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

MR Lekganyane ORCID iD is 0000-0001-8434-7885

AH Alpaslan ORCID iD is 0000-0002-7049-0805

Maditobane Robert Lekganyane, AH (Nicky) Alpaslan

A lacuna in the indigenous social work literature on how home-based caregivers caring for people living with HIV and AIDS (PLWHA) would like to be supported by social workers in their caregiving duties led to the launching of a qualitative investigation. This investigation was conducted in South Africa to look into (i) the challenges experienced by caregivers in exercising their duties of caring for PLWHA, (ii) how they manage such challenges, and (iii) suggestions on how social workers can support them. This article presents findings specifically pertaining to suggestions made by the caregivers on how social workers can support them.

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

Maditobane Robert Lekganyane, Nicky Alpaslan

MR Lekganyane ORCID iD is 0000-0001-8434-7885

AH Alpaslan ORCID iD is 0000-0002-7049-0805

Dr Maditobane Robert Lekganyane, Department of Social Work, University of South Africa, Pretoria, South Africa.

Prof AH (Nicky) Alpaslan, Department of Social Work, University of South Africa, Pretoria, South Africa.

INTRODUCTION AND BACKGROUND

As public health care facilities face difficulties in managing a huge number of patients with AIDS-related conditions, home-based care (HBS) became an alternative form of relief for many of them (Campbell & Foulis, 2004:5; Friedman, Mothibe, Ogunmefun, & Mbatha, 2010:14; Mashau, Netshandama & Mudau, 2015:1; Qalinge, 2011:51; Tshabalala, 2008:1;World Health Organisation, 2010:15). In South Africa HBC remained largely informal until 1999, when Cabinet mandated the Departments of Social Development (DSD) and of Health (DOH) to oversee the implementation of the HBC programme (Friedman *et al.*, 2010:7). With a clear mandate to provide comprehensive health and social services to PLWHA ensuring their maximum comfort, functioning and health within or close to their homes (DSD 2006:1), caregivers became clearly visible in communities where they reached out to patients who missed their scheduled treatment. Such patients, as noted by Bester and Herbst (2010:460), can fit into one of the following three categories:

- **Category 1 patient:** Patients in category 1 do not exhibit any manifestation of opportunistic infections associated with AIDS. They normally meet with the caregiver either individually or as part of the group to receive antiretroviral (ARV) support. Antiretroviral support entails the necessary guidance and advice provided to patients who are on ARV treatment by the caregiver with the aim of ensuring the required compliance;

- **Category 2 patient:** These patients need nursing care from a professional and psychosocial care from a caregiver at least once a week.

- **Category 3 patient:** In this category one finds patients who are bedridden and need significant clinical care, which requires caregivers to pay at least two visits per week, one of which requires a professional nurse.

Given the multifaceted nature of HIV and AIDS, caregivers are generally involved in rendering multiple services to PLWHA and their families (Schietinger, 2005:37; Valjee & Van Dyk, 2014:1). Such duties entail, among other things: mediating between patients and clinics (Rödlach, 2009:243); caring for bedridden patients at their homes; providing practical help in using walking aids; and supporting patients' families (DSD, 2006:18; Tshabalala, 2008:7). They also provide symptomatic treatment of AIDS-related conditions (DSD, 2006:18). After the patients' death home-based caregivers (HBCGs) would continue to support families in the burial process by offering bereavement counselling as well as support to children and family members who are left behind (Akintola, 2005:19).

THE SIGNIFICANCE OF SOCIAL WORK SUPPORT FOR HBCGS

Lack of counselling, social support from relatives and communities, and inadequate care equipment and supplies to care for patients as reported by the participants in Kangethe's (2009b:118) study contribute to poor motivation and reduction of care productivity amongst the HBCGs. For HBC programmes to succeed, a high level of support is essential (Kangethe, 2009a:29). Furthermore, Jacques and Stegling (2004:191) imply that HBC programmes could hardly survive without social work involvement. On the contrary, the human suffering, for both patients and caregivers, will be exacerbated in the absence of the necessary material and psychosocial support from social workers.

Social workers have been involved with people affected by HIV since the early days of the epidemic. They have been instrumental in advocating for the clients' rights, participated in policy and programme development, and engaged stakeholders (Hampton, Buggy, Graves, McCann and Irwin (2017:92). This ties in with the definition of social work as provided by the International Federation of Social Work (in Thompson & Thompson, 2016:xxix) in part stating that "Social work is a profession and an academic discipline, based on practice and driven by social justice, human rights, collective responsibility and respect for diversity, aiming to promote social change and development, social cohesion, empowerment and liberation of people … to address challenges faced by human beings and to enhance their well-being."

The foregoing definition and the view expressed by Hampton *et al.* (2017:92) imply that social workers, from both practice and academia, need to be at the epicentre of HBC and address the challenges faced by caregivers and enhance their well-being through the application of various theories, structures and indigenous knowledge. Ideally, they would protect the rights of caregivers, address the social injustices confronting them, and lobby for collective responsibility in ensuring that caregivers, patients and their families receive the necessary support. Some authors (Hall, 2008:55; Jacobs & Lurie, 1984:89; Reckrey, Gettenberg, Ross, Kopke, Soriano & Ornstein, 2014:331) go as far as to describe the role of social workers in HBC as a distinguished one that cannot be performed by any other person. They serve as brokers who link patients with resources (Tshwarang & Malinga-Musamba, 2012:292) and act as the glue that links clients and families to various systems (Berzoff, Lucas, DeLuca, Gerbino, Browning, Foster & Chatchkes, 2006:46).

Such social work support for HBCGs seems to be critical given the clear documented evidence that care work for PLWHA, mainly done by women in predominantly patriarchal societies, is by nature stressful and discouraging (Grant & Parpart, 2011:504; Kolhi, Purohit, Karve, Bhalerao, Karvande, Rangan, Reddy, Paranjape & Sahay, 2012:1; Mashau *et al.*, 2015:1; Musangali, Daire & DeLorenzi, 2016:451; Rowan, Lynch, Randall & Johnson, 2015:59).

Caregivers are faced with the same stigma as PLWHA and they are also confronted with challenges facing their patients that are beyond their scope of practice (Akintola, 2005:16; Ama & Seloilwe, 2010:2; Kipp, Tindyebwa, Karamagi & Rubaale, 2006:694; Lekganyane, 2017:134; Mohammad & Gikonyo, 2005:4). For this reason Partab (2010:496) states that care work does not only require optimal care to patients with serious illnesses and functional impairments, but also entails care for the caregivers.

