

RESILIENCE IN HOME-BASED CAREGIVERS IN LIMPOPO, SOUTH AFRICA

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ABSTRACT

This study examines resilience in home-based caregivers (HBCs) in Limpopo South Africa. The PEN-3 model is used to investigate cultural influences on care-giving and frame the relationships, expectations, and cultural identity of care-giving in the context of African cultures. Data were gathered from participants' responses in 4 focus group interviews held in South Africa. The results highlight the positive and supportive aspects of HBCs, recognize the existential and unique features, and explain the negative experiences shared by HBCs. The findings from this study emphasize the need for persons of African descent to maintain the African ideology of "collectivity" in care-giving.

Keywords: *HIV/AIDS; resilience; home-based caregivers; SOUTH AFRICA, PEN-3*

INTRODUCTION

Sub-Saharan Africa has the highest number of people living with HIV/AIDS (PLWHAs). An estimated 33.4 million people are living with HIV globally (WHO, 2008-2009). According to WHO (2008-2009), Sub-Saharan Africa continues to be the region disproportionately affected by the HIV/AIDS pandemic accounting for 67% of all people living with HIV, of which 60% are of women. According to UNAIDS (2007), in South Africa an estimated 18.1% of adults age 15 to 49 are living with HIV, while 3,200,000 women age 15 years and older are infected with the HIV virus. In 2007, approximately 350,000 adults and children died of HIV/AIDS, while an estimated 1,400,000 children lost their mothers, fathers, or both parents to HIV/AIDS (UNAIDS). In Limpopo Province, approximately 396, 877 people are infected with HIV: 47, 000 new infections, 39, 474 people already sick, and 24 000 AIDS-related deaths (Dorington et al. 2006).

Background

The HIV/AIDS pandemic places tremendous pressure on HIV infected households in South Africa. It is predicted that "HIV is the fastest way for families to move from relative wealth to

relative poverty” (Rotheram-Borus, Flannery, Rice, & Lester, 2005, pg. 981). For example, a study investigating the effect of HIV/AIDS-related mortality on household dependency ratios in rural South Africa revealed that household dependency ratio—composite index that reflects the combined effect of all demographic events and processes in the household: births, deaths, ageing, and in-migration and out-migration—in some parts of South Africa is high, thereby increasing the effect of losing a productive-age member (Madhavan, S., Schatz, E., & Clark, B., 2009). HIV/AIDS related mortality can put different strains on household resources and increase its care-giving responsibilities for children and elderly within HIV affected households (Madhavan et al. 2009). Also, care-giving can create major time burdens for caregivers, exacerbating poverty among previously poor caregivers (Hansen et al., 1998; Lindsey et al., 2003; Akintola 2004a). Madhavan et al. (2009) concluded that the age distribution of HIV/AIDS related deaths is primarily affecting the most productive age group of the African population. Because young people are more likely to contract and die of HIV/AIDS, the elderly are left with no choice but to take on care-giving and breadwinning roles for adult children with symptomatic HIV infection and orphaned grandchildren made vulnerable by the death or illness of one or both parents (Boon et al. 2009). In both developed and developing countries, the death or illness of one or both parents brings about the establishment of “child-head households”—children assuming adult roles and responsibilities for other members of the family (Rotheram-Borus, Flannery, Rice, & Lester, 2005, pg. 982). These roles and responsibilities assumed by children in such instances have been shown to have a significant impact in altering their life course (Rotheram-Borus et al. 2005). As a result, the need for home-based care becomes even more crucial in this regard.

