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A Qualitative Inquiry Into the Occupational Challenges Faced by Home-Based Caregivers of People Living With HIV in South Africa’s Gauteng Province

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Abstract

Community home-based caregivers caring for people living with human immunodeficiency virus (PLWHIV) are instrumental in relieving the demand pressures experienced by healthcare service centers. Although their contributions to the healthcare system are essential, they do so under difficult conditions necessitating social work support. This study was conducted in the Gauteng province of South Africa in 2017 to explore the occupational challenges faced by community home-based care caregivers of PLWHIV. Following the qualitative research approach, eighteen caregivers were identified and sampled using purposive and snowball sampling techniques in semi-structured interviews. The data was manually analyzed according to Tesch’s eight steps of qualitative data analysis. This gave rise to four themes: reception by community members, uncooperative clients and families, unsupportive healthcare professionals, and working in unsafe conditions. Following relevant ethical principles such as informed consent, confidentiality, and anonymity throughout the study, trustworthiness was continuously upheld through the principles of prolonged engagement, triangulation, member checking, thick description, and audit trail. The need for psychosocial support programs for caregivers, community and family educational programs, and strengthening partnerships for caregivers, communities, and healthcare professionals is recommended, given the success of community home-based care (CHBC) services for PLWHIV.

Keywords

Care; challenge; HIV; home-based; social work

Introduction

Civil society has been a crucial role player in responding to HIV through structures such as community home-based care (CHBC) organizations from its early years (Murphy et al., 2021; Simelela et al., 2015). During the 1980s, for instance, CHBC organizations mushroomed, recruited, and deployed volunteers through non-governmental organizations (NGOs), community-based organizations (CBOs), and faith-based organizations (FBOs) to, among others, assist people suffering from acquired immune deficiency syndrome (AIDS)-related conditions (Aantjes et al., 2014). Their primary responsibility included, as it is still now, rendering CHBC services through caregivers who are ordinary men and women qualified either as healthcare practitioners, trained lay community workers, peer health workers, or volunteers (Wesonga, 2015; Wood et al., 2018). The aim was to promote hope, independence, and quality of life for clients and their families by rendering physical, psychosocial, palliative, and spiritual care to clients within their homes (Larki & Roudsari, 2020; Mashau et al., 2015). They also educate PLWHIV on HIV care and prevention issues, bath and feed them, counsel them and their loved ones, clean their houses, and conduct follow-ups on missed return dates for antiretrovirals (ARTs) or other treatment prescripts (Wesonga, 2015; Wood et al., 2018).

Within the field of HIV, CHBC aims to reduce AIDS-related deaths and increase the clients' lifespan by supporting them to get treatment (Root et al., 2013). In South Africa and Zambia, the campaigns led by community-based caregivers achieved 90% of new diagnoses of HIV-infected persons, of whom 90% were placed on antiretroviral therapy, and 90% of viral suppression (the UNAIDS' 90-90-90 targets) (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2019). Community home-based care is particularly essential given the UNAIDS' support for community-led initiatives to achieve 30% of testing and treatment services by community-led organizations, 60% of programs to support the achievement of societal enablers by community-led organizations, and 80% of service delivery of HIV prevention programs for key populations and women by the community, key population, and women-led organizations (UNAIDS, 2020).

Although health-related challenges are generally shared across many countries, the African continent is particularly notorious for poor health conditions and the adverse impact of pandemics. The highest HIV infection rates and AIDS-related mortality are in low-income countries, with Africa as their epicenter (Simbayi et al., 2019; Statistics South Africa, 2021). The continent is generally known for its neglected, underfunded, and deteriorating healthcare systems (Oleribe et al., 2019). For instance, a report by the World Health Organization (WHO) (2017) revealed the exposure of African people to a heavy and wide-ranging burden of diseases. Despite the efforts made by countries such as South Africa to improve the quality of healthcare systems, some of these challenges continued.

In South Africa, healthcare challenges are further intensified by inequality and social exclusion reinforced by the disparity between those who can and cannot afford quality healthcare services (Ndebele et al., 2021). These challenges necessitate alternative measures to relieve or support the system; hence, CHBC became widely adopted at the community level (Morton et al., 2018). It was expected that CHBC would provide the necessary care and support to PLWHIV, relieve public healthcare systems from the pressure of demand for healthcare services, and make healthcare services accessible to clients within their communities and households (Moshabela et al., 2015; Wesonga, 2015; Wood et al., 2018). Although some of these expectations are achieved, caregivers in CHBC face several occupational challenges that, if not adequately addressed, have the potential to erode their successes. Some of their challenges are psychosocial in nature and, therefore, necessitate further support from social workers. Thus, social workers must fully comprehend these challenges and develop strategies to improve the CHBC program. Despite the crucial role that social workers can play in CHBC, they are not privy to its dynamics and challenges (Lekganyane, 2020; Lekganyane & Alpaslan, 2019). This study sought to contribute to this knowledge gap by exploring the occupational difficulties faced by caregivers when caring for PLWHIV through the CHBC in South Africa's Gauteng province.

The relevance of social work in HIV community home-based care

Community home-based care programs were established to increase the quality of life and limit hospital stays by rendering healthcare services to clients within their homes, particularly in resource-limited settings (Moshabela et al., 2015; Wood et al., 2018). They sought to overcome barriers such as transport costs and waiting periods, lowering the costs of health care services, reducing demands of the already limited hospital beds, reducing stigma, and improving the uptake of HIV testing and access to treatment, care, and support (Wesonga, 2015; Wood et al., 2018). The mandate of CHBC is also central to social work, which seeks to promote social change and develop social cohesion by empowering and liberating people according to social justice, human rights, collective responsibility, and appreciation of human diversity (International Federation of Social Workers, 2014).

Social workers have interests similar to those of CHBC since they are both concerned about promoting the welfare of people who face challenges such as illness in society (Dako-Gyeke et al., 2018). As Wesonga (2015) described, CHBC holds the family together and reduces the expenses of having a client cared for away from the family. In the same way, social workers provide holistic care to clients in collaboration with other multidisciplinary healthcare teams. Unlike institutionalized care, wherein an emphasis is placed on healing the condition or illness, CHBC is sensitive to the culture and value systems of the communities (Larki & Roudsari, 2020). This reflects the central value of social work, which considers clients as part of the broader family, cultural, and community contexts and related factors impacting the client's condition (Dako-Gyeke et al. 2018). This broader perspective is an essential advantage within the African context, particularly among families with limited resources. Furthermore, some African cultures and traditions require family members to be dignified by being cared for within their families.

Larki and Roudsari (2020) argued that CHBC benefits clients, families, and the healthcare system. To the client, it provides general satisfaction, quality of life, adherence to treatment, prevention of mother-to-child transmission, and biomedical, social, and psychological outcomes (Larki & Roudsari, 2020; Wanga et al., 2019; Wood et al., 2018). To the family, it promotes the involvement of its members in caring for their loved ones. It also creates and enhances awareness among the client's family members and provides them with voluntary counseling and testing. For the healthcare system, the benefits of CHBC include containment of health-related costs and reduced workload and time spent on services among healthcare practitioners (Larki & Roudsari, 2020; Wood et al., 2018). Given its primary objective of promoting social justice, social work also extends to CHBC with occupational difficulties compromising caregivers' optimal provision of services to PLWHIV. Their primary purpose is to alleviate human suffering in many settings (Dako-Gyeke et al., 2018), including among caregivers who may be unable to function optimally in caring for PLWHIV. Social workers are at the epicenter of CHBC and must address the challenges caregivers encounter

(Lekganyane & Alpaslan, 2019). This means caregivers could be clients to social workers, and the latter should render the same support services that they would render to their clients.

