Home-based care volunteer identity and participation in HIV/AIDS care and support in rural KwaZulu-Natal, South Africa

by

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DECLARATION

I declare that the thesis hereby submitted to the University of KwaZulu-Natal, for the degree of Doctor of Philosophy (Psychology) has not been previously submitted by me for a degree at this or any other university; that it is my work in design and execution, and that all material herein contained has been duly acknowledged.

_____   _____

T. NAIDU (MS)   Date

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DEDICATION

For my children Khairiv and Dhruv, my husband Rajen

and

My parents Siva and Vimla.

ACKNOWLEDGMENTS

NOTES

1) The reference section at the end of this thesis includes references for Chapters 1, 2 and 10.

2) References for each published and submitted paper appear at the end of each chapter according to referencing style relevant to the specific journal in which the paper appears or was submitted to.

ABSTRACT

This thesis explores home-based care volunteer (HBCV) identity and how it is shaped by context in rural KwaZulu-Natal, South Africa. The literature on home-based care in Africa is dominated by the "burden of care narrative" which is supported by the themes of "women as caregivers", "poverty" and "stigma". The literature presents government and stakeholder collaboration as the general solution to alleviating the burden of care on women caregivers. A wider scope for research within the themes is necessary to discover alternative solutions to the problem of the burden of care. . This study ventured to expand the scope of current research by exploring the area of HIV and AIDS home-based care volunteer (HBCV) identity and participation in care and support. Fifteen HBCVs were interviewed about their work and personal life stories and interviewed reflexively using narrative interviewing. Findings indicate that the women's stories were dominated by narratives of gender, poverty and socio-political factors (social field narratives). Meta-narratives influencing the women's lives were stories of communal motherhood, aspirations to service-oriented work and religious beliefs and commitment. The women's personal life stories revealed that they saw themselves as distinctively caring. Connections between the different aspects of identity and context revealed that the women made sense of their community participation through their personal identities as strong and loving mothers and the association with the group identity of community mothering. Home-based-care volunteerism was explored as a form of agency in response to a lack of recognition, support and acknowledgement for AIDS caregivers and their patients. Researcher reflexivity through autoethnography and poetry contributed to achieving depth in the study and to the understanding that HBCVs strive for space recognition, acknowledgement and validation for their work . In a resource strained context a balance must be found between material compensation and respect and recognition which can be effective in sustaining community initiated volunteerism.

Chapter 1

General Introduction

1.1. Background

In recent years, HIV/AIDS has become a seemingly overwhelming health problem in South Africa. In 2009, the South African national adult (15–49 years) HIV prevalence was 17.8%. The HIV epidemic has reached a plateau in South Africa levelling off to just below 30%. However, the absolute number of people living with HIV (PLHIV) is on the increase with approximately 100 000 additional PLHIV each year. South Africa's 2012 country report to UNAIDS of the estimated number of PLHIV in 2009 was 5.63 million, placing South Africa at the top of the list of countries with the highest number of infections in the world (UNAIDS, 2012). Over the past twenty years, the highest HIV prevalence among the 15–49 year olds has been recorded in KwaZulu-Natal, which remained stable at 39.5%. There has been a noticeable decline in AIDS-related mortality in recent years, with the annual number of AIDS deaths reduced from about 257 000 in 2005 to about 194 000 in 2010 (ASSA, 2011). Whilst the latest reports indicate that the epidemic might be levelling off in South Africa, the effect of a large percentage of the economically active population that are already infected will persist for years and perhaps generations into the future (UNAIDS, 2012). In the shadow of this pandemic there is a need to explore all avenues to curtail the consequences on those already infected and affected. In addressing the needs of those already infected, the issue of care and support takes centre stage. Despite the roll-out of anti-retroviral treatment nationally, the issue of care and support remains important. Poverty and other socio-economic factors produce a lack of social support; impede access to good nutrition and treatment, increase stress and impact on adherence. This results in opportunistic infections and other HIV and AIDS-related conditions, thus placing pressure on under-resourced personal and community care and support reserves.

Whilst this work does not focus on treatment of HIV and AIDS, it would be remiss to ignore that the optimism associated with the national roll-out of anti-retroviral treatment (ARV) might in some instances be misplaced in rural contexts of care and support. Poor accessibility and uptake of ARVs are linked to poverty and the associated problems produce a deluge of difficulties for patients and care and support resources which work to counteract the positive outcomes expected with the increased accessibility of ARV treatment.

South Africa's Progress Report on the Declaration of Commitment on HIV/AIDS indicated that the impact of HIV/AIDS in South Africa has resulted in many creative approaches to care and support (UNAIDS 2012a). Prominent amongst these is the development of community-based models of palliative care. South Africa's Country Report indicates that the Department of Health adopted a new primary health care (PHC) model that focuses on individual and the family issues in health promotion, prevention, and rehabilitative and referral services as opposed to a model based exclusively on curative services (UNAIDS 2012a). The intention was to avoid the disconnected outcomes that resulted when numerous community health care workers visited families. Rather this revised approach aims to create a situation where a single integrated team establishes relations with families in the catchment area. It emphasises strong community participation as well as inter-sectoral collaboration (UNAIDS, 2012a). It has been noted that communities and families in sub-Saharan Africa, including South Africa, bear the responsibility for the care and support of those affected by AIDS (Akintola, 2006; Campbell & Foulis, 2004; Harding & Higginson, 2005a; Orner, 2006). The South African government committed itself to a National Strategic Plan to reduce the rate of new HIV infections by 50% by 2011. South Africa also proposed to reduce the impact of

HIV and AIDS in individuals, families and communities and society by expanding access to appropriate care and support to 80% of all HIV-positive people and their families by 2011. It would seem that the main route for the realisation of this plan involves the integration of home and community-based services emphasising community and inter-sectoral collaboration into the newly initiated Home and Community-based Care Programme. In theory, this programme promotes the idea of an integrated team to establish relationships with communities and families in a catchment area to facilitate the integrated delivery of care and support.

The UNAIDS 2012 Country Report for South Africa notes that home and community-based care (HCBC) is a central pillar of the care component of the integrated response to HIV and AIDS. The Report acknowledges that HCBC is provided mainly through non-governmental and community-based organisations. The South African government has initiated a new HCBC support programme, the objective of which is to ensure access to care and follow-up through a functional referral system; and access by children and families who are affected and infected by HIV and AIDS to social-welfare services within their communities.

Government envisages that at a grassroots level, the momentum behind this programme will be driven by a cadre of community caregivers (CCGs). The South African Country Report indicates that the South African Department of Health currently provides stipends to 42 756 community caregivers (CCGs) supporting people living with AIDS and other conditions (UNAIDS, 2012a). This represents an improvement of 40% from the 25 278 CCGs who received stipends in 2009/2010. No specification is given on the exact amount of the stipend; however, the report indicates that it contributes to sustaining the commitment of caregivers. Nevertheless, there was and continues to be a

large cadre of volunteers who contribute to the home-based care aspect of HIV and AIDS care and support in communities. Whilst the newly designated group of community care givers work in exchange for a modest stipend of approximately R500–R1 400 ($60–$200) per month there are still volunteers who offer their services without compensation. Despite the introduction of the community care giver position, volunteers are still an essential part of the service as the need for home-based care services exceeds the number of available CCGs.

1.2. Overview of volunteerism

The next section provides an overview of the literature relevant to this study beginning with a view on the literature on volunteerism in general. This is followed by a look at volunteerism in context with some reference to cultural influences and then volunteerism in relation to HIV and AIDS care. A view of HIV and AIDS care volunteerism in Africa is explored and deliberation is presented on South African policy initiatives directing lay health work, the category within which volunteer care work is assimilated. HIV and AIDS care and support volunteerism is addressed before considering the association between motivation and identity in relation to initiation and persistence in volunteerism. The concept of identity in relation to volunteerism has not previously been investigated in HIV and AIDS care and support in Africa. This area warrants some attention in order to fully grasp community participation in the African context. The latter is especially relevant so as to understand the possible implications of recent policy initiatives, to combine various lay health workers into a single generalist category, on lay health worker identity.

1.2.1. Volunteerism

Volunteering means any activity in which time is given freely to benefit another person, group or organisation. Volunteers benefitting from the activity, whether this includes material rewards or not, is an issue under debate (Wilson, 2000). Caring, involving personal or emotional labour amongst family and friends is not regarded as volunteering, which is considered to be formalised and public (Snyder & Omoto, 1992). Volunteers offer their services for various reasons including altruism, hobby, community service, charity or to gain experience depending on context. In some instances, volunteering may present the only opportunity for people to keep busy and create the opportunity to be recognised as being willing to work. This latter characterisation of the volunteer is one that was ascribed to volunteers in this study. For the purpose of this study, volunteers were defined as those who give time and effort freely to benefit people other than family and who may receive some –usually intermittent – material reward.

1.2.2. Volunteering and context

Context and local culture are likely to influence the nature and practice of volunteerism as with all aspects of social life. The "individualism–collectivism cultural syndrome" describes what appears to be the most significant difference amongst cultures (Triandis, 1996: 407). Western cultures tend to emphasise personal attitudes, beliefs, needs, personality and idiosyncratic values whereas in non-Western cultures, norms, collective needs, collective self-definitions and values tend to be regarded as more important. Broadly, the former is referred to as individualist and the latter as collectivist (Triandis, 1996). The two diverge fundamentally on the following dimensions: the meaning of self, the structure of goals, and behaviour as a function of norms and attitudes and the focus on the needs of the in-group or social exchanges. (Triandis, 1995)

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envisaged cultural syndromes as dimensions of cultural variation that can be used as parameters of psychological theories. Overall, people in collectivist cultures give precedence to group goals over personal and individual goals. There is a likelihood that people form collectivist cultures will focus on the context rather than the content in making attributions and communicating (Triandis, 2001; Triandis, 2001; Wang, 2008). They define themselves as part of a group and give less credence to internal than to external processes as determinants of social behaviour. People in collectivist cultures also define relationships with in-group members as communal, make more situational attributions and are more likely to be self-effacing.

Triandis'(1996) conception of the 'individualism–collectivism cultural syndrome' has been used fairly extensively to make sense of cultural variations nationally and globally. However critique has been levelled at the approach cautioning that restraint should temper an indiscriminate application of the recommendations from research as most studies have tended to make certain assumptions. These assumptions include one that noting that mostly researchers have tended to treat cultures as nations, and culture as a continuous quantitative variable. Most research based on the individualism-collectivism dichotomy conflates all kinds of social relationships and distinct types of autonomy whilst disregarding contextual specificity in norms. Culture is measured as the personal preferences and behaviour reports of individuals. The external validity of the measures used is rarely explored with studies assuming cultural invariance in the meaning of self-reports and anchoring and interpretation of scales whilst reducing culture to abstract verbal knowledge. (Oyserman, et al, 2002). Fiske (2002) recommends that a variety of complementary methods, each replicated against similar studies and checked against results from the other methods would produce more reliable research on culture.

It is important to note that in a globalised world, manifestations of individualism and collectivism may be indistinct and include variations and combinations of the traits of each across a spectrum from collectivism to individualism, largely influenced by context. Historically, African culture can be described as tending towards collectivism (Mkhize, 2004). This is most clearly espoused in the concept of *ubuntu* which is a major tenet of the African worldview philosophy. It is a multifaceted concept rooted in collectivism which cannot be fully described from a Western perspective. Hanks (2008) notes some approximations, include "the desire to live in harmony with others and to submit one's own needs for the benefit of the social framework in which one lives" (Van Vlaenderen, 2001), p. 150), and the idea that a person can only be a person through others so the individual's whole existence is relative to that of the group (Bracke, Christiaens, & Wauterickx, 2008). *Ubuntu* refers to the quest for harmony and solidarity of the group as the motivating force for human action and thought (Kamwangamalu, 1999; Van Vlaenderen & Cakwe, 2003; Verster, 1986). Identity is always perceived relative to the group. There is no humanness in existence independent of the group. This will be addressed to some degree and in relation to home-based care volunteers in this thesis.

Despite its apparent utility there has been some critique regarding the overuse of the concept of *Ubuntu* in community based work in South Africa. *Ubuntu* is often presented as the panacea for all social ills in African contexts. However some authors have noted that *ubuntu* reflects elements of "totalitarian communalism" which renounces elevating an individual above the community" and can therefore be overpowering. There are likely to be negative consequences for expression of individuality that are contrary to the norm In such contexts *ubuntu* may be seen as a constrictive or tyrannical custom of dislocated African culture which rejects the individual beyond the community" (Louw,

2001; Kochalumchuvattil, 2010). Taken in the context of community work this view of *ubuntu* would be counterproductive to community development by rejecting the agency demonstrated by individuals in communities. Moreover given this view, an emphasis on *ubuntu* where communities are encouraged to rely on the their own resources has the effect absolving government of its role in community development and perpetuating the status quo of capitalist societal norms of gender class and race. Specifically in relation to the conditions of HIV and AIDS care and support this has implications for impoverished African women who provide unpaid care in communities.

Observations on the differences between collectivist and individualist cultures are significant when it is noted that the majority of work on volunteers in the context of HIV and AIDS has been done in the United Kingdom and the United States, cultures which are considered essentially individualist. There is therefore much to be learned about volunteerism in predominantly collective cultures. Research in individualist cultures suggests that volunteering has a positive effect on the mental health and well-being of volunteers (Borgonovi, 2008; Crook, Weir, Willms, & Egdorf, 2006b). Volunteers in individualist cultures are motivated to volunteer by virtue of their individual identity, the personal satisfaction they achieve from their volunteer work, personal values and to some extent the expectation they perceive from others (Finkelstein, Penner, & Brannick, 2005; Ramirez-Valles & Brown, 2003). At the same time, volunteers are likely to experience burnout and stress, desire for support grief and emotional overload (Crook et al., 2006a; Finkelstein et al., 2005; Held & Brann, 2007).

Notably research on volunteerism in individualist cultures places emphasis on examining personal motivation, personal values, personality traits, individual characteristics, individual benefits to the volunteer, psychological well-being, and

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psychological commitment. Participation in social networks is most likely to take place amongst the wealthiest, most educated members of a community (Baum et al., 2000). Evidence available from collectivist cultures suggests that volunteering is viewed differently in these cultures. People might feel that they are obligated to volunteer because of socially constructed roles and spiritual beliefs (Akintola, 2006; Songwathana, 2001; Songwathana, 2001). In addition, informal helping behaviour may be seen as volunteering and more consistent with cultural practices within a particular culture (Ramirez-Valles & Brown, 2003).

Volunteerism in the South, usually developing countries in Africa, South America and South-East Asia is influenced by circumstances of poverty, or to gain recognition, to avoid boredom from unemployment or by cultural precepts about community involvement (e.g. *ubuntu*) (Songwathana, 2001; Sundeen, Garcia, & Wang, 2007). Volunteers working in HIV and AIDS care in South Africa gain rewards in the form of self-growth, knowledge skills and competencies from training and experience and community appreciation (Akintola, 2010). Evidence supports the proposal that in more individualistic cultures or well-resourced environments, intrinsic motivation factors tend to prevail while poor socioeconomic conditions could contribute to more extrinsic motivation factors (e.g. potential financial gain and recognition).

1.2.3. HIV and AIDS care volunteerism

Volunteerism is a relatively untapped area of investigation within HIV and AIDS research in South Africa. Whilst there has been some investigation into the impact and influence of volunteer caregivers on the spread and management of HIV and AIDS internationally, this investigation has been relatively limited when compared to other areas. This is an important area to research as volunteers often form the bridge between

HIV and AIDS-affected communities and formal health authorities and researchers and they are relied on heavily. Despite the fact that NGOs and CBOs are operational in a community it can often be volunteers who are the most important resource at the grassroots level facilitating and implementing interventions, communicating, educating and initiating advocacy (Campbell, Gibbs, Maimane, & Nair, 2008).

It is important to note that community networks around care and support pre-existed the advent of HIV and AIDS in communities. Communal living, traditional precepts, poverty and the consequences of apartheid compelled people to share resources and rely on each other for their daily needs. People were able to help and support each other whilst continuing with their daily lives. However HIV and AIDS introduced unprecedented challenges on all levels and put immeasurable pressure on all human and material resources. Long periods of economic inactivity due to illness, increased care needs resources-constrained conditions and high infection rates exacerbated social, economic and health burdens on communities and people who had not had the chance to recover from the effects of apartheid. It became necessary for people to abandon activities of daily living due to illness or to care for ill family members. As the numbers of those affected by HIV and AIDS increased people began to volunteer to care others in their community apportioning time from the own productive activities. Rather can creating a care and support networks HIV and AIDS stretched existing resources to well beyond capacity creating a strain even on those not directly affected.

In the case of HIV and AIDS home-based care, volunteers tend to be women in the community who are neighbours or extended family members of people living with HIV and AIDS (Akintola, 2006; Ama & Seloilwe, 2011; Kipp, Nkosi, Laing, & Jhangri, 2006; Ndaba-Mbata & Seloilwe, 2000; Olenja, 1999; Orner, 2006; Tarimo, Kohi,

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Outwater, & Blystad, 2009). This is illustrative of the collectivism significant in rural regions in South Africa (Mkhize, 2004). In cultures that operate on the basis of collectivism, most aspects of life are of community concern. Social location within in a community takes precedence over individual uniqueness in identity as would be found in individualistic cultures. As suggested by research into HIV and AIDS volunteerism in other collectivist cultures such as in Mexico and Thailand, volunteerism can be defined and operates with significant differences as compared to individualist cultures. Volunteerism may be personally motivated and supported by the cultural, religious, kinship and social obligations to provide care (Ramirez-Valles & Brown, 2003; Songwathana, 2001).