Home-Based Care

Studies examining the impact of care-giving on family caregivers have shown that care-giving has a negative impact on the physical and mental health of family caregivers (Orner, 2006). In addition, caregivers may also be at elevated risk for contracting infections such as HIV/AIDS and tuberculosis (Lindsey et al., 2003; Akintola 2006). Studies among family caregivers in Ghana, Tanzania, South Africa and the Democratic Republic of Congo showed that caregivers are also victims of adverse socio-economic consequences, stigma and discrimination, isolation and lack of support (Nnko et al. 2000, Mwinituo 2006, Nkosi et al. 2006, Orner 2006). Van Dyk (2001) stated that caregivers are often frustrated by issues associated with their roles— “lack of basic essentials, inaccessibility of basic medical care, debilitating nature of patient’s condition, lack of knowledge about infection, fear and anxiety associated with stigma and discrimination, frustration associated with the premature discharge of the family’s loved one, as well as the behavior and lifestyle of the sick person, and overwhelmed by the extended roles and lack of support” (pg. 135–143).

Additionally, the HIV/AIDS pandemic places enormous burden on healthcare services in Sub-Saharan Africa. In South Africa, PLWHAs constitute the vast majority of patients seeking medical attention in public health facilities (Shisana et al. 2002). Health services are often unable to provide patients with the care they require; as a result families are faced with the task of caring for their sick family members at home (Ndaba-Mbata & Seloilwe, 2000). Furthermore, the healthcare system in South Africa is experiencing an increase in HIV/AIDS infections and deaths among nurses and other healthcare personnel thereby placing strains on public health services

needed by patients (Aitken & Kemp 2003). Studies conducted in Zaire found that the prevalence of HIV infection among health care professionals increased from 6.4% to 8.6% between 1984 and 1986 (Mann JM, Francis H, Quinn TC, et al., 1986 and N’Galy B, Ryder RW, Bila K, et al., 1988). Uebel et al. (2007) explained how health care workers living in areas where the prevalence of HIV infection is high, the disease becomes community acquired, thus the prevalence of HIV infection among health care workers becomes comparable to that of the communities in which they live. Relatedly, a anonymous survey involving 595 health care workers across race groups in 4 different provinces in South Africa found an overall HIV infection prevalence of 15.7%, compared with an estimated prevalence of 15.5% among adults in South Africa (Shisana O, Hall EJ, Maluleke R, Chauveau J, Schwabe C., 2004). Aitken and Kemp (2003) explained how poor compensation of healthcare workers and poor working conditions of nurses and other healthcare professionals has led to large-scale emigration to foreign countries of these healthcare workers resulting in a critical shortage of nurses and other medical personnel in South Africa.

For this and many more reasons, a number of government and non-governmental agencies have adopted home-based care as an alternative to hospital care. As a result, PLWHAs are often sent home to be cared for by their family members. Institutionally, home care programs for people with AIDS (PWAs) started in North America and Europe as an alternative to help minimize hospital expenses, and to assist families and other caregivers cope with the challenges of caring for PWAs (Spier & and Edward 1990). However, the act of selfless care-giving has been a part of Africa culture. This practice provides the value for Africans to see themselves as part of the historically large community (collective) to which they belong (Mbiti, 1969: 108-109). Considering the difficulties associated with providing home-based care in Africa, due to the crowded and substandard conditions in which most PWAs live, Spier & Edwards (1990) concluded that, what PWAs need most is “counseling, lots of personal contact and empathy and a sense of belonging” (p. 144). Nevertheless, in Norway the emphasis of home-based AIDS care is focused on domestic tasks such as cleaning, laundry and shopping (Bunch, 1998); while in the USA home-based AIDS care is centered on problems in home maintenance, individual coping, nutrition, feeding and fatigue (Ungvarski & Hurley, 1995) . Home-based care PWAs was introduced in a number of African countries during the late 1980s and early 1990s (Sims & Moss, 1995). In South Africa, home-based caregivers advise, inform and counsel patients (L R Uys, 2002) with the supervision of registered nurses. According to Steinberg et al. (2002), volunteers make-up a substantial proportion of HIV/AIDS caregivers in South Africa. Volunteer caregivers are usually not members of the patient’s family but often people recruited from HIV infected communities by AIDS organizations (Akintola, 2008). They are trained to assist family members in providing care for the PLWHAs (Blinkhoff et al. 2001, Steinitz 2003, Akintola 2006) and to work hand in hand with clinics and hospitals (Campbell, C; Nair, Y; Maimane, S; Sibiya, Z; 2008). Few volunteer health workers have basic education and they worked with little or no payment to cover their expenses (Campbell, C; Nair, Y; Maimane, S; Sibiya, Z; 2008). For example, at the time the present study was conducted in 2005, participants received a stipend of R500-00 (\$64.5970) from the ****South African**** government to cover HBCs daily transportation and to enable them purchase food and drinks. However, the provision of this stipend soon came to an end when the program ended in 2006 and 2007. Even though much has been written on caregivers—challenges: physical, psychological, and coping mechanisms— much has not been