A strength-based perspective to the occupational challenges of HIV home-based care

The strength-based perspective is associated with Saleebey's (1996) *Strengths Perspective in Social Work Practice*. Central to this perspective is that people's characteristics, environments, and multiple contexts shape their lives and promote resilience instead of deficits (Caiels et al., 2021; Pulla, 2017). It holds that despite the challenges people encounter, they find ways of resiliently managing them. It primarily focuses on the strengths possessed by individuals based on their life stories, narratives, and factors that influence their identities (Pulla, 2017). The strengths perspective seeks to change how social workers and other counseling professionals assess and support individuals needing care and support by moving away from needs and deficits toward resources and strengths (Caiels et al., 2021). From this perspective, caregivers can change themselves to adapt to difficult working conditions. Challenges characterize their environment, and plenty of resources exist to enable them to develop coping mechanisms. A complete comprehension of the conditions in which caregivers render their services is based on the following principles as proposed by Pulla (2017):

- A belief by researchers that people (including caregivers) can change and grow through their strengths and capacities. These strengths and capacities enable caregivers to change and grow from their challenges.

- A belief that problems can prevent people (including the caregivers) from noticing their strengths. In other words, the challenges experienced by caregivers may obscure their strengths and capacities. Helpers should, therefore, highlight these strengths to enable caregivers to realize and utilize them optimally in improving their conditions.

- People have the expertise to solve problems. Caregivers should be knowledgeable enough with relevant expertise to resolve their challenges. As much as researchers can investigate and find challenges associated with caregiving, caregivers ultimately know how to resolve or manage such challenges best. Therefore, consideration of the caregivers' views in research studies is essential to the strengths-based perspective; hence, this study relied on the caregivers' narratives.

Methodology

This was a descriptive qualitative study grounded in an interpretive paradigm. The study's purpose necessitated a deeper analysis of the challenges of CHBC for PLWHIV from a social work perspective; hence, qualitative research was deemed suitable. Qualitative research was chosen because not much was known about the subject of caregivers and HIV CHBC. It was considered essential to summarize specific events experienced by participants and describe CHBC-related challenges, enhancing a comprehensive understanding of the participants' experiences in working with PLWHIV (Duda et al., 2020; Nassaji, 2015). The approach to qualitative research reporting adopted for this study was an adapted synthesized approach proposed by O'Brien et al. (2014), which includes title, abstract, introduction, methods, findings, discussion, and limitations.

The population for this study was CHBC caregivers who were caring for PLWHIV in the Gauteng province of South Africa. Purposive and snowball sampling techniques were used to sample participants from this population. Google search and researcher's networks were explicitly used to identify six HIV CHBC organizations in the province, which were then approached telephonically, through walk-ins and emails, with a formal request to interview the caregivers. Five organizations granted positive responses, from which fifteen caregivers agreed to be interviewed. Following a snowball approach to sampling, two of the thirteen caregivers were then requested to suggest others who may have an interest, resulting in a total of eighteen participants. To qualify for inclusion, participants had to be:

- *Eighteen years and older.*
- *Employed by a CHBC organization.*
- *Caring for persons living with HIV in Gauteng province.*
- *Have at least one year of experience caring for PLWHIV through a CHBC organization.*

The study setting

Gauteng province was selected for this study due to its high HIV burden (South African National AIDS Council [SANAC], 2017). Simbayi et al. (2019) studied the prevalence rates of HIV over five years between 2002 and 2017 and found Gauteng to be amongst the top three of South Africa's nine provinces. In 2002, the province's prevalence rate was 14.7%, dropping to 10.8% and 10.3% in 2005 and 2008, respectively. During 2012 and 2017, Gauteng's prevalence rates increased to 12.7% and 12.8% respectively. These developments, together with other broader factors such as the county's economic state and demographic dynamics such as inequality, gender-based violence, migration, and others, expose the province to HIV and, therefore, place it in the spotlight regarding interventions such as CHBC.

Data collection

In collecting data, the study utilized individual semi-structured face-to-face interviews supported by an interview guide. The rationale for adopting semi-structured interviews was mainly due to the anticipated possibility of participants sharing sensitive experiences and necessitating a safe environment. The choice was mainly because semi-structured interviews allow participants to share their experiences freely, privately, and without limitations while allowing the researcher to probe and clarify their responses (Belotto, 2018).

The data collection tool (the interview guide) was developed based on the literature review and the overall aim of the study and subjected to peer review and pilot testing before final adoption. It contained six closed-ended questions for gathering sociodemographic data and five open-ended questions focusing on participants' experiences. The researcher conducted the interviews in English and Setswana (a native language spoken by both the researcher and the participants). They were later translated into English by the researcher. Each interview lasted for approximately 60 minutes.

Data analysis

Thematic data analysis was explicitly adopted to manually analyze the data, with inductive exploration guiding the identification of recurring themes (Nassaji, 2015). Thematic analysis was chosen for its suitability in studies that involve the recognition of meanings and interpretation thereof. In qualitative research, data analysis involves merging analysis and interpretation by integrating data collection with data analysis (Jnanathapaswi, 2021). In other words, data analysis and collection occur at the same time. This study occurred in two ways. Firstly, data collection was used to determine the sufficiency of data, and secondly, at the end of data collection, the overall meanings that participants ascribed to their experiences were determined. In the first phase, analysis assisted in establishing data saturation, a stage wherein no additional information was provided by the participants (Saunders et al., 2018). This occurred after 18 interviews, wherein participants began to repeat similar experiences.

In the second stage, analysis was conducted immediately after data saturation as a rigorous process guided by Tesch's thematic analysis approach (Creswell, 2014). It began by deidentifying all interviews through pseudonyms and transcribing them word-for-word immediately. The interviews were then read, with essential information recorded in the margins to develop an overview of the data. Once all interviews were transcribed and broadly read, each was read carefully to generate ideas given the study objectives. A list of four themes and seven sub-themes was then compiled, to which abbreviations were fitted. Abbreviated themes and subthemes were written in the margins next to data segments matching a particular code. All related themes were then grouped for a final decision about the abbreviations for each theme and its related code/abbreviation. The data material (storylines) belonging to each theme and subtheme were then assembled in one place and preliminarily analyzed. A final analysis with four themes and seven subthemes was compiled and adopted.

Trustworthiness

Regarding trustworthiness, prolonged engagement, triangulation, member checking, thick description, and audit trail were upheld (Maher et al., 2018; Nowell et al., 2017). Prolonged engagement involved building rapport with participants and getting to know the study sites. Triangulation was upheld by collecting data from participants of different ages and experiences and using literature from diverse disciplines (i.e., psychology, health, social work, and general social sciences). Member-checking was satisfied by allowing participants to authenticate the interview transcripts, while thick description and audit trail involved reporting by supporting the findings with interview extracts and detailing the methodological process followed.

Consideration of ethical principles

The study proposal was scrutinized and approved by the University of South Africa's Departmental Research and Ethics Committee (Ref No: DR&EC_05/06/13_33197083), whereby ethical clearance was granted. The researcher ensured that the following ethical considerations were followed: informed consent, voluntary participation of participants, confidentiality of their personal information, anonymity, and data protection. A potential risk for this study was the possibility of exposing participants to emotional turmoil by evoking past sensitive experiences through the interviews. This was prevented by adopting some therapeutic techniques, such as empathic listening.

Researcher characteristics and reflexivity

The researcher is an academic who worked as a social work practitioner for seven years. As a social work practitioner, he provided psychosocial support to HCBC caregivers of PLWHIV and mobilized resources for their organizations. He was, therefore, an insider with prior experience regarding some of the participants' challenges that were part of his investigation. This previous experience may have clouded the study, particularly by failing to adequately probe or clarify some of the responses because of his underlying assumptions that he understood some of the participants' experiences.

The research findings

The findings are presented through the sociodemographic data and the data based on the research questions, hereafter classified as emerging themes and subthemes.

Sociodemographic findings

In this study, eighteen caregivers participated. Most participants were women (16), predominantly of African descent (15), alongside one Indian woman, one woman from a mixed racial background, and one Caucasian man. The age distribution among the caregivers included one individual aged 52, eight in their thirties, six in their forties, and two in their late twenties. Among the study participants, three had obtained educational qualifications surpassing the level of matric certificates (equivalent to a high school diploma), while six lacked such credentials. The range of their experience in caring for people living with HIV (PWLHIV) spanned from two to twenty-three years. The compensation they received, either in the form of salaries or stipends, varied between 800 ZAR (USD 43) and 3,000 ZAR (USD 161). A summary of the sociodemographic participants' features is provided in Table 1 below:

Table 1: The Sociodemographic Features of the Participants

Pseudonym	Gender	Race	Age	Years of experience	Education	Salary/stipend (ZAR)
Participant 1	Female	African	31	2	Grade 12	1,500
Participant 2	Male	African	43	7	Grade 12	2,500
Participant 3	Female	African	28	4	Grade 12 & counseling	1,500
Participant 4	Female	African	42	3	Grade 12	1,500
Participant 5	Male	Caucasian	45	23	Grade 12	1,500
Participant 6	Female	Indian	38	6	Grade 12 & counseling	3,000
Participant 7	Female	Mixed-Race	38	2	Grade 12	2,500
Participant 8	Female	African	58	4	Grade 12	1,000
Participant 9	Female	African	42	12	Grade 12	1,500
Participant 10	Female	African	39	7	Grade 10	1,000
Participant 11	Female	African	31	2	Grade 12	1,000
Participant 12	Female	African	38	5	Grade 12	2,500

Pseudonym	Gender	Race	Age	Years of experience	Education	Salary/stipend (ZAR)
Participant 13	Female	African	47	8	First Aid certificate	1,500
Participant 14	Female	African	45	2	Grade 9	1,000
Participant 15	Female	African	39	7	Grade 10	2,500
Participant 16	Female	African	38	12	Grade 10	1,500
Participant 17	Female	African	27	2	Grade 9	1,500
Participant 18	Female	African	34	9	Grade 10	1,500

Note: 1 USD = 18.7 ZAR

Emerging themes and subthemes

In responding to questions regarding their occupational challenges, participants reported various challenges, which were categorized into four themes: reception by the community, lack of cooperation from clients and their family members, unsupportive healthcare professionals, and unfavorable conditions of employment. Table 2 below presents these themes, further introduced and discussed later.

Table 2: Themes and Subthemes

Theme	Subtheme
Theme 1: Reception by the community	
Theme 2: Lack of cooperation from the clients and their family members	*Subtheme 2.1: Dealing with clients with unstable moods.* *Subtheme 2.2: Challenges of managing non-compliant clients.* *Subtheme 2.3: Family members who neglect clients and rely on caregivers.*
Theme 3: Unsupportive healthcare professionals	
Theme 4: Unfavorable conditions of employment	*Subtheme 4.1: Exposure to unsafe environments* *Subtheme 4.2: The risk of infection to HIV, TB* *Subtheme 4.3: Lack of transport* *Subtheme 4.4: Being overworked with no decent stipend.*

Theme 1: Reception by the community

Caregivers reported that reception by the community was terrible, with community members being suspicious that they were infected with HIV. Furthermore, community members did not want to welcome caregivers into their households; neither did they want to associate with them due to fear of stigma. In some instances, these community members would actively stigmatize the caregivers.

Subtheme 1.1: Community members who thought caregivers were also living with HIV.

Caregivers explained that some community members suspected that they were living with HIV.

Participant 1 had this to say:

> *"I was wearing a WWS T-shirt* [caregivers' uniform] in the salon. *So those people were not talking to me, but I could hear them talking about me. They said at WWS* (the CHBC, to which she was attached) *that only employed people are sick, which is why they can care for other sick people."*

Participant 2 explained the reaction of some community members:

> *"They look at you in a negative light and begin to think that you will infect them."*

Like her colleagues, Participant 7 felt that community members thought they were also sick:

> *"I think they think we are sick as well, and maybe we have HIV."*

Participant 16 also explained her encounters:

> *"I happened to find myself in a house where I found this man whom I explained the purpose of my visit, and he told me that his child does not eat milk for HIV-positive people. My purpose there had nothing to do with HIV but ordinary milk. My heart was so painful for some time."*

Subtheme 1.2: Unwelcoming households

Another challenge experienced by caregivers was being unwelcome in the households. Participant 4 explained how she was not welcome:

> *"…. We can see that we are not welcome by how they talk to us and how they look at us. When you explain that you are so and so from hospice, they won't wait for you to finish. They would just say, I am busy."*

During the interview with Participant 11, she also referred to being unwelcome:

> *"When they see you approaching them, they make excuses to get away from you. They immediately develop reasons or excuses to go away. Some will tell you that they are going out, and the other will tell you that she will bathe the child. They don't want to wait and hear what you say."*

Participant 8 experienced both the positive and negative experiences of treatment by family members:

> *"Some of them would welcome us, and some do not. The moment you come and introduce yourself, they would simply say I am busy; I do not have time. Obviously, she does not even give you a chance to explain."*

Our interview with Participant 13 revealed how family members would sneak away when caregivers were coming:

> *"Challenges are when you walk in someone's sneaks when you knock, and they close the doors."*

Subtheme 1.3: Community members do not want to associate with caregivers due to fear of stigma.

In addition to being unwelcome in the households, people refrained from associating themselves with the caregivers due to fear of stigma. Participant 9 explained her displeasure with the way people did not want to associate with them because of stigma:

> *"When people see us in blue and white uniform, they think we have AIDS. We always experience that kind of stigma and discrimination."*

Participant 14 also alluded to the fear of stigma:

> *"…And then the main thing that does not get well with me is that stigma does not come to an end. If people could tolerate HIV and realize that we are there to help them."*

Participant 5 explained how a marked vehicle that they used to visit clients became a symbol of stigma:

> *"…. as we normally knock and start by telling them that we are from a home-based care, then they would respond by saying we [referring to caregivers] are not the nurses."*

Participant 15 thought the fear of stigma is still eminent even today:

> *"I think sometimes the fear of stigma is so bad that up to today, I am staying in a block of flats with 54 flats, and not one of them, even if I put a notice on my door, will approach me directly and say, I am HIV positive. I think they are just scared to come to my front door so that other people will see that they approached me. I have met some of them at the clinics, but where I stay, they don't want to be associated with me because of the stigma."*

Subtheme 1.4: Stigmatization of caregivers by community members

Besides being avoided by members of the community due to fear of stigma, caregivers also reported that they were subjected to stigma due to their involvement with PLWHIV. Participant 9 told the researcher that they would be labeled and called names:

> *"…those are the challenges we have that no longer make us feel free with the community because they take us like 'kaaknurse"* [Afrikaans for nurses who clean poo or feces].

