

HIV and AIDS-related Courtesy Stigma: South African Caregivers' Experiences and Coping Strategies

Lekganyane Maditobane Robert

Abstract

Home-Based Caregivers (HBCGs) remain significant in mitigating the impact of Human Immune Virus and Acquired Immune-deficiency Syndrome (HIV and AIDS). They ensure that despite the overloaded health care systems, AIDS patients remain cared, supported and treated with dignity in their family environments. Despite this commitment, HBCGs face several challenges which were not adequately scrutinised from the scientific perspective. This qualitative study aimed to explore and describe the HBCGs' experiences of and coping strategies with courtesy stigma as one of their work-related challenges. Twenty-five HBCGs who were identified and recruited through purposive and snowball sampling techniques took part in this study. Data which was analysed and verified revealed that caregivers are undermined, devalued and even insulted due to their association with people living with HIV. This study further highlighted several pillars of strengths which keep them doing this work despite its difficulties. Implications of the findings are engaged and recommendations drawn from the social work perspective.

Keywords: HIV and AIDS, Coping, Courtesy stigma, Home Based-Caregivers

Introduction

The scourge of HIV and AIDS in most of the African countries have resulted in strained health care facilities and overburdened health personnel, calling for immediate alternative for the institutionalisation of AIDS patients. This led to

the mushrooming of Home-based care (HBC) projects mainly driven by volunteers (HBCGs) aimed to relieve the health care system (Hayes, 2009; Young & Busgeeth 2010:2). By home-based care, the World Health Organisation (WHO, 2002:6), refers to any high quality and appropriate care, including physical, psychosocial, palliative and spiritual care provided to patients and their families within their homes to ensure hope and maintain their independence. Among the advantages of HBC is the multi-purpose role played by HBCGs in sustaining the scale-up of Antiretroviral Therapy; relieving public institutions and families from the burden of caring for PLWH; the ability to encourage patients to be hopeful; to feed, bathe, dress and walk the patients (Wouters *et al.* 2012:11; Akintola 2005:8; Akintola, 2005:2; Akintola 2005:7). In addition, HBC equips HBCGs with various skills which also help them to resolve their own personal problems (Cambell, Nair, Maimane & Gibbs 2008:163).

Despite its benefits to society, HBC is a demanding and strenuous work for HBCGs (Sigh, Chaudoir, Escobar & Kalitchman 2011:2; Department of Social Development, 2006; Akintola 2005:133). One of the difficulties faced by HBCGs is the stigma of caring for PLWH (Singh, Chaudoir, Escobar & Kalitchman 2011:2; Ogunmefun, Gilbert & Schatz 2011; Rödlach 2009:429; Van Dyk 2009: 50). Although much is known about the experiences of HIV and AIDS its related stigma among PLHW themselves, little has been scrutinised and documented around stigma incurred by HBCGs as a result of caring and supporting PLHW. This resulted in scarcity of literature around this phenomenon, suggesting that programmes and policies developed to fight it may be inefficient. Ideally HBC programmes should involve the communities and contribute towards ending HIV and AIDS and its related stigma at the community level (Wringe, Cataldo, Stevenson & Fakoya 2010:3; Steinitz 2003:57). The reality is that instead of fighting HIV and AIDS and its related stigma, HCBGs suffer from the same stigma which they are supposed to end (Turner & Mullan 1998:138). Literature suggests that instead of supporting HBCGs in fighting HIV and AIDS, community members stigmatise them (Mashau & Davhana-Maselesele 2009; Mieh, Airhihenbuwa, & Iwelunmor, *n.d.*:189; Snyder, Omotto & Cain 1999). A South African cross-sectional study by Singh *et al.* (2011:839) revealed that 49% of HBCGs caring for PLWH personally experienced discrimination for caring for PLWH. A detailed understanding of the HCBGs experiences of courtesy stigma is necessary to set

a base upon which to guide appropriate intervention programs and policies aimed at addressing HIV and AIDS stigma.

The Nature of Stigma and HIV and AIDS-related Courtesy Stigma

Stigma is a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons (Goffman, 1963; Link & Phelan, 2001; Petros, Airhibenbuwa, Simbayi, Ramlagan, & Brown, 2006; Visser, Makin, Vandormael, Sikkema, & Forsyth, 2009). Whereas Byrne (2000:65) define stigma as a form of disgrace aiming to discredit and set a person apart from others, Goffman (1963:3) describe a stigmatised person as someone whom we reduce into a ‘tainted and discounted one’.