studied regarding resilience in home-based caregivers in Limpopo South Africa. The PEN-3 model is used to examine cultural influences on care-giving and frame the relationships, expectations, and cultural identity of care-giving in the context of African cultures.

The Concept of Resilience

The concept of resilience is derived from the disciplines of physics and metallurgy (John Paul Lederach, pg. 24). Resilience, in this context, is applied to a special family of metal that when placed under intense heat will lose shape, soften and melt, however when re-cooled has an incredible ability to return to its initial shape (John Paul Lederach, pg. 23). Nonetheless, in developmental psychology and social work resilience is examined in children who have withstand and rebound from vulnerable and high-risk situations, thus finding their way toward expressively healthy childhoods and responsible adulthoods (Walsh, 1996, John Paul Lederach, pg. 24).

Contrary to the typical interpretation of resilience, this article advances a culturally sensitive view of this concept, thus defining resilience as the “sensation of being voiceless” (John Paul Lederach, pg. 24). John Paul Lederach explained how the process from being voiceless to acquiring a voice requires the need for people to feel close enough to procedures that affect their daily personal and collective lives, so that a sense of meaningful conversation is actually possible. In the Western world, resilience has been viewed as residing within the individual, with the family often dismissed as dysfunctional (Walsh, 1996). However, in African cultures, the involvement and support of the collective— government and non-governmental agencies, families of PLWHAs, and community members—in assisting HBCs acquire a voice to adequately provide care to PLWHAs is highly urged.

THEORETICAL FRAMEWORK

The PEN-3 model developed by Airhihenbuwa (1995, Airhihenbuwa & Webster, 2004; 2007a) is used as the conceptual framework on which this study will be organized. This model proposes a strategy for organizing and analyzing cultural influences on health behaviors and planning culturally appropriate health education programs (Iwelunmor et al. 2006/2007). Also, PEN-3 provides a cultural framework for researchers and interventionist by urging them into partnering with communities when defining health problems and seeking solutions to those problems (Airhihenbuwa, 2007a). Having been developed initially as a basis for comprehending health behaviors of persons of African descent (Airhihenbuwa & Webster, 2004), the PEN-3 model is used in the identification of positive, unique, and negative aspects of African cultures.

PEN-3 consists of three dimensions: cultural empowerment, relationships and expectations, and cultural identity (Airhihenbuwa, 2007a). The Relationships and Expectations and Cultural Empowerment domains are the “assessment” dimensions, which enable researchers/interventionists evaluate communities of interest before planning interventions. The first dimension of the assessment domain is relationships and expectations (perceptions, enablers, and nurturers). We examined how HBCs perceptions of HIV and AIDS helped enabled and nurtured PLWHA. The second dimension of this evaluation framework is cultural empowerment (positive, existential, and negative). We examined the extent to which the three levels of relationships and expectations are positive and supportive of PLWHA, existential in

that it is maintaining African values, and negative in making HBCs voiceless due to the lack of support. According to Airhihenbuwa (2007a), existential values—cultural beliefs and practices, and/or behaviors that make the culture unique, which has no harmful health consequences—should not be targeted for change, but rather integrated to help improve interventions undertaken in such communities.