1.2.4. HIV and AIDS volunteerism in Africa

In sub-Saharan Africa, informal volunteers assume the majority of the HIV and AIDS care and support burden (Akintola, 2006;Campbell & Foulis, 2004; Harding & Higginson, 2005; Orner, 2006). Of these caregivers, the majority are women and they are usually related to the patient (Akintola, 2006; Harding & Higginson, 2005). Most of these volunteers are usually unemployed or cannot get gainful employment due to their caregiving duties and they are emotionally burdened (Chimwaza & Watkins, 2004; Harding & Higginson, 2005; Orner, 2006). Volunteer caregivers are socially isolated and cannot associate with others in the community as much of their day is consumed by caring for their charges (Chimwaza & Watkins, 2004). However, there is another category of volunteers other than family caregivers. These are women in the community who volunteer to care for people living with HIV and AIDS but who are not related to those to whom they offer care. Typically, these volunteers are unemployed women, some of whom come to volunteerism via their personal experience of caring for an affected

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relative, or out of religious motivations or personal initiative to participate in community activities, or altruism (Akintola, 2010; Root & Van Wyngaard, 2011). Some volunteer in the hope of being recognised for their work by organisations and be offered formal employment. This type of volunteer care is evident throughout Africa including South Africa (Akintola, 2006; Kang'ethe, 2009; Rödlach, 2009; Root & Van Wyngaard, 2011)

1.2.5. Volunteerism and lay health worker policy in South Africa

Despite volunteers' visible involvement in the care and support networks around HIV and AIDS, the possibility that the voices of home-based care volunteers will be ignored or disregarded is ever present. This tendency is related to the discursive association of gender with care and support. The latter relates to the belief about female volunteers as de facto caregivers by virtue of socio-cultural and contextual precepts surrounding care and support (Akintola, 2006; Lindsey, Hirschfeld, & Tlou, 2003).

Government policy and policy research categorises volunteers who offer home-based care as lay healthcare workers. Criticism has already been levelled at policy development and implementation that do not consider gender dynamics experienced by lay health care workers (Akintola, 2006; Daniels, Clarke, & Ringsberg, 2012; George, 2008). The South African government's record of lay health worker policy represents an example of what Ige & Quinlan (2012) describe as African governments incidental as opposed to transformational leadership in response to the HIV and AIDS pandemic. Any attempt on the part of the government to propose or implement a policy in a way that is detrimental to the well-being of it people especially on the matter of HIV and AIDS redefines the 'citizen as an enemy' (Derrida, 1997; Ige & Quinlan, 2012). A timeline tracking government action on lay health care workers involvement in health in South Africa since 1913 reveals that this sector of health has historically been marginalised in

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government's health policy initiatives. Lay health care workers have been a reality in health in South Africa since before the days of Apartheid (Daniels et al., 2012). Although they were never officially part of the formal healthcare system in the sense that they did not enjoy the same labour benefits as other healthcare workers, lay health care workers nevertheless played an important role in general health care, pre and antenatal care and as DOT supporters in national TB programmes. There was a decrease in the drive for national community health care workers in the 1980s however, interest re-emerged globally especially in the context of HIV and AIDS (Schneider, Hlophe, & van Rensburg, 2008). South Africa is no exception in this trend. There has been a rapid growth in a range of lay workers (home-based care volunteers, lay counsellors, DOT (Directly Observed Treatment) supporters, orphan caregivers, etc. (Schneider & Lehmann, 2010). In the 1990s, as in other parts of South and East Africa, non-governmental and faith-based organisations emerged using lay workers to provide HIV and AIDS care and support. In 2000, the South African government began allocating grants to expand home and community-based care. There was an increase in state-supported NGOs employing community care-givers (Schneider et al., 2008). Over the past decade, South Africa has been developing its lay health worker policy (Daniels et al., 2012). The national government declared 2002 the year of the volunteer, mobilising community volunteers across all sectors. In 2004, the term "community health worker" (CHW) was introduced as an overarching term for all the community and lay health care workers in the health sector, and the national CHW Policy Framework was introduced (Daniels et al., 2012). Lay health care workers continue to remain outside the formal health system and are employed and managed through non-governmental organisations. The focus on lay health work in sub-Saharan Africa can be attributed to the need for a

readily available and inexpensive workforce that is able to deliver on disease-specific initiatives (Schneider et al., 2008). More recently, the Community Caregiver Policy Framework, now in its sixth draft, has been introduced. Its aim is to align varying practices towards lay workers in provincial governments and to create one overarching concept of community caregiver (CCG). Home-based care volunteers' ability to be a successful on this programme is partly based on their willingness to extend themselves beyond home-based care tasks and develop sufficient knowledge to pursue other goals.

In KwaZulu-Natal, rural women form groups to offer volunteer care to community members affected by HIV and AIDS as in other regions of Africa and South Africa. The main area of interest of this study is home-based care volunteer identity and their participation in the care and support networks around care and support in a rural KwaZulu-Natal community.. Whilst informal volunteerism forms the mainstay of the care and support to AIDS patients in rural African communities (Akintola, 2006; Campbell & Foulis, 2004; Harding & Higginson, 2005; Orner, 2006), little is known about the identity (social and personal) of volunteers and the way this influences their volunteerism (community participation). This study used a qualitative narrative research approach to explore AIDS care and support volunteers' personal stories about their identity and volunteerism in a rural KwaZulu-Natal community affected by HIV and AIDS.

1.2.6. Volunteerism: motivation and identity

Most volunteerism takes place within organisational contexts. Volunteer identity is related to the status of the organisation and the volunteer's degree of identification with the organisation. Similarity between organisational values and member values (value congruence) increases identification with the organisation, perceived legitimacy of the

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organisation and increases the likelihood that the volunteer's self-concept will be linked to the volunteer role within the organisation and has a positive effect on volunteer dedication (Grube & Piliavin, 2000; Finkelstein et al., 2005; Laverie & McDonald, 2007; Planalp & Trost, 2009). A volunteer's self-esteem is increased if she or he perceives her/his role as being important to the success of the organisation. Social networking associated with volunteering contributes to the volunteer role identity and increases the likelihood of volunteer persistence (Grube & Piliavin, 2000). Continued volunteerism is likely to contribute to the internalisation of volunteer role identity.

There is a reflexive relationship between community participation (volunteering) and individual identity. (Abrahams, 1996). Community participation (volunteering) within an organisation contributes to collective identities which, in turn, refer to the production of communities and identities with a purpose and mission in power relation struggles. Identities at the intersection of race, class and gender are consistent with community participation. Abrahams (1996) observed that women's participation in community organisations enables them to advance salient aspects of their identity and that community participation creates opportunities for women to embrace as well as negotiate identities as mothers, homemakers and elders.

Motivation is a popular area for investigation within volunteer research (Akintola, 2010; Carpenter, Gardiner, & Palmer, 1990; Planalp & Trost, 2009; Wilson & Musick, 1999). Motivation is the process that initiates, guides and maintains goal-oriented behaviours. Intrinsic (personal/internal) and extrinsic (environmental/external) factors act positively and negatively on motivation. People volunteer for numerous reasons including altruism, to learn more about the world, to utilise unused skills, to develop psychologically, to gain career-related experience, to strengthen social relationships or to

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reduce negative feelings such as guilt and to address personal issues(Clary & Snyder, 1999). The motivation to volunteer can vary depending on the social status of the potential volunteer, his or her financial resources and his or her views of the community towards volunteering. Those who are financially well resourced tend to volunteer for altruistic reasons, as a hobby, for charity or to gain experience. Those who are not financially well-off tend to volunteer to gain career experience and for altruistic reasons (Wilson & Musick, 1999). Altruism in volunteering is multidimensional and does not preclude benefits or harm to the volunteer. It may benefit both parties (reciprocal), one party only, or group interests or it may benefit one party and be disadvantageous to the other (induced) (Seelig & Dobelle, 2001).

The motivation to volunteer is influenced by both intrinsic and extrinsic factors which may vary according to context, culture and socio-economic status and gender. Motivation accounts for the initiative to volunteer. However, once the individual begins volunteering, it is similarity between organisational values and personal values, perception of the importance of personal roles in the organisation, and social networking associated with the volunteer role identity that increase the likelihood of volunteer persistence. The relationship between volunteering and identity is reciprocal. Community participation through volunteering influences social and personal identity, and the social and personal identity has a role to play in whether people choose to volunteer and in the type of organisation within which they choose to volunteer. Issues at the intersection of race, class and gender are consistent with community participation creating opportunities to embrace or negotiate identities (Abrahams, 1996). Understanding identity in relationship to volunteerism offers the potential to understand which people will volunteer in which organisations within communities and how

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organisational identity can promote volunteer persistence through resonance with the social and personal identities of volunteers.

Motivation to volunteer lies in how people see themselves (personal identity) and how they see themselves in relation to others (social identity) (Grube & Piliavin, 2000; Finkelstein et al., 2005; Laverie & McDonald, 2007; Planalp & Trost, 2009). A precondition to participation in social networks is a coherent sense of self (personal identity) and identification with a particular social group (social identity) (Abrahams, 1996). The process through which individuals become recognised as belonging to a specific group is always constructed within socially accepted and understood precepts of what it means to be a person in that particular group. The opinions and perspectives of social and cultural communities (collective memory, canonical narratives) can be reflected in the way individuals speak about themselves or tell their personal stories (Bruner, 1991; Plummer, 2001; Wang, 2008). According to Bruner (1991) personal stories reflect the prevailing theories about "possible lives" that are part of an individual's culture (canonical narratives) and cultures are characterised by the narrative models made available for describing the course of a life. Wang (2008) notes that collective memory is a socially shareable memory system that encompasses constructive processes at all levels from the individual to the communal to the cultural

Further it is only through the experience of recognition that one becomes constituted as a socially viable human being. This is consistent with the African view of personhood and becoming a person (*ubuntu*). In this way, personal identity and social identity are synchronous. In the African view of what it means to be a person, social life and interaction and identity formation are inextricably intertwined. One cannot address

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community participation without addressing identity development and personhood and vice versa. HIV and AIDS care volunteerism is discussed in detail in Chapter 2.

The following section presents an overview of how the social constructionist framework was employed for the understanding of how meaning is constructed through language and narrative in human sense-making. Attention is given to how this theoretical framework offers a perspective for the conceptualisation of identity and agency. The section ends with a theoretical view of narrative research methodology with particular attention to narrative interviewing.

1.3.   Theoretical framework

A social constructionist framework based on postmodernism was adopted for this study. Narrative theory underpinned by a social constructionist framework provides a theoretical perspective to understand the social construction of home-based care volunteer identity, the emerging data and researcher's reflections.

1.3.1. Social constructionism and the narrative construction of identity

Social constructionism is based on a postmodern perspective which eschews a view of knowledge as abstract and universal, and propagates a view of knowledge as socially useful and contextually relevant. In social constructionism, the emphasis is on language use and interpersonal and intrapersonal communicative practices (Burr, 2003). Language and thought are inseparable and language is seen as the foundation of all thought. Language provides a system to understand experience, and structruralists have demonstrated the randomness of how human experience is shaped by language. Consequently, language is a site of contention and conflict. Social constructionist psychologists have proposed that what is described, understood and even seen does not represent an objective reality but a socially constructed perspective (Gergen, 1985; Burr,

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2003; Gergen, 1985; Taylor, 2006). Therefore, understanding of self and others is "an artefact of communal interchange" (Gergen, 1985, p. 266). Speech and language are seen as constituting meaning rather that referring to an external objective world (Gergen, 1985).

There are two basic modes of knowing: the paradigmatic or logio-deductive (paradigmatic) mode and te narrative mode (Bruner, 1985). The pradigmatic mode attempts to operationalise a formal mathematical system of understanding through processes such as categorisation and conceptualisation. It deals with general causes and aims to establish empirical truths. Narrative knowing is the second mode. It deals with human intention and action and attempts to put the complexity of human intention and action into the specifics of experience and locate that experience in time and space (Bruner, 1985; Bruner, 1985). Narrative is a basic human strategy for understanding time, process and change. It differs from, but is not inferior to, "scientific" modes of explanation that describe phenomena as examples of general laws (Bruner, 1991; Hermans, 2008, p99). Social constructionist psychologists subscribe to the narrative mode of knowing to understand human intention and action in the world and how this intention and action unfold and interact with time and space to produce a perpetual unfolding of identity. However the two modes are not mutually exclusive and may co-exist or intertwine in the research context as researchers approach the lived experience of others in the paradigmatic mode and their personal experiences in a narrative mode. In social science research the two modes may even be seen to be mutually dependant as analysis of data may require a paradigmatic mode whilst presenting results may be accomplished in a narrative mode. Waldram (2012) notes that in some contexts the narrative and paradigmatic modes engage each other substantially and are not

incommensurable as Bruner initially suggested. Legal cases, medical records and broadly science texts can be seen as having narrative dimensions where the paradigmatic mode can be employed to analyse narrative paradigmatic dimensions which can presented of analysed in the narrative mode.

The term "narrative" has often been used synonymously with 'story" with the idea that human beings construct stories to create meaning or understanding of their world, lived experiences and their own identities (Riessman, 2008). Narratives are simultaneously personal and social. Socio-cultural environments provide the context for the construction of identity through narrative. The broader socio-cultural stories that provide the context for identity narratives are referred to as meta-narratives, master narratives or grand narratives. Meta-narratives are global or encompassing cultural narrative schemas, which organise and explain knowledge and experience (Lyotard, 1984). Meta-narratives support local stories and personal narratives through a network of meanings that reflect cultural themes and beliefs that give the story consistency and legitimacy (Zilber et al., 2008). Narratives are important in the process of constructing selves and identities. People understand their identity through the stories they relate and the stories they relate to. This may create the impression that uniqueness, agency and individuality are not possible because thinking, acting and inter-subjective communication are developed and sculpted by the cultures in which the subjects are immersed and such identity is largely determined by grand narratives, master narratives or meta-narratives. However meta-narratives are essentially modernist and aim at their own legitimation (Lyotard, 1984; Taylor, 2006).

In postmodern thought, meta-narratives have been replaced by the idea that there are polyvocal, contextual and evolving stories of personhood. People do not always seek to validate their subjective experiences in reference to a dominant meta-narrative. Rather, there are multiple options for identity largely independent of a transcendental "truth". Identity narratives are not constructed independently of meta-narratives but may conform, oppose, resist or accept meta-narratives based on subjective social goals. Personal narratives are shaped, but not governed, by socio-cultural conventions about language. The context, setting and audience, the specific located aim of a story, its communicability, and the narrative resources available to the storyteller scaffold what is said and how it can be narrated (McAdams, 1997; Taylor, 2006).

Narrative theorists see narratives as both resources and as "identity performances" (Bruner, 1985; Bruner, 1991; Mishler, 1986). They assume that identity construction is not an event but an enduring project. Identity and social identity consist of a perpetual series of choices for the subject. Social identity construction is not restricted to the subject and abstract other or a given hierarchy of identities (race, class, nationality). Rather, it consists of numerous persons, groups and communities who are inter-relationally experienced or "imagined" by the person. In postmodern life, there are multiple attachments which must be co-ordinated relative to one another. The purpose of this co-ordination is to support the identity process in context, to respond to the question of belonging and to allow for the self-recognition and recognition of the self by others. The construction of a social identity is both a theoretical and political concern. In the context of a global world, the construction of social identity is challenged by the lack of social cohesion, rapid social change and heightened mobility, which may lead to disconnection from communal meta-narratives/ and thereby to the loss of community.

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People are compelled to negotiate attachments with others and are positioned within them by others. Identity is not simply demonstrated but must be repeatedly negotiated, tested, confirmed, rejected or qualified (Kraus, 2006).

A social constructionist view sees the construction of identity as being influenced by dominant discourses and power. Judith Butler (1990, 1993) extends this perspective in her idea of performativity, in which a Discursive practice enacts and therefore produces what it names. Performance, gender identity and power are inextricably linked. Thus, the social construction of (gender) identity is tied in with notions of rationality, discourse and power (Clark, 2008). Consequently, every group becomes a social artifact—a unit shaped, recreated, and rallied in accordance with dominant cultural scripts and foci of power.

Another perspective is that people do narratives in social interactions (Bamberg, 2006; Bamberg, 2006). In telling stories, people offer performances of who they are, their objectives and what they want to convince audiences of. Otherwise stated, narrative can constitute social action (Atkinson & Delamont, 2006). People perform and achieve through narratives because narratives have important social functions, such as holding moral force and attaining social status. Stories allow people to experiment with future behaviour before making lasting decisions (Brody, 2002). Contemporary identity theory is concerned with the constructability of identities (Kraus, 2006;p104). The basic premise of this type of identity theory lies in a view of narrativity as a multidimensional resource for the understanding of self-construction rather than seeing narratives as discrete units. Through narrative, meaning is negotiated and renegotiated and identity undergoes perpetual reconstruction (Kraus, 2006; McAdams, 1997; Riessman, 2008).