Stigma is not a new phenomenon. During the seventeenth century, physical marks were used to disgrace and discredit criminals and traitors who violated norms and offending the gods and causing pollution and moral sickness (Shoham, 1970:11). In this case it was adopted as a cleansing mechanism to purify immorality and appease the gods. Slicing, burning and advertising the slaves, criminals and traitors as tarnished and morally polluted was common among the ancient Greeks (Neuberg, Smith & Asher, 2000; Major & Eccleston, 2005). The stigmatised people were avoided, especially in public places as they were unfit for regular society (Goffman 1963; Neuberg *et al.*, 2000).

Resulting from the aforementioned practice is three types of stigma: *abomination of the body*, *blemishes of individual character* and *tribal stigma* (Goffman, 1963:4; Biernat & Dovidio, 2000:100). By *abomination of the body*, Goffman refers to some physical deformities such as the visible and deteriorating body due to illness. In this case people become labelled, blamed, avoided, and even humiliated due to their clearly visible signs and symptoms which are believed to be associated with diseases such as AIDS. *Blemishes of the individual character* refer to a type of stigma which is directed to individuals because of their features such as mental illness, disability, homosexuality and others. In this case, people become stigmatised because they possess features which are different from an average person. With *tribal stigma* (which is also called ‘courtesy stigma’, ‘stigma-by-association’ or ‘secondary stigma’), stigmatisation is extended to those who somehow

associate with the stigmatised (i.e. family members, friends, care givers, colleagues etc.). Although stigma is divided into various categories, Goffman (1963:5) observed that its features are the same. Courtesy stigma as defined by Mitchell and Knowlton (2009:612) refers to being discredited for being associated with a person who has a stigmatizing illness.

The eruption of HIV and AIDS and its fears and misconceptions resulted in stigma directed to PLWH. Those who are living with or suspected to be living with HIV were seen as frightening and immoral and became isolated, humiliated and in some instances even killed because they were living with, or suspected to be living with HIV (Mlobeli, 2007; Pape, 2005). In some cases the practice was through courtesy stigma, extended to their associates who also suffered victimisation and humiliation due to their association with them (Majumdar & Mazaleni, 2010).

Stigma as Ablon (2000:3) noted, can be understood by considering the nature of the illness; its history; its attributed characteristics; its sources of the creation and perpetuation; the nature of the populations perceived to carry the illness; the kinds of treatments and practitioners required for the condition; and how individuals with stigmatised conditions cope with insults that endanger their personal identity, social life, and economic opportunities. HIV is considered infectious and AIDS is an incurable disease associated with immoral acts like promiscuity, injecting drug use, sex work and homosexuality (Snyder, Omoto & Crain 1999:121). Through courtesy stigma, HBCGs experience stigma based on this dimension due to their involvement with an incurable disease associated with immoral conduct of sex workers, drug users and homosexuals.

With the dimension: sources of stigma, Ablon (2000:3) believes that sources of stigma develops from the negative attitudes held by the general society and values which are perpetuated by the media and social interactions. HIV and AIDS is generally frowned upon by society and in some cases the family members of PLWH. These negative attitudes may also be extended to those who provide care and support to the patients.

Thirdly stigma could be understood through the nature of the stigmatised people which in the case of HIV and AIDS relates to the mostly poor and black PLWH who are from the already marginalised racial population. Here the dominant reason for stigmatising the HBCG is their affiliation with these patients who are from marginalised and poor population background.

With the fourth dimension, consideration is placed on the type of treatment and practitioners required by PLWH (Ablon, 2002:2). The drained health care systems resulted in HBCGs who are mostly women from poor background with lower educational qualifications. At the center of this is HBCGs who are poorly qualified, for being involved with this illness which drains the health care system and strain the patient with a lifetime treatment. The HBCG's poor educational level and their association with these groups earns them courtesy stigma.

Finally stigma relates to how PLWH cope with humiliation and derogatory attitudes and treatment that threaten their social standing (Ablon, 2000:2). Lack of support systems for them to cope better will further expose them and their caregivers to stigma. This basically suggests that patients who lack support will by association also expose their caregivers to stigma.