Cultural identity (person, extended family, and neighborhood) is the third dimension of the PEN-3 model. This dimension is the “application” domain, which emphasizes the need for researchers/interventionists to return to the communities from which their findings were acquired, to share their findings, and to further learn from these communities before deciding where to begin their interventions: point of entry (Airhihenbuwa, 2007a).

METHOD

Data gathered from the study “Stigma, Culture, and HIV and AIDS in the Western Cape, South Africa: An Application of PEN-3 Cultural Model for Community-Based Research” (Airhihenbuwa et al. 2009), is used in this study. The aforementioned study was a capacity building HIV and AIDS stigma research in South Africa for Black post-graduate students in the University of Western Cape and the University of Limpopo. Focus group discussions were conducted among home-based caregivers over a period of **one to two** years in three different communities in South Africa—Khayelitsha and Gugulethu, and Mitchell’s Plain. Participants were made known of the study’s content and proceedings in their native languages by the focus group facilitators; informed consents were solicited from each participant.

Sample

A total of 4 focus groups (FGs) interviews were conducted among 41 participants. The numbers of participants differed in each FGs. For example, FGs one, two, three, and four comprised of nine, eleven, ten, and eleven participants respectively. HBCs were interviewed to provide a better understanding on how they perceived their work—positive, existential, and negative perceptions.

Data Collection

During the interviews, probes were used by focus group facilitators only when permission was inquired and granted by participants. Focus group interviews were facilitated by post-graduate students and they followed an open-ended questions format. Data were collected using languages preferred by the participants—either isi-Xhosa, English, or Afrikaans. The focus group interview guide for this portion of the above mentioned study comprised of **18-28** questions or scenarios for the duration of **30-60 minutes**.

Data Analysis

Using NVivo software package for data analysis, four home-based caregivers transcripts were coded using two forms of notes—free notes and trees notes. Free notes coding is the first stage of data analysis with NVivo and it involves coding participants’ transcripts verbatim. Also,

free notes coding requires no form of organization or grouping of main themes. However, in tree notes coding, main codes generated by free notes are condensed into manageable categories to enhance a better understanding of the results produced. After all transcripts were coded, the number of free notes codes generated differed between transcripts. For example, transcripts one, two, three, and four produced 135, 163, 182, and 167 free notes respectively. However, there were five predominant themes (tree notes) generated: HBCs, community members, HIV/AIDS, family members of PLWHA, and government and non-governmental agencies.

RESULTS

The following three main themes emerged from the analysis of the focus group interviews: HBCs as sources of hope and support (positive perceptions, positive enablers, and positive nurturers); HBCs assuming the role of family (existential perception, existential enablers, and existential nurturers); voicelessness of HBCs due to the lack of support (negative perception, negative enablers, and negative nurturers). As recommended by Airhihenbuwa, when implementing PEN-3, researchers and interventionist must first present the positive and the existential aspects of the communities being studied, before stating the negatives. The aforementioned themes are illustrated with quotes from the participants. Quotes were organized into one of the nine possible categories of the PEN-3 analysis framework. Even though quotes were organized in the general study, in this paper, the results were organized into positive, existential, and negative aspects of the Cultural Empowerment domain of the PEN-3 model.

HBCs as Sources of Hope and Support (Positive)

Focus group discussions and in-depth interviews revealed that HBCs were accepting of and willing to provide care for PLWHAs and their families. This finding is consistent with that of previous studies which highlighted how most HBCs expressed satisfaction in their work and in helping others (L R Uys, 2002). The following quotation illustrates this further,

I don't see a problem with my scope of work in relation to HIV/AIDS. I only see a person who is sick, alike me that need to be given medication to prolong his/her life. I don't have to be confused that I will get an illness. I don't have to judge, but to admit.