1.3.2. Identity and agency in narrative

Narratives can be effective in social and individual transformation (Burr, 2003). People use narrative to claim and question identity by accepting, rejecting, questioning, or negotiating contextually imposed precepts of identity (Burr, 2003; Taylor, 2005; Taylor, 2006). Identity construction can be influenced by a lack of resources, including narratives that constrain and limit dimensions of identity. Depending on power relationships within a society, the contesting of meta-narratives may be overt and visible or subtle and covert (Holland, Ramazanoglu, Scott, Sharpe, & Thomson, 1990). Contesting of meta-narratives may also be affected by factors such as personal identity; whether there are others that are contesting the same meta-narratives and the degree to which a society tolerates agency. Agency involves the capacity to make choices and act upon them (Burr, 2003). Agency involves questioning and negotiating of contextually imposed identity precepts. Individuals may accept some aspects of contextually imposed identity precepts and question, modify and renegotiate others (Castells, 2009). Agency and individuality could become part of the motivation towards a multitude options offered in the world, rather than subjective unprocessed ways of thinking, acting and communicating. Agency may be expressed through narrative performance and social action. The extent to which personal agency can be found in social constructionist accounts of the person has not been elucidated. However Burr (2003) proposes that it seems obvious that this perspective demands an agentic person at least in his or her ability to manipulate discourse and use it for his or her own purposes. It is crucial that context be incorporated into the analysis of narrative. Burr (2003) notes that, while personal narratives may be shaped to some degree by cultural narratives, people are still the authors of their own stories. Narrative performances are the site of struggle over

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personal and social identity rather than a representation of a fixed unified, stable or final personification of the self which serves as the origin or accomplishment of experience (Langellier, 2001).

The social constructionist perspective adopted in this thesis is that reality is constructed through narrative. People tell stories to make sense of the world, their personal identity and their positions in the world (McAdams, 1997). Personal narratives are shaped rather than governed by communal meta-narratives. Identity is a constantly evolving project in which subjects employ narratives in various ways to adopt, resist, reject, oppose or deny communal meta-narratives in order to achieve social or personal goals (McAdams, 1997). Of central significance to this study is that narrative performance is the arena in which personal and social identities are contested rather than a site from which it originates or is finalised. In the exploration of home-based care volunteer identity through narrative inquiry we can gain insight into how home-based care volunteers' narrative performances reveal the contention or constant renegotiation between their social and personal identities and are moulded by (cultural) meta-narratives. This is likely to offer a perspective on what the volunteers' intentions are and which messages they want to convey, personally and socially through their narrative performances

1.3.3. Narrative research methodology

Contemporary narrative research is based on post-structuralist, postmodern and deconstructionist approaches to narrative within the humanities (Squire, 2008). In narrative research, narratives are the means of human sense-making and autobiographical storytelling or personal narrative is located in cultural context (Squire, 2008). The act of

storytelling serves the dual function of identity development and reflecting the norms and expectations of the culture within which the storytelling takes place. Some stories dominate, influence and determine social cultural and historical ideas. These stories are called master narratives, grand narratives or dominant cultural narratives (Hammack, 2008; Riessman, 2007; Squire, 2008). Individuals, groups and communities construct identity though the medium of storytelling (Riessman, 2008). Personal constructions of identity interconnect with a community of life stories, or "deep structures' about the nature of life in a particular culture (Riessman, 2008). Personal constructions hold similarities and have elements that are also recognisable as communal or cultural stories so that associating biography and society becomes possible through the close analysis of stories (Bruner, 1985). From this standpoint, this study proposed to illuminate both personal and meta-narratives of informal volunteerism around HIV care and support in the community and the relationship between them.

A narrative approach allows the researcher to see different and contradictory layers of meaning and to bring these into useful dialogue with each other (Squire, 2008). The dominant framework adopted in current social science narrative research is experience-centred, culturally-oriented approaches to narrative, and this approach was used in the current study. A narrative perspective assumes that there are individual, internal representations of phenomena, events, thoughts and feelings to which narrative gives external expression (Squire, 2008). An experience-centred focus emphasises that such representations can vary drastically over time and across circumstances so that a single phenomenon can produce different stories even from the same person. This approach assumes that narratives are sequential and meaningful, are definitively human, re-presenting experience (reconstituting it as well as expressing it) and displaying

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transformation or change (Squire, 2008, p. 42). In addition a culturally oriented perspective balances this individually centred perspective by allowing personal narratives of identification to be seen in the context of broader narratives. Norms of appropriate identity performances become unconsciously inculcated into individuals (Butler, 2004). This implies that individuals inevitably "perform" the behaviours associated with the cultural grand or master narratives associated with the group with which they identify. The exploration of personal narratives is likely to give insight into the social identities of volunteers and the master narratives with which they identify (Squire, 2008). Application of this perspective on narrative makes the assumption that there are connections between individual and cultural narratives. From this viewpoint, narratives are seen as dialogically co-constructed and not exclusively expressions of internal states. Narratives might also be shaped by the audiences to which they are told and the political contexts from which they emerge (Riessman, 2008).

A social constructionist view holds that the world is constructed through language (Burr, 2003; Gergen, 1985). Social and contextual meta-narratives illustrate social positions of the self. Such positions or voices are expressions of contextually situated selves that are constantly involved in dialogical relationships with other voices and constantly subjected to differences in power (Hermans, 2001; Hermans & Kempen, 1998). Social and contextual meta-narratives are expressed in social interaction as the voices of authorities, professional jargon, socio-political ideologies, social circles, dialects, national languages, and social expectations and co-constitute what the speaker's individual voice is saying (Hermans, 2003). Personal meaning is not entirely private and subjective, nor is it exclusively public and "true". It is rather dialogical and performed in a borderline area between oneself and others. To tell stories in an interview context,

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people perform them in a marginal area or shared space. Interviewing establishes a specific setting for the dialogical production of personal narratives and social life and as such should not be seen as a channel for extracting the subject's viewpoint but rather as the diverse discursive performances of individuals within particular social settings (Tanggaard, 2009). Interviewing provides a context for revealing how language "makes" people and produces and changes social life (Tanggaard, 2009). Research interviews are unavoidably polyphonic, flourishing with the use of many voices, words and discourses that shape the interaction. Interviewing may be seen as a location for reproducing polyphonic dialogues, where multiple voices and discourses interrelate to produce knowledge about personal narratives and social life (Tanggaard, 2009).

Tanggaard (2009) considers the issue of the research interview as a dialogical context for the production of social life and personal narratives. He contends that interviewees and interviewer are positioned in social networks of power that grant different rights and obligations to speakers. In the interviews conducted for this study, the interviewer was conventionally perceived as holding power in the interview process and more so in this context with the interviewer being a university researcher and the interviewee a home-based care volunteer (HBCV). The reflexive interview was introduced to create space for participants to voice their ideas and opinions. The process incorporated efforts to diffuse or divest power in favour of the interviewee. Techniques such as employing the generative metaphor (is characterised by the carrying over of frames or perspectives from one domain to another) (Chapter 4) and reflexive questioning (a method of questioning that prompts the interviewee to reconstruct meaning or shift contexts) were employed to this end. The social constructionist tenets of identity, as constructed through language and the dialogical context of the interview as polyvocal or

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multi-voiced, create the context for the reflective interview in which the interviewer acquiesces power and allow previously silenced aspects of identity to be voiced. In the case of the HBCVs, this involved hearing about hidden aspects of their identity through the voices of friends and family.

Reflexivity and reflexive practice are integral elements of the qualitative research process. Contributing to rigor, reflexivity is a process through which the individual engages with an existent body of knowledge. It involves engaging in an analysis of how personal action measures up to accepted, professionally defined paradigms. Conversely, in reflexive thinking (or practice) researchers consider various ways in which they themselves influence research findings and consequently what comes to be accepted as knowledge (Crouch, 2002; Sandelowski & Barroso, 2002). Reflective practices involve consideration of researchers' personal and emotional perspectives. An account of reflexive processes is presented in Chapters 8 and 9.

1.4. Outline of the project and study area

The study formed part of a project investigating social capital around HIV/AIDS care and support. The project explores social capital at the, bonding, bridging and linking levels using a variety of qualitative and quantitative methods (Dageid, Sliep, Akintola, & Duckert, 2011). Social capital theory differentiates between 'bonding', 'bridging' and 'linking' forms of social capital. Bonding social capital includes trust and reciprocity in closed networks (in which members of networks are known to each other), facilitating coping with daily life. Progress and development is facilitated across social levels through bridging or linking social capital. Bridging social capital involves overlapping networks (where members of one group may gain access to the resources of another group because of overlapping membership). Linking social capital involves social

relations with those in authority, which might be used to acquire resources or power . (Putnam 1998; Narayan 1999; Woolcock 1998)

The setting was a rural community in a hilly region about 40 kilometres outside Durban, South Africa. The population of the region comprised approximately 10 000 inhabitants. There was little infrastructure with only one main tarred road, one clinic, a number of owner-managed general stores, taverns and informal hawkers. Transportation in the area was challenging due to the hilly terrain, unpredictable weather conditions and general inaccessibility by road. Most people made use of mini-bus taxis as the only form of transport and in rainy weather, un-tarred roads were inaccessible even on foot. Homes were generally constructed of mud, wood and metal with a few brick and mortar houses.

Poverty is endemic in the region with most households having an average income of approximately R500–R2 000 per month. The unemployment rate is high (50–80%) as people generally leave the community to seek employment as there is very little potential for formal employment in the community. The community is severely affected by HIV and AIDS with the infection rate amongst pregnant women being around 40% (UNAIDS South Africa Country Report, 2012). Extrapolating that there are on average 3–4 people per household, this would imply that the entire community consists of people affected by HIV and AIDS in some manner.

1.5. Research question

To explore identity of volunteer caregivers to obtain insight and an in-depth understanding of how home-based caregivers make sense of their volunteerism at a personal and contextual level.

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1.5.1. Objectives

The following objectives were identified as contributing an in-depth exploration of the research question namely to

- obtain an interpretive understanding of the research narrative on home-based care in Africa through a synthesis of qualitative literature;

- consider how a contextually relevant approach can be taken to explore the identity of home-based care volunteers;

- understand the social construction of home-based care volunteer identity in the context of HIV/AIDS; and

- explore home-based care volunteers' participation in HIV and AIDS care and support through volunteerism as a form of agency.

1.6.   Rationale for the study

Volunteerism around AIDS care in Africa is different from the volunteerism on HIV and AIDS care in the West. Contexts created by vastly different socio-economic, historical and cultural environments produce challenges for volunteers that vary greatly, both on the continent and in comparison to the West. Whilst HIV and AIDS care and support in Africa in general has benefitted from some research interest there has been little attention on volunteerism in the context of HIV and AIDS care and support. Research on HIV and AIDS care and support volunteerism in Africa tends to focus on the excessive burden placed on caregivers in general and volunteers' motivation for offering care. It does not make intuitive sense for people to be motivated to volunteer to care for HIV and AIDS patients given the highly demanding nature of the care work and the unsupportive and difficult conditions under which the work is conducted. The rationale supporting this thesis is the endeavour to explore identity of volunteer caregivers in order

to obtain greater insight and an in-depth understanding of how home-based caregivers make sense of their volunteerism at a personal and contextual level. Narrative research methodology was used as research method to facilitate an understanding that focuses on home-based care volunteers' (HBCVs) perspective. In order to keep context in focus, contextual reflexivity was employed so that HBCVs' narratives made sense within their in socio-historical and cultural situation. Reflexivity both on the part of the participants and the researcher is highlighted in the thesis, facilitating rigour and a depth of understanding in the research process.

1.7. Framework of the thesis

This thesis is comprised of seven papers and an introduction, research design and conclusion chapters. Four papers have been published in peer-reviewed journals and one chapter in a peer-reviewed book. Three have been submitted to peer-reviewed journals.

The thesis makes a commitment to poetry as a mode of research representation and researcher reflexivity. An extended comment on this form seems warranted here. Chapter 9 consists of two poems presenting poetry as a form of research representation and Chapter 8 incorporates the use of poetry as a medium reflection in research. Chapter 6 describes the how a generative metaphor was used in the data collection exploring the idea that through metaphor, poetic voice exists in everyday language and if attended to and explored this creates the potential to uncover untapped ideas. Horne (2009) notes that whilst some authors such as Susan Sontag (1978) have rebutted attempts to represent HIV and AIDS metaphorically based on the idea that "punitive" associations may be given to illnesses and those who are ill when negative metaphorical meanings are imposed, others such as Lakoff and Johnson (1980) show that choosing metaphors to describe phenomena is not merely verbal decoration but central to the way we perceive,

understand and define reality. In the case of HIV and AIDS in Africa this is illustrated by the many poets who have attributed various metaphors which Horne (2009) describes as the apocalyptic, death, racial, war and gender metaphor to dealing with the phenomenon and lived experience of HIV and AIDS. Horne (2009) offers an insightful account of the representations of HIV and AIDS in African poetry and argues that whilst metaphorical conceptions of HIV and AIDS are not unique to southern Africa but when analysed within the southern African situation they take on different meanings. Based in the context of South Africa's liberation struggle for example the military metaphor that Sontag opposed is not necessarily destructive and may allow the imagination to transform perceptions of AIDS in ways that are potentially positive.

Chapter 3 (Paper 1) uses systematic review and meta-synthesis of qualitative research to examine the dominant ideas in the literature about home-based care in Africa. A systematic review of qualitative literature was undertaken and a meta-synthesis of themes was done. "Burden of care" emerged as the dominant theme in the literature on home-based care in Africa. "Women as caregivers" and the "stigma" around HIV and AIDS grounded on a base of poverty as the second most common theme supporting and sustaining the burden of care narrative were documented. Researchers recommend that stakeholders and government collaborate to alleviate this burden on communities and especially impoverished women. The "burden of care" narrative has been instrumental in highlighting the impact that care and support of people living with HIV and AIDS (PLWHAs) has on indigent communities in Africa and especially on women. One reads the literature with the hope of seeing a change in direction that the research on home-based care in Africa will take in the future. However, there is little indication that this is imminent at this stage. Ideally, new directions should offer some solutions or alternatives

for dealing with problems that have been effectively highlighted thus far in the literature. In order to develop alternative and generative solutions to addressing the burden of care other avenues related to this phenomenon must be explored in addition to obtaining a clearer picture on the impact and extent of the burden of care.

Potential alternatives may be generated via a closer look at the subplots (major themes) in the storyline on home-based care in Africa. Indications in the literature point to the fact that home-based care is most commonly offered by female family members of the affected person. This places even greater financial, emotional and social strain on families as these women experience physical, emotional and psychological strain from caring for sick relatives. Moreover, PLWHAs are unable to work, placing greater demand on family financial resources. Some women in communities offer care voluntarily to people in their communities who are not related to them. Usually, these women are part of volunteer groups/organisations. In this instance, researchers are interested in what motivates these women to volunteer under such difficult and burdensome conditions. Motivation to volunteer incorporates intrinsic (personal) and extrinsic (contextual and environmental) factors that initiate, guide and maintain goal-oriented behaviours towards volunteering. It has been noted in other environments that there is a scarcity of information regarding the "micropolitics" of women's participation in health movements in general and little is known about who participates in grassroots organisations, the motivations for participation and the lived experience of participants (Schneider, 2009,p237). Exceptions include the contribution by Ramirez-Valles & Brown (2003) who explored frame alignment, an interactive process constituted by the associations between the life stories women in Mexico bring into their activism and the NGO into which they are recruited, and (Akintola, 2010) who explored the motivations

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of volunteer female home-based caregivers in South Africa. Kang'ethe (2010) studied human rights in relation to home-based care, noting that caregivers experience various human rights infringements.

The current study endeavoured to follow an as yet unexplored direction by exploring home-based care volunteer identity from the orientation that identity is socially constructed in constantly unfolding interaction between the individual and his or her social context. Motivation provides an understanding of the factors that initiate, guide and maintain goal-oriented behaviours. Understanding the social construction of identity in context provides perspective on how extrinsic and intrinsic motivational factors interact with social context and meta-narratives to produce volunteer role identity. Synchronicity between volunteer role identity, social, personal and organisational identity supported by meta-narratives is instrumental in ensuring volunteer persistence. The social construction of home-based care volunteer identity was selected as the focus for in-depth exploration in this study for the following reasons:

1. Minimal research on volunteer identity could be located outside of western contexts.

2. Research on volunteer identity in Africa could not be located.

3. Research on HIV and AIDS home-based care has not yet explored the area of volunteer identity.

A qualitative narrative approach was adopted in order to obtain an in-depth understanding and rich picture or thick description of the context of home-based care volunteer identity in context. This approach takes the view that identity is contextually situated and constructed in narrative. Alternatively stated people construct their identities collaboratively in context. Identity is shaped by the context and cultural precepts (meta-

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narratives) in which it emerges. Identity construction is interminable and identity is constantly altering and adjusting to respond to immediate and future challenges, expectations and intentions of and on the self. Given this contextually bound understanding of identity it is imperative that any exploration of identity give due credence to an examination of the context in which identity unfolds.