Lazarus and Folkmans' Coping Theory

Coping is a continuously changing process of cognitive and behavioural efforts aiming to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources in a person's possession (Frydenberg 2014:83; Laux & Weber 1991:235; Lazarus & Folkman 1984:141). The coping theory posits that in our interaction with the environment, we encounter stressors of which some are overwhelming and exceed our coping ability. In order to manage the stressors, we engage in appraisal which eventually enables us to adopt either or both emotion-focused coping and problem focused coping. Appraisal means we evaluate the stressful situation as either harmful or challenging and then decide on whether to address it by adopting emotion-focused coping, problem focused coping or both (Frydenberg 2014:83; Barbosa, Figueiredo, Sousa & Demain 2011:491; Ntoumanis, Edmunds & Duda 2009:251; Laux & Weber 1991:235; Lazarus 1993:238). On the one hand emotion-focused approach to coping involves modifying the meaning of the stressful event without dealing with the stressor itself (Folkman, 1984:844; Frydenberg 2014:84). A caregiver would in this instance ignore or avoid the stigma and pretend as if it doesn't exist. The problem-focused coping on the other hand involves taking actions to address the stressor itself by managing its causes. As part of our coping effort, we draw from resources such as health, energy and positive beliefs which are part of our personality features and the

problem solving skills, social skills, social support and material resources from our environment (Lazarus & Folkman 1984:159-164). In other words, how HBCGs decide to cope with stigma is determined by the outcome of the appraisal process and available resources.

Research Methodology

Qualitative research which was exploratory, descriptive, phenomenological and contextual in design was used to understand HBCGs' experiences of courtesy stigma in caring for PLWH as one of the work-related challenges and their coping strategies in dealing with it. Whereas exploratory and descriptive research designs enabled participants to express and describe their experiences openly and freely, phenomenological and contextual designs enabled them to share some of their lived experiences from within their respective working contexts.

Participants and Sampling

Participants who met the inclusion criteria were identified and recruited through purposive and snowball sampling which gave rise to twenty-five HBCGs from South Africa's Gauteng, Limpopo and the North West provinces. Eighteen of them were from Gauteng province; three were from Limpopo province and four from North West province, with 22 blacks, two coloureds and one white. Whereas participants were mainly women (a total of 22) with only three males, their educational qualifications ranged from grade nine and grade twelve.

Data Collection and Data Analysis

Semi-structured interviews contained in a five-item interview guide with open-ended questions were used to explore the participants' lived experiences of courtesy stigma in caring for PLWH within their working contexts. Analysis involved transcribing and translating the data from indigenous languages (Setswana, Northern Sotho and Zulu) to English and later followed the eight steps of data analysis proposed by Tesch (in Creswell, 2014:198).

Ethical Issues

Relevant ethical protocols were observed during and prior the process of research. In addition, permission to conduct the study was negotiated and granted by authorities from all organisations. There was informed consent document detailing voluntary participation, the participants' rights like anonymity and confidentiality clauses.

The Research Findings and Discussions

The study found HBCGs experience courtesy stigma in various forms from people who related to them in different ways. Due to their involvement with PLWH, community members suspected that HBCGs were infected with HIV; HBCGs were undermined by nurses at the local clinics and some labeled and mocked by community members. Negative reactions from both community and family members of their patients were common with some gossiping about and avoiding the HBCGs.

Working with PLWH gave some of the community members an impression that HBCGs are themselves infected.

During their visits to their patients' houses, HBCGs meet community members who suspected that they were also living with HIV since they work with PLWH.

‘What is difficult is being associated with them. Like as you interact with people living with HIV, people tend to think that you are somehow affects you directly and you cannot do this job unless you are also HIV positive...when you walk equally with them, they tend to remain behind because they tend to say, let not people see me walking with this person because if they see me I am going to be associated because he is working with [PLWH]’ [Mokete].

‘They diagnose us through the families. When we going to the families to care for the sick then they just think, they think these people [HBCGs] are caring for the sick patients diagnosed with HIV, it means they are also diagnosed...’ [Lenong].

‘As you see my body is so small, people would say, there is no way that this person can work with [PLWH] if she is not sick herself; she also has AIDS that is why she is working with [PLWH]. Or when they see you coming to the hospice, they would say it means she also has AIDS’ [Lenyalo].

‘... I do this work, and the moment you do this kind of work, they would think that you are also sick. Yes there are those who are sick but they tend to believe that everybody who do this kind of work is sick. They would say we help these patients because we are also sick’ [Jini].

HBCGs are given negative reactions by household and community members

Negative reactions from the patients’ family and community were some of the difficulties faced by HBCGs due to their involvement in HIV and AIDS:

‘The way they [family and community] talk to us and the way they look at us we can see that we are not welcome. When you explain that you are so and so from hospice, they won’t wait for you finish, they would just say, I am busy. I won’t be given a chance to even explain the purpose of my visit’ [Selinah]

‘Yes it happens once you stop the car, then you getting in, especially if you want the address, is this address 1281, no no no [reaction by a household member], you are working with those people with HIV, please don’t park next to our gate, we don’t have an HIV positive person in here. They just say before you even ask’ [Lenong].