Given the mentioned work-related challenges encountered in executing their care duties and the need for "caring for the carer", the researchers embarked on a search for research-based literature in the field of social work on the topic of social work support to caregivers caring for PLWHA. This search led to the conclusion that there is silence on the topic of HBC, caregivers and caring for PLWHA from the social work sphere. The topic has been the focus of research in disciplines of public health (Akintola, 2008), psychology (Van Dyk, 2007; Valjee & Van Dyk, 2014), anthropology (Rödlach, 2009) and nursing (Ama & Seloilwe, 2010). Only three studies (Primo, 2007; Qalinge, 2011; Tsheboeng, 2015) conducted from a social work perspective touched on this topic.

This led the first author to ask if there is any link between the general absence of social workers in the field of HBC that he noticed during his time as a field social worker, and the scarcity of discipline-specific body of knowledge on the topic under scrutiny. For Creswell (2016:88), the lack of discipline-specific knowledge on a particular topic denotes the "need for more literature" since "the topic has been understudied", or that "there is little research on the topic". This led the researchers to embark on this research journey with the aim of exploring the work-related challenges of caregivers caring for PLWHA and how they manage these challenges. In addition, we envisaged eliciting suggestions from them as to how and with what they would like to be supported by social workers. Through this study the researchers intended to supplement the sparse body of knowledge on the topic from a social work perspective, as well as to inform social work practice, policy and future research.

THE THEORETICAL FRAMEWORK UNDERPINNING THE STUDY

In explaining the use of theory in a qualitative study (such as the one reported here), Wu, Thompson, Aroian, McQuaid, & Deatrick (2016:497; 498) state that theories serve as orientating and organising frameworks for exploring topical areas without imposing preconceived ideas and biases. In understanding the caregivers' experiences related to the management of their work-related challenges, as well as eliciting their suggestions for social support in this care work role, the researchers adopted as theoretical framework the middle-range theory of caregiving dynamics as developed by Loretta Williams (2003) from the field of nursing. Adoption of a theory from another discipline as theoretical framework for a social work study is not an uncommon practice in the realm of social work, according to Simpson (in Yegidis, Weinbach & Myers, 2018:15).

Loretta Williams, a registered nurse and a professor at the University of Texas, conceived the middle-range theory of caregiving from her inductive literature review. She considers the relationship between the caregiver and the patient as a caregiving trajectory, where commitment, expectation management and role negotiation (as forces) are of paramount importance for the growth and development of such a relationship (Williams, 2014:317; Williams, 2014:10). Where caregivers demonstrate commitment by way of dedicating themselves to the patient – prioritising their needs, being present to support them, displaying a positive attitude and self-affirming loving connection with their patients – the caring relationship flourishes (Williams, 2014:311; Williams, 2007:382).

Expectation management is a force identified by Williams (2014:313) that keeps the caregiving relationship on track. In managing expectations, the caregiver and the patient set out to envision tomorrow, get back to normal, take one day at a time, gauge behaviour, and reconcile the twists and turns of treatment (Williams, 2014:313; Williams, 2007:382-383). In envisioning tomorrow, the partners on this caregiving trajectory either project the future as hopeful when the treatment turns out to be working and the condition is improving, or respond with anxiety and fear that the condition will deteriorate (Williams, 2014:313; Williams, 2007:382).

When a sense of recovery is noticed, both the caregiver and the patient adopt the expectation of getting back to normal, believing that they can now get back to their normal lives. Where a patient develops the ability to self-care and performs all activities without reliance on the caregiver for assistance, the caregiver shifts her focus to personal interests (Williams, 2014:313; Williams, 2007:382). In further managing expectations, the caregiver and the patient also engage in what Williams refers to as "taking one day at a time". At this stage the relationship is focused on addressing a current challenge with fewer worries about the future, which is uncertain anyway (Williams, 2007:382-383; Williams, 2014:313).

Owing to the caregivers' intense involvement with patients, they are able to gauge their behaviour. In noticing behaviours from patients that could be threatening the caregiving dyad, they can respond accordingly (Williams, 2014:313; Williams, 2007:383). Reconciling the twist and turns of treatment is another dimension for managing expectations (Williams, 2007; 383; Williams, 2014:313). This entails the caregiver reconciling the fact that certain things are just beyond both her and patient's control by

simply accepting them as they are. In doing so, the caregiver accepts the fact that she is a human being with shortfalls and cannot address everything.

The third force driving the growth and development of the caregiver-care receiver relationship is role negotiation. In this regard the caregiver becomes involved in the activities of appropriate pushing, getting a handle on the caring responsibility, sharing responsibilities, attending or listening to the patient's voice, and vigilant bridging (Williams, 2014:315; Williams, 2007:383). With appropriate pushing, the caregiver ensures that the patient is appropriately 'pushed' to adhere to the rules and guidelines of treatment. In getting a handle on the caring responsibility, the caregiver adopts ways of coping and persevering with the demands of the care work and additional caregiving roles stemming from changes in the patient's condition (Williams, 2014:315; Williams, 2007:383). By sharing responsibilities, the caregiver assesses the patient's needs and determines who else should play part in addressing them and lobbies for their involvement (Williams 2014; Williams, 2007:383). In further maintaining role negotiation, the caregiver attends and listens to the patient's voice by prioritising the patient's views, opinions and preferences. Finally, role negotiation entails vigilant bridging – liaising with health care systems to address the patient's needs (Williams, 2014:615-Williams, 2007:384).

In addition to commitment and the activities of expectation management and role negotiating as forces driving the caregiver-care receiver dyad forward, Williams (2014:312) identified self-care, new insights and role support as the so-called "enablers" assisting the caregiver in the care work role.

Self-care requires the caregiver to remain healthy and fit, physically, psychologically, socially, emotionally and financially, enabling her to fulfil the caregiving commitments and activities (Williams 2014:312). Self-care is possible in a supportive physical environment: by cultivating healthy habits, 'letting it out' and 'getting away from it' (Williams, 2014:312). A supportive environment requires having physical accommodation, food and any other physical amenities available that would enhance their caregiving relationships. Cultivating healthy habits requires the caregiver to remain healthy enough to continue giving care to their patients. In 'letting it out' the caregiver finds ways of dealing with the frustrations and challenges that she comes across during the caring trajectory such as talking to a confidante, going out to a movie or consulting a professional for therapeutic interventions. Lastly, 'getting away from it' means caregivers get away from caring simply by taking breaks. They try to forget about their normal caregiving duties and focus more on themselves.