Chapter 4 (Paper 2) offers a detailed account of the consideration of the narrative environment in this study. Contexts, which extend from interactional to institutional environments are as important as text for narrative analysis. Narrative work and narrative environments are reflexively interlaced and researchers must 'observe listen and document narratives everyday practices' in addition to what it said and recorded' to obtain a rich perspective on narrative (Gubrium & Holstein, 2009): 15). The steps taken to ensure that methodological and ethical reflexivity was maintained throughout the study are comprehensively described in Chapter 4. This approach was adopted to prioritise ethical research practice and validity through consistent ethically and methodologically reflexive practice in the research process. Ethical and methodological reflexivity are described in combination as 'contextual reflexivity'. The purpose contextual reflexivity was to ensure that data emerging from narrative interviews would be interpreted and understood in relation to the context in which it was said and recorded. Chapter 3 illustrates how ethical reflexivity on the context was used to achieve ethics in practice such that ethics and reflexivity were co-dependent. Community cultural precepts were acknowledged and followed in general interaction in the community. Respecting community 'rules' and expectations provided an ethical basis to questioning in the interviews that were to follow. Methodological reflexivity was the second element that comprised contextual reflexivity. A dynamic interview process; dialogue between

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researchers; the interviewer's reflective journal as well as dialogue and interviews with the interpreter were all methodological strategies that were used to keep an orientation to the research context.

Chapter 4 (Paper 3) describes the social construction of home-based care volunteer identity. Having obtained an understanding of the context in which the home-based care volunteers' work in Chapter 3 the next step in the process was to obtain an in-depth understanding of how home-based care volunteer identity operated in this context. Fifteen members of a group of home-based care volunteers were interviewed three times each. The first interview was about the work in general and the issues that they faced. The second autobiographical interview began with a single question about the story of their personal history. The third interview was reflexive interviewer where and the participant reflected collaboratively on content of the previous interviews and ideas based on a series of questions. Analysis revealed contextual narratives consisting of social field narratives (socio-historical context) and meta-narratives (tacit community and cultural rules about life and personhood), and personal narratives relating to personal, group and volunteer identity. Contextual and narratives of the volunteers were reflexively connected with field notes and reflexive journals to understand the social construction of home-based care volunteer identity. . Narratives inter-relate to construct the home-based care volunteer identity. Social field narratives of poverty, gender, lost educational opportunities and the socio-political history of South African produce a feminisation of responsibility. The latter produces a coerced agency in women in rural communities. This is a situation where women are compelled into financial responsibility as a result of men's migrant labour, female headed households and other social factors related to a context of poverty. In the group studied the socially constructed elements of agency and

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mother collaborate to produce a group (volunteer role) identity inspired by the agency and the community 'mother identity'. The interaction of the women's personal identity elements shaped in the context by social field narratives and meta-narratives produce and perpetuate the volunteer role identity of the home-based caregiver in this context. These narrative categories are not exclusive within or between levels and both supportive and detrimental interactions may occur within narratives between or within dimensions (personal, social field and meta-narratives). Boundaries between may be seen as overlapping permeable or blurred and in reality these narratives would be in constant dynamic interplay depending on how the individual decides to or is influenced or compelled to used them. For example there is likely to be overlap between the religious and mother aspects of identity in the relation to love and being a compassionate doer. This is supported by HBCVs in other studies which have been shown to hold religious identity or faith as central to HBC identity and activity.

Chapter 6 (Paper 4 – book chapter) offers a detailed account of the application of a generative metaphor in the research process. This is an essentially methodological process that emerged during the interview process and was used to enhance the participants' reflexive capacity and bring layers of meanings that are present outside of cognisance into conscious awareness. One of the interviewees mentioned that to be an effective home-based care volunteer required the 'mind of a mother'. This resonated with the overall group identity of 'motherly love' as espoused by the name *Uthandolomama*. This resonance of this metaphor was verified with other members of the group in ensuing interviews through reflective questioning on whether the term made sense to them and what meaning they attached to the term in both personal and volunteer groups terms. The metaphor was used generatively to explore and enhance different

aspects of identity associated with the metaphor and that related to home-based volunteer care. The use of the generative metaphor facilitated the understanding of implicit aspects of identity by rendering them explicit through the process of collaborative reflection on the metaphor by the interviewer and participants. The community mothering or 'other mothering' aspect of identity particular to this volunteer group identity and resonant with communal meta-narratives of women's identity in Africa (Wane, 2000; Cockerton, 2000) was evident in the identity associations that were made.

Chapter 6 illustrates how a generative metaphor was used to recognise and facilitate the explicit understanding of a tacit but crucial aspect of the home-base care volunteer group identity. The use of the generative metaphor in the context of a reflective interview allowed both the participants and the interviewer to gain a richer understanding of the community mothering as aspect of volunteer role identity in this context. It was also noted that the generative mhad the effect of excluding those who did not fit the persona it represented e.g. men and 'mothers who did not care'.

Chapter 7 (Paper 5) presents and develops the idea that home-based care volunteers perform or demonstrate agency through their work by promoting the notion of paid home-based care for HIV and AIDS patients in opposition to the current situation of care that relies on the labour of indigent female relatives of people living with HIV and AIDS. In this paper the interview data from three sets of interviews are analysed using dialogical performance analysis. The two most commonly identified themes were poverty and space. The women's stories connected poverty, traditional values, personal identity and a change of community values over time as creating the need for volunteerism. The argument in this chapter is that through their investment in volunteer care work the HBCVs resist the legitimising (conventional) identity of women as caregivers in the

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home. They install alternative ways to represent their identity as volunteer caregivers (resistance identity). The volunteer caregiver identity has the potential to attract the attention of powerful stakeholders who have the potential to change their positions possibly through the offer of paid work. Despite South Africa's reputation as a well-resourced country there is significant competition for resources between small groups associated with HIV/AIDS care. HBCVs' inter-relational struggle for identity and place a shortage of government distributed resources, fosters tensions between groups in competition for resources and informs the identity perspectives of the group members. A socio-political history of poverty and gender- and race-based oppression in South Africa provokes agency and activism stemming from a historical mistrust of the government. Home-based care groups offer government the opportunity to invest in the initiative they show via voluntary caregiving. Government could, through support of these groups, assist in providing HIV patients with home-based care while simultaneously creating space in which women can explore emergent aspects of identity contributing to their own empowerment and self-development.

Chapter 8 (Papers 6). Paper 6 gives an autoethnographic account of the researcher's identity construction as a researcher and draws parallels with the participants' identity construction as home-based care volunteers' identity. I illustrate how, in my own experience as a researcher, I used autoethnographic poetry to make sense of or capture nascent ideas before they eluded my consciousness. The notion that space from the familiar, created corporally through physical distance or figuratively through dialogical conversation, constructs the possibility for new dimensions of identity to be pondered , is explored. In my experience as a researcher, dialogical conversations with my doctoral supervisor and the study interpreter as well as my own reflexive journal

entries and poetry provided a guide and orientating presence on this journey. The participants shared that reflective dialogical discussions in the interview process served a similar purpose for them. In this this paper I consider the importance of witnessing and being witnessed as a form of affirmation and validation. In qualitative research witnessing refers to listening to and affirming the experiences of research participants. The researcher as a witness accepts what is heard and accountability for acting upon it, not on the personal needs a desire of affinity between researcher and participant (Stein and Mankowski, 2004). Witnessing another in the process of 'becoming', or seeing and acknowledging that which exists but is silent, hidden or voiceless is an important part of qualitative research practice. Autoethnographic poetry facilitated the understanding that my identity as a researcher was realised through witnessing and affirmation by others (supervisor and experts in the field). In the same way the home-based care volunteers were validated in their discussions and reflections about their work through being witnessed by researchers. Considering silence, witnessing and acknowledgment, in my personal experiences during research process elevated the voices of the home-based care volunteers around issues of identity. The volunteers' work spoke loudly in the silences around the assumption that caregiving is the responsibility of impoverished rural female relatives of people living with HIV and AIDS (PLWHAs) (Chapter 7). Highlighting home-based care through witnessing and validating in research (Chapter 3) has the potential to attract attention to care and support relative to treatment and prevention. Paper 7 presents an example of poetry that was published separately.

1.8. Conclusion

This section provided an overview HIV and AIDS care and support volunteerism in general and with specific reference to Africa and KwaZulu-Natal South Africa. Relevant literature on volunteerism and the influences of context on volunteerism was reviewed and the influences of changes in the lay health worker policy in South Africa over time were briefly addressed. Some consideration was given to the interaction between motivation and identity in the impetus to volunteer and persistence in volunteering. Finally a description is presented of how narrative theory and research methodology underpinned by social constructionism is employed to understand how home-based care volunteers made sense of their identity. The section ends with a description of each of the seven papers comprising this thesis connect by how paper contributes to overall argument. The next chapter (Chapter 2) describes the research design, procedure and methods employed in the study.

1.9. List of Papers

Paper 1   The storyline of home-based HIV/AIDS care in Africa: A narrative meta-synthesis of qualitative research.

Submitted as: Naidu, T. & Sliep, Y. The storyline of home-based HIV/AIDS care in Africa: A narrative meta-synthesis of qualitative research. To Social Science & Medicine

Paper 2   Contextual reflexivity: Towards contextually relevant research with South African HIV/AIDS Home-Based Care Volunteers.

Published as	**Naidu, T. & Sliep, Y. (2011) Contextual reflexivity: Towards contextually relevant research with South African home-based care volunteers.** *International Journal of Qualitative Methods,10*(4) 431-443.
Paper 3:	The social construction of identity in HIV/AIDS home-based care volunteers in rural Kwazulu-Natal, South Africa.
Published as	**Naidu, T., Sliep, Y., & Dageid, W. (2012). The social construction of identity in HIV/AIDS home-based care volunteers in rural KwaZulu-Natal, South Africa.** *Journal of the Social Aspects of HIV/AIDS Research Alliance (J-SAHARA)* **9(2)113-125**
Paper 4:	Generative metaphor in community-based action research: Making culturally relevant connections.
Published as	**Naidu, T. (2011). Generative metaphor in community-based action research: making culturally relevant connections. In Dageid, W., Sliep, Y., Akintola, G. & Duckert. F.(Eds)** *Response-ability in the era of HIV and AIDS.* **Bloemfontein: SUN MeDIA**
Paper 5:	Understanding the agency of home-based care volunteers: establishing identity and negotiating space in AIDS-home-based care in rural KwaZulu-Natal, South Africa.
Published as	**Naidu, T. & Sliep, Y. (2012). Understanding the agency of home-based care volunteers: establishing identity and negotiating space in AIDS-home-based care in rural KwaZulu-Natal, South Africa.** *African Journal of AIDS Research (AJAR).* **11(2) 143-152.**

Paper 6:   Am I a poet researcher?

Submitted as   Naidu, T. Am I a Poet-Researcher? To *Critical Arts South-North Cultural and Media Studies.* Themed issue on revisiting the ethnographic turn in contemporary art

Paper 7:   Reflective release: Two poems about doing qualitative research with home-based care volunteers in KwaZulu-Natal, South Africa.

Published as: **Naidu, T. (2011).   Reflective release: Two poems about doing qualitative research with home-based care volunteers in KwaZulu-Natal South Africa. *Qualitative Inquiry, 17*(4). 343-344**

Chapter 2

Research Design

2.1. Introduction

This section provides a general overview of the methods employed in this study. There is some degree of overlap with methods described in the papers. However this section is necessary to provide a general orientation to the overall methodology as well as detail on specific aspects of the method that could not be included in the published articles due to editorial requirements.

The study employed a narrative research approach in the collection and interpretation of some sections of the data. This section provides detail on the complete procedure followed in the study. Detail is provided about participants, data collection and management, data analysis, rigour and ethical considerations.

2.2. Methods and procedure

This section provides an overview of the study. Entry into the community to conduct the study was negotiated as part of a larger project exploring the social networks around HIV and AIDS care and support in the community into which this study was subsumed. The first phase of the study involved making preliminary visits to the community with members of the project team to obtain an appreciation of the context and to ensure that the researcher was familiar with community members. During this stage, ethnographic observations and reflections were noted, arrangements were made for interview venues, and sound equipment was tested. Informal meetings were held with the interpreter to build rapport and to plan how the interpretation process would take place. A local home-based care volunteer group was identified as a source of potential

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participants. The interpreter had worked with the participants providing interpretation in other research projects so participant-interpreter rapport had already been established.

The next phase involved conducting interviews with the group members. The interview process consisted of three interviews with each of fifteen home-based care volunteers and was conducted over a ten-month period. The interviews were conducted in isiZulu and English with the aid of the interpreter who was fluent in both languages. Recordings of the interviews were made on a voice-sensitive digital recorder. The venue for the interviews was a small local community centre located on the one main tarred roads that wound through the community. The community centre consisted of a one-roomed building set on a dusty plot and surrounded by a wire fence and gate. It was situated adjacent to a community-run crèche and included the community health care workers' on-site food garden. Interviews had to be scheduled to accommodate the schedule of the youth group who operated from the same venue. About seven months into the interview process, we were prohibited from conducting interviews at the community centre at the insistence of the retired community worker who was by all accounts the self-appointed caretaker of the centre. Remaining interviews were then conducted at another small venue on a dusty potholed road which was almost inaccessible by vehicle.

The interview process in each case began with a semi-structured interview regarding the work experiences of the home-based care volunteers. A series of examanent questions stimulated the interview process; however, space was left for explanation and discussion by the participant who was free to include ideas and expand the interview in any direction. There was no time limit on the interviews. The series of exmanent questions (questions that reflect the interest of the researcher and are his or her

formulations and language) prepared by the interviewer (Appendix A) was addressed during the course of the interview . During the interview these were supplemented by immanent questions. These are questions that which translate the researchers' knowledge and language using the words and expressions emerging from the interviewee's narration The second interview was an autobiographical interview in which a single generative question initiated the interview. The participant was free to tell her life story in the manner she preferred. Some clarification and comment from the interview encouraged the narrative mode of the interview to provide detail on events, stories and characters that emerged. The third interview was a reflective interview during which the participants' reflections on the content and process of the first two interviews were elicited. The end of the interview was collaboratively agreed upon by the interviewer and participant as no time limit was set. Interviews lasted on average between forty and ninety minutes. Interview prompts, designed to encourage reflection, were based on data collected in the first two interviews and the interviewer's reflections on the content of the first two interviews (Appendix C). Interviews with the different home-based care volunteers were conducted concurrently at different stages so that one participant might be interviewed for the first time, another for the third time and yet another for the first time in the same week. This was done to ensure there was opportunity to cross-check emergent data within and between interviews and therefore obtain richer data. A period of approximately four weeks was allowed between the second and third interviews to afford a space for personal reflection by both the participants and interviewer.

As the interviewer, I kept field notes, a reflexive journal and research diary during the period that interviews were conducted. Field notes were documented in the field before, during and immediately after interviews. This consisted of ethnographic data

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about the environment and community, chance meetings with people related and unrelated to the study, observations about participants' non-verbal behaviour and the tone and general mood during interviews. Notes about the content of the interviews were also included and used to plan and prepare for successive interviews. The reflexive journal documented my personal thoughts and reflections on the research process, my role and influence as a researcher in all aspects of the process and the way I was affected by the process. This was recorded at different times throughout the interview process. The research diary – which eventually covered eight notebooks – documented technical and formal aspects of the study, among others ideas and directions stimulated by the context, literature, reflective ideas and dialogical discussions. The research diary also incorporated ideas and guidelines stimulated by dialogical discussions with the doctoral supervisor. All notes and reflections were recorded either on site, at meetings or soon after to ensure some degree of trustworthiness and to avoid omitting or disregarding important details. In the latter stages of the study, poetry and creative non-fiction were used to document reflections and notes (see Chapters 8 and 9 and Appendix D).

Interviews were transcribed and translations were verified during transcription by a second isiZulu who was speaker fluent in English. Transcripts were then loaded onto the NVIVO8 qualitative data management program and analysed reflexively incorporating reference to transcripts and reflexive journals, the research diary and field notes. Research reports were produced in the form of published papers, manuscripts, poetry and creative non-fiction. Finally, this was drawn together by means of a narrative thread to produce the thesis.

In addition to a general literature review for the study, a systematic meta-narrative approach was adopted in reviewing the literature describing home-based care in Africa.

This ensured that a comprehensive picture of the literature on the topic was obtained. A specific and detailed methodological approach was used to survey and select relevant literature. Articles documenting qualitative research on home-based care in Africa were collected and uploaded in portable document format (PDF) onto the qualitative data management program NVIVO9.1 in preparation for analysis. A narrative approach was used to review the literature with the intention of uncovering the developing storyline in the literature on home-based care in Africa.

2.2.2. Participants

The participants in the study were 15 home-based care volunteers who lived and worked in the community where the study was conducted. They belonged to a group that provided care to those in the community too ill or infirm to care for themselves. Participants were recruited via purposive and convenience sampling, and participation in the study was voluntary and based on referrals by the group leader. All the participants lived in the community and were aged between twenty-five and sixty years old. None of the participants were formally employed. All had attended formal schooling and had obtained between a Grade 5 and Grade 12 level of education. None of the group members had any formal training in nursing or care work, although three had experience of caring for sick relatives. Eleven of the participants had worked in the informal employment sector as domestic workers or doing "piece jobs" (a colloquial South African term for intermittent casual paid work). The women all spoke isiZulu as their home language and had some understanding of English. Typically they would begin by volunteering in the group for a period of six months or more after which they would receive a small government stipend as and when this was available. At the time that interviews were conducted nine women were receiving the stipend.

During the research process, I documented my own development as researcher as a consequence of conducting the research through reflexive journaling and poetry writing. Consequently, I may be seen as a participant as this reflexive practice contributed to the depth of understanding of the home-based care volunteers narratives and identity construction. This is documented in detail in Chapter 8.