‘I remember the [nurse] asked me once to identify families with new born babies and call the parents to come and collect some milk at the clinic. I happened to find myself in a house where I found this man ... and he told me that his child does not eat milk for HIV-positive people’ [Kgomo].

‘One thing that I don’t like is that the moment I enter in a particular

household to execute my duties, you find that you are not taken serious by the family members – the parents and siblings of the patient. They will answer me in such a way that I get hurt. So, if you ask them to prepare some water, a child or a wife will ask me what for, while knowing very well that I am here to bath their father or husband' [Martin].

'...Some as you enter they would increase the volumes on the music and TVs, they won't even give you chairs nor welcome you. They would say, Your person [the patient] is not here... the family would make statements like these people who come here every day are embarrassing us because of you [referring to the patient]' [Dineo].

HBCGs are avoided by community members, patients' families and the patients themselves

What emerged from the participants' narratives was that community members, the patients and their families avoided them due to their HIV and AIDS work:

'As I knock, they [patients' family] would invite me into the house and as I enter they would respond to my greetings and then vanish as if they are going to fetch something outside without saying a word. I would only realise after some time that I am alone' [Pekwa].

'Okay there is a funeral or wedding. You come in on Friday and the family have given some women from the neighbourhood some vegetables to prepare for the wedding or funeral, you... find that they were talking about you and your work. So the moment you take a cabbage and try to assist in peeling, people will mumble and go as far as to ask all of those who were with you in a group to join their groups. So, you will eventually find yourself peeling the whole bag alone' [Pekwa].

'Yeah, they don't want to be associated with me because they know I am involved with [PLWH]' [Paul].

HBCGs are called names due to their involvement with PLWH

Among the HBCGs' experiences was name-calling which they earned out of their caring work:

‘So, when they see us walking they would say, this ones are working for KFC [a derogatory term implying that they are working with PLWH]’ [Mokete].

‘And when we go out for field work, there is a name that we are called with called ‘boMmamakaka [mothers of shit]’ [Selinah].

‘When people see us wearing our t-shirts, they make hurtful comments like, here comes the HIV people’ [Amelia].

People gossip about HBCGs who are caring for PLWH

Community members are reported to be spreading rumours through gossiping about the HBCGs and their work:

‘...I once heard people saying, you see where [Pekwa] is working, they bath HIV-positive people and remove the napkins, so you would never know whether when they do that they put in some gloves or not’ [Pekwa].

‘...she has been bathing patients for sixteen years..., she might be HIV [positive], she might be full-blown [reached AIDS stage]...’ [Lenong].

‘Community members have a way of spreading the news [about HBCGs]. Gossipmongers spread the news and there is no way of running away from it [Zulu].

HBCGs are Mocked by Community Members

Mocking by community members took a center stage in HBCGs' narratives:

‘...Let us say is a group of boys or these women who play some cards under a tree in a family where you are supposed to go in. As you enter

they would begin laughing while you are still at the gate. Yeah, and you could see that they are not laughing at what they are busy with, they are laughing at you. And even as you get closer to them and begin to introduce yourself, they would continue to laugh and ask funny questions' [Nakedi].

HBCGs feel undermined by nursing staff from the clinic

Among the reported experiences of HBCGs was being undermined by the nursing staff from the clinics:

'Sometimes sisters [nurses] undermine us because we are the caregivers. Mainly as we do our job, we would come across some patients who needs to be taken to the clinic and once we arrive at the clinic you would find sisters who would undermine you as a caregiver because our work is an odd one...' [Jini].

Contrary to those who reported their experiences of courtesy stigma, it emerged to some that community members were welcoming and appreciating the HBCGs.

'They were calling us the healers. We were at one of our patient's gate and one woman passed across us and said greetings to you healers. You really heal people'. Then she just passed. So we often get those kinds of words. Yes even the concerned neighbours they know. Some would say my other cousin was helped by care givers and when she realise that there is a patient, she would go and advise them to contact us' [Mpshe].

'I think the community appreciates my work....Sometimes I would be doing my visits to the patients and a woman would just call me and say I see you are wearing black and white [a uniform), there is a patient in so and so address... That to me shows that the people are realizing the importance of our work' [Pekwa].

'People know what our uniform looks like. I have already explained that many people know about [our work] They give me respect and they have accepted me. Sometimes people treat me like a fully-fledged

[qualified] nurse. They respect me and they give me dignity' [Zulu].

The Coping Strategies Adopted in Overcoming Courtesy Stigma

A picture which was painted by the participants in coping with courtesy stigma was a multifaceted one involving to simply ignore the negative treatment and continue with their daily tasks, withdrawing from relatives and spending time with their own families, receiving support from management and other professionals, educating the community on the importance of their work as well as by simply leaning on God.