In addition, HBCs counseled and provided information to PLWHAs, hence enabling patients cope better with their positive HIV status. This may be indicative of the knowledge HBCs acquired through training and from their daily interactions with patients. One participant remarked, "I would like to indicate that we have a better understanding because we treat the people and we are able to see them". Another participant expressed,

My client was in Grade 11, and recently discovered that he was HIV/AIDS positive, so he thought the was no future to live for, so he decided to take the suicide route, until I counseled him, he then adjusted quite well.

Furthermore, the participants in this study assumed some of the responsibilities of healthcare workers in South Africa, thus allowing the understaffed and underfunded public healthcare systems to adequately provide care for PLWHAs (Rödlach, 2009). As evidenced in the responses of many participants, HBCs assisted in the provision of basic physical care

rendered to PLWHAs in South Africa. One participant explained, “They are grateful, because we don’t disguise them; we help them with a smile on our faces, even when we are removing those waste products. We maintain some collaboration”. As another participant expressed it,

It is not the same, for a person who has full blown AIDS, he/she might be bedridden and unable to do anything for himself/herself and the patient will first require you to bath him and take him to the toilet, but with other patient they can still do thing for themselves.

HBCs assuming the role of Family (Existential)

Participants expressed dedication and determination to support PLWHAs and their families (Rödlach, 2009). This finding reinforced the findings of Mbiti, Menkiti, Asante, Akbar, Karenga, Myer, and Graham which urges the need for collectivity rather than personhood in African cultures. The notion of collectivity demands the responsibility of the whole, hence what happens to the individual happens to the collective, and what happens to the whole group happens to the individual (Mbiti, 1970, p.141). For this reason, it wasn’t uncommon for HBCs to assume the role of families even when illness was not the responsibility of family members. The following quotations highlight this further:

You will find that someone is having a client that is sick, and need to taken to a clinic, and/or a certain referral be made, you will have to devote yourself.

The client may refuse to go to a clinic/doctor if informed by the family members, but if it is me the home based carer I will work with him/her until I win the trust of the patient.

The participants mentioned the deaths of community members due to HIV/AIDS as a motivational factor for which they provided care to PLWHAs and their families. As remarked by several participants, “It is because people are dying as a result of this disease, which is why we devote ourselves”. As evidenced in the responses of most participants, the act of selfless care-giving is existential (unique) to African cultures, which encourage persons of African descent to view themselves and their roles in the society as belonging to the community at large (Mbiti, 1969: 108-109). This collective nature of identity is further expressed in the African proverb “I am because we are and because we are therefore I am” (Mbiti, 1970, p. 1410).

Moreover, care-giving enabled HBCs develop a sense of belonging and kinship with other members of the society (Mahilall, 2006) in which they worked and resided. These relationships allowed HBCs acquire a sense of purpose and connection with families and community (Akbar, 1976), thus the notion that individuals cannot be understood separately from the collective (Myers, 1988). This finding is clearly exemplified in the words of one participant, “It is the work that I have vowed to do, I said to, myself I will work for the community”. Another participant expressed, “We only understand that there is no cure, but the only best thing that we can do, is to help this people that are infected and affected with HIV/AIDS”.

The participants repeatedly described care-giving as a selfless act of providing care to PLWHAs, in spite the risk of contracting the HIV/AIDS virus. One participant remarked, “We are not protected. We are risking with our own lives for caring for these people who are bedridden. You just care”. This may be indicative of the concept of oneness which requires a

shift in thinking toward valuing human beings above the social and economic status that has been assigned to them (Graham, 1999). Also, in-depth discussions and focus group interviews revealed that HBCs willingly rendered care to PLWHAs. As expressed by one participant, “It’s because we choose to work out of love”. Another participant said, “It is coming out of passion”.