2.2.3. Data collection and management

This section notes how data were collected and managed for analysis. An action research approach was adopted towards data collection and analysis where each stage of interviewing informed the next and each stage was also informed by interpreter and researcher discussions and reflections on field notes. The study employed the following methods of data collection:

1. Interviews

2. Dialogical discussions

3. Reflexive research diaries and field notes

2.2.3.1. Interviews

A series of three interviews were conducted with each of the fifteen home-based care volunteers. The first was a semi-structured (constructivist) interview exploring the nature of the work. The second was an autobiographical interview in which the participant was requested to recount her life story. In the third reflective interview, the participants' reflections on the first two interviews were explored. Interviews were between forty and ninety minutes long. The duration of the interview depended on mutual agreement between the interviewer and participant on when all issues considered relevant by both had been satisfactorily addressed. An action research approach was used

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in which each interview stage was influenced by and built on the previous stage. The underlying intention was to develop a rich narrative picture of the home-based care volunteers' life and identity. The interviews were conducted in isiZulu with the assistance of an interpreter fluent in both English and isiZulu

2.2.3.2. Dialogical discussions

Dialogical discussions were held throughout the data collection and reporting process with the research supervisor and the translator. Discussions with the supervisor were invaluable in creating a rich, creative and dialogical space in which the researcher could explore the various meanings and interpretations of the data as they emerged. It created the context to consider alternative and creative methods of data representation and documenting of the reflexive process in research. The action research approach was supported through these dialogical discussions as the outcomes of the discussions influenced the interview and data interpretation processes. Concepts, ideas and interpretations of the research context emanating from these discussions were recorded in the research diaries and reflected on at various stages during the data collection process and interpretation process.

Discussions with the interpreter during the data collection process offered insight into how interpersonal dynamics in the interview process could be situated. Moreover, these discussions preserved a fluid approach to the interview process as well as within interviews ensuring that interviews and the process of interviewing were not rigid and repetitive. This contributed significantly to the quality of data collected. Further detail on how these discussions contributed to overall validity and authentically situating the research in the African context is provided in Chapter 3. These discussions were

recorded as part of the field notes. Ideas and information from these discussions influenced the direction and process that the interviews followed and aided in the interpretation of emerging data in relation to the context.

2.2.3.3. Researcher's reflexive diaries and field notes

I maintained a detailed reflexive diary throughout the research process. Three formats were used: an electronic record, research prose and research poetry. This process underpinned an in-depth understanding of how the home-based care volunteers constructed and presented an unfolding of identity during the interview process. The process supported my interpretations and contextualisation of the emerging data whilst concurrently supporting the tracking of my own development and personal and professional growth as a researcher.

2.2.4. Methods of analysis

The following methods of analysis were applied

1.   Thematic analysis

2.   Content analysis

3.   Narrative analysis

     a.   Holistic content and holistic form analysis

     b.   Structural analysis

     c.   Dialogical performance analysis

2.2.4.1. Thematic analysis

Thematic analysis was used as a first level of analysis of the data in this study (Braun & Clarke, 2006). In the systematic meta-synthesis of qualitative literature presented in Chapter 2, studies were analysed thematically through the application of thematic synthesis methodology (Thomas & Harden, 2008). PDFs of published articles documenting relevant studies were loaded onto NVIVO. 9.1. Articles were free coded and the "free codes" were organised into themes and a modification of dimensions of narrative analysis was applied within the themes (Creswell, 2007).

In Chapter 4, which focuses on the social construction of home-based care volunteer identity, themes were identified based on reviewing interview data in relation to dominant socio-cultural and historical discourses in South Africa and personal identity representations in the interviews. Interview transcripts were then read for context and incorporating narrative analysis strategies (Fraser, 2004; Riessman, 2008). Data were connected reflexively with field notes, reflexive journals and relevant literature to facilitate theory building.

2.2.4.2. Content analysis

Chapter 3 concentrates on how reflexivity was employed with regard to ethics and methodology to develop an understanding of the narrative context. Gubrium and Holstein (2009) note that narrative environments are complex and encompass close relationships, local culture, status, jobs, organisations and intertextuality. Ethnographic data noted in field diaries and observational notes were reflexively incorporated into the interpretation process to consider how the elements influenced and contributed to an understanding of the narrative context. In this instance, an analysis of the narrative

environment occurred during the process of developing an understanding of the context through contextual reflexivity (ethical and methodological reflexivity).

Sections of the field notes were documented in the form of poetic reflection. Poetry was used as a research and reflective tool to document observations, emotions and experiences. Results of the content analysis of these notes and reflections are reproduced in Chapter 7. I have chosen to describe the type of analysis done here as content analysis because I focused on concepts rather than distinct themes in the analysis. This analysis is a particularly subjective interpretation partly because I am analysing my own field notes and reflective journals. The analysis effectively represents a meta-reflection on concepts that were common in the realisation of identity between myself and the HBCVs. For example being witnessed and acknowledged in the performance of identity reinforces that identity. In the analysis I looked for elements and dimension common to myself and the HBCVs in processing emerging aspects of identity. In my own process this was evident in the content of my reflections. In the case of the HBCVs it was evident in the references included in their stories. I consider an auto-ethnographic reflection on the legitimacy of the my voice as a researcher in relation the issues of space, witnessing and projecting voice with the home-based care volunteers.

2.2.4.3. Narrative analysis

Following on the thematic analysis conducted on the articles selected for review in Chapter 2 (review of literature) various approaches to narrative analysis were applied. Holistic content analysis was applied to the literature on home-based care to explore and establish links across the research on home-based care in Africa and identify themes for the entire story (Lieblich, Tuval-Mashiach, & Zilber, 1998). Holistic form analysis was

applied to establish a basic outline of home-based care in Africa with reference to how the story was told in the research and literature. Holistic form, looks at plot analysis, patterns of progression or regression. These results are presented in a table in Chapter 3. Holistic content analysis which looks at the text as a whole to find themes was applied to identify dominant themes in the literature. Categorical form analysis was then applied to the individual themes (categories) to discern a plot in each specific theme identified in the literature in relation to the overall narrative (Lieblich et al., 1998).

In Chapter 6, which focuses on how participants perform agency, **structural analysis** was applied to interview data to determine *where* and *when* specific themes or ideas were mentioned, as well as the order of presentation of ideas and topics within these themes (Riessman, 2008). This analysis process was also applied to understand how interviewees constructed arguments and narratives to convey their ideas and convince, collaborate with, or correct the interviewer. For example the HBCVs wanted a care centre in the area which they could work from. They only mentioned this at the end of the interview when asked whether there were questions that they wanted to ask the interviewer.. These sections were grouped together as a theme and dialogical performance analysis was applied to examine how various narrative devices such as the type of words, tone, use of extended narratives and examples within the interviews were employed by the participants to perform identity and convey objectives, ideas and perspectives to the interviewer and external audiences (Riessman, 2008). (See Appendix I)

2.3. Rigour: validity and reliability

It is not commonly intended for the results of qualitative studies to be generalisable. Arguably, most of the value of qualitative research lies in context-dependent detail (Golafshani, 2003; Sandelowski & Barroso, 2002). Nevertheless, it is assumed that qualitative research should incorporate standards of rigour through aiming for credibility, transferability, dependability and confirmability (Guba, 1981). Credibility is a measure of how well the research findings are supported by the data (Lincoln & Guba, 1985). Dependability refers to whether the same results would be if it were possible to observe the same thing twice. Since context is ever-changing the latter is not possible the researcher must be responsible for describing the changes that occur in the setting and how these changes affected the way the study was approached. Transferability is the degree to which the results of qualitative research can be generalized or transferred to other contexts or settings. Confirmability is the degree to which the results could be confirmed or corroborated by others (Guba and Lincoln, 1985).

Rigour in the study was addressed through a range of practices. Credibility was steered by a number of practices. Firstly, there was prolonged engagement with the research group and environment to check perspectives and allow participants to become accustomed to the researcher. Data collection occurred over a period of ten months. In addition to the interviews, multiple contacts were made with participants in different settings such as the food garden, community gatherings and at local community centres. Secondly, reflexivity and reflexive practices were used in interviews and in recording researcher observations and reflections. In qualitative research, the researcher's interpretation of material presented and a justification of that interpretation is a function

of validity (Mishler, 1990; Polkinghorne, 2007; Rolfe, 2006). Thirdly, member-checking was employed by interweaving of the informant contact hours so that information from one interview was checked with that from another informant before a subsequent interview with the first. Ideas, the themes and interpretations were taken back to two focus groups of volunteers from the group to verify if the connections and associations made by the researcher resonated with them. Fourthly, in the interview process, question repetition across interviews, the expansion of the content of questions across different interviews and indirect questions about participants' experiences contributed to establishing credibility. In addition, triangulation of data was applied. Here data collected via life history interviews, and structured interview data were compared with data from reflexive interviews and observations to further promote credibility. Interviews conducted in isiZulu-English with the assistance of an interpreter were recorded and transcribed by a second isiZulu speaker who verified and cross-checked the interpretation during transcription. The interpreter was actively included in the planning of the interview process. Her views on the interview content and process were incorporated into the process. This enhanced the richness of the data collected and contributed to triangulation of data in the research process.

Transferability was demonstrated through providing dense background information on the participants. In the interest of transferability, a review of literature on home-based care in Africa and careful consideration of the social and historical context assisted in determining that the study participants were largely consistent with rural home-based care volunteers in Africa. Dependability was targeted through a dense description of the methods employed. Confirmability was indicated through the intensive application of reflexive analysis to show researcher awareness and influence on the data.

Qualitative research reports should be read in conjunction with a detailed reflexive research diary so that quality may be properly assessed, and published research papers should include reference to such a diary (Rolfe, 2006). Traditional ethnographic prose and creative methods (poetry and creative writing) were used to record observations, insights, reflections and opinions in a reflexive research diary. Employing a reflexive diary accommodated new perspectives on the research content and processes of this study that would not otherwise have been conceivable. Chapter 3 details how rigour was supported through the practice of contextual and ethical reflexivity. Chapter 5 offers a perspective on how creative reflexivity contributes to validity in qualitative research. Chapter 7 presents an alternative creative method of data representation that some authors have suggested contribute to validity in qualitative research (Ellis & Bochner, 2000; Piirto, 2002; Richardson & Adams St. Pierre, 2005).

Validity issues in narrative research arise because of "languaged" descriptions given by participants. The disjunction between actual experience and storied description is affected by the limits of language to capture the complexity of depth and experience (Polkinghorne, 2007). Reflection may enhance the ability to perceive the layers of meaning that exist outside of awareness. Resistance to reveal the complexities of the full range of emotional meanings of particpants' experiences based on social desirability and the fact that texts are co-created by interviewer and participants are two other sources of disconnection between actual experience and the storied description experiences (Polkinghorne, 2007)). Poetry and other narrative techniques and devices possess the characteristics that bridge this disjunction to some degree. These methods may increase sources or pathways for connectedness between actual experienced meaning and storied description by offering audiences varied avenues to engage with the contextual and

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emotional dimensions of the data. Chapter 5 explores a method for challenging the limits of reflection on the disjunction between actual experience and storied description through the application of a generative metaphor. According to Polkinghorne (2007), focused listening and exploration uncover a multiplicity of experienced meaning. Question repetition and the application of the generative metaphor served as a member check (to verify the credibility of data (Chapter 6). Member checking refers to the practice of checking interpretations and conclusions and data, analytic categories, with members of those groups from whom the data were obtained.

2.4. Ethical considerations

Ethical clearance to conduct the study was obtained from the University of KwaZulu-Natal Humanities Development and Social Sciences research Ethics Committee. Written consent to participate in the study was obtained from all participants following an explanation of the nature of the study. Furthermore,

1. pseudonyms were used for all participants; and

2. other identifying information, such as local place names, was omitted from written reports of the data.

Access to the participants was in strict accordance with accepted practices within the community and already established relationships formed by other researchers. Original data collected in course of this study were available only to the researcher, research supervisor interpreter and translator/transcriber. Ethical issues considered and applied in this work in addition to those required by institutional tenets are explained and discussed in detail in Chapter 4. Interview recordings will be kept in the possession of

the researcher for a period of five years following publication of the study. Data was stored on computer and on compact disc.

2.5. Conclusion

This chapter offered a comprehensive outline of the research design and methods employed in this study. The intention was to offer an orientation to the research design of the study and provide detail where it was not possible to do so in the individual papers. Chapter 3 is the first of the series of six papers comprising the thesis and presents a meta-narrative synthesis of qualitative literature on home-based care in Africa.

Chapter 3

The storyline of home-based HIV & AIDS care in Africa: narrative meta-synthesis of qualitative research

Submitted as: Naidu. T. The storyline of home-based HIV & AIDS care in Africa: narrative meta-synthesis of qualitative research to *AIDS Care*

Abstract

Home-based care forms the greater part of palliative care for AIDS patients in Africa. Much of the research in this area is represented by qualitative studies. Thematic synthesis was used to assess and evaluate studies on home-based care volunteers/caregivers in Africa and to produce a narrative meta-synthesis of the literature. A chronological thread was tracked to understand how the home-based care narrative has unfolded on the continent. The literature on home-based care in Africa is characterised by the dominant "burden of care" theme supported by three major themes of poverty, stigma and women as caregivers. At the tail end of the narrative is a trend towards understanding more nuanced aspects of home-based care, caregivers, their experiences and context. Researchers draw attention to the need for greater government and other stakeholder collaboration in home-based care across the continent. Emphasis on the "burden of care" narrative has been valuable in revealing significant scope and detail about the reality of home-based caregivers or volunteers in Africa. We argue that solutions to the problems associated with home-based care are unlikely to come from a continued focus on the impact of the 'burden of care'. More detailed qualitative and quantitative investigation into home-based for AIDS patients in developing countries is required to develop alternatives to the 'burden of care' placed on impoverished communities.

Keywords: *burden of care, home-based care, AIDS, Africa gender, stigma, poverty*

Introduction

The World Health Organisation (WHO) defines palliative care as an essential component of HIV care from the point of diagnosis to the end of life and to bereavement (World Health Organization, 2006). Feasible, accessible and effective palliative care in Africa remains an unresolved issue. marred by context and resource constraints. Palliative care needs in Africa are continent-specific, especially in the context of poverty and HIV disease (Harding & Higginson, 2005). Many countries in Africa have not considered palliative care as a public health problem as limited resources have resulted in prevention and treatment strategies taking precedence (Blinderman, 2009; Webster, et al., 2007). The need for palliative care continues to outstrip supply, and researchers have noted a significant deficit in skilled palliative care practitioners (Downing et al., 2010; Mastrojohn et al., 2009).

AIDS care and support in Africa

There has been much activism around the issue of AIDS prevention and treatment and comparatively little around care and support (De Cock et al. 2002). A more systematic inquiry is required into when, where and what kinds of NGOs are more likely to pressure for policy reform and political opening through a drive for engagement with the state (Boone & Batsell, 2001). Notably, countries such as Tanzania, Uganda, Malawi and Kenya have implemented treatment and prevention strategies with the support and action of political leadership (Ronald & Sande, 2005). However, in countries such as Zimbabwe and South Africa this has been done despite the political leaders' initial denial and inertia on the matter (Ige & Quinlan, 2012). In the case of South Africa in particular, political action on the issue of treatment has been the result of vocal activism by NGOs

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such as the Treatment Action Campaign (TAC) (Fourie, 2006; Nattrass, 2008; Whiteside, 2002). Social activism on palliative care and care and support has been less vociferous than in the case of prevention and treatment.

Home-based care is the main form of care that is available to those suffering from AIDS in the terminal stages of the illness in Africa (Harding & Higginson, 2005). As people return to their rural homesteads once they become too ill to work, the responsibility for their care usually falls to family members, volunteers from the community and faith-based organisations (Welaga et al., 2009). This phenomenon is prevalent throughout Africa; however, little attention has so far been given to how and why it emerged, how it has developed, and the associated reasons for this development in the context of gender, poverty and political climate on the continent. These are important issues to explore for meaningful action towards alleviating the 'burden of care' on indigent communities in Africa.

Reviewing the literature on the home-based care in Africa is a substantial task. It encompasses work done on the entire continent and seeks to understand a body of knowledge from various countries that employ a range of methodologies to investigate varying aspects of home-based care. No specific distinction is made in the literature between family caregivers and volunteer caregivers. For this review, we define volunteer home-based care as care offered without remuneration or with inconsistent remuneration to persons with HIV and AIDS.

Three reviews have been conducted on home-based care in Africa and each has looked at a different area of the phenomenon (Akintola, 2008b; Campbell & Foulis, 2004; Ogden et al. 2006). the sequencing of events over time in such a way that a 'plot' emerges (Greenhalgh et al., 2005). In this review we track key insights that emerge from

associations between socio-political issues and responses to home-based care in Africa within research discourse chronologically. The emerging narrative and dominant themes are tracked with a view to understanding how home-based care is viewed on the continent in the context of the socio-political and economic environment. This approach offers a perspective on previous research and suggests the direction in which research is potentially pointed.

Methods

This systematic narrative meta-synthesis proceeded in four stages. A systematic search strategy was developed, data bases were searched, records were screened for relevance and data was synthesised based on a narrative thread.

Research design

Thematic synthesis methodology (Thomas & Harden, 2008) was used to produce a chronological narrative meta-synthesis of the research on home-based care in Africa.