Through continued training and education, caregivers will keep their knowledge and skill-levels on aspects related to caregiving up to date. This will contribute to developing new insights, which will enable caregivers to remaining committed to the caregiving dyad. For caregivers to persevere in executing their caring duties, role support is required. Role support, according to Williams (2014:316), comes down to the following:

- Being assured of and having the patient's family and other parties' support available to ensure committed and optimal caregiving;

- Being aware of the fact that the caregiver cannot be a jack-of-all-trades in the caregiving dyad and that support can be enlisted to take up some caregiving duties and responsibilities, and share them;

- Experiencing or having a sense of knowing that others care about the caregiver. Such knowledge can sustain the commitment and perseverance on the side of the caregiver;

- Providing the material and financial resources required to meet the needs of both the patient and caregiver, and ensure the effective execution of the caregiving duties;

- Receiving helpful information about people in the community and other resources available that the caregiver can approach and employ to ensure the best care for the patient.

RESEARCH CONTEXT

The research was confined to three of the nine provinces in South Africa – Gauteng, North-West and Limpopo – because of financial constraints and the fact that the first author was tasked with the fieldwork responsibility. Twenty-five caregivers caring for PLWHA from 12 HIV and AIDS HBC organisations serving mainly rural black communities and townships were recruited purposively through snowball sampling and the use of formal and informal networks. The sampling selection criteria used were that participants had to be (i) 18 years or older; (ii) of any gender and racial group; and (iii) a caregiver who renders home-based care services to PLWHA under the auspices of an HBC organisation and be willing voluntarily to be interviewed and recorded. In the Limpopo province one organisation, which was serving a nearby township, was identified and three caregivers from this organisation offered to participate. In North-West province, four participants from two organisations, one serving a rural area and another serving a township, were recruited and agreed to participate. In Gauteng eighteen caregivers were recruited from nine organisations, with two of these organisations serving Pretoria central and surrounding areas, and seven serving townships around Pretoria.

RESEARCH METHOD

A qualitative research approach was adopted for this investigation; a qualitative research study investigates the meaning of people's lives in their real-world roles and explores the depth and complexity of the human experience (Morrow, 2005:209; Wu *et al.*, 2016:494). Within the qualitative research approach the researchers employed the collective instrumental case study and phenomenological research designs, complemented by an explorative, descriptive and contextual strategy of inquiry.

Individual, face-to-face, semi-structured interviews facilitated by five topical questions and additional probing were used for collecting data from the caregiver participants. Data were analysed thematically according to Tesch's (Creswell, 2014:198) eight steps of qualitative data analysis.

To ensure the trustworthiness of the research findings, the researchers inter alia applied triangulation to data methods and data sources, member checks and peer consultation, and an independent coder impartially analysed the collected data (Lietz & Zayas, 2010; Shenton & Hayter, 2004).

Ethical clearance for this study was obtained from UNISA's Social Work Departmental Ethics and Research Committee (DR&EC) (Ref No: DR&EC_05/06/13_33197083). Participants' consent (in writing) was obtained after they had been comprehensively informed about the aim, logistics and procedures of the research; they were informed that the information shared would be managed in a confidential manner; their identities would remain anonymous and they would be given pseudonyms. In addition, counselling would be offered should the need for debriefing arise.

THE RESEARCH FINDINGS

The research findings in a form of demographic data on the participants as well as the themes and sub-themes derive from the following topical question put to the participants: How and with what would you like social workers to assist you as caregivers caring for PLWHA?

Demographic data on the participants

Participants were mainly women (22 out of 25), with only one having a qualification beyond matric. Concerning the racial and gender particulars of the participants, two women participants were Coloured women; one woman, Indian; one White man, two Black men and the rest (19) were Black women. The participants' involvement in caring for PLWHA ranged from eight months to 23 years and their ages ranged from 28 to 58 years of age. The fact that 22 out of the 25 participants are female corroborates the existing body of evidence on caregivers who care for PLWHA (Marincowitz, Jackson, & Fehrsen, 2004; Orner, 2006:237; Schneider, Hlophe & Van Rensburg, 2008), which shows that an HBCG is generally a female, underscoring the view that caregiving is women's work (Akintola, 2005:6; Kolhi *et al.*, 2012; Maes & Kalofonos, 2013:57).

From the responses provided by participants on a topical question, six themes were identified and adopted after a consensus discussion between the authors and an independent coder. These themes are presented below.

Theme 1: HBCGs need psychosocial support from social workers

As skilled welfare officers, social workers should be involved throughout the caring process (Berkman, 1996:543) by addressing the psychosocial needs of the families (Ama & Seloiwe, 2010:1). The need for psychosocial support from social workers was the aspect most suggested by the participants. Their need for psychosocial support was further categorised resulting in the need for counselling, debriefing, and support groups emerging as subthemes. These ways of providing support to professionals in the field of AIDS work were also suggested by Emlet (1993:28).

Sub-theme 1.1: Counselling

Dineo, Mpshe, Letsatsi and Lenyalo were of the view that through counselling they will be empowered and become skilled to better cope with the bad treatment from some members of the community. They would have a platform to share their challenges and develop the courage to continue caring for PLWHA. Dineo was of the view that social workers should provide counselling to help them cope with the negative treatment form the community:

> *"I think she* [referring to a social worker] *must provide counselling with regard to the way in which the community members are treating us. She must try to help us how to deal with such treatment and give us support."*

Mpshe expressed similar sentiments by saying:

> "[If I was the] *social worker, the first thing I would do is to do counselling with caregivers … I would have spoken to them so that they can offload their challenges."*

For Letsatsi, the social worker should only render counselling to new caregivers:

> *"I think I will tell him* [referring to the a social worker] *to arrange for some counselling sessions for new care workers and ensure that those that are here for some time are also provided with counselling."*

In another interview Lenyalo said counselling would give them courage and support:

> *"I … think to consistently provide them with counselling and encourage them and support them on what they do."*

This call by caregivers for psychosocial support in the form of counselling will strengthen the forces paramount for the growth and development of the caregiver-receiver dyad as highlighted in the middle-range theory of caregiving dynamics as outlined by Williams (2014:317; 2014:10). Through counselling, the caregivers' commitment will be fuelled; they could benefit in the arena of expectation management, specifically in terms of helping (both themselves and the patient) in envisioning tomorrow, getting back to normal, taking it one day at a time, gauging behaviour and reconciling the twists and turns of treatment, as well as role negotiations.

When focusing on the aspect of counselling per se, Sheppard (2004:6) notes that being involved in a skilled and principled counselling relationship facilitates self- knowledge, emotional acceptance and growth, optimal personal resource development and an opportunity to work towards a more satisfactory and resourceful life. In counselling, the focus is on identifying and/or managing challenges related to decision-making and coping, generating insights and knowledge development, and working through feelings of inner conflict or improving relationships. Thus, through providing counselling to the caregivers, social workers can focus on self-care, assisting them to acquire new insights and provide role support, highlighted as enablers by Williams (2014:313) for the caregiver to continue throughout the caregiving process.

Several other researchers (Dow & McDonald, 2003:28; Jacques & Stegling, 2004:180) underscored the caregiver-participants' call for counselling in affirming that this is one avenue through which social workers can support caregivers. In Grant and Parbat's (2011:514) study on gender and home-based care for HIV and AIDS and TB patients in Zimbabwe's rural and urban areas, mention was made of emotional support as one of the interventions they were lacking. For Kangethe (2009b:118), lack of counselling for caregivers results in lack of guidance, direction and motivation and reduces the quality of care to patients. Kangethe (2008:360), in a study on the challenges that referral systems pose to caregiving in Botswana, found that caregivers who were caring for PLWHA lack counselling services that could provide psychological support. The participants were of the view that the counselling would equip them with knowledge, especially in terms of the correct interventions for their patients. Lack of counselling and encouragement were also found to be one of the challenges faced by caregivers who took part in Kangethe's (2009b:118) Botswana study of the critical challenges faced by caregivers of PLWHA and other terminally ill patients.

Sub-theme 1.2: Debriefing

Three participants (Paul, Selina and Zulu) referred to the aspect of debriefing as a means to provide psychosocial support to caregivers caring for PLWHA. Paul, referring to himself as a hypothetical social worker, explained how debriefing can help caregivers focus on themselves:

> *"I will firstly provide a debriefing session and then I also think that relaxation things. I will provide an opportunity where they can really be themselves and not in that role of caregiver. That they can be valued as a person in total not only ... [as] caregivers ... Because they also get stressed and have personal problems that they must deal with and how do you deal with those problems before you can deal with somebody else's problems."*

From Selina's perspective, quarterly debriefing sessions should be conducted to help them share their challenges. As she mentioned, referring to herself as a hypothetical social worker:

> *"I would have the quarterly debriefing sessions where I would sit down with them and interview them just like the way you are doing now so that we can talk about our challenges ... I think debriefing session can be very helpful".*

Zulu was straight to the point when coming to her need for debriefing:

> *"I would require assistance with debriefing sessions ... ."*

As defined by Mashau and Davhana-Maselesele (2009: 41), debriefing is "a process through which HIV and AIDS home-based caregivers can be able to verbalise their fears, pain and problems to a professional psychologist, who will in turn help them get treatment." It should be noted that in the context of this study, caregivers were very explicit that this debriefing should be provided by a social worker. The call for debriefing by the participants is not uncommon. Simpson (2006:43) recommended, based on her findings in her study as to whether caregivers for PLWHA receive sufficient psychosocial support, that debriefing form part of what she referred to as "an extensive care of the carer programme." Debriefing was also noted by Van Dyk (2007:424) as one of the means through which caregivers could be supported to better cope with the stress of working with PLHWA. Bester and Herbst (2010:459) suggest that debriefing opportunities be provided through supervision as a means of supporting caregivers to cope with burn-out or compassion fatigue.

Sub-theme 1.3: Support groups

Support groups were also mentioned as means to provide psychosocial support to caregivers caring for PLWHA. Vanessa spoke about this along the following lines:

> *"They* [referring to the caregivers] *need more group therapy. When I am saying group therapy, I mean learning to play games, because sometimes we are more serious and then you do not know how to relax. They need to be taught how to relax, how to let go of the day, every day, every single day. And they need to be taught to take care of themselves first, before they*

even go out there and give care, because when you give care you forget how to care for yourself."

Xhathula remarked,

"I believe maybe if we have our support groups she [referring to the social worker] *can come and encourage us and that will make us feel special to know that there are some who appreciate what we do, unlike those who do not see our help, seeing us as useless people who walk in the sun hanging bags…"*

Vanessa's and Xhathula's suggestions to have support groups for caregivers corroborate the WHO's (2013:71) proposal encouraging caregivers to form support groups so that they can share experiences and ideas on coping and caring for patients. Such support groups, as noted by Mashau and Davhana-Maselesele (2009:46), promote emotional support and afford caregivers the opportunity to share their experiences and support one another on how to cope with stressful events. Bester and Herbst (2010:465) endorse the idea of support groups when stating that caregivers should be trained on how to form support groups amongst themselves. Support groups, according to Toseland and Rivas (2014:20), foster mutual aid; enable members to cope with stressful life events; revitalise and enhance members' coping abilities for effective adaptation and coping with future stressful live events. In the context of a support group, caregivers can share how they cope with the various work-related challenges, learn from one another and acquire coping skills to be able to be more effective in their caring relationships (Steinberg, 2004). Support groups assist members to overcome feelings of alienation, stigmatisation and isolation, and in these groups their experiences are validated, affirmed and normalised (Toseland & Rivas 2014:23).

To sum up: support groups will provide opportunities to the caregiver caring for PLWHA to exercise self-care, which Williams (2014:313) regards as one of the enablers keeping the caregiver committed and will foster the forward movement, growth and development of the caregiving-care receiving dyad.

Theme 2: Suggestions for social workers to lobby for financial support on behalf of caregivers

Some of the participants, in sharing their suggestions on how to be supported by social workers, expressed the need for social workers to use their skills to lobby on their behalf for better stipends or salaries and financial support, either from within their organisations or by sourcing funds from companies outside their organisations.

Malume made her wish for social workers to assist very clear:

"Although is not about money, I would also say she/he [referring to the social worker] *could help us with money. Caregivers are earning a very low salary."*

The need for social workers to lobby for financial support also emerged in our interview with Selinah*:*

"… the issue of money is the main problem here. It is this issue that makes us to feel discouraged. R800 is a very little money for one to survive. I would suggest that the social worker work closer with management to represent the interests of caregivers."

Jini also wished that social workers could help with financial support*:*

"If I was the social worker … I'd ensure that they receive stipend like other caregivers because their work is strenuous too. I would advocate for them."

If she was a social worker, Vanessa would advocate for financial support:

"I would advocate or look into how they [caregivers] *can together get better salaries, more benefits on their side; education and with that more salary and benefits, which they can qualify in something."*

For Yena, using companies to give caregivers financial support may be helpful:

> *"[If I happen to be the social worker] I would try to get funds for them because there are lot of companies in South Africa, I would get them funds because we can't get money from one place to help this whole society but if there were funds to help these care workers."*

The participants' accounts in terms of financial support is confirmed by the participants in Akintola's (2005:21) study, where the caregivers expressed a general dissatisfaction about the lack of a stipend, which they believed should not necessarily be seen as a reward for their services, but as a token of appreciation to assist them in addressing some of their basic needs. Although caregivers who took part in Kangethe's (2009b:119) study did not directly express their need for financial support, they cited lack of motivation and feeling demoralised because of a lack of incentives, rewards or any form of motivation. For these participants, the lack of any incentive was the reason for caregiving work not being attractive to young men and women (Kangethe, 2009b:119). In addition, Rowan *et al.* (2015:61) point out that dissatisfaction with salaries, promotion and opportunities can be associated with burn-out.

Theme 3: Suggestions for social workers to advocate for the interests of caregivers
The participants also suggested that social workers could support them by taking on an advocacy role by representing them in management meetings to lobby their case, and through advocacy to enhance the level of appreciation of the caregivers' contribution to communities as well as educate the community to become involved in caring.

Zulu and Selinah were the ones who spoke about social workers supporting them by advocating for their interests at management meetings. Zulu remarked,

> *"I believe that if a social worker could plead our cases to our superiors, we might be able to get feedback faster."*

Selinah's take was for social workers to take on the role of a watchdog to protect the interest of the caregivers. She explained:

> *"I would suggest that the social worker work closer with management to represent the interests of caregivers. But I think if a social worker is closer to them, they would start doing the right thing. As it stands now, we do not know anything about the budget. The social worker would then confirm things like whether it is true that the Department of Health says they must give us R800. So, if there is someone like a social worker who represent the social workers at their meetings, they would now begin to do things the right way and the social worker would take part in the decision-making process on behalf of the caregivers."*

Given the informal nature of home-based care, which lacks organised labour structures such as unions and associations, it is not surprising for caregivers to call for social workers to be their representatives and lobby on their behalf to meet their interests. Giving social workers an advocacy role is not foreign to social work, as social workers are regarded as agents of change for improving the social function of both caregivers and the recipients of care (Hampton *et al.*, 2017:92; Zastrow, 2014:44).

For Selinah, Zulu and Malume, the support of social workers as their "advocates" should not only be limited to promoting and guarding the interests of the caregivers, but they were also of the view that social workers should intercede by appreciating their work and sensitising other role players to follow suit.

Selinah emphasised this when stating,

> *"She* [a social worker] *could also encourage us because we lack someone who can give us some courage by simply appreciating our work. We need words such as 'guys, you are doing a very good job' from social workers."*

Zulu added that appreciation of caregivers' work should be expressed through concerted efforts to help caregivers to address their needs:

> *"It might be possible for our needs to be addressed ... Maybe the social worker would be able to help us get these needs. At least that will make us to feel like we are making a difference."*

For Malume**,** the social worker was believed to be someone who would advocate for the interests of caregivers by making people realise the contributions that they make in the communities:

> *"I would expect him/her* [referring to the social worker] *to help us to be well recognised, to be appreciated so that people can see how big our contribution is."*

Malume's suggestion ties in with the fact that the communities they serve receive caregivers' caring for PLWHA with mixed emotions. Some caregiver-participants in Akintola's (2005:21) study on the role of volunteers in HBC for PLWHA reported that they are well known in their communities and highly appreciated for what they are doing, while others reported a lack of appreciation for their efforts. This is in spite of the fact that they have been involved for years in community development projects. Kangethe (2009b:119) cites a Thailand HBC programme that identified support and acknowledgement from the neighbourhood as a special need for caregivers.

Social workers, as noted by Strug, Grube and Beckerman (2008:9), are more skilled in empowering communities to assist with care in communities – especially their ability to enlist the support of community members to assist caregivers. In this regard, they can advocate for support for caregivers caring for PLWHA, but also educate communities about the caregivers' care work and how they could support and assist.

In an attempt to support caregivers caring for PLWHA in their communities, Tshwarang and Malinga-Musamba (2012:292) urge social workers to play a crucial role by mobilising for partnerships between caregivers and communities as an avenue for passing information to clients, their families and the entire community. Social workers can use public forums and community gatherings to educate the community on the work of HBGCs caring for PLWHA and how community members can offer support (Furstenberg & Olson, 2008:58). Such education drives are pivotal, as highlighted in Kangethe's (2009b:119) study on the topic of the challenges faced by caregivers in Botswana including the lack of support for caregivers by the community. This state of affairs prompted Kangethe (2009b:119) to recommend for advocacy and education, and to challenge men and youths to take part in home-based care and supplement the duties of caregivers, who are mainly older women. In Jacques and Stegling's (2004:178) view, not only should the community be involved in caring for AIDS patients, but also the family in order to open discussions around HIV prevention. Such initiatives launched in Uganda led to community-based support networks of lay people, community leaders and trained AIDS community workers to assist patients and caregivers (Jacques & Stegling, 2004:179). However, Jacques and Stegling (2004:179) caution that involving the community members should be approached carefully and in a calculated fashion, especially in communities where economic and gender imbalances prevail. In other words, in cases where there are economic and gender disparities, the focus should be directed towards recruiting individuals as caregivers from those groups who are underrepresented economically and in terms of gender.

Theme 4: Suggestions for social workers to handle cases that fall beyond caregivers' scope of practice

Especially when visiting their patients, caregivers caring for PLWHA often are confronted with complexities that are beyond their scope of practice. This is not surprising, in the light of the call by Reckrey *et al.* (2014:2) for social workers to help in addressing patients' unmet needs. Strug *et al.* (2008:6) admit that patients, in addition to being plagued by this pandemic, also encounter relationship challenges with lovers, friends and members of the extended family. They also experience disclosure dilemmas, family planning decisions and gender inequalities *(*Strug *et al.*, 2008:6). Some of the participants mentioned that they encountered challenges beyond their scope of practice and this is where they would like the support of social workers to intervene. One of the participants, Dineo, explained her wish for social workers to be placed in each HBC organisation:

"I wish each home-based care organisation can have a social worker so that they can help us with families that have some social problems like those with children who are without the birth certificates, children from foreign countries and so on. Sometimes you find families that do not have any income. There is nothing that we can offer apart from a small food parcel. So, I wish we could have a social worker."

Amelia felt that social workers should make time to understand their challenges:

"[If I was the social worker] … I would accompany the care workers to home visits so that I can understand their challenges. Where I see that there are problems, I would try to help."

Kgomo was very clear on how social workers could assist:

"I think she [referring to the social worker] *must help us with these patients who close doors and chase us away, and those families that do not take care of their patients. I wish social workers could provide them with some necessary counselling so that they can take responsibility for their patients."*

Pekwa explained how she would advise social workers, if given an opportunity:

"I would advise her [referring to the social worker] *to look into families that do not have income and whose patients cannot take medication due to lack of food and to those that do not receive any grant."*

Mokete described in detail his desire for social workers to handle cases not within their scope of practice:

"For example, if we go in the field we encounter a lot of social problems then we would refer them to her [referring to the social worker] *so that she can intervene from her level. So, next time when I visit the patient I would only deal with the health part of it … I should not look at the social and health problems like, for instance, when you get into the household, you find that the patient has some children and they do not receive any grant and they do not have birth certificates. So, you will be running to connect to Home Affairs and from Home Affairs to SASSA and all these things. So, I think if we have a social worker, we would be relieved and reduce a burden of work, because she may address other things easily through her networks. At least she is a professional and when she gets to those offices, they will understand that she is talking from their level. But if you go as a caregiver and not a professional, it becomes much difficult."*

The issues raised in relation to social workers handling cases that fall beyond the caregivers' scope of practice is not a new phenomenon. For example, Arno (1986:1327) states that social workers should liaise between the patient and relevant government departments and service providers for the benefit of the patient, as suggested by one of the participants, Mokete, above. For Reckrey *et al*. (2014:4), social workers should, among other things, liaise with local resources and agencies for the patients' benefit. In Mashau and Davhana-Maselesele (2009:45) home-based caregivers reported how their patients are poor and indicated the need for social workers to assist them with food parcels. In support of the experiences of participants like Kgomo quoted above, researchers (Primo, 2007:22; Valjee & Van Dyk, 2014:9) explain that caregivers are often stressed by, among other things, patients' difficult behaviour.

Theme 5: Suggestions for social workers to lobby for stakeholders and other professionals to assist the caregivers

This suggestion for social workers to lobby with stakeholders and other professionals to support the caregivers boils down to providing role support, as explained in the middle-range theory of caregiving dynamics (Williams, 2014; 2007; 2003) enabling them in their caregiving relationship. This theme emerged during our interviews with Lenyalo and Lenong.

For Lenyalo, a social worker could liaise with doctors in the interests of the patients.

"She may liaise with the doctors to help them get grant that can assist them."

In Lenong's view, social workers should play a liaising role in linking caregivers with relevant stakeholders/other service providers. She explained how she would to this if she was the social worker,

"I would make sure that caregivers have access to offices like the social development department, home affairs department, department of housing and the department of health to make their job easier because a caregiver is the one who works close to such people."

This kind of support required from social workers is in line with a recommendation by Furstenberg and Olson (2008:58), who urge social workers to advocate for client services, mobilising resources, developing and maintaining relationships with other organisations and stimulate service delivery.

Theme 6: Suggestions for social workers to provide capacity building/training

One of the key drivers or enablers assisting caregivers in moving the caregiver-care receiver dyad forward highlighted in the middle-range theory of caregiving dynamics is developing "new insights" (Williams, 2014:312). Gaining a new perspective or insight may assist to ease the burden of the caregiving responsibilities and duties. New insights can be gained through training and capacity building – a suggestion put forward by three of the participants.

Ching was of the view that if caregivers were trained, they would be in a better position to respond to some of the difficult questions asked by the patients. He elaborated as follows:

"[I] would like him [referring to the social worker] *to offer us training. For us to have more knowledge so that he knows what to do when we visit the patients and also to answer the questions they ask. It is embarrassing when a patient asks a question and you don't know what to say, because they think we know everything since we wear uniform."*

Vanessa explained how she would approach the aspect of training if she was the social worker*:*

"Then, now you just came to deal with HIV/ADS. You have no cooking clue how to deal with the others [referring to related aspects] *that coming with that, and the way it started. It started somewhere and that is how it ended up HIV/AIDS. And then you don't have any cooking idea what to do with that. And counselling, I teach them, I would make sure they go on the courses for counselling. Counselling, I wouldn't take an in-depth medical, but just foundation medical on the disease and related diseases to HIV/AIDS; social aspects, abuse, alcohol, drug abuse, just foundation. I wouldn't take them in-depth but give them, equip them, just equip them to be able to better do what they do."*

Mamadee's suggestion was,

"… to offer them training. So that they can understand, what the patients are going through."

The view expressed by Musangali *et al.* (2016:451) was that f caregivers' lack of understanding of the disease and adequate support from health care underscores the suggestion for social workers to provide capacity building and training. This is further strengthened by Jacques and Stegling's (2004:15) opinion that education and training in managing a terminal disease is essential for medical staff who are involved in residential and home-based care. Equipping caregivers with skills through training will ensure that patients receive quality care and caregivers know exactly how to protect themselves (Jacques & Stegling, 2004:180). These suggestions for training seem to be even more crucial after a finding reported by Kangethe (2009a:31) in a study he conducted in Botswana. In that study on the topic of critical coping challenges facing caregivers of persons living with HIV and AIDS and other terminally ill persons, Kangethe (2008:359) found that HBCGs had not been exposed to any form of training for years and their organisations lacked training plans for them.

CONCLUSION

Through this study we made available a platform for caregivers caring for PLWHA to express, in their own voices, their preferred ways in which social workers could offer them support. Using the middle-range theory of informal caregiving dynamics, we found that their suggestions reaffirmed the significance of social work involvement throughout the caregiving trajectory. HBCGs direct need for psychosocial support in a form of counselling, debriefing, team building and support groups was clearly expressed, as some of the interventions that could help them cope better with their daily overwhelming work. In addition to the psychosocial difficulties associated with their caregiving, financial support was noted as an aggravating challenge, further paralysing their caregiving dyad and hampering its development. Although they were very clear that financial support is not necessarily their highest priority, they believed that social workers could play a crucial role in lobbying for them to at least have support so that they can address some of their basic needs and those of their families.

The general belief among caregivers was that they could not address all matters relating to caregiving on their own. They believed that social workers could play an advocatory role for their interests by serving as their representatives at management level and by promoting appreciation of their contribution. Because they believed that caregiving is a collective initiative, they felt that the community should somehow be involved and this could be achieved if social workers could educate and encourage members of the community to take part in caregiving. For HIV and AIDS HBC programmes to be successful, a critical social work role, as noted by participants, would be for social workers to turn the task of caring into a smooth exercise by equipping caregivers with the necessary skills through training, by directly providing social work services to cases that require social work intervention, and by lobbying for stakeholder involvement. Our view is that by addressing the issues raised by the participants, a healthy working environment for HBCGs could be created, the HBC programme will be strengthened and the battle against HIV and AIDS and its related factors could be successful.

RECOMMENDATIONS FOR SOCIAL WORK PRACTICE, TRAINING AND RESEARCH

It is critical to note that the battle against HIV and AIDS is not an easy one for caregivers, who are confronted with various challenges, which they strongly believe could be addressed if social work support is provided. Based on the suggestions made by caregivers, the following recommendations for social work practice are offered.

- Training institutions offering social work education and training should include in the syllabi learning outcomes to equip social work students with knowledge and skills on how to support HBCGs.

- Continuous professional development (CPD) programmes and activities as regulated by the SACSSP should be organised to familiarise social workers with the plight of HBCGs caring for PLWHA, and to sensitise the social workers about HBCGs' support needs. In addition, the programmes should furnish social workers with the skills to support caregivers for PLWHA in the management of their personal and work-related challenges.

- The Departments of Health and Social Development should develop, promote and implement psychosocial programmes that are aimed at supporting the HCBGs.

- The Department of Health and Social Development should spearhead the development of a policy on caring for the caregiver to be rolled out through all HBC organisations

- Funding agencies should consider the funding of social work positions in HBC organisations to ensure that there is an in-house social worker to immediately offer support when required.

- Further studies be conducted in the following subject areas:

- Social work counselling as support intervention for home-based caregivers caring for PLWHA in South Africa;

- The significance of community involvement in supporting caregivers who are caring for PLWHA in South Africa;

- Capacity building as an intervention to support caregivers caring for PLWHA.

REFERENCES

AKINTOLA, O. 2005. **Community responses to HIV/AIDS: The role of volunteers in home-based care for people living with HIV/AIDS in South Africa.** [Online]. Available: http://womin.org.za/images/impact-of-extractive-industries/womens-unpaid-labour-and-social-reproduction/O%20Akintola%20-%20Community%20Responses%20HIV-AIDS%20and%20HBC.pdf. [Accessed: 08/04/2014].

AKINTOLA, O. 2008. Defying all odds: coping with the challenges of volunteer caregiving for patients with AIDS in South Africa. **Journal of Advanced Nursing,** 63(4):357-365.

AMA, N.O. & SELOILWE, E.S. 2011. Analysis of the burdens of caregivers providing care to people living with HIV/AIDS in Botswana. **Journal of the International AIDS Society,** 13(14):1-8.

ARNO, P.S. 1986. The non-profit sector's response to the AIDS epidemic: community-based services in San Francisco. **American Journal of Public Health**, 76(11):1325-1331.

BERKMAN, B. 1996. The emerging health care world: implications for Social Work practice and education. **Social Work**, 41(5):541-551.

BERZOFF, J., LUCAS, G., DELUCA, D., GERBINO, S., BROWNING, D., FORSTER, Z. & CHATCHKES, E. 2006. Clinical Social Work education in palliative and end-of-life care. **Journal of Social Work in End-of-Life & Palliative Care**, 2(2):45-63.

BESTER, N. & HERBST, A. 2010. The role of hospice caregivers in caring for families infected with, or affected by, HIV/AIDS. **Social work**, 46(4):450-468.

CAMPBELL, C. & FOULIS, C. 2004. Creating contexts for effective home-based care of people living with HIV/AIDS. **Curationis,** 27(3):5-14.

CRESWELL, J.W. 2014. **Research design.** 4th Edition. Los Angeles: Sage Publications.

CRESWELL, J.W. 2016. **30 Essential skills for the qualitative researcher.** London: Sage Publications.

DOW, B. & MCDONALD, J. 2003. Social support of structural change? Social work theory and research on caregiving. **Australian Social Work,** 56(3):197-208.

EMLET, C.A. 1993. EAP's: A viable means for supporting professionals working in AIDS. **Employee Assistance Quarterly,** 8(1):27-34.

FRIEDMAN, I., MOTHIBE, N., OGUNMEFUN, C. & MBATHA, T. 2010. **A National audit of registered and unregistered home and community-based care organisations in South Africa.** Durban: Health Systems Trust.

FURSTENBERG, A. & OLSON, M.M. 2008. Social work and AIDS. **Social Work in Health Care,** 9(4):45-62.

GRANT, M. & PARPART, J.L. 2011. Gender and home-based care for HIV/AIDS and TB patients in rural and urban Zimbabwe. **Canadian Journal of African Studies,** 44(3):503-523.

HALL, N. 2008. We care don't we? Social worker, the profession and HIV/AIDS**. Social Work in Health,** 44(1):55-72.

HAMPTON, G., BUGGY, M., GRAVES, J., MCCANN, L. & IRWIN, J. 2017. Grappling with realities: policy and practice in HIV social work. **Australian Social Work,** 70(1):92-103.

JACOBS, P.E. & LURIE, A. 1984. A new look at home care and the hospital social worker. **Journal of Gerontological Social Work,** 7(4):87-99.

JACQUES, G. & STEGLING, C. 2004. HIV/AIDS and home-based care in Botswana. **Social work in Mental Health,** 22(2):175-193.

KANGETHE, S. 2008. Challenges that the referral system poses to care giving as experienced by Kanye community home-based care (CHBC) programme in Botswana. **Social work/Maatskaplike Werk,** 44(4):355-368.

KANGETHE, S.M. 2009a. Challenges impacting on the quality of care to persons living with HIV/AIDS and other terminal illnesses with reference to Kanye community home-based care programme. **Journal of Social Aspects of HIV/AIDS,** 6(1):24-32.

KANGETHE, S.M. 2009b. Critical challenges facing caregivers of persons living with HIV/AIDS and other terminally ill persons: The case of Kanye care program, Botswana. **Indian Journal of Palliative Care,** 15(2):115-121.

KIPP, W., TINDYEBWA, D. KARAMAGI, E. & RUBAALE, T. 2006. Family caregiving to AIDS patients: the role of gender in caregiver burden in Uganda. **Journal of International Women's Studies,** 7(4):1-13.

KOLHI, R., PUROHIT, V., KARVE, L., BHALERAO, V., KARVANDE, S., RANGAN, S., REDDY, S., PARANJAPE, R. & SAHAY, S. 2012. **Caring for caregivers of people living with HIV in the family: A response to the HIV pandemic from two urban slum communities in Pune, India.** [Online] Available : http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0044989&type=printable [Accessed 22/02/2018].

LEKGANYANE, MR. 2017**. Experiencing and managing work-related challenges by home-based caregivers caring for people living with HIV and AIDS: guidelines for support from a social work perspective.** Pretoria: Unisa. (PhD Thesis)

LIETZ, C.A. & ZAYAS, L.E. 2010. Evaluating qualitative research for Social Work practitioners. **Advances in Social Work,** 11(2):188-202.

MAES, K. & KALOFONOS, I. 2013. Becoming and remaining health workers: Perspectives from Ethiopia and Mozambique. **Social Science & Medicine,** 87(2013):52-59.

MARINCOWITZ, G. JACKSON, C. & FEHRSEN, G.S. 2004. Who are good home-based care volunteers? **South African Family Practice,** 46(2):29-31.

MASHAU, N.S., NETSANDAMA, 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 Science,** 44(1):66-71.

MASHAU, N.S. & DAVHANA-MASELESELE, M. 2009. Experiences of HIV/AIDS home-based care givers in Vhembe district of the Limpopo province. **Curationis,** 32(4):40-47.

MOHAMMAD, N. & GIKONYO, J. 2005. **Operational challenges of community home based care (CHBC) for PLWHA in Multi-country HIV/AIDS programs (MAP) for Sub-Saharan Africa.** [Online]. Available: http://www.worldbank.org/afr/wps/wp88.pdf. [Accessed: 22/06/2016].

MORROW, S. 2005. Quality and trustworthiness in qualitative research in counseling psychology. **Journal of Counseling Psychology**, 52(2):250-260.

MUSANGALI, DAIRE & DELORENZI, 2016. The impact of caregiver coping strategies and patient level of functioning on perception of caregiver burden among caregivers of persons living with HIV/AIDS in Kenya. **Journal of HIV/AIDS & Social Services,** 15(4):450-463.

ORNER, P. 2006. Psychosocial impacts on caregivers of people living with AIDS. **AIDS Care,** 18(3):236-240.

PARTAB, R. 2010. Reflections on burnout and self-care management in Social Work. **Social Work/Maatskaplike Werk,** 46(4):496-592.

PRIMO, M.W. 2007. **Caring for the caregiver in HIV and AIDS programmes.** Mafikeng: University of North West. (MA Dissertation)

QALINGE, L. 2011. Community Home-Based care programme: a marginalised key community resource. **Social work/Maatskaplike Werk,** 47(1):51-57.

RECKREY, J.M., GETTENBERG, G., ROSS, H., KOPKE, V., SORIANO, T. & ORNSTEIN, K. 2014. The critical role of social workers in home based primary care. **Social Work Health Care,** 53(4):330-343.

RÖDLACH, A. 2009. Home-based care for people living with AIDS in Zimbabwe: Voluntary caregivers' motivations and concerns. **African Journal of AIDS Research***, 8(4):423-431.

ROWAN, D., LYNCH, S., RANDALL, E. & JOHNSON, H. 2015. Deconstructing burnout in HIV service providers. **Journal of HIV/AIDS & Social Services,** 14(1):58-73.

SCHIETINGER, H. 2005. **Supportive and palliative care for people living with HIV/AIDS.** [Online]. Available: http://www.aiha.com/wp-content/uploads/2015/07/11-Supportive-Palliative-Care-for-People-Living-with-HIV-AIDS.pdf. [Accessed: 26/07/2016].

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.

SHENTON, AK. & HAYTER, S. 2004. Strategies for gaining access to organisations and informants in qualitative studies. **Education for Information,** 22(2004):63-75.

SHEPPARD, G. ND. Notebook on ethics, legal issues, and standards for counsellors. [Online] Available: https://www.ccpa-accp.ca/wp-content/uploads/201.5/05/NOE.What-is-Counselling-A-Search-for-a-Definition.pdf. [Accessed: 22 February 2018].

SIMPSON, S. 2006. **A technical report exploring whether caregivers of people living with HIV/AIDS receive sufficient psychosocial support: A South African descriptive study at community care project.** Stellenbosch: University of Stellenbosch. (MA Dissertation)

SOUTH AFRICA. DEPARTMENT OF SOCIAL DEVELOPMENT. 2006. **Situational analysis and needs assessment of management capacity among home and community-based care service providers.** [Online]. Available: http://www.gov.za/sites/www.gov.za/files/DSD_HCBC%20-Report_14012010.pdf. [Accessed: 12/07/2015].

STRUG, D.L., GRUBE, B.A. & BECKERMAN, N.L. 2008. Challenges and changing roles in HIV/AIDS social work. **Social Work in Health Care,** 35(4)1-19.

THOMPSON, N. & THOMPSON, S. 2016. **The Social Work companion.** New York: Palgrave.

TOSELAND, RW. & RIVAS, R.F. 2014. **An introduction to group work practice.** UK: Pearson.

TSHABALALA, A.M. 2008. **Overview of home/community-based care. In: PEU, M.D. (ed) Home/community based care**. Pretoria: Van Schaick. TSHEBOENG, F.S. 2015. **The effects of home-based care of HIV/AIDS patients on caregivers: a case study of Mafikeng.** Mafikeng: University of North West. (MA Dissertation)

TSHWARANG, P.N. & MALINGA-MUSAMBA, T. 2012. Social workers working with HIV and AIDS in health settings: a case study of Botswana. **Practice Social Work in Action,** 24(5):287-298.

VALJEE, L & VAN DYK, A. 2014. **Impact of caring for people living with HIV on the psychosocial well-being of palliative caregivers.** [Online]. Available: http://www.-curationis.org.za/index.php/curationis/article/viewFile/1201/1422. [Accessed: 19/05/2016].

VAN DYK, A. 2007. Occupational stress experienced by caregivers working in the HIV/AIDS field in South Africa. **African Journal of AIDS Research,** 6(1):49-66.

WILLIAMS, L.A. 2003. Informal caregiving dynamics with a case study in blood and marrow transplantation. **Oncology Nursing Forum,** 30(4):679-686.

WILLIAMS, L.A. 2007. Whatever it takes: informal caregiving dynamics in blood and marrow transplantation. **Oncology Nursing Forum,** 34(2): 379-387.

WILLIAMS, L.A. 2014. **Theory of caregiving dynamics. In: Smith, J. & Liehr, P.A. (eds). Middle range theory for nursing**. New York: Springer. 309-328.

WORLD HEALTH ORGANIZATION, 2010. **Priority interventions: HIV/AIDS prevention, treatment and care in the health sector.** Geneva: WHO.

WU, Y.P., THOMPSON, D., AROIAN. K.J., MCQUAID E.L. & DEATRICK, J.A. 2016. Commentary: Writing and evaluating qualitative research reports. **Journal of Paediatric Psychology**, 41(5):493–505.

YEGIDIS, B.L., WIENBACH, R.W. & MYERS, L.L. 2018. **Research methods for social workers.** 8th Edition. New York: Pearsons.

ZASTROW, C.H. 2014. **Social Work with groups: a comprehensive work text.** United Kingdom: Cengage.