HBCGs cope by simply accepting the status quo and continue with their work

For some participants, the experiences of courtesy stigma did not bother them. They continued to serve their patients as if they do not have any challenge:

‘People have spoken about me but I have told myself that I am not going to allow them to destroy my spirit. I just leave them and say, if I work with PLWH and I am HIV positive is fine...’ [Lenyalo].

‘I am not sure but even if they can say this and that gossiping, I am not afraid of what they are going to say. I am going to continue doing what I am doing’ [Letsatsi].

‘I am ignoring that, and especially because...is not necessary to tell them that I am not HIV [positive] I was tested I was never diagnosed...Is not my duty to say that...’ [Lenong].

‘In this stage of my life I feel like I am living my own life and I don’t care what they feel. If I feel like I want to care for another person why not? I have had some reactions before from them over the years. I will just do my own things’ [Paul].

‘I do not take it as personal. We know how patients react towards mem-

bers of the community, so in that case I am also a member of that community. So I do not take it personal, I tell myself that I will come again tomorrow until they welcome me' [Dineo].

A HBCG cope by withdrawing from the relatives

Withdrawal from gatherings where relatives would be there was reported as one of the strategies to cope with stigma:

‘...So I try to avoid getting closer to extended family members and relatives because once you associate yourself with them, they develop a negative attitude towards you. They look at you in a negative light and begin to think that you will infect them. I just think so, that is my thought that is why in most cases I do not care about them. I only meet them when there is a specific issue that requires me to be there and I go there just to deal with that issue and leave’ [Mokete].

A HBCG cope through support from management and colleagues

In other instances, management and colleagues were reported to be playing a crucial role of supporting HBCGs to cope with stigma:

‘We have superiors. Like today, is the day for lectures. We don’t do home-visits. At 4, we attend the MGM meeting [Monday General Meetings]. We discuss challenges that we encounter when we do home visits. It is where we tell our superiors about the challenges that we encounter our superiors give us guidance on how to react to different situations’ [Zulu].

A HBCG cope through some help from other professionals

Lenyalo explained how other professionals assist her:

‘There is a professional nurse who tries to support us. most of the time when we encounter these problems we share them with her and she would go out with us and as we enter the households, she would explain to them nicely that we are working with [PLWH] and if we work with this people it does not mean that we are also infected...’.

Caregivers cope by educating the community about their work

In coping with the negative treatment, HBCGs decided to educate the community about their work:

‘...I then started to clarify that with other members of the community by saying, if I am visiting you, it does not mean that I have come for HIV and AIDS’ [Kgomo].

‘Well, in most cases we try to educate the people because that is the main part that we are trying to do because there is no other way that we can reduce the stigma in a community besides through education’ [Mokete].

Caregivers cope by simply leaning on God

What emerged as one of the coping strategies to address the stigma was the HBCGs’ belief in God. They believed that it was through God’s will that they found themselves caring for PLWH:

‘You console yourself by saying even if she closed the door for me, she is sick and one day I will come for her. And because God is there with us, you would even find that they would call you for the same patient [Cassie].

‘The person who helped me was the pastor. We have a pastor here and she would read scriptures in the mornings and revive our spirits... I told myself that God is there, I am going to help them and I did this course because I like it’ [Nakedi].

‘[If] it was not for God, I would have quitted long time ago, is because God is good for me, so, yeah’ [Paul].

‘We are also in that diagnosis. For us is a calling God allocated us to do that’ [Lenong].

Discussion

The findings of this study revealed that HBCGs experience HIV and AIDS-related courtesy stigma, a revelation found in some existing literature (Ama & Seloibe 2011:2; Akintola 2008:362; Akintola 2005:15&16; Bennet, Ross & Sunderland 1996:145). In line with the source of stigma as one of the dimensions identified by Ablon (2002:4), participants' experiences of courtesy stigma were found to be in various forms and from various sources such as members of the communities where the patients were residing, nurses from the local clinics wherein they used to refer their patients and family members of the patients. HBCGs' association with PLWH created an impression around the communities that they are also HIV-positive and were therefore blanketing their HIV-positive statuses by simply being involved in caring for PLWH. This perception earned them negative attitudes and negative reactions from members of the community with some avoiding them whenever they show up. This finding supports what was found in Akintola's (2005:15&16) South African study of the role of HBCGs in HBC for PLWH wherein being visited by a caregiver was attached to stigma, resulting in caregivers being rejected by their patients' families. For Rödlach's Zimbabwean (2009:428) study, families of the patients went as far as to hide their sick patients whenever the HBCGs were around. In another Mexican study aiming to explore the perceptions and experiences of HIV-affected caregivers concerning HIV-related stigma, Poindexter and Linsk's (1999:50) revealed that participants experienced stigma from their friends and families. A South African study which addressed factors most likely to facilitate or hinder mobilisation of community resources by Campbell *et al.* (2008:512) found that in some cases stigma manifested itself through caregivers who would walk distances to houses rumoured to have patients only to be turned away by the families.

The findings in relation to the participants' experiences of stigma from the clinic nurses were not a new revelation by this study. In his Botswana study focusing on the challenges and bottlenecks affecting the referral system, Kang'ethe (2009:60) revealed that medical staff had negative attitudes towards the HBCGs and their patients. This was contrary to Singh *et al.*'s (2011:843) revelation wherein HIV and AIDS caregivers reported support from the nurses leading to willingness to care.

Evidence pertaining to name calling HBCGs was found to be in support of Akintola's (2005:13) South African study where participants

received nasty comments and called names like ‘Good Samaritans’ who waste time through volunteering by members of their communities.

Besides having gone through these odd experiences, it also emerged from my study that not everything was doom and gloom as participants reported some appreciative attitudes and reactions from members of the community, a revelation corroborating with the findings by Chimwaza and Watkins (2004:805) where community members provided support to caregivers.

Despite having to go through these difficulties, HBCGs were not deterred from caring for their patients and families. They manipulated their ways out of these difficulties through a variety of coping mechanisms which both confirmed Lazarus’ and Folkman’s emotion-focused coping and problem focused coping (Barbosa *et al.* 2011:491; Ntoumanis *et al.* 2008:251; Laux & Weber, 1991:235; Lazarus, 1993:238). Problem-focused coping aiming to address stigma became evident from one participant [Mokete] who decided to draw skills from his resources by educating the community on the importance of their work. Emotion-focused coping was also adopted and enhanced by available resources where participants decided to use people like management, colleagues and other professionals as resources to help them cope better with stigma while some opted to simply ignore the status quo and proceeded with their work as if nothing happened. Although positive belief may have emerged as one of the resources used, it was particularly evident when they highlighted their faith in God as one of the adopted coping strategies.

Conclusions

This study attempted to expand the pool of literature around HIV and AIDS-related stigma. It cautioned us that the fight against this epidemic is not yet over. In support of some of the existing studies, it has shown that the plight of HBCs who are supposed to contribute in ending this scourge has turned them into victims of the very stigma which they are supposed to fight. Communities served by these HBCGs and families of the patients were particularly found to be the main culprits. It is however not all of these communities and families that were found to have frowned upon the HBCGs because of their involvement with PLWH; some were touched by the courage and dedication of these men and women to such an extent that they would even offer them

respect by participating in the HBC program through making referrals. As much as it has shed some light on the experiences of HIV and AIDS courtesy stigma by HBCGs, it is crucial to interpret these findings with caution since it involved a sample of only twenty-five participants from South Africa's three of the nine provinces.

This study has shown how HIV-related courtesy stigma interferes with the HBCGs' daily operations. It has shown that unless their challenges, with stigma are addressed, they will find it difficult to successfully fight the scourge of HIV and AIDS epidemic. It is on this note that the following recommendations are made:

- Programmes should be designed by professionals like psychologists and social workers to specifically support the HCBGs to overcome their challenges with courtesy stigma.
- Community education programs must be rolled out throughout the communities to educate the communities on the significance of HBCGs and their roles within the society. These programmes should also empower the communities to also take a responsibility by being involved in HBC programmes.

References

- Ablon, J. 2002. The Nature of Stigma and Medical Conditions. *Epilepsy & Behaviour* 3:2-9.
- Akintola, O. 2008. Defying all Odds: Coping with the Challenges of Volunteer Caregiving for Patients with AIDS in South Africa. *Journal of Advanced Nursing* 63:357-365.
- 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. HIV and AIDS-related Courtesy Stigma. Available at: <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 on 08 April 2014).
- Ama, N.O. & E.S. Seloibe 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.

- Barbosa, A., D. Figueiredo, L. Sousa & S. Demain 2011. Coping with the Caregiving Role: Differences between Primary and Secondary Caregivers of Dependent Elderly People. *Aging & Mental Health* 15,4:490-499.
- Bennet, L., M.W. Ross & R. Sunderland, R. 1996. The Relationship between Recognition, Rewards and Burnout in AIDS Caring. *AIDS Care* 8,2:145-153.
- Biernat, M. & J.F. Dovidio 2000. Stigma and Stereotypes. In Heatherton, T.F., R.E. Kleck, M.R. Hebl & J.G. Hull (eds.): *The Social Psychology of Stigma*. London: Guilford Press.
- Byrne, P. 2000. *Stigma of Mental Illness and Ways of Diminishing it*. Available at: <http://apt.rcpsych.org/content/6/1/65>. (Accessed on 22 September 2016).
- Campbell, C., Y. Nair, S. Maimane & A. Gibbs 2008. Hearing Voices: Grassroots Perceptions of an Intervention to Support Health Volunteers in South Africa. *Journal of Social Aspects of HIV/AIDS* 5,4: 162-177.
- Campbell, C., Y. Nair, S. Maimane & Z. Sibiya 2008. *Supporting People with AIDS and their Carers in Rural South Africa: Possibilities and Challenges*. Available at: <https://core.ac.uk/download/pdf/93742.pdf>. (Accessed on 15 August 2016).
- Chimwaza, A.F. & S.C. Watkins 2004. Giving Care to People with Symptoms of AIDS in Rural sub-Saharan Africa. *AIDS Care* 16,7:795-807.
- Creswell, J.W. 2014. *Research Design*. 4th Edition. Los Angeles: Sage.
- Folkman, S. 1984. Personal Control and Stress Coping Process: A Theoretical Analysis. *Journal of Personality and Social Psychology* 46,4: 839–852.
- Frydenberg, E. 2014. Coping Research: Historical Background, Links with Emotion, and New Research Directions on Adaptive Process. *Australian Journal of Psychology* 66,1:82-92.
- Goffman, E. 1963. *Stigma: Notes on Management of Spoiled Identity*. London: Cox & Wyman.
- Hayes, S. 2009. Home-based Care Alliance in Kenya, Improving Governance and Transforming Communities in the Context of HIV/AIDS. In Harman, S. & F. Lisk (eds.): *Governance of HIV/AIDS, Making Participation and Accountability Count*. New York: Routledge.
- Kang'ethe, S.M. 2009. 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.

- Krohne, H.W. *Stress and Coping Theories*. Available at: http://userpage.fu-berlin.de/schuez/folien/Krohne_Stress.pdf. (Accessed on 18 August 2016).
- Laux, L. & H. Weber 1991. Presentation of Self in Coping with Anger and Anxiety: An Intentional Approach. *Anxiety Research* 3,4:233-255.
- Lazarus, R.S. & S. Folkman 1984. *Stress, Appraisal and Coping*. New York: Springer.
- Lazarus, R.S. 1993. Coping Theory and Research: Past, Present, and Future. *Psychosomatic Medicine* 55:234-247.
- Link, B.G. & J.C. Phelan 2001. Conceptualizing Stigma. *Annual Reviews Sociology* 27:363-385.
- Link, B.G. & J.C. Phelan 2001. Conceptualizing Stigma. *Annual Reviews Sociology* 27:363-385.
- Major, B. & C.P. Eccleston 2004. Stigma and Social Exclusion. In Abrams D., J. Marques & M.A. Hogg (eds.): *Social Psychology of Inclusion and Exclusion*. New York: Psychology Press.
- Majumdar, B. & N. Mazaleni 2009. The Experiences of People Living with HIV/AIDS and of their Direct Informal Caregivers in a Resource-poor Setting. *Journal of International AIDS Society* 13:1-9.
- Mashau, N.S. & M. Davhana-Maselesele 2009. *Experiences of HIV/AIDS Home-based Caregivers in Vhembe District of the Limpopo Province*. Available at: <http://www.curationis.org.za/index.php/curationis/article/viewFile/985/922>. (Accessed on 18 May 2016).
- Mieh, T.M., C.O. Airhihenbuwa & J. Iwelunmor n.d. *Resilience in Home-based Caregivers in Limpopo, South Africa*. Available at: http://forms.gradsch.psu.edu/diversity/mcnair/mcnair_jrnl2010/files/Mieh.pdf. (Accessed: 04 May 2016).
- Mitchell, M.M. & A. Knowlton 2009. Stigma, Disclosure and Depressive Symptoms among Informal Caregivers of People Living with HIV/AIDS. *AIDS Patient Care* 23,8:611-617.
- Mlobeli, R. 2007. *HIV/AIDS Stigma: An Investigation into the Perspectives and Experiences of People Living with HIV/AIDS*. Available at: http://etd.uwc.ac.za/usrfiles/modules/etd/docs/etd_gen8Srv25Nme4_8704_1189595766.pdf. (Accessed: 04 May 2016).
- Neuberg, S.L, D.M. Smith & T. Asher 2000. Why People Stigmatise: Towards a Biocultural Framework. In Heatherton, T.F., R.E. Kleck, M.R. Hebl & J.G. Hull (eds.): *The Social Psychology of Stigma*. New York: Guilford Press.

- Ntoumanis, N., J. Edmunds & J.L. Duda 2009. Understanding the Coping from Self-determination Theory Perspective. *British Journal of Health Psychology* 14: 249-260.
- Ogunmefun, C., L. Gilbert & E. Schaltz 2011. Older Female Caregivers and HIV/AIDS-related Secondary Stigma in Rural South Africa. *Journal of Cross Cultural Gerontology* 26,85:85-102.
- Pape, A.A. 2005. *Social Morality and Misplaced Responsibility: HIV/AIDS-Related Stigma*. Available at: <http://www.szasz.com/undergraduate/pape.pdf>. (Accessed: 18 June 2016).
- Petros, G., C.O. Airhibenbuwa, L. Simbayi, S. Ramlagan, & B. Brown 2006. HIV/AIDS 'othering' in South Africa: The Blame Goes on. *Culture, Health and Sexuality* 8,1, 67-77.
- Poindexter, C.C. & N. Linsk 1999. HIV-related Stigma in a Sample of HIV-affected Older Female African American Caregivers. *Social Work* 44,1:46-61.
- Rödlach, A. 2009. Home-based Care for People Living with AIDS in Zimbabwe: Voluntary Caregivers' Motivations and Concerns. *African Journal of AIDS Research* 8,8:423-431.
- Shoham, S. 1970. *The Mark of Cain, the Stigma Theory of Crime and Social Deviance*. Jerusalem: Israel University Press.
- Shenton, A.K. 2004. Strategies for Ensuring Trustworthiness in Qualitative Research Projects. *Education for Information* 22:63-75.
- Singh, D., S.R. Chadoir, M.C. Escobar & S. Kalichman 2011. Stigma, Burden, Social Support, and Willingness to Care among Caregivers of PLWHA in Home-based Care South Africa. *AIDS Care* 23,7,:839-845.
- Snyder, M., A.M. Omoto & A.L. Crain 1999. *Punished for their Good Deeds: Stigmatisation of AIDS Volunteers*. Available at: <http://abs.sagepub.com/content/42/7/1175.full.pdf+html>. (Accessed on 22 September 2016)
- South Africa. Department of Social Development. 2006. *Situational Analysis and Needs Assessment of Management Capacity among Home- and Community-based Care Service Providers*. Available at: <http://www.info.gov.za/view/Download/FileAction?ID=127112>. (Accessed: 2016/08/22).
- Steinitz, L.Y. 2003. When Spider Webs Unite. *Journal of HIV/AIDS & Social Services* 2,1:45-62.
- Turner, H.A., L.I. Pearlin & J.T. Mullan 1998. Sources and Determinants of Social Support for Caregivers of Persons with AIDS. *Journal of Health and Social Behaviour* 39,2:137-151.

- Van Dyk, A. 2009. Occupational Stress Experienced by Caregivers Working in the HIV/AIDS Field in South Africa. *African Journal of AIDS Research* 6,1:49-66.
- Visser, M.J., J.D. Makin, A. Vandormael, K.J. Sikkema & B.W.C. Forsyth 2009. HIV/AIDS Stigma in the South African Community. *AIDS Care* 21,2:197-206.
- World Health Organization 2002. *Community Home-based Care in Resource-limited Settings: A Framework for Action*. Geneva: WHO.
- Wouters, E., W. van Damme, D. Rensburg & C. Masquillier 2012. Impact of Community-based Support Services on Antiretroviral Treatment Programme Delivery and Outcomes in Resource-limited Countries: A Synthetic Review. *BMC Health Services Research* 12,194:1-17.
- Wringe, A., F. Cataldo, N. Stevenson & A. Fakoya 2010. Delivering Comprehensive Home-based Care Programmes for HIV: A Review of Lessons Learned and Challenges Ahead in the Era of Antiretroviral Therapy. *Health Policy and Planning* 25,5:1-11.
- Young, T. & K. Busgeeth 2010. *Home-based Care for Reducing Morbidity and Mortality in People Infected with HIV/AIDS (Review)*. Available at: <http://www.mrc.ac.za/cochrane/homebasedcare.pdf>. (Accessed: 27 April 2013).

Lekganyane Maditobane Robert
PhD Candidate
University of South Africa (UNISA)
lekgamr@unisa.ac.za