Data collection

Searches of key databases, hand-searching key journals, and 'snowballing' (ancestral referencing or electronic citation tracking) were conducted by the first author in May 2010 and updated in September 2011 and June 2012. The databases, MEDLINE, CINAHL, PsycINFO, Web of Knowledge, JSTOR, and African Journals Online, were searched for articles published during the period January1985 to June 2012. The search terms used were home-based care, Africa, AIDS/HIV, palliative care, volunteer and 'burden of care'. In total, 1997 articles were found of which 68 were retrieved. The abstracts were perused to determine whether the relevant study used a qualitative design

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and whether it referred to HIV and AIDS home-based care offered by family members or volunteers in Africa. Only reports of qualitative studies of home-based care in Africa were included. Thirty-five studies were identified as fitting the inclusion criteria.

Data analysis

Studies were tabulated and categorised by two independent researchers according to study design and analysis methods used within the study to evaluate the methodological quality of studies in this area. Data from the various studies were verified to establish overall validity of the studies (Table 1).

Next, key dimensions of home-based care that have been researched over time were identified by tracking the developments in research chronologically. All articles that were collected were loaded onto NVIVO9.1 in PDF form and analysed using a modification of dimensions of narrative analysis (Creswell, 2007). 'Free codes' of findings were organised into descriptive themes within these analytical dimensions.

Results

The results are presented in two sections:

a. Table of research studies presented chronologically.

b. Dominant narrative themes in the research and chronological thread within each theme.

Table1 Qualitative Research Studies

Study	Site	Research questions	Sample method	Study population and sample size	Data collection method and procedure	Method of analysis
		Aim of study				
Mensah 1994	Ghana	To evaluate the impact of a home care programme	Random	137 patients, caregivers and leaders	interviews	Not specified
Hansen 1998	Zimbabwe	Cost and quality of community home-based care	Purposive	60 patients and caregivers and 4 facility-based outreach schemes	interviews	Not specified
Olenja 1999	Kenya	Community attitudes toward HIV/AIDS and home-based care	Random	Community members/people living with AIDS and key informants and school children	interviews, focus group discussions, social mapping, composition writing	Not specified
Nnko, 2000	Tanzania	Change in quality of care based on previous experience(s) of caregivers)	Purposive	21 main care providers/patient relations	In-depth interviews	Not Specified
Ndaba-Mbata 2000	Botswana	Knowledge available to family caregivers	Snowball	15 family caregivers	In-depth interviews	open coding thematic analysis/constant-comparison method
Chimwaza, 2004	Malawi	Caregivers' diagnoses of patient's illness ;care provided, support received; and 'burden of care'	Purposive	15 caregivers	Interviews	Systematic coding (thematic analysis)
Johnson 2004	Kenya	Role played by CHWs in providing home-based care	Not Specified	55 participants organisational leaders, government workers, community members, government leaders; CHWs, 9 youth	Participant observation, focus group, interviews	not specified
Phorano, 2005	Botswana	Home care issues – risks of poorly managed human waste disposal in home-based care	Purposive	85 caregivers, community stakeholders	Interviews, focus group, participant observation	Thematic analysis
Orner, 2006	South Africa	Psychosocial impacts on caregivers	Purposive and snowball	45 primary caregivers of PWAs	Interviews	Grounded theory analysis

de, Zerden, 2006	South Africa	Needs, fears and motivations of front-line care workers	Random	37 home-based care workers	Semi-structured questionnaires, focus groups, site visits, field observations	Method of analysis for both were not specified
Akintola, 2006	South Africa	Experiences of informal caregivers of people living with HIV	Purposive	21 primary 20 volunteer caregivers 10 key informants	Participant observation, informal discussions interview, archival records	Grounded theory (constant comparison)
Waterman 2007	Kenya	How HBC professionals reduce stigma to reduce, prevent and treat HIV/AIDS	Purposive	50 HBC professionals in 27 focus groups	Focus group interviews	Thematic analysis (inferred not specified)
Aga, 2009	Ethiopia	Conceptions of care as a cultural phenomenon	Purposive	6 key informants, 12 general informants	Semi-structured and In-depth interviews, recorded field notes	Thematic analysis
Akintola, 2008a	South Africa	Caregiver challenges and coping		20 HBCVs, key informants	In-depth interviews; observation	Thematic analysis
Campbell, 2008	South Africa	Community perceptions of a grassroots-level intervention to support HBCV	Purposive convenience	34 community members	In-depth Interviews and focus groups	Thematic content analysis
Campbell, 2008	South Africa	Community networks to assist people with AIDS and their caregivers, and the factors shaping these networks	Purposive	55 participants PLWHA, caregivers, health volunteers, local leaders, young people, public and private sector groups	45 in-depth interviews, 13 focus groups	Interpretive thematic analysis
Makoae and Jubber 2008	Lesotho	Experiences of home-based family caregivers obtaining medical care for patients	Purposive	21 family caregivers	In-depth interviews	Phenomenological
Rödlach, 2009	Zimbabwe	Volunteers' motivations and concerns for caregiving	Convenience	Voluntary caregivers, PLWHA health workers, township residents	Observations, about 220 interviews, archival sources, mass media	Grounded theory analysis/thematic
Mazzeo 2009	Zimbabwe	Home-based care (HBC) services for PLHIV and relationships between stakeholders	Purposive	170 participants HBC patients, caregivers, community health workers, NGO and government staff	In-depth Interviews and focus groups, observation	Thematic analysis – grounded theory approach
Pallangyo, 2009	Tanzania	Experiences of informal female caregivers	Purposive	8 female family caregivers	Semi-structured interview method	Thematic analysis (NS)
Agbonyitor, 2009	Nigeria	Challenges of PLWHA in HBC programme; frustrations of volunteers benefits and weaknesses of programme	Voluntary participation	30 PLWHA and 22 HBCVs (faith based HBC programme)	Focus groups and in-depth interviews	Thematic analysis

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Campbell, 2009	South Africa	Experiences of female health volunteers effects of participation on volunteer's agency	NS	Health volunteers in community	Interviews and field diaries	Thematic analysis
Aga et al.2009	Ethiopia	Family caregivers' perception of social, cultural, structural factors influencing care	Purposive	6 key informants and 12 general informants	Semi structured interviews, participant observation	Thematic Analysis
Kang'ethe, 2009	Botswana	Challenges influencing the state of caregiving in the CHBC programme	NS	82 primary caregivers, 4 CHBC nurses and 1 co-ordinator	Focus groups, interviews for CHCB nurses and co-ordinator	Thematic analysis
Mashau 2009	South Africa	Experiences of HIV and AIDS home-based caregivers	Purposive	15 home-based care-workers	In-depth interviews, field notes	Thematic analysis
Tshililo 2009	South Africa	Experiences of family members	Purposive	12 home-based caregivers	In-depth phenomenological interviews	Thematic analysis
Tarimo 2009	Tanzania	Experiences of family caregivers to patients at home	Purposive	20 family caregivers	In-depth interviews	thematic content analysis
Makoae, 2009	Lesotho	Caregivers experiences of bodily care before ARVs were readily available	Purposive	21 caregivers	In-depth interviews	thematic analysis
Akintola, 2010	South Africa	Perception of rewards amongst volunteers	Purposive	55 volunteer caregivers	Open-ended interviews	Thematic analysis
Maes, 2010	Ethiopia	Impact of poverty and insecurity on volunteers well-being and the sustainability of the AIDS treatment	Purposive	19 volunteer caregivers, 6 community workers, 6 supervisor nurses	Participant observation interviews, focus group, household food insecurity access scale	Thematic analysis
Majumdar, 2010	South Africa	Challenges faced by people who are living with HIV/AIDS and caregivers	Purposive and snowball	9 HIV patients and caregivers (9), community leaders, local health care providers	In-depth interviews, focus groups	Thematic analysis
Kang'ethe, 2010	Botswana	Human rights dimensions of informal caregiving	convenience	82 caregivers, 5 CHBC nurses	Focus groups, participant observation; interviews	Thematic analysis
Kang'ethe, 2010b	Botswana	Stress associated with palliative care giving	Convenience sampling	82 caregivers and 5 nurses	Focus group discussions, participants observation, interviews	Thematic analysis
Akintola, 2011	South Africa	What motivates people to volunteer as caregivers?	Purposive	57 volunteer caregivers	Interviews and focus groups	Thematic analysis
Makoae, 2011	Lesotho	Meaning attached to food in HIV/AIDS caregiving	Purposive	21 caregivers	In-depth interview	Thematic analysis

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TABLE 1 Table of Qualitative research studies

Dominant themes in the narrative on home-based care

Home-based care has been studied mainly is Southern and East Africa. This trend may be due to the higher incidence of HIV and AIDS in these countries, especially in South Africa.

The following emerged as dominant themes:

1. the 'burden of care'

2. poverty

3. women as caregivers

4. stigma

5. government and stakeholder collaboration

Twenty-five of the studies selected for this analysis mention poverty as the fundamental reason for the 'burden of care' falling on communities in Africa. Twenty-two studies cite 'stigma' and another 22 cite 'women as caregivers' as contributing elements that complete this picture. Twenty-nine studies refer to the 'burden of care' as the epitomising feature of home-based care in Africa, supported by the shared context of poverty, stigma and women as caregivers. A combination of stakeholder collaboration (communities, patients, and families) and government participation is proposed by researchers as the most viable means to relieve the 'burden of care' from women and communities.

The 'burden of care': Home-based care as the 'best option' (1994–2004)

Initially home-based care was proposed as the most feasible option for AIDS care in Africa, citing patients' and families' preferences and 'cost effectiveness' (Mensah, 1994;

Olenja, 1999). The 'burden of care'' narrative emerged and was quickly thickened by researchers. The 'burden of care' had fallen on families and communities despite their incapacity, lack of preparedness, and inability to deal with the responsibility on all levels. By this stage, family structures in Africa had been so tremendously transformed that traditional features that would have cushioned the burden were no longer prevalent (Nnko, 2000; Olenja, 1999). The 'burden of care' encompassed all aspects of the lives of caregivers, ranging from the emotional, social and physical to the financial. What appeared initially as modest costs of care were devastating for caregivers who struggled to afford the most basic necessities (Chimwaza & Watkins, 2004).

Irrefutable evidence for the "burden of care" (2005–2012)

Home care came to be seem as demanding and socially isolating, sequestering caregivers from participation in social activities and calling for caregivers to be patient, tolerant, committed and kind (Kipp et al., 2006; Ndaba-Mbata & Seloilwe, 2000). Caring for other household members increased the psychosocial impact on caregivers. The emotional costs and a lack of support for the household caregiver from relatives and government increased the stress (Orner, 2006; Pallangyo & Mayers, 2009). Amongst the social and emotional costs cited in the literature were witnessing chronic suffering, death and occasional antagonism of care recipients and emotional pain, while hopelessness and despair also contributed to the caregivers burden (Akintola, 2006; Maes et al., 2010; Mashau & Davhana-Maselesele, 2009). Caregivers expressed resentment at feeling that caregiving was comparable to a full-time job, but not regarded as such. There were no counselling programmes in place to assist caregivers in dealing with the losses, stigma and discrimination that accompany the care of AIDS patients (Rödlach, 2009; Tarimo et al., 2009).

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Physical care cited by 32 studies as an important element of care included feeding, bathing, dressing, transferring, toileting, and ambulating. Assistance with activities of daily living such as house-cleaning, shopping, meal preparation, collecting water and firewood, and transportation to clinics, hospitals churches and traditional healers added to the burden. Latter stage physical care demands were more intense and included turning bedridden patients; wound, skin and mouth care; massages, bed baths and keeping night vigils (Agbonyitor, 2009; Kang'ethe, 2010; Lindsey, Hirschfeld, & Tlou, 2003; Ndaba-Mbata & Seloilwe, 2000; Nnko, 2000; Pallangyo & Mayers, 2009; Uys, 2003).

Hidden costs of care were related to food access and food security as well as loss of income for caregivers who sacrificed gainful employment to offer care. Caregivers had difficulty getting access to nutritious food, and rising food costs created distress and demotivation contributing to food insecurity (Agbonyitor, 2009; Maes et al., 2010; Makoae, 2011). A lack of costing studies precluded definite conclusions about the relative costs of home-based care to other stakeholder-based care. However if both forms of care are compared on equal terms, home-based care may well be more expensive than institutional care (Akintola, 2008b).

Poverty

Cumulatively, all aspects of the 'burden of care' are linked to the endemic poverty in the Africa region. Patient demands are overwhelming and costly, and physical space in small houses shared by many, debunked the myth that family-based care was a good option (Olenja, 1999). Even middle-class families quickly became poor due to the costs of funerals (Lindsey et al., 2003). The financial 'burden of care' is the most obvious link to poverty, adding to the social and emotional 'burden of care' (Chimwaza & Watkins, 2004).

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People delay treatment because they cannot afford costs or use drugs that were cheaper but ineffective as a result of the 'poverty trap' (Emanuel et al., 2008:747). HIV seemed to affect disadvantaged communities disproportionately, hitting hardest on those households that were the most underserved in terms of basic public services such as sanitation and piped water (Tshililo & Davhana-Maselesele, 2009). Social fall-backs were stretched to the limit and even the most modest costs of caregiving, such as soap and foods craved by AIDS patients, were beyond the means of caregivers (Chimwaza & Watkins, 2004; Johnson, 2004; Nnko, 2000; Johnson & Khanna, 2004; Makoae, 2009; Tshililo & Davhana-Maselesele, 2009). AIDS is a 'poverty-friendly' disease because most homes affected by HIV/AIDS are progressively consumed by poverty (Kang'ethe, 2009:29). The selling of assets, family members leaving paid work to care for sick relatives, and the loss of family members in their productive years contribute to the context of poverty (Ndaba-Mbata & Seloilwe, 2000). Neighbours often help or support in the care of patients, and family members living in other areas arrive to assist contribute to the poverty burden in communities (Nnko, 2000; Ntsebu et al., 2001). Home-based caregivers take the initiative to relieve some of the worst effects of poverty by starting food gardens and selling their beadwork; however, this is often inadequate (Shaibu, 2006).

Women as caregivers

The 'burden of care' falls excessively on women within families, thus affecting women's health and well-being, increasing emotional stress and social isolation, and intensifying existing gender disparities (Akintola, 2006; Ama & Seloilwe, 2011; Kipp et al., 2006; Ndaba-Mbata & Seloilwe, 2000; Olenja, 1999; Tarimo et al.,2009). The fact that women often have less access to cash implies that the care they provide is beyond their means

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(Nnko, 2000). Orner (2006) observed that the majority of caregivers in South Africa are women, yet little attention is devoted to the relationship between gender and the psychosocial impacts at household level with reference to gender programmes and policy implications. Often, elderly women and young girls are caregivers or supporters of female caregivers (Lindsey et al., 2003; Orner, 2006). Kipp et al. (2006:31) note that "care for the caregiver" needs to be a funded aspect of all HIV/AIDS programming, and that resources allocated to gender must take priority.

Many studies have largely ignored the costs associated with home-based care currently borne by unpaid female caregivers (Akintola, 2006; Akintola, 2008a; Akintola, 2008b; Mazzeo & Makonese, 2009; Olenja, 1999; Opiyo, Yamano, & Jayne, 2008; Tarimo et al., 2009). Women performing caregiving duties for HIV- and AIDS-affected families and community members often do so in addition to caring for their families. They suffer the severe economic burden imposed by caregiving, which restricts their options for paid work and subsistence farming. This could eventually lead to food insecurity and a weakened economic position (Akintola, 2008a; Akintola, 2008b; Olenja, 1999; Opiyo et al., 2008; Tarimo et al., 2009; Makoae, 2011).

AIDS imposes a caregiving burden on women because they are not adequately empowered to take control of their lives. Care by women is unrecognised and undervalued and a traditional upbringing, emphasising domestic chores and little relation to the public and economic spheres for women, reinforces the 'burden of care' (Pallangyo & Mayers, 2009; Tarimo et al., 2009). Unfair and uneven care responsibilities betweenmen and women intensifies the gender differentials between men and women (Kang'ethe, 2010; Olenja, 1999). Kang'ethe (2010) suggests that unequal gender and power relations that set caregiving up as women's work pose human rights concerns.

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Stigma

In the early 1990s, HIV presented caregivers with a moral dilemma as to whether to provide care or not. Fear and discrimination undermined efforts to identify, treat and control the disease and the opportunity to offer sufferers compassionate care. Society's moral and ideological attitudes towards AIDS became relevant to caregiving (Olenja, 1999). Ntsebu et al. (2001) suggest that programmes offering access to care early in the continuum helped to reduce stigma and discrimination, as patients in the early stages of the disease are not emaciated and easily identifiable as AIDS patients. Caregivers' reluctance to name the disease was a common phenomenon. Caregivers' references to typical symptoms, their previous experiences in caregiving and patients' previous sexual behaviour suggested that they suspected the HIV positive diagnosis (Chimwaza & Watkins, 2004; Nnko, 2000). Stigma and discrimination are recognised as barriers in the global battle to overcome HIV/AIDS. These factors isolate the fragile family unit and continued to represent the biggest obstacles to care and prevention (Chimwaza & Watkins, 2004).

Stigma exacerbated the emotional burden associated with care and negatively influenced caregivers' health (Kipp, Nkosi, Laing, & Jhangri., 2006; Kipp, Tindyebwa, & Rubaale, 2007; Tarimo et al., 2009). Volunteer caregivers often experienced stigma and discrimination in the forms of reluctance on the part of people living with HIV/AIDS (PLWHAs) and their families to allow volunteers access into the home, in seeking treatment, late disclosure of their HIV status and poor support of home-based caregivers from the families (Mashau & Davhana-Maselesele, 2009; Rödlach, 2009). Potential volunteer caregivers are reluctant to assume this burden, which could lead to responsibility for family members such as children, following the patient's death (Pallangyo & Mayers, 2009).

According to (Ama & Seloilwe, 2011), the stigma surrounding HIV/AIDS care can be a burden to caregivers as the community's attitude of rejection of HIV-positive people affects caregivers' initiative to provide care. In some instances, stigma and discrimination can be so exclusionary that HIV and AIDS clients refuse help to avoid the attached stigma (Kang'ethe, 2010; Shaibu, 2006). Male caregivers are especially stigmatised due to cultural taboos against caring for females and men did not spend as much time in the home as compared to the time spent on income-generating activities. In some cases, men are seen as deviant for doing unmanly duties and are insulted and teased by other men (Akintola, 2006; Nnko, 2000; Pallangyo & Mayers, 2009). Women are reluctant to report health-related burdens of care as this is construed as complaining and contravening social cultural expectations of women as caregivers (Akintola, 2006).

Stakeholder collaboration and government participation

Stakeholder collaboration and government participation are presented as key elements to alleviating the pressure on communities by the HIV and AIDS care and support. Comprehensive care must involve multi-sector inputs such as clinical attention, nursing care, social welfare and the help of religious or community groups (Nnko, 2000). No single organisation can provide all the services needed; thus, programmes that provide services through networking with other government, non-governmental and community organisations are the most viable model of community care and most likely to be replicable where missionary, NGO and community-based care programmes exist (Ntsebu et al., 2001). Rödlach (2009) noted that presenters at a UNAIDS conference held a decade previously pointed out that synergy between community members, government agencies, and NGOs was key to carrying out effective home-based care for people living with HIV& AIDS. More extensive

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collaboration between government, non-profit organisations, and churches to strengthen the commitment and motivation of volunteers in order for voluntary caregiving to reach its potential was called for (Akintola, 2010) .

Politics of the setting is very important to the success of any programme training home-based volunteers. Cultural issues, must be taken into consideration as cultural competence on the part of the health workers in communities is essential (Shaibu, 2006). Campbell, Nair, Maimane, and Sibiya (2008) note that well-intended short-term development programmes – implemented by northern professionals' flying in and out of poor countries for short periods – can undermine local capacity to mount effective and sustainable HIV/AIDS management responses in African settings. Community context might best be facilitated through formal partnerships involving all groups (Shaibu, 2006). In the absence of formal support external to the community, it is unlikely that members in marginalised communities will get any further than they have to date in responding to HIV/AIDS. Creating a modestly skilled health service economy to alleviate the economic devastation of HIV and AIDS is an appeal for the sake of patients and families.

Ama and Seloilwe (2011) concluded, based on work conducted in Botswana, that in order to ensure that the burdens of caregivers were reduced, there was a need for a comprehensive community home-based care (CHBC) programme that would ensure that the role of caregivers in CHBC was adequately recognised by government and the community. Furthermore, there was improved support for caregivers, which included psychosocial support (care for caregivers), adequate remuneration, training and provision of transport for caregivers to visit their clients. In Botswana, the government asked communities for assistance with service delivery to people with HIV or AIDS through the institutionalising of the CHBC programme and by placing its management structures within the existing district health

structures. Thus, the government exploited the cultural and social values embedded in people's belief that communities have an obligation to take care of those members of society who are distressed. There has been a consistent trend in the research on home-based care (HBC) in Africa for authors to present stakeholder collaboration and more active government participation as the main means to alleviate the burden on of HIV and AIDS care on communities.

Discussion

The 'burden of care' narrative emerged and continues to dominate the storyline of care. The emergence of the 'burden of care' as a dominant narrative in the discourse on home-based care served to highlight in detail the complex nature of the 'burden of care'. Researchers contributed to thickening this narrative by exploring various facets of the negative impacts of care on communities, families and individuals. This emergent narrative highlighted that, although home-based care was initially touted as a panacea for the increasingly evident problem of people suffering from AIDS-related conditions, it rapidly became evident that this is a wholly inadequate solution. One of conditions that facilitated the emergence of this narrative was that the care burden was solidly in existence all over Africa and had been for some time. A second was the impact that caring for seriously ill people in the home had on the physical, economic, social and psychological resources of families and communities.

The 'burden of care' narrative was and is an important one to highlight. Social forces and traditional views of women resulted in the burden falling overwhelmingly on women. Poverty and inequality exacerbated the situation. Research has resulted in this issue being propelled into the forefront of attention. Research in this area is dominated by qualitative studies, which are methodologically useful to elucidate and describe the nature of the problem.

Quantitative studies are required to obtain an idea of the extent of the problem in terms of its scope, magnitude and intensity in statistical terms. The paucity of quantitative studies may be due to poor funding, shortage of validated outcome measures, multiple sources of potential bias, inadequate research capacity and skills, logistical challenges to data collection and transfer, and the absence of formalised mechanisms for ethical research in some African countries (Harding et al., 2008).
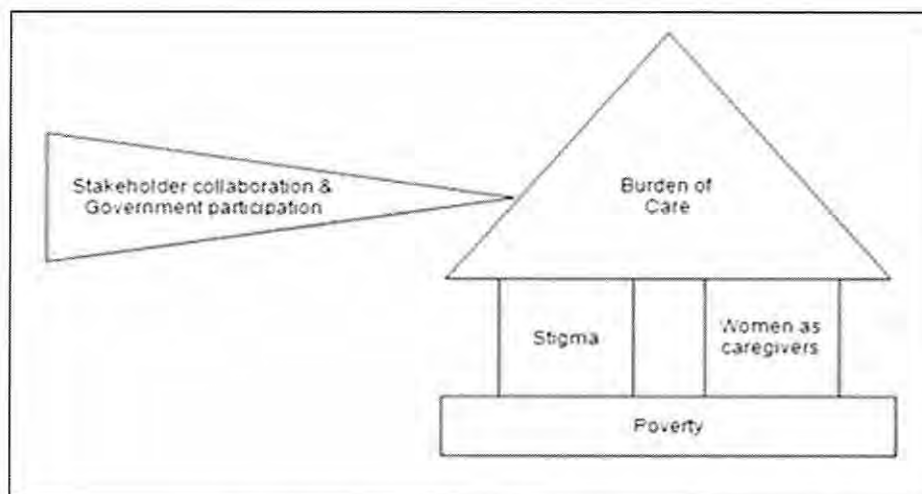
Figure 1: Relationship amongst dominant themes around HIV and AIDS home-based care research in Africa

The themes of poverty, stigma and women as caregivers actively support the 'burden of care' narrative. The other important theme is the lack of collaboration between stakeholders (Campbell & Foulis, 2004; Mazzeo & Makonese, 2009) and the lack of reliable government participation. Dominant discourse in research and policy rhetoric highlight the need to promote community participation and partnerships for HIV/AIDS management (Campbell & Gibbs, 2008).

The interaction of poverty and HIV and AIDS has been extensively documented with HIV and AIDS being seen as the major threat to development, economic growth and poverty alleviation in much of Africa (Casale & Whiteside, 2006; Whiteside, 2002). In the poverty/epidemic cycle, poverty increases the spread of HIV and AIDS, which in turn increases poverty (Whiteside, 2002). This cycle makes it necessary to look beyond financial poverty to understand these associations. Studies on the impact of HIV and AIDS have focussed on 'economic' variables. However, the impact of HIV/AIDS on poverty is extensive and affects relational goods, public goods and issues of social reproduction (Casale & Whiteside, 2006; Whiteside, 2002). Social reproduction refers to the social relations, which can be a resource in alleviating the impact of HIV and AIDS on individuals and communities. In the context of poverty, these social resources are severely overburdened as illustrated in the section on 'burden of care'. HIV and AIDS increase the vulnerability of rural communities and lower resistance to environmental challenges by undermining the social foundations of communities. Social resources of the family and community are easily depleted by the demands of accommodating the needs of HIV and AIDS patients, making it difficult for communities and individuals to progress in other areas. Changes in dependency patterns, loss of assets and skills associated with adult mortality, the burden of caring for sick adults and orphaned children, the interaction between malnutrition and HIV infection and AIDS decimates communities and can lead to famine (De Waal & Whiteside, 2003).

Stigma and discrimination were prominent in the studies reviewed. The theme of World AIDS day 2002 was 'Stigma and Discrimination' and despite these issues having been discussed in many conferences since stigma and discrimination remain a problem in sub-Saharan Africa (Shaibu, 2006). Chimwaza and Watkins (2004) note the assumptions that most people sick with HIV are women and that women are responsible for the spread of HIV.

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The tendency in communities for women to be the primary caregivers of PLWAs, whether as family or as volunteer caregivers, linked gender discrimination with care and stigma and set up a persisting relationship between these three elements (Orner, 2006).

Waterman et al. (2007) state that stigma may affect the efficacy and outcomes of home-based care programmes by preventing people from participating in care initiatives and fostering denial and secrecy. A combined and sustained effort from all the key HIV and AIDS care role-players is warranted for the successful reduction of stigma and discrimination (Waterman et al., 2007).

Researchers have posited that a lack of adequate collaboration between stakeholders and insufficient government support combine to create the ideal conditions for the 'burden of care' to fall squarely on those already the most vulnerable – indigent women. Women in impoverished rural communities have had to assume care for ill family and community members (Akintola, 2006). This phenomenon begs the question: Why has the voice of civil society not been as strident in the case of care and support as it has been for treatment and prevention? Ige and Quinlan (2012) posit that African governments' responses to the HIV and AIDS pandemic demonstrate a pattern of incidental as opposed to transformational leadership. The responses have been to react rather than to ensure consistency over time in decision-making and in setting and revising policies. Moreover, public criticism of efforts to curb HIV and AIDS displays people's dissatisfaction with what is apparently government denial of citizenship by proposing and implementing policies that are detrimental to people's well-being (Ige & Quinlan, 2012). The answer in South Africa at least lies in the timeline related to the political climate. In South Africa, social advocacy groups were instrumental in realising treatment for HIV positive people. Yet, no such gains have been made on care and support in the terminal phase of the illness. In many quarters, 'care' is seen as beginning and ending

with treatment. Some countries, such as Botswana, have had government co-ordinated and supported home-based care programmes almost from the onset of the epidemic.

As it became increasingly apparent that the problem of AIDS transcended all imaginable boundaries and challenged health knowledge on all fronts – from the microscopic to the global and political – attention in the realm of home-based care shifted focus. The problem of AIDS poses a challenge at all levels and while governments pay attention to it on one level, problems grow in other areas. The situation is complicated in -a country such as South Africa with the distraction of post-apartheid nation building during the Mandela administration and rampant denial by the Mbeki administration (Fourie, 2006; Nattrass., 2008). In Zimbabwe, political instability nurtured rather than stemmed the AIDS crisis. By contrast, countries such as Uganda, Botswana, Malawi and Tanzania, while significantly under-resourced, put more political effort behind the AIDS cause at all levels. Whilst this did not result in eradicating AIDS or the need for home-based care in these countries, it resulted in solutions that were synchronous with each county's needs.

In South Africa, with so much of the attention from civil society focussed on first persuading government to acknowledge that AIDS is caused by HIV; and then agree to offer support for treatment and prevention, the issue of care and support was relegated. A perusal of the earlier literature on the topic of AIDS care across Africa reveals a trend indicating that it was initially not expected that governments would or even would need to participate in care. Prior to the advent of anti-retroviral treatment (ARVs), life expectancy was low and people succumbed quickly once they developed AIDS, especially in countries such a Malawi where health and nutritional status is generally low. In Uganda, civil society support was mobilised early in the epidemic through organisations such as the AIDS Support Organisation (TASO). This organisation is a collaboration of people directly and indirectly affected by AIDS,

government and civil society. TASO directed attention to one-on-one counselling and stigma reduction contributing to the reduction in infection rates in Uganda (Kaleeba et al, 1997). Ige and Quinlan (2012) present a comparison between Senegal, a country generally regarded to have curtailed an epidemic through astute political leadership and despite poor resources, and South Africa a relatively well resourced country with the highest HIV and AIDS rates in the world attributable largely to inconsistent political action. The pattern of civil response to HIV and AIDS emerged more slowly in countries like South Africa where people have access to better food and health resources. Later, with the introduction of ARVs, life expectancy increased and other types of challenges such and poor nutrition and poor compliance emerged.

Conclusion

Home-based care for AIDS as the most feasible option for HIV and AIDS care and support was an overly optimistic view, considering the scale and intensity with which AIDS engulfed the world (especially Africa and other developing regions); (Fourie, 2006). The care and support narrative was easily silenced in relation to the louder more vociferous narratives around prevention and treatment

Initial academic writing on the topic contributed to this silencing by promoting the idea of home-based care as the most viable and desirable for patient, family and community. However, even at this stage there was some recognition that the problem was festering.

This narrative meta-synthesis reveals that the research on home-based care has followed a particular plot, predictably one that resonates with the context of AIDS in Africa. The primary themes of this narrative are poverty, women as caregivers, and stigma – all of which support the dominant 'burden of care' narrative. This storyline is likely to continue into the future. On the other hand a silence about what exactly should be done to alleviate the

burden of care overshadows the story, and questions remain on how the story will unfold. The four major themes underpinning the narrative contain intriguing sub-plots that spark hope or despondency (e.g. women in competition to be recognised for caregiving or ARVs offering false hope that care will not be required). Potential clues to the directions in which research on home-based care in Africa could and should be heading lie within the sub-plots of the themes of poverty, stigma, women as caregivers and government-stakeholder collaboration. Future research must explore these sub-plots extensively.

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Chapter 4

Contextual Reflexivity: Towards Contextually Relevant Research with South African HIV/AIDS Home-Based Care Volunteers

Article

Contextual Reflexivity: Towards Contextually Relevant Research with South African HIV/AIDS Home-Based Care Volunteers

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Abstract

What are the processes through which researchers understand context and its value in the qualitative research process? This is an important question for researchers to consider and is especially pertinent in non-Western environments where Western research precepts have traditionally been followed. This article proposes that continually addressing ethics in practice (ethical reflexivity) and maintaining methodological reflexivity keeps the researcher on the path to a deeper and broader perspective of the contextual salience of emerging data. The combination of the latter, which is referred to as 'contextual reflexivity,' produces an iterative-reflective-generative process, consistent with an Afrocentric view on research. This process includes ethical reflection on research activity beyond institutional requirements, as well as inter-relational reflexivity. Field material and reflective research journal extracts from a study on HIV/AIDS home-based care and support volunteers' (HBCVs) identity provide illustration of this process in practice.

Keywords: contextual reflexivity, culture, ethics, HIV/AIDS, HIV care, translation

Introduction

The centrality of the context to understanding the construction and communication of life stories has been emphasized by theorists (Gubrium & Holstein, 2009; Lieblich, Tuval-Mashiach, & Zilber, 1998). The methodological implications of describing and interpreting context in relation to text while maintaining its relative parity have received less attention (Bishop, 2007; Zilber, Tuval-Mashiach, & Lieblich, 2008). Until recently, consideration of context in qualitative research has been an addendum to the core business of a focus on text. In order for data to be relevant, context should be taken into account throughout the research process.

This is especially pertinent in non-Western environments, where little has been written about qualitative research methodology. Most qualitative researchers and writers are from the West. Little has been said to date about conducting qualitative research in the general context of a collectivist culture or specifically in a collectivist African rural context. African culture can be described as collectivist (Mkhize, 2004). Collectivist cultures give precedence to group goals over personal and individual goals. There is more focus on the context rather than the content in making attributions and communicating. People define themselves as part of a group and give less credence to internal than to external processes as determinants of social behavior. Collectivist cultures define relationships with in-group members as communal; make more situational attributions and are likely to be self-effacing (Triandis, 2001; Wang, 2008).

Denzin & Lincoln (2003) note, "sadly qualitative research serves as a metaphor for colonial knowledge, for power and for truth" (p. 1). They assert that colonizing nations relied on the human disciplines to produce knowledge about strange and foreign worlds and representations of the"Other" thus contributing to qualitative research becoming a "dirty word" (Denzin & Lincoln, 2003, p1). Currently there is greater cultural sensitivity amongst Western researchers; this facilitates collaboration with indigenous researchers in the application of novel approaches to research. Likewise, an emerging group of researchers from non-Western cultures use research approaches and methodologies suited to the cultures from which they originate and within which they perform research (Lincoln & Gonzalez y Gonzalez, 2008). Africa has generally been an outsider on the world stage of qualitative research. Western research methodologies, which are primarily rooted in individualist ideologies and perfunctorily applied, perpetuate norms of Western-based research.

There is still a paucity of literature by African researchers advocating for an Afrocentric approach to qualitative research (Mkabela, 2005). The Afrocentric paradigm as proposed by Asante (1987, 1988, 1990) offers alternative research paths to those presented by "colonial or neo-colonial researchers" (Mkabela, 2005, p. 178). This paradigm locates research from an African viewpoint and creates Africa's own intellectual perspective focusing on Africa as the cultural center for African experiences and interpreting data accordingly. Mkabela (2005) proposes that in the multicultural reality of the South African context, the Afrocentric paradigm serves as a liberating intellectual movement towards a pluriversal perspective on research. This Afrocentric view is not intended to foster an ethnocentric 'them vs. us' perspective aimed at rebuking Western researchers and Western-inspired methodological approaches. Rather, it is an attempt to draw attention to the alternative possibilities and perspectives that could unfold with locally inspired approaches in Africa and possibly other parts of the world.