Participant 17 was undermined by the kind of work she was doing and the salary that she earned:

> *"What I do not like is the way people look at me. Some undermine me. They would say Oh, she is working there…. Maybe it is because I am not getting enough salary, I am not driving a car, and you are always on my feet. Others would just look at how you dress and say she works for free there."*

Participant 14 reported how caregivers are taken for granted and subjected to stigma and discrimination:

> *"Caregivers are taken for granted. And that they are nothing, especially to see their significance, but the important thing is that it is not all who discriminate against them. Yes, there is stigma and discrimination, but not everyone is like that. Most don't like us, but they call us when they are in trouble. They know we help people but don't want to welcome you."*

Unlike their colleagues, Participants 16 and 14 were well treated. Participant 16 had this to say,

> *"Well, to my side, they treat me well."*

In the case of Participant 14, members of the community were welcoming:

> *"Yes, out of the six that were planting our goodness, people started to refer clients, and the health sector also increased its scope in providing ARVs. So, this assisted us a lot, and the community started to accept us because when we go to a client who has denied, for instance, they have issued some ARVs on time… So now I can say we are generally accepted in the community."*

Theme 2: Lack of cooperation from the clients and their family members

Other participants' response was the lack of collaboration between clients and family members. Their experiences involved dealing with clients with unstable moods managing non-compliant clients and families who neglected their clients.

Subtheme 2.1: Dealing with clients with unstable moods.

In their endeavor to render care and support services to clients and family members, caregivers had to deal with clients who were moody and difficult to manage.

For Participant 13, the clients' moodiness took the form of being impatient and shouting:

> *"Sometimes other clients are impatient. When we try to speak to the client, she doesn't respond, and when we take a break, waiting for the water to be hot so that we can give her a bath, she shouts at us, saying, 'Why are you sitting there? Get in here and do your work.' Such things…. "*

Participant 18 was dealing with a stubborn client:

> *"And sometimes you find that the client is stubborn and always insults the family. And the family as well retaliates by disowning the family."*

Unlike her colleagues, Participant 17 reported that although clients were sometimes moody, their behavior was understandable given the stress that they were experiencing:

> *"We take it like it's a stress of being a client; sometimes a client has moods."*

For Participant 11, some clients would simply lie to them and say there is no client in their households even if the caregiver can see that the person who is talking is the client:

> *"You can visit a particular household, introduce yourself, and explain that you are from so and so organization and what your purpose is. Sometimes, you could see that the same person you are talking to is a client, and yet you would find her saying we do not have a client in this house. So, you can't say you are lying you are a client. You simply pass."*

Subtheme 2.2: Challenges of managing non-compliant clients.

In addition to clients who were moody and difficult to manage, caregivers were also subjected to clients who were non-compliant with their treatment and who did not take their advice, and this posed a challenge to their occupational duties and often resulted in frustrations.

Among the participants who experienced difficulties with non-compliant clients was Participant 18:

> *"Some you will find that a wife takes her treatment and the man* [husband] *does not want to. Some men would take their treatment and start complaining that they are now developing some breasts and eventually leave it."*

For Participant 15, non-compliance was sometimes due to the client's negligent:

> *"… it's either somebody in the family was negligent after finding out the status and lived recklessly or didn't comply."*

In the case of Participant 10, it was highly disappointing to work with a client and later learn that he had defaulted despite the support and advice that was given:

> *"What I hate is a client who defaults even after you have supported and explained to them the importance of adhering to the treatment as prescribed and even advised them on the clinic where they are supposed to go. The next time she is supposed to go to the clinic, she waits for you to come and take her there."*

Participant 12 reported that the non-compliant clients were frustrating their family members, who would then share their frustrations with her:

> *"Some would come to me and tell me that they are trying to encourage the client to protect herself, but she does not listen to them."*

Subtheme 2.3: Family members who neglect clients and rely on caregivers.

Alongside moody and non-compliant clients, caregivers were dealing with family members who would neglect the clients and rely on them for care and support.

Participant 2 explained how some family members would remain uninvolved in caring for the client even though caregivers took time to explain the importance of their involvement:

> *"Currently, I am caring for a client staying with her aunt. Sometimes, I would not go there due to ill health. So, when I got there, I would find the client in wet clothes with dirty nappies, and when I asked her aunt why she didn't assist the client, she simply said, nobody pays me. You are getting paid, so you must do it. And sometimes she would even break my heart by saying things like but why can't this client of yours die?"*

Participant 11 also shared sentiments similar to Participant 2:

> *"They have some people in the household, but nobody cares. So even when there are people in the house, they wait for us as if the client is not a member of their own family. So, when we first enter the household, we explain to them that we have our own fifty percent and you as a family have your share of fifty percent of responsibility."*

In another interview, Participant 8 also attested to the family members' reliance on caregivers:

> *"You will find that, for example, if* [I am the one] *who is sick, they will take me to the clinic not knowing what the problem is, and immediately after diagnosis, the family rejects me. So instead of getting some help from my own family, I would be helped by people from the streets."*

Theme 3: Unsupportive healthcare professionals

Interacting with healthcare professionals is essential for caregivers to succeed in rendering services to clients and their families. However, as the participants revealed, they sometimes met unsupportive healthcare professionals.

Regarding healthcare professionals, Participant 1 said:

> *"By then, we had a sister* [a nurse] *who was a bit young, and we told her that the family requested us to get the client admitted to X hospice, and the sister did not take us seriously. So it happened that the client died, and the family started blaming us... Although I felt like our sister was wrong in that case. She should have allowed the client to go there because when they are there, their treatment routine is closely monitored."*

In the case of Participant 18, the unwelcoming attitude of a sister (a nurse) was a concern:

> *"The sister in charge asked me where I got this type of client, and I explained that her old mother called me to come and help. She then asked me why you don't take her to S* [a different clinic] *where she comes from."*

For Participant 4, healthcare personnel would not be considerate of the fact that she is a caregiver who has accompanied a client:

> *"For our clinic, I work directly with them. I've encountered numerous occasions where they'll treat you as stupid when you walk in. From reception, you came in with a client; why must you bring the client here? Then you'll explain why the client comes. Okay, you can sit there and wait; the client must be here. And I'll say no, I can't sit there and wait. I*

> *didn't come here to sit here and wait. I came here to assist the client. Then they will ask to assist with what?"*

Participant 17 was disappointed in the clinic staff:

> *"…for me to take them there* (to the clinic) *is another problem as they would look down at me because I just come and expect them to do their job in a certain way, which is disappointing. Maybe for me to go and advocate for that person is disappointing…. But somewhere, we have a good network with clinics and other places where they can get help."*

Similar views were uttered by Participant 11, who said:

> *"Sometimes sisters* [nurses] *undermine us because we are caregivers. Mainly, as we do our job, we come across some clients who need to be taken to the clinic, and once we arrive at the clinic, you would find sisters who would undermine us as caregivers because our work is odd and it appears as if we are not human beings."*

Contrary to her colleagues, Participant 9 experienced support from clinic officials:

> *Sisters* [nurses] *are helping us. They encourage us and help us solve other problems.*

Theme 4: Unfavorable conditions of employment

Unfavorable working conditions of employment were also highlighted as one of the operational challenges, with caregivers pointing to their exposure to unsafe environments, risk of being infected with HIV and TB, lack of transport, and being overworked without a decent stipend or salary.

Subtheme 4.1: Exposure to unsafe environments

Exposure to unsafe environments unmerged in various forms, with participants reporting that they sometimes get exposed to rape as well as unsafe communities.

Participant 1 was afraid of visiting a male client when he was with another male friend due to fear of being raped:

> *"So, I resolved that whenever this guy visits my client, I am not going because I was scared for my safety. I was lucky he was my neighbor, so I could see and know the times they normally met when he was alone. I raised it with my seniors, but no one took me seriously. I was scared but did not show them* [the two males] *that I was scared. I had to share it with my colleagues and not my husband because I knew my husband would say I must leave this work…."*

In another interview, Participant 18 explained the unsafety of visiting clients during the night:

> *"The only challenge is when I stay far from the client, who must take treatment at 8:00 p.m., as walking late at night would not be safe."*

In Participant 12's case, her main concern was exposure to rape:

> *"Some would take such an advantage of seeing us as women and close the doors and attempt to rape you."*

For Participant 14, performing their duties safely was her main priority:

> *"We know that clients need our attention, but we also need to keep ourselves safe to continue to serve the community."*

Subtheme 4.2: The risk of infection to HIV, TB

Given the modes of HIV and TB infection, the risk is always present among people who are exposed to clients suffering from these conditions. This was also a primary concern for participants of this study.

Participant 7 reported her concerns regarding being infected with HIV and TB as follows:

> *"We then called the ambulance to come and collect the client and take him to the hospital. When the client goes to the clinic, it is confirmed that they have contracted TB. This means that I was close to the client before knowing that they were infected with TB."*

Fear of infection was also raised by Participant 15:

> *"My biggest fear is that we could easily become infected. This is risky for us…"*

In another interview, Participant 4 said she needed training to prevent infections:

> *"We want to be trained in counseling so that we can help our clients confidently and without fear of contracting any disease."*

Participant 8 also alluded to fear of contracting HIV when she started caring for PLWHIV:

> *"There was a period where I even got frightened because when I enrolled for nursing, the only life-threatening disease that I knew of was AIDS…"*

Subtheme 4.3: Lack of transport

Unfavorable working conditions for caregivers also resulted from a lack of transport. Participant 18 told the researcher that:

> *"What we need most as caregivers is transport because most of the time we walk and our lives are in danger because we ask for a ride to get there. … sometimes we can't help a client because of lack of knowledge so that it could be helped by transport."*

Another participant who alluded to transport-related challenges was Participant 10:

> *"We do not have a transport to take us to the field. If you get a client injured, you must use your airtime to call an ambulance…"*

For Participant 14, transport used to be an issue for them, but it was later resolved:

> *"Knowing that I have four clients who are all bedridden and that they are all scattered, it was a serious challenge for us, but it has been solved now because we have got vehicles to reach them."*

Subtheme 4.4: Being overworked with no decent stipend or salary

What also emerged as a concern for the participants was that they were overworked but not adequately remunerated.

Participant 9 spoke about being overworked by saying:

> *"Caring for caregivers is the most important thing because you think they have had a huge workload for the past two months."*

Participant 12 was concerned about a low stipend and being overworked:

> *"For example, our stipend is very low, and it happened that during December, we were working through skeleton staff, only to find that only caregivers were here."*

In the case of Participant 16, being paid low stipend was one of the reasons for her to consider leaving the organization:

> *"Well, sometimes, because of pressure, you can even [think] about going because when we talk about the stipend, we are talking about something that is not sustainable because it does not have any increase and there are no benefits…."*

Participant 10 explained that stipend is also an issue in other organizations:

> *"Other caregivers from other organizations are also complaining about…stipends."*

Discussion

The overall purpose of this study was to explore the occupational challenges faced by caregivers caring for PLWHIV. From the interviews conducted with eighteen caregivers, the research findings gave rise to four main themes: Reception by the community, Lack of cooperation from the clients and their family members, Unsupportive healthcare professionals, and Unfavorable conditions of employment, which are further analyzed below in the context of existing literature.

Bad reception by members of the community

Poor reception of caregivers by community members, who believed that they were caring for PLWHIV because they were also infected, made the caregivers' work difficult. By closing doors and preventing caregivers from entering their houses, community members sought to avoid any association with these caregivers. This practice points to the power of HIV-related stigma, with the potential to strain relationships and available support systems (Mitchell et al., 2022). Stigma can, among others, be experienced through avoidance, exclusion, discrimination, reluctance to assist, and fear of adverse treatment by members of the public (Wu et al., 2015). In the context of this study, community members were preventing possible adverse treatment by the public. Wu et al. (2015) investigated network stigma toward PLWHIV and their caregivers in Guangxi, China. One of the lessons from their study was that close relationships between PLWHIV and their caregivers reduced the level of anticipated stigma (i.e., the stigma expected from members of the public). This may suggest that the adverse treatment received by the caregivers from community members indicated that the relationship between the caregivers and their clients was not close enough.

Despite the challenges of rejection by the community members, some positive aspects were associated with the difficulties experienced by the caregivers. A South African study that examined the positive, existential, or negative roles and expectations influencing HIV caregiving, for instance, found caregivers to be resilient in responding to HIV-related stigma (Mieh et al., 2013). One of the lessons highlighted by this study was that caregivers demonstrate resilience in responding to HIV and its related stigma. Furthermore, South Africa has, through the National Strategic Plan (2023-2028), prioritized the reduction of stigma and discrimination to advance rights and access to services, therefore making it challenging to continue the stigma (South African National AIDS Council [SANAC], 2023). In Lesotho, Nyaphisi and Obioha (2015) investigated the challenges of HIV and AIDS-related community home-based healthcare delivery and reported similar findings, with community members, chiefs, and family members being unwelcoming towards caregivers and chiefs refusing to assist caregivers when organizing community meetings. In dignifying caregivers and clients, their study drew attention to the need for social policies that govern HCBC programs and food security for both PLWHIV and their caregivers (Nyaphisi & Obioha, 2015).

Uncooperative clients and family members

Concern regarding uncooperative clients and their family members was also a common issue raised by the participants, with some clients, reported to be moody and some simply not complying with their prescribed treatment. Sometimes, family members would be uninvolved in caring for and supporting the clients and leave them for the caregivers. This is despite the overall aim of caregiving being to provide care and support to both the clients and their family members. The issue of uncooperative clients and family members should be considered within a broader context of CHBC as a social problem, with factors such as limited knowledge and fear of stigma in mind. The revelations on uncooperative family members and clients showed that Larki and Roudsari (2020) view CHBC as promoting family solidarity by preserving traditional care patterns that encourage family members to take responsibility in caring for the client, which should be considered with caution. However, it was encouraging that these participants did not allow such experiences to undermine their crucial responsibilities of caring for and supporting PLWHIV. They were apparent in their mission of delivering much-needed care to clients regardless of their challenges.

Larki and Roudsari (2020) also pointed to the negative attitudes that family members of PLHIV have towards them to the extent that they would even isolate these clients. Despite these negative attitudes and the isolation of clients, the study also showed that CHBC programs involving the participation of families have the potential to spread knowledge and awareness around issues of HIV and to, in turn, improve their negative attitudes. On another note, Ogunmefun et al. (2011) argued that family members are stigmatized by associating with these clients, which in this instance may suggest that isolating the clients and not cooperating with the caregivers prevented the stigma from the broader community.

From the strengths-based perspective, it is essential to consider neglect of clients by families from a broader perspective of stigma, discrimination, and fear of HIV, as well as other enabling factors that keep caregivers continuing with their caring duties. Notwithstanding the reported lack of support for caregivers, existing evidence also points to the availability of support among caregivers through activism and organization encouraged by their need for communication, bonding, and self-empowerment (Mashau et al., 2015; Ransom & Asaki, 2013). A South African study of resilience among Gauteng-based caregivers of PLWHIV demonstrated mutual support characterized by mutual agreement to work as a team among caregivers in addressing client-related difficulties. The study also indicated that some clients showed their comprehension and appreciation of caregivers' services by cooperating with them (Mokoena, 2014).

Unsupportive healthcare professionals

Lack of support from healthcare professionals was also flagged as an issue bothering the caregivers despite the importance of their community-based services, which often reach remote areas inaccessible to healthcare professionals such as nurses. In such instances, one would expect overwhelming and cooperative support from healthcare professionals and caregivers. Unfortunately, that was not the case. In this context, Carries et al. (2023) report that caregivers are undermined due to factors such as poverty, stigma, and lack of support. Generally, working with PLWHIV is a community effort involving professionals like nurses to oversee the caregivers' work and provide support where necessary. Ironically, what this study revealed is contrary to this general practice. It is also contrary to some parts of existing literature that point to caregiver support from nurses (Mokoena, 2014; Murphy et al., 2021). Mokoena (2014) pointed to the various support initiatives provided by nurses, with some assisting caregivers with gloves and masks, though they were not enough.

Support that is provided to these caregivers remains inadequate, given the challenges that they are facing. A Malawian study of support for caregivers of PLWHIV in Lilongwe by Dippenaar et al. (2011) pointed to a variety of caregivers' need for practical assistance, money, food, relief of caring for the clients, treatment and education, infection prevention as well as prayers and counseling. Some caregivers even felt that nurses should visit the clients with them and listen to their issues to offer the necessary mental support. Whereas some participants were concerned about nurses' failure to visit their clients since they enrolled in treatment, some felt that nurses could be crucial in educating them on adequately caring for their clients (Dippenaar et al., 2011).

Although caregivers who participated in a South African study of the impact of psychosocial well-being of caregivers by Valjee and van Dyk (2014) alluded to a lack of support from the government, they did not move to the extent of naming nurses from the clinics as participants of this study did. Concerns raised by caregivers regarding the lack of support from nurses should also be considered in a broader spectrum of healthcare-related challenges, including the emotional and physical strain, burnout, stress, and exhaustion suffered by nurses themselves due to the shortage of staff (Moshidi et al., 2021). A review of roles, barriers, and recommendations for HIV community-based caregivers in Sub-Saharan Africa by Ngcobo et al. (2022), for instance, demonstrated the frustrations experienced by nurses themselves, who, among others, were infuriated by the absence of structured platforms for raising concerns about the work of caregivers. Therefore, what complicates the caregivers' support needs is that nurses also need such psychosocial support.

Although a lack of support from nurses may result in a knowledge gap among the caregivers and expose them to the risk of infection, particularly if the necessary precautions are not followed, it may also be a positive factor in encouraging caregivers to remain independent. The Networking HIV & AIDS Community of Southern Africa (NACOSA) (2013) highlighted some experiences and expertise caregivers possess that enable them to continue rendering services even in impoverished and isolated communities.

Unfavorable conditions of employment

It also emerged that caregivers were confronted by unfavorable working conditions, particularly exposure to HIV and TB infections and lack of transport and other resources. These experiences occurred in response to calls by some researchers to improve the conditions in which caregivers work (Dippenaar et al., 2011; Mokoena, 2014; Osafo et al., 2017).

A lack of transport is common in many African communities, but it is worse in under-resourced communities where CHBC organizations are located (Mashau et al., 2015; Nyaphisi & Obiola, 2015; Osafo et al., 2017; Pindani et al., 2013). A Lesotho's Roma Valley study of the challenges of HIV-related CHBC, for instance, found lack of transport as a major obstacle hampering the success of CHBC and preventing nurses, social workers, counselors, and caregivers from attending community visits (Nyaphisi & Obioha, 2015). In some studies, caregivers complained about transport and walked long distances on foot without adequate food and the necessary equipment like a first aid kit (Mokoena, 2014; Ngcobo et al., 2022). Lack of transport also hampered access to rural villages needing crucial CHBC services (Nyaphisi & Obioha, 2015). In Malawi, a study of the perceptions of PLWHIV regarding CHBC also pointed to transport-related challenges that hampered the caregivers' referral system, resulting in clients taking up to a week to be transferred to the hospital (Pindani et al., 2013).

Linked to transport-related challenges was the exposure of female caregivers to risk of safety issues like rape, lack of decent stipend, and being overworked, which confirmed the findings of some previous studies (Valjee & van Dyk, 2014). Considering these challenges from a strength perspective, it is essential to note the UNAIDS' (2021) observation that health workers, social workers, and unpaid caregivers remain available even though they work in unsafe and exploitative working conditions while underpaid, under-resourced, and underappreciated during the most acute phases of the crises. In Morton et al.'s (2018) South African study of structural barriers to South African volunteer home-based caregivers, caregivers reported several challenges, including a lack of stipend. They called for a reduction of their working hours. In Ngcobo et al. (2022), it was revealed that caregivers were poorly integrated into the mainstream healthcare system, particularly the clinic-based HIV treatment facilities. These reflected the strengths through their willingness to continue providing services to PLWHIV despite a lack of proper remuneration. They could simply quit in silence if they were unwilling to continue.

The strength-based perspective reminds us that besides these challenges, some positive factors keep caregivers to continue caring for their clients. By merely participating in these challenging conditions, caregivers demonstrated their resilient mechanisms. However, in a different context, a study of African American gay and bisexual men in house and ball communities found that by merely participating in these communities, volunteers demonstrated social support and the spirit of volunteerism (Kubicek et al., 2013). The same argument can be submitted regarding caregivers whose involvement in caregiving reflects the spirit of commitment to their course. The coexistence of challenges, strengths, and opportunities was shown in other studies, such as Kubicek et al. (2013), where homophobia and related stresses resulted in distress associated with suicidality, anxiety, guilt, sexual problems, and the need for social support from other social outlets. These issues, in turn, became sources of resilience or protection from adverse outcomes associated with stigma and discrimination.

Despite the issues raised by the participants, some positive elements were demonstrated through the passion to render care and support in the context of these hardships (Nyaphisi & Obioha, 2015). Participants of this study pointed to various challenges but did not report that they intended to resign from caring for PLWHIV. Instead of leaning on the negatives, they remained committed, with some hoping that people would ultimately tolerate HIV and realize the importance of their services. However, these positive reports do not undermine existing evidence of the pressures and despondencies experienced by some caregivers due to low wages, rejection by the community, and lack of resources and support (Mamukeyani, 2021; Morton et al., 2018).

Conclusions and recommendations

This study reported that community home-based caregivers are exposed to various occupational challenges, such as poor reception and lack of appreciation for their contribution by the clients, clients' family members, and some community members. They work with limited or no resources under potentially harmful conditions while exposed to rape and other risks and lack support from some healthcare professionals, particularly the nurses. As champions of psychosocial support, particularly for vulnerable people like caregivers, social work can be the first line of intervention by executing the following:

- Rendering psychosocial programs to support caregivers in managing their occupational challenges.

- Conducting more awareness campaigns and programs to educate the communities about the problem of HIV-related stigma and the value of supporting and protecting caregivers who are doing a caring job.

- Frontline social workers should facilitate partnerships between caregivers, local healthcare professionals, family members, and other community stakeholders to enhance cooperation and support for the CHBC work.

Strengths, limitations, and implications

This study bridges a knowledge gap around the occupational challenges caregivers face in South Africa. Although it was conducted among a relatively small sample, interpretation of the findings can be done cautiously and applied in other settings, particularly given a detailed description of the methods and the process followed. The study highlighted CHBC as one of the crucial health services. Yet, it is not adequately resourced and supported to effectively improve the lives of clients and their families and the working conditions of the caregivers.

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References

Aantjes, C., Quinlan, T., & Bunders, J. (2014). Integration of community home based care programmes within national primary health care revitalisation strategies in Ethiopia, Malawi, South-Africa and Zambia: A comparative assessment. *Globalization and Health*, *10*(1), Article 85. https://doi.org/10.1186/s12992-014-0085-5

Belotto, M. J. (2018). Data analysis methods for qualitative research: Managing the Challenges of coding, interrater reliability, and thematic analysis. *The Qualitative Report*, *23*(11), 2622–2633. https://doi.org/10.46743/2160-3715/2018.3492

Caiels, J., Milne, A., & Beadle-Brown, J. (2021). Strengths-Based Approaches in Social Work and Social Care: Reviewing the evidence. *Journal of Long-term Care,* 401–422. https://doi.org/10.31389/jltc.102

Carries, S., Mkhwanazi, Z., Sigwadhi, L. N., Moshabela, M., Nyirenda, M., Goudge, J., & Govindasamy, D. (2023). An economic incentive package to support the wellbeing of caregivers of adolescents living with HIV during the COVID-19 pandemic in South Africa: A feasibility study protocol for a pilot randomised trial. *Pilot and Feasibility Studies*, *9*(1), Article 3. https://doi.org/10.1186/s40814-023-01237-x

Creswell, J. W. (2014). *Research design: Qualitative, quantitative and mixed methods approaches* (4th ed.). Sage.

Dako-Gyeke, M., Boateng, D. A., & Mills, A. A. (2018). The role of social work in the provision of healthcare in Africa. In N. Nortjié, W. A. Hoffman, & J. De Jongh (Eds.), *African perspectives on ethics for healthcare professionals* (pp. 107–118). Springer.

Dippenaar, J., Chinula, G., & Selaledi, B. M. (2011). Support for lay caregivers of patients with HIV and AIDS in Lilongwe, Malawi. *Africa Journal of Nursing and Midwifery*, *13*(1), 22–33. https://uir.unisa.ac.za/bitstream/10500/9065/1/ajnm_v13_n1_a4.pdf

Duda, S., Warburton, C., & Black, N. (2020). Contextual research. In M. Kurosu (Ed.), *Human-Computer interaction. Design and user experience* (pp. 34–49). Springer, Cham. https://doi.org/10.1007/978-3-030-49059-1_3

International Federation of Social Workers (IFSW). (2014, July). *Global definition of social work.* https://www.ifsw.org/what-is-social-work/global-definition-of-social-work/

Jnanathapaswi, S. G. (2021). *Thematic analysis & coding: An overview of the qualitative paradigm.* APH Publishing Corporation.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2019). *Communities at the centre – Defending rights, breaking barriers, reaching people with HIV services.* https://www.unaids.org/sites/default/files/media_asset/2019-global-AIDS-update_en.pdf

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2020). *HIV Prevention 2025 Roadmap: Getting on track to end AIDS as a public health threat by 2030.* https://www.unaids.org/sites/default/files/media_asset/prevention-2025-roadmap_en.pdf

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2021). *Unequal, unprepared, under threat. Why bold action against inequalities is needed to end AIDS, stop COVID-19 and prepare for future pandemics.* https://www.unaids.org/sites/default/files/media_asset/2021_WAD_report_en.pdf

Kubicek, K., McNeeley, M., Holloway, I. W., Weiss, G. B., & Kipke, M. D. (2013). "It's Like Our Own Little World": Resilience as a factor in participating in the ballroom community subculture. *AIDS and Behavior*, *17*(4), 1524–1539. https://doi.org/10.1007/s10461-012-0205-2

Larki, M., & Roudsari, R. L. (2020). Home-based care, the missing link in caring of patients living with HIV/AIDS and their family members: A narrative review. *PubMed*, *8*(3), 190–208. https://doi.org/10.30476/ijcbnm.2020.82771.1085

Lekganyane, M. R. (2020). Motivational factors for caring for people living with HIV in South Africa: Home-based caregivers' experiences. *Social Work*, *56*(4), 478–493. https://doi.org/10.15270/56-4-888

Lekganyane, M. R., & Alpaslan, N. (2019). Suggestions by home-based caregivers caring for people living with HIV and AIDS on how social workers could support them in managing their work-related challenges. *Social Work*, *55*(2), 141–156. https://doi.org/10.15270/55-2-712

Maher, C., Hadfield, M., Hutchings, M., & de Eyto, A. (2018). Ensuring rigor in qualitative data analysis: A design research approach to coding combining NVivo with traditional material methods. *International Journal of Qualitative Methods*, *17*(1). https://doi.org/10.1177/1609406918786362

Mamukeyani, E. (2021). Difficulties experienced by caregivers of HIV/AIDS orphans: A qualitative study for rural-based caregivers. *Open Access Library Journal*, *8*(6), Article e6721. https://doi.org/10.4236/oalib.1106721

Mashau, N. S., Netshandama, V. O., & Mudau, M. J. (2015). Voluntary home-based caregivers' perceived needs for support: A study in the Mutale Municipality in South Africa. *Journal of Social Sciences*, *44*(1), 66–71. https://doi.org/10.1080/09718923.2015.11893461

Mieh, T. M., Iwelunmor, J., & Airhihenbuwa, C. O. (2013). Home-based caregiving for people living with HIV/AIDS in South Africa. *Journal of Health Care for the Poor and Underserved*, *24*(2), 697–705. https://doi.org/10.1353/hpu.2013.0091

Mitchell, M. M., Hansen, E., Tseng, T. Y., Shen, M. R., Catanzarite, Z., Cruz-Oliver, D. M., Parker, L., & Knowlton, A. R. (2022). Caregiver role strain in caring for vulnerable persons living with HIV: Correlates of caregiver and care recipient reports. *AIDS Care*, *34*(10), 1314–1320. https://doi.org/10.1080/09540121.2021.1968997

Mokoena, R. (2014). *The resilience of caregivers at a Gauteng-based hospice with people living with HIV/AIDS.* [Master's thesis]. University of South Africa. https://uir.unisa.ac.za/bitstream/handle/10500/18405/dissertation_mokoena_r.pdf?sequence=1&isAllowed=y

Morton, D., Mayekiso, T., & Cunningham, P. (2018). Structural barriers to South African volunteer home-based caregivers providing quality care: The need for a policy for caregivers not affiliated to primary healthcare clinics. *African Journal of AIDS Research*, *17*(1), 47–53. https://doi.org/10.2989/16085906.2017.1397719

Moshabela, M., Sips, I., & Barten, F. (2015). Needs assessment for home-based care and the strengthening of social support networks: The role of community care workers in rural South Africa. *Global Health Action/Global Health Action. Supplement*, *8*(1), Article 29265. https://doi.org/10.3402/gha.v8.29265

Moshidi, M. L., Malema, R. N., Muthelo, L., & Mothiba, T. M. (2021). Provision of care to the people with HIV: Voices of professional nurses in the public hospitals of Limpopo Province, South Africa. *International Journal of Environmental Research and Public Health/International Journal of Environmental Research and Public Health*, *18*(6), Article 3112. https://doi.org/10.3390/ijerph18063112

Murphy, J., Moolla, A., Kgowedi, S., Mongwenyana, C., Mngadi, S., Ngcobo, N., Miot, J., Evans, D., & Pascoe, S. (2021). Community health worker models in South Africa: A qualitative study on policy implementation of the 2018/19 revised framework. *Health Policy and Planning*, *36*(4), 384–396. https://doi.org/10.1093/heapol/czaa172

Nassaji, H. (2015). Qualitative and descriptive research: Data type versus data analysis. *Language Teaching Research*, *19*(2), 129–132. https://doi.org/10.1177/1362168815572747

Ndebele, N., Mlambo, V. H., Molepo, J. N., & Sibiya, L. (2021). The South African health sector and the World Health Organization South Africa's health sector and its preparedness for the National Health Insurance (NHI): Challenges and opportunities. *European Journal of Economics, Law and Social Sciences, 2021*(1), 334–350. https://iipccl.org/wp-content/uploads/2022/03/Pages-from-023.pdf

Networking HIV & AIDS Community of Southern Africa (NACOSA). (2013, July). *Recognition for home-based carers.* https://www.nacosa.org.za/wp-content/uploads/2016/04/home_based_carers_position_paper_july_2013.pdf

Ngcobo, S., Scheepers, S., Mbatha, N., Grobler, E. & Rossouw, T. 2022. Rones, barriers, and recommendations for community health workers providing community-based HIV care in Sub-Saharan Africa: A review. *AIDS Patient Care and STDs, 36*(4), 130–144. https://doi.org/10.1089/apc.2022.0020

Nowell, L., Norris, J. M., White, D., & Moules, N. J. (2017). Thematic analysis. *International Journal of Qualitative Methods*, *16*(1). https://doi.org/10.1177/1609406917733847

Nyaphisi, M., & Obioha, E. E. (2015). Challenges of HIV and AIDS-related community home-based health care delivery system in Roma Valley, Lesotho. *Anthropological Notebooks*, *21*(1), 83–105. https://anthropological-notebooks.zrc-sazu.si/Notebooks/article/view/176

O'Brien, B., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine*, *89*(9), 1245–1251. https://doi.org/10.1097/acm.0000000000000388

Ogunmefun, C., Gilbert, L., & Schatz, E. (2010). Older female caregivers and HIV/AIDS-related secondary stigma in rural South Africa. *Journal of Cross-cultural Gerontology*, *26*(1), 85–102. https://doi.org/10.1007/s10823-010-9129-3

Oleribe, O. O., Momoh, J., Uzochukwu, B., Mbofana, F., Adebiyi, A. O., Barbera, T., Williams, R. J., & Taylor-Robinson, S. D. (2019). Identifying key challenges facing healthcare systems in Africa and potential solutions. *International Journal of General Medicine*, *12*, 395–403. https://doi.org/10.2147/ijgm.s223882

Osafo, J., Knizek, B. L., Mugisha, J., & Kinyanda, E. (2017). The experiences of caregivers of children living with HIV and AIDS in Uganda: A qualitative study. *Globalization and Health*, *13*(1), Article 72. https://doi.org/10.1186/s12992-017-0294-9

Pindani, M., Maluwa, A., Nkondo, M., Nyasulu, B. M., & Chilemba, W. (2013). Perception of people living with HIV and AIDS regarding home based care in Malawi. *Journal of AIDS & Clinical Research*, *4*(3), Article 1000201. https://doi.org/10.4172/2155-6113.1000201

Pulla, V. (2017). Strengths-based approach in social work: A distinct ethical advantage. *International Journal of Innovation, Creativity and Change*, *3*(2), 97–114. https://www.ijicc.net/images/Vol_3_iss_2_nov_2017/Pulla_2017.pdf

Ransom, P. E., & Asaki, B. (2013). Home-based caregivers in Africa: Alliance building, advocacy and policy environments. *Journal of Health and Human Services Administration*, *36*(3), 367–391. http://www.jstor.org/stable/23621805

Root, R., Van Wyngaard, A., & Whiteside, A. (2015). Reckoning HIV/AIDS care: A longitudinal study of community home-based caregivers and clients in Swaziland. *African Journal of AIDS Research*, *14*(3), 265–274. https://doi.org/10.2989/16085906.2015.1059864

Saleebey, D. (1996). The strengths perspective in social work practice: Extensions and cautions. *Social Work, 63*(4), 296–305. https://doi.org/10.1093/sw/41.3.296

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2017). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality and Quantity*, *52*(4), 1893–1907. https://doi.org/10.1007/s11135-017-0574-8

Simbayi, L. C., Zuma, K., Zungu, N., Moyo, S., Marinda, E., Jooste, S., Mabaso, M., Ramlagan, S., North, A., Van Zyl, J., Mohlabane, N., Dietrich, C., Naidoo, I., & the SABSSM V Team. (2019). *South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2017: Towards*

Achieving the UNAIDS 90-90-90 Targets. HSRC Press. https://hsrc.ac.za/uploads/pageContent/10779/SABSSM%20V.pdf

Simelela, N., Venter, F., Pillay, Y., & Barron, P. (2015). A political and social history of HIV in South Africa. *Current HIV/AIDS Reports*, *12*(2), 256–261. https://doi.org/10.1007/s11904-015-0259-7

South African National AIDS Council (SANAC). (2023, March). *National Strategic Plan for HIV, TB and STIs 2023-2028.* National Department of Health. https://sanac.org.za/wp-content/uploads/2023/05/SANAC-NSP-2023-2028-Web-Version.pdf

Statistics South Africa. (2021, July). *Statistical release: Mid-year population estimates.* https://www.statssa.gov.za/publications/P0302/P03022021.pdf

Valjee, L., & van Dyk, A. C. (2014). Impact of caring for people living with HIV on the psychosocial well-being of palliative caregivers. *Curationis*, *37*(1), Article a1201. https://doi.org/10.4102/curationis.v37i1.1201

Wanga, I., Helová, A., Abuogi, L., Bukusi, E. A., Nalwa, W., Akama, E., Odeny, T., Turan, J. M., & Onono, M. (2019). Acceptability of community-based mentor mothers to support HIV-positive pregnant women on antiretroviral treatment in western Kenya: A qualitative study. *BMC Pregnancy and Childbirth*, *19*(1), Article 288. https://doi.org/10.1186/s12884-019-2419-z

Wesonga, B. (2015). Components, practices and benefits of home based care of HIV and AIDS clients in Kenya: Butula Local community's perspective. *African Journal of Education and Social Sciences, 2*(2015). https://arjess.org/social-sciences-research/components-practices-and-benefits-of-home-based-care-of-hiv-and-aids-patients-in-kenya-butula-local-communitys-perspective.pdf

Wood, E., Zani, B., Esterhuizen, T., & Young, T. (2018). Nurse led home-based care for people with HIV/AIDS. *BMC Health Services Research*, *18*(1), Article 219. https://doi.org/10.1186/s12913-018-3002-4

World Health Organization (WHO). (2017, June). *The African Regional Health Report.* https://www.afro.who.int/sites/default/files/2017-06/african_regional_health_report2006_0.pdf

Wu, F., He, X., Guida, J., Xu, Y., & Liu, H. (2015). Network stigma towards people living with HIV/AIDS and their caregivers: An egocentric network study. *Global Public Health*, *10*(9), 1032–1045. https://doi.org/10.1080/17441692.2014.1003572