The participants often mentioned feelings of confidence in themselves and their work as a result of the useful knowledge they had gained on HIV and AIDS (Mahilall, 2006). One participant remarked, “I just feel proud and it is also volunteering and it’s platform for me to learn”. Furthermore, participants felt that the training they received enabled them educate their community members to take precautionary measures to protect themselves (Akintola, 2008) from contracting the HIV virus. One participant expressed, “It is difficult to work with this people, but given the love we are committed to care and educate these people”. This finding highlights the need for people of African descent to fulfill their duties to the collective (Menkiti, 1984).

Voicelessness of HBCs due to lack of support (Negative)

In spite of the willingness of HBCs to provide care to PLWHAs, home-based care programs receive very limited support from the government (Steinberg et al. 2002) and also from donor agencies to fund caregivers salaries (Akintola, 2004b), thereby leaving care organizations with little option but to rely primarily on volunteers to provide care (UNAIDS 2000; Akintola 2004b). With the absence of support and the lack of recognition displaced by the government, HBCs in South Africa are finding it very difficult to carry out their daily duties. Recent data showed that home-based care organizations in South Africa are in need of assistance from government and non-governmental agencies (NGO) in order for HBCs to be able to provide care efficiently. The following quotations exemplify this further:

Phutanang itself as Home based care is lacking funds, so far we asked for donations from the DoPW. Our budget is low that it does not allow us to have a proper accommodation.

I plead with other companies that have a social responsibility to help in providing us with the necessary needs even companies abroad.

Because care organizations in South Africa receive little or no financial support from government and non-governmental agencies (Akintola, 2004b), HBCs are lacking the necessary skills and capacity building preparations required to effectively assist with the enormous needs they encounter in their work (Rödlach, 2009). The following participant’s description is illustrative:

I want to refer to the statement of N0. 3, that we received different training and we are still lacking in training and we are using our knowledge to counsel.

The lack of training, I am not sure if carers will answer that openly, the gloves are the only thing that we use, we don’t know how to handle the patient, when the patient is presenting minor complications of his/her.

Although the participants in this study did not expect anything in return, they expressed a desire for some recognition (Rödlach, 2009) for their work. HBCs felt that the work they were doing was similar to a full-time job but was not regarded as such (Rödlach, 2009). Also, HBCs

expressed feelings of frustration and disappointment due to the lack of support and the absence of recognition displaced by the government regarding their work. The following quotations explain this further:

The government should increase the payment of Home-based carers because the work that they are doing is difficult and the government should register the home-based carers.

I would like the government to acknowledge that we are overworked, and we don't have anyone to take care of us as we do a lot of work.

Additionally, HBCs encountered various challenges from the families of PLWHAs. This may be indicative of the fact that the families of PLWHAs are afraid of been stigmatized and discriminated against by their friends and relatives within the communities in which they resided. Furthermore, studies have revealed that stigmatization of the families of PLWHAs is a harmful and damaging issue (Campbell et al. 2005) that can tremendously impact the reputation of the families to whom PLWHAs belong. This finding showed that community members have not yet come to the realization that HIV/AIDS exist. The following quotations explain this further:

Many people have not agreed that HIV/AIDS exist, they do not agree with us, because we the Home Based Carers have realized that HIV/AIDS do exist. We observed people that we treat, to evidence that HIV/AIDS is not something that is a figure of speech, it exists.

Is just that people don't believe that HIV/AIDS exist because there is no grave that is imprinted on it as the grave of a person who died from HIV/AIDS.

In addition, the participants mentioned that family caregivers feared to touch and make close contact with their AIDS relatives (Rödlach, 2009), thereby increasing HBCs daily care-giving responsibilities. Moreover, research have shown that people living with AIDS experience continuous hardships due to blames directed at them for their conditions, and misconceptions regarding causal social contact with them (Herek, Capitanio, & Widaman, 2002). Also, because the HIV infection carries the stigma of immorality, promiscuity and prostitution in Africa, stigma associated with the disease and its related shame has increased (Rödlach, 2009). This finding is clearly expressed in the following quotes:

The family members of the HIV/AIDS infected person can hide the sick person until he/she dies. They may think that it is "Makgoma" or they are bewitched.

Some of the family member oust the patient, if you are the carer every time you come for the patient they just refer you to the patient, this implies that the family members have thrown in the towel, leaving the patient all to the home based carers.

Participants stated that their patients trusted and thus shared confidential information with them. Even though HBCs did not encounter difficulties keeping the confidential information of their HIV positive patients, they found it rather challenging maintaining the privacy of their client's conditions (Akintola, 2008) particularly from other members of the patient's family who resided within the same households. One participant explained,

The other challenge that we encounter is that you are the one that will know the patient, the family members knows that he/she is a patient but they don't even know his/her room. They will know that they have a patient. Again they will know that they have a patient, but they will turn to you as the carer to ask

about the condition of the patient and as a carer you have to maintain the issue of confidentiality, if the patient have not disclosed to them you also have no right to tell them.

Participants explained how PLWHAs refrained from disclosing their positive HIV status for fear of stigmatization and discrimination, thus isolating themselves from sources of support (Nnko et al. 2000, Akintola 2004a, 2006). Furthermore, studies have indicated that stigmatization and discrimination against PLWHAs are primary barriers to effective HIV prevention, treatment, care, and support (Shisana et al., 2005) aimed at increasing HIV/AIDS awareness and decreasing its spread. As one participant stated, “We find it as a challenge because people have not yet accepted their status, they don’t want to disclose their status to the carers, and they don’t want to take treatment”. Another remarked, “To concur with No.4, they are afraid to make contact with the community because they are rejected. When you as the carer you visit the patient for treatment they are afraid to see”.

In spite of HBCs selfless act to provide care for PLWHAs, participants expressed feeling less competent to adequately alleviate the pain and suffering of their patients (Akintola, 2008). Also, HBCs constant exposure to the suffering and the loss of terminally ill patients (Defilippi, 2003b) had a psychological and emotional impact in their lives. One participant stated, “It affects me to an extent that I feel guilty, because some of my patients die and leave small children to have no one to care for them and it bring about child-headed households”. Another participant remarked,

It affect me, more or less the same as the previous speaker. We interact with the patient; at times you meet a patient while he/she is at an HIV stage. You can see the problem that the patient is going through as well as his family problems. When you are on your own you imagine about the family situation of the patient, while on the other side the demands of the family are waiting for you. As the carer you will just wish like you can find a vaccine that you can give the patient to make him feel better.

Patients overload was a major problem encountered by the participants in this study. HBCs often mentioned feelings of exhaustion and burnout as a result of their case loads. This may be indicative of the increasing number of AIDS patients in South Africa, thus HBCs have become responsible for visiting (Rödlach, 2009) and providing care to many households in which PLWHAs resides. One participant said,

When I am looking on our workload, I will be talking from the organization frame of reference. The work that we do require us to see 7 patients, and all of them come with challenges. There is no single day that goes by without any problems. The work is too heavy; there is no carer that has only 2 patients. Even I the coordinator it takes me 2 to 3 days before I finish the work I am supposed to be doing.

DISCUSSION

It is evident that the HIV/AIDS pandemic is wreaking havoc on Sub-Saharan Africa. However, studies have shown that South Africa has the highest number of PLWHAs in Sub-Saharan Africa. Furthermore, numerous studies have concluded that the HIV/AIDS pandemic places tremendous strains on: HIV infected households, family caregivers of PLWHAs, healthcare services, and home-based caregivers in South Africa. For these and many more reasons, this article examined resilience in Home-Based Caregivers in Limpopo South Africa.

The findings from this study explained how the African ideology of “collectivity” is central in assisting HBCs acquire a voice in South Africa. The concept of resilience defined as the “sensation of being voiceless” was important in shaping HBCs positive, existential, and negative perceptions regarding care-giving in the following ways. First, most of the 41 participants expressed satisfaction in their work and in helping others, this may be indicative of HBCs training, daily interactions with patients, and understanding of HIV and AIDS that made them accepting of and willing to provide care for PLWHAs and their families. As evidenced in the responses of most participants, HBCs served as sources of hope and support to PLWHAs and their families.

Second, the existential aspect of selfless care-giving of the African culture played a vital role in shaping HBCs perceptions of and decisions to provide care for PLWHAs and their families. This finding exemplifies the African ideology of belonging to the collective and being part of the whole (Graham, 1999). Indeed, the participants in this study expressed the need to feel connected to and supported by other members of the society (Mahilall, 2006) in which they worked and resided. As a result, HBCs saw themselves and their roles in the society as belonging to the whole community (Mbiti, 1969: 108-109), thus enabling HBCs assume the role of family.

Lastly, the results indicated that in spite of HBCs willingness to provide care to PLWHAs and families, HBCs encountered various challenges from government and non-governmental agencies, families of PLWHAs, and community members. Care organizations receive very limited support from government and non-governmental to fund HBCs salaries, thereby making it difficult for HBCs in South Africa to carry out their daily responsibilities. Furthermore, the findings revealed that community members have not yet come to the realization that HIV/AIDS exist, thus decreasing the levels of involvement and support rendered to HBCs by other members of the society. Also, because the HIV infection is associated with numerous stigmas such as immorality, promiscuity and prostitution, families of PLWHAs are finding it difficult to provide care to their AIDS relatives, hence increasing the responsibilities of HBCs in providing care to PLWHAs.

This finding is consistent with the findings of Graham (1999) that social problems and human dysfunction arise when people become separated and disconnected from their independent human relationships. In contrast to the notion of “collectivity”, the ideology of “personhood” was rather displayed in this study. For example, the participants provided care for PLWHAs and their families because they wanted to and not because they had to. However, the results showed that HBCs received little or no support from the collective—government and non-governmental agencies, families of PLWHAs, and community members—to efficiently provide care. Despite the negative consequences associated with providing care to PLWHAs and the families, future research should aim at providing care and support to HBCs in South Africa. Additionally, the need to develop interventions that urges collectivity in African cultures is of the utmost importance.

Limitations

Like all interventions, the limitations of this study are as follows: findings are limited based on the selectivity of participants. Also, the level of openness expressed by the participants may vary in their responses to questions asked in the in-depth discussions and focus group interviews. Such concerns often arise from conducting research on sociocultural issues associated with life threatening conditions such as HIV/AIDS. The sample size used in this study was relatively small yet adequate for the qualitative method employed in this study. However, the results should not be considered representative of HBCs in South Africa, thus the need for future studies to examine resilience in HBCs in other provinces of South Africa is urged in order to better understand cultural influences on care-giving in South Africa. Finally, the findings from this study emphasize the importance of the African ideology of “collectivity” in care-giving in the context of Africa culture, thus the interpretation of this concept is not applicable to HBCs in other cultures.

CONCLUSION

The results highlight the positive and supportive aspects of HBCs, recognize the existential and unique features, and explain the negative experiences shared by HBCs. Moreover, the findings from this study emphasize the need for persons of African descent to maintain the African ideology of “collectivity” in care-giving. Akbar (1976) concluded that “the unity of the African cosmos is like a spider web; its least element cannot be touched without making the whole vibrate”. The aforementioned quotation exemplifies the primary essence of this study: the involvement and support of the collective—government and non-governmental agencies, families of PLWHAs, and community members—in the provision of care for PLWHAs. Because the HIV/AIDS pandemic is and will continue to negatively impact the world, particularly the continent of Africa, the need for the collective in assisting HBCs acquire a voice is highly urged if the act of selfless care-giving for PLWHAs is to be continued in African cultures.

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