The two authors of this article are South African by birth but not of indigenous African ancestry, not personally affected by poverty, not rural dwellers and non-isiZulu speakers. We therefore take the perspective of 'outsider –insider' in relation to the women in this study. Our strong relational

position of over ten years of experience in the field provides a tangible link to the context. The 'outsider-insider' position compels greater attention and reflexivity. The effects of this process are presented in this article.

Although the Afrocentric view represents a useful paradigm from which to advocate for more contextually relevant research in Africa, the issue of pragmatic application remains. What tools are available to the qualitative researcher to facilitate an understanding of context and its resonance with data in the research process in Africa? Reflexivity is an essential and recognized tool in qualitative research (Bishop, Sonn, Drew & Contos, 2002; Denzin, 2000; Flick, 2002; Finlay, 2002; Bishop, 2007). Moreover, reflexivity in qualitative research is consistent with the principles underlying the Afrocentric research paradigm in which researchers are expected to be a 'centered' or located as an agent instead of as the 'Other' (Mkabela, 2005). We propose a consideration of ethical reflexivity and methodological reflexivity in qualitative research practice to achieve contextual reflexivity. South African researchers Gilbert & Sliep (2009) offer a perspective on how reflexivity can be employed in the practice of social action and towards contextually relevant research. They advocate moving beyond reflexivity of self- in- action to an understanding of reflexivity within inter-relational processes. They elaborate further, suggesting that inter-relational reflexivity occurs dialogically and has the inherent capacity to initiate social action. Its processes entail the collaborative deconstruction of power, negotiation of accountability and responsibility, and a concern for moral agency. The application of inter-relational reflexivity then has the potential to initiate the translation of critical awareness relative to others into social action (positive performativity).

We unpack the processes of accomplishing contextual reflexivity using the example of a qualitative research study exploring AIDS home-based care volunteer identity in an African collectivist, resource-poor context. A position of openness and "positive uncertainty" was adopted to achieve a constantly reflective approach (Gelatt, 1989, p. 252). We show how and why a three-stage interview process emerged from the intention to give voice to the HIV/AIDS home-based care and support volunteers' (HBCVs). This process of giving voice, creating the platform to be heard, and realizing the value of being heard was the social action we intended to implement. The processes of contextual reflexivity offered the means through which to achieve this in a contextually relevant manner. We describe how ethical reflexivity and methodological reflexivity were employed to attain contextual reflexivity. As a consequence of this the research process was dynamic as new insights and data generated from the reflections were acted upon. Bishop et al. (2002) describe this as an iterative-reflective-generative approach to the research journey where each step of the research process informs the next by a process of reflection on action and action on reflection.

Orientation to the study

Volunteers form the core of home-based care and support for people living with HIV/AIDS in resource-poor countries like South Africa; yet, little is known about their identity and their reasons for volunteering. The aim of the study was to understand the social construction of identity by HBCVs. As the research process progressed, we realized that there was a need to create space for volunteers to tell about their work, their lives and themselves in ways that facilitated legitimacy and awareness of their identity. This study was part of a large project investigating various dimensions of social capital around the care and support of HIV and AIDS in a specific region of rural KwaZulu-Natal, South Africa.

HBCVs are unemployed women in the community who care for AIDS patients who are in an advanced stage of the disease stage or other sick people who are unable to care for themselves. The study participants were usually not related to the patients; HBCVs performed their duties in addition to personal obligations to their families. The volunteers' commitment was evident from the fact that there is limited access to running water and electricity in the community and daily household chores often include fetching water from a communal tap, collecting firewood and tending to the family food garden, in addition to cooking and cleaning the family home before tending to patients. Local government gives some of the women a stipend of R500 (€60) a month; this is referred to as 'soap money.' Most of this is spent on minibus taxis (the only available public transport) in the hilly community where houses are spread over a large area. For example, visits to three houses, on foot and public transport, could take a full day. HBCVs regularly use the money that they are paid to buy food, soap and other necessities that their patients cannot afford. HBCVs' family members sometimes also contributed financially or in kind to the 'work' of HBCVs. In the AIDS care and support hierarchy, HBCVs occupy the lowest rung. Until recently there has been little government acknowledgment of the indispensable role which the volunteers play in AIDS care and support in rural South Africa. As a result, HBCVs have been invisible as a group and as individuals. The women hope that participation in community-based AIDS care, a contribution based on altruistic sentiments and communal cultural expectations, will lead to paid work and the opportunity for self-improvement (Akintola, 2010).

In this study, fifteen HBCVs were interviewed in three successive interviews. The interviews were conducted in isiZulu (an indigenous and official South African language) and translated into English in situ by a mother-tongue isiZulu speaker fluent in English. We show how the interview process was continually altered in response to contextual reflexivity towards the social action of initiating the home based care volunteers' realization of the power of voice.

Ethical reflexivity: Ethics in context (practice)

Reflexivity in qualitative research practice may be used as a means to achieve ethics in practice such that ethics and reflexivity are co-dependent. Our intention was to pose a challenge to ourselves as researchers in this context: to maintain a constantly reflexive ethical position rather than to accept that our ethical responsibility was fulfilled once ethical clearance had been approved by the institution. A position of ethical reflexivity requires researchers to interrogate the relationships between their value positions and the ways in which they conduct and write about their research (Gerwirtz & Cribb, 2006; Bhattacharya, 2007). We aimed to maintain an attitude of applying ethics in practice rather than be satisfied with ratified "procedural ethics" (Guillemin & Gillam, 2004, p. 263). According to Sliep (2009), participation in social action that will strengthen marginalized voices requires moral action or agency derived from a shared understanding of the local context and a shared value system.

Conventional ethical processes were followed. Institutional ethical clearance to conduct this study was obtained from the University of KwaZulu-Natal, Human and Social Sciences Ethics Committee. The purpose of the study was explained in isiZulu to each interviewee separately at the beginning of interview process. A consent form in isiZulu (with English translation on the reverse) was signed by each interviewee. The issues of confidentiality and access to interview data were discussed and presented in writing. Participation in the study was voluntary and the HBCVs were informed that they could withdraw consent at any time in the process. In addition to the conventional processes, ethical reflexivity was carried out as it related to community setting and interviewee selection.

Ethical reflexivity: The community setting

Prior to commencing the research process, it was necessary to consider the community's tacit rules about behavior and relationships. Gaining entry into the community and obtaining permission to conduct the research was a process that required consideration of the traditional and cultural requirements of engagement with the community as a whole and with individual members. Gilbert & Sliep (2009) characterize this as "action in the creation of social space in which stakeholders representing different interests come together to engage in joint activities to address issues of inequality and power" (p. 469). We took this position in order to address ethical concerns and preempt, if possible, potential ethical problems before they arose (Guillemin & Gillam, 2004). The project was presented to the local traditional leader (chief) to obtain consent prior to conducting the research. The complexity of deconstructing power became apparent when the local traditional leader would not offer support for any research or intervention that had AIDS prevention as its aim. This was because of his belief that HIV does not cause AIDS. Having previously been a supporter of prevention, he adopted this position after attending an international AIDS conference in Montreal. Mindful that without his consent we would not have the co-operation of the people, we had to carefully consider how to present the project. We presented the project emphasizing care and support as pivotal. Care was presented as imperative for the community regardless of the causes of AIDS. A Western perspective might see the researchers as having taken a position of acquiescence. However, considering the community members' support and respect for traditional leaders, we realized that adopting a challenging position, supported by the dominant (Western) scientific discourse on AIDS, would not be contextually resonant. This would likely have alienated the traditional leader and provoked him to exercise his power to deny permission for the study. Moreover, community members would not have participated or co-operated without the chief's approbation.

The cultural precepts of this rural African community were acknowledged and followed in keeping with and accepting the value of understanding an orientation to collective values in African indigenous culture. Mkabela (2005) describes this as using the collective as a centered paradigm. This paradigm recommends that researchers adopt a participatory approach which allows for learning by, with and from community members in order to establish a working relationship in which people's interests and values are more authentically represented in research. Moreover, spaces of social action created by activating relationships with others provide possibilities for the development of transformational agendas that foster new social practices and institutions (Gilbert & Sliep, 2009). This attitude was advanced by complying with certain expectations from community members. For example, people often required car rides to the public transport stop or into the city. HBCVs also made enquiries about how to access government, non-governmental and educational funding and resources. The tacit implication in this collectivist setting was that a request for help could not be refused. Travelling with members from the community provided the opportunity for unrehearsed conversations between HBCVs and researchers, thus providing access to social facts and other elusive information not easily accessed in formal interviewing (Brown & Durrheim, 2009). During such conversations, the interviewer was able to hear further information about how women construed identity; AIDS care work, and different groups and organizations in the community. This information informed interview questioning and contributed to deeper and more informed engagement with the women's preferred outcomes.

We adopted our ethical position based on the previously observed pattern in which community members believed that when people in the community receive attention from outsiders, significant change would follow. We were mindful, in planning, methodology and performance, to offer realistic responses without creating false hope. Furthermore, a request for help also

included an implicit offer for future help should this be required. Access to resources, such as a car, implied privilege and knowledge about resources. This obligated one to help others who were in need. Through participation, the interviewer is accepted by community members and the conditions for communal participation through inter-relational reflexivity are established. Questioning of the current power relations and *status quo* then becomes possible. As 'critical consciousness' is embedded in action, it is necessary for researchers to find ways to work towards collectively negotiated conditions and preferred outcomes (Freire, 1970; Gilbert & Sliep, 2009). Engaging with community members increased the interviewer's awareness of being part of the webs of power and created opportunities for the interviewer to work towards discovering shared values with the participants as a starting point for moral agency.

Ethical reflexivity: Interviewee selection

The selection of interviewees was organized by the leader of the home-based care group. Given our ethical stance as researchers, we respected this process and the leader's authority, despite the possibility that people chosen could have been biased to the leader's interests and causes. We explained the importance of the selection process and that the main interest was in discovering who the HBCVs were and learning about their ideas about themselves as individuals and as a group. This was done in order to share power in a way that incorporated precautions against bias and ensured synergy between the researchers' and the leader's ideas. An Afrocentric view sees research in communities as a negotiated partnership which encourages people to define the degree and conditions of their participation (Mkabela, 2005). The women chosen by the leader expressed varied perspectives and we concluded that the leader's intention to present a comprehensive view of the volunteer and group identity appeared to supersede other biases. Indeed, many of the interviewees did further the cause of constructing a community care center, which was the group's collective agenda. However, some interviewees told of a lack of faith in the leadership as a result of poor understanding and support at a time of personal need and the overall lack of transparency in leadership style. It must be noted that in such a collectivist environment it is unusual for people to speak out against people in positions of authority.

Methodological reflexivity

Research that incorporates an attitude of 'positive uncertainty,' reflection on the research process and an iterative-generative-reflexive approach, creates openness to the unexpected in the research process (Gelatt, 1989; Bishop, 2002; Gilbert & Sliep, 2009). The researcher is then able to integrate knowledge based on theory (conceptual) and on reflection in action (professional) (Bishop et al., 2002; Bishop, 2007; Denzin, 1997). "All parties in the dialogue have subjectivities and emotional lives that they bring to the research relationships" (Riessman, 2005, p. 467). This notion of interconnected subjectivities in qualitative research is one that has been extensively explored and much emphasis has been placed on the researcher's consideration of her reflexive position as part of the action contributing to the construction of the narrative (Spry, 2001; Guillemin & Gillam, 2004; Gerwirtz & Cribb, 2006; Gilbert & Sliep, 2009). There is a need to move beyond the reflexivity of self-in-action to an understanding of reflexivity in relational processes and an acknowledgement that reflexivity is relational, tied to context, dynamic and perpetually iterative (Gilbert & Sliep, 2009). Inter-relational reflexivity created in the relational space of social action creates the conditions for transformative social action.

The interviews were not static in structure or purpose. A reflexive position was employed throughout the interview process using a variety of means. The following elements, which evolved through the research process, are discussed in detail: dynamic interview process,

dialogue between researchers, reflexivity of self-in-action (interviewer's reflexive journal), dialogue and interview with the interpreter, and reflexivity in the interview setting.

Dynamic interview process

The interview process was continually revised as we considered the type of interview approach to adopt. We began with a structured interview guide. In reviewing and reflecting on the first interview guide, it became clear that this approach would make the voice of interviewer/researcher overly dominant. The interviewee's voice, and by association important contextual information, would be silenced. In light of our ethical position (that reflexive practices should work in the direction of making that which is unseen visible and that which is silenced, heard), we altered our research process to create space for the interviewees' voices to be represented proportionately (Sliep, Weingarten, & Gilbert, 2004). The semi-structured interview guide had the potential to provide useful data in the overall study, so rather than abandoning it, we incorporated it as the first of three interviews with participants. The second interview was a narrative life-story interview. The interview process emerged from constant reflective discussion between the two researchers and the interpreter. The interviewer (TN) used the forty-minute drive from the city to the rural area where the interviews were conducted to reflect on imminent interviews. During the round trip journey between the interpreter's home and the interview venue, the interviewer and interpreter discussed the planned or completed interviews. On the return journey to the city the interviewer made a stop at a coffee shop in a nearby town to record reflections on the interviews and discussions with the interpreter.

Dialogue between researchers

One of the researchers (TN) conducted the interviews whilst the other (YS) acted as an ethical sounding board, intentionally uninvolved in the actual interviews but actively involved in an ongoing reflexive process with the interviewer. This determined the shape of the interview process. YS also negotiated entry into the community with all stakeholders and gave particular attention to the *Inkosi* (traditional leader/chief). At these meetings the *Inkosi* asserted his position of power by speaking in isiZulu. He also raised issues of concern about other researchers who had previously concluded research in the area without offering feedback to the community when the study was completed. YS took responsibility for bringing research findings to the community in an accessible format; the traditional leader agreed to take responsibility for dissemination of the details of the project amongst his *izinduna* (headmen). This is an example of negotiating accountability and responsibility.

Given our intention to deconstruct the influences of power from institutional structures and discourse we examined the influences of power which we, as researchers, were subject to. In addition, we examined the influences of power within the discourses of qualitative research that we were subjected to as African researchers. Consequently, we made a commitment to continually examine our ethical and methodological positions through a process of dialogical reflexivity. In defining the research question, we actively reflected and readjusted accordingly. Initially, our broad research question was based on concepts generally associated with volunteer identity. However, as the project progressed the question came to include contextually relevant aspects of identity in Zulu culture and the local socio-historical environment. For example the women in the home-based care volunteer group based their volunteerism on personal and communal identity precepts of women as mothers and women as caregivers. In Zulu culture becoming a mother is consistent with attaining status as an adult woman in the community. Older women are traditionally respected as mothers of the community (matriarchs). As our research

progressed it became evident that the mother identity in Zulu culture was related to the women's motivation and identity as volunteers. This was explored further (Naidu, 2011a).

The following example indicates that dialogue with a co-researcher can keep the interviewer oriented to the context within which interviewing is being conducted. Following a reflective discussion between the researchers about a series of interviews conducted in the field, YS suggested that community voices could be evoked and included in a more discernible way by asking the women what family members, friends and community members thought about their work. The women would also be encouraged to reflect on how their ideas about themselves and their work were influenced by being interviewed about it. Reflection on contextual evidence they offered, provided an authentic means to achieve this. Evidence from the interviews showed that volunteers' work was largely unrecognized or ignored in the community. There were traditionally and culturally based expectations that their role as women and mothers compelled them to care. However the women's personal life stories revealed the unseen aspects of their identities as ambitious, future-oriented, decisive, innovative, proactive and entrepreneurial. These qualities set them apart from those who did not volunteer. Through our discussions we realized that by creating the conditions for these hidden aspects of identity to be witnessed, through the voices of significant others and dialogical reflection on the content of the interviews, the women could realize the power behind the own voices. An extract from the interviewer's reflective journal offers some insight into how this influenced the interview process.

> The part of this identity that needs witnessing is the ambitious, future oriented, decisive, innovative, proactive and entrepreneurial attitude – to be developed in reflective interview. The structure of the interview process developed and was altered according to the data that emerged. At this stage the reflective interview needed to be expanded to explore:
>
> * How the HBCVs ideas about themselves changed through their involvement in home based care work.
> * How their ideas about their work and themselves were influenced by the interview process (the co-construction of a narrative identity?)
> * Whether they or others in their lives could bear testimony to the veiled aspects of their identity (the ambitious, future oriented, decisive, innovative, proactive and entrepreneurial attitude) that emerged as a undercurrent in the work and life stories
>
> TN Reflective Journal <u>01/10/2009 p17-18</u>

The third interview encouraged reflective dialogue about the content of the first two interviews and, most significantly, called upon the volunteers to reflect on the voices of the community and of significant others as they reflect on HBCV work.

Reflexivity of self-in-action (interviewer's reflective journal)

As illustrated above, a reflective journal and reflective poetry writing served to track the ethical positioning of the interviewer by ensuring constant involvement supported by reflection outside the actual interviews (Naidu, 2011b). Keeping a reflective journal represented introspection or reflexivity of self-in-action (Finlay, 2002; Gilbert & Sliep, 2009). This aspect of reflