://doi.org/10.1186/1758-2652-13-9

SACN. (2017). *Despite being a once forgotten folk with existing challenges people are coming back home* (Vol. 27). Winterveldt.

Schneider, H. & Russel, M. (2014). A Rapid Appraisal of Community Based HIV / AIDs Care and Support Programmes in South Africa. University of Witwatersrand, Johannesburg, South Africa.

Schneider, H., Hlophe, H., & van Rensburg, D. (2008). Community health workers and the response to HIV/AIDS in South Africa: tensions and prospects. *Health policy and planning*, *23*(3), 179–187. https://doi.org/10.1093/heapol/czn006

Shisana, O., Rehle, T., Simbayi, L.C., Zuma, K., Jooste S., Zungu, N., Labadarios, D., & Onoya, D. E. A. (2014). South African National HIV Prevalence, Incidence and Behaviour Survey, 2012. *HSRC Press*, 194.Pretoria, South Africa.

Shisana, O., Rehle, T., Simbayi, L., Zuma, K., Jooste, S., & Pillay-van-Wky,

V. (2009). South African national HIV prevalence, incidence, behaviour and communication survey, 2008: a turning tide among teenagers? *HSRC Press*. Pretoria, South Africa.

Sokol D. K. (2006). Virulent epidemics and scope of healthcare workers' duty of care. *Emerging infectious diseases*, *12*(8), 1238–1241. https://doi.org/10.3201/eid1208.060360

Thurman, T. R., Kidman, R., & Taylor, T. (2013). *The impact of paraprofessional versus volunteer-driven home visiting programs on the wellbeing of orphans and vulnerable children: Evidence from a longitudinal evaluation in Kwa-Zulu Natal, South Africa.* New Orleans Louisian.

Thurman, T. R., Taylor, T. M., Nice, J., Luckett, B., Taylor, M., & Kvalsvig, J. D. (2018). Factors associated with retention intentions among Isibindi child and youth care workers in South Africa : results from a national survey, 1–7.

Thurman, T. R., Yu, S., & Taylor, T. M. (2009). *A psychosocial support model for Child and Youth Care Workers serving Orphans and Vulnerable Children in South Africa*. New Orleans Louisian.

Torpey, K. E., Kabaso, M. E., Mutale, L. N., Kamanga, M. K., & Mwango, A. J. (2008). Adherence Support Workers : A Way to Address Human Resource Constraints in Antiretroviral Treatment Programs in the Public Health Setting in Zambia, *3*(5). https://doi.org/10.1371/journal.pone.0002204

Tsodzo, C. C. (2007). The Challenges of The HIV and AIDS Pandemic Among Informal Settlements – A Case Study of Hatcliffe Extension in Harare, Zimbabwe.

UNAIDS. (2000). Caring for carers. Managing stress in those who care for people with HIV and AIDS. *Geneva UNAIDS*.

UNAIDS. (2011). On the Fast-Track to end AIDS. *Life Sciences*, *88*(21–22), 917–921. https://doi.org/10.1073/pnas.86.15.5781

UNAIDS. (2017). The Global HIV / AIDS Epidemic. *The Henry Kaiser Family Foundation*, (January), 4.

Van Deventer, C., & Wright, A. (2017). The psychosocial impact of caregiving on the family caregivers of chronically ill AIDS and/or HIV patients in home-based care : A qualitative study in Zimbabwe, 1–7.

Vitoria, M., Granich, R., Gilks, C. F., Gunneberg, C., Hosseini, M., Were, W., & De Cock, K. M. (2009). The global fight against HIV/AIDS, tuberculosis, and malaria: Current status and future perspectives. *American Journal of Clinical Pathology*, *131*(6), 844–848. https://doi.org/10.1309/AJCP5XHDB1PNAEYT

Walsh, A., Mulambia, C., Brugha, R., & Hanefeld, J. (2012). The problem is ours`, it is not CRAIDS. Evaluating the sustainability of Community-Based Organisations for HIV/AIDS in a rural district in Zambia. *Globalization and Health*, *8*(1), 40. https://doi.org/10.1186/1744-8603-8-40

Wanger, C., Kawulich, B., & Garner, M. (2012). *Doing Social Research: A global context*. New York: McGraw Hill Education.

Weinstein, J. N., Geller, A., Negussie, Y., Baciu, A., Practice, P. H., & Division, M. (2017). *Communities in Action*. https://doi.org/10.17226/24624

World Health Organisation. (2014). Global status report on noncommunicable diseases. *World Health*, 176. https://doi.org/ISBN 9789241564854

World Health Organisation. (2017). Community health worker programmes in the WHO African region. https://apps.who.int/iris/handle/10665/254739

World Health Organisation. (2020). Psychosocial Support. Retrieved from https://www.who.int/hiv/topics/psychosocial/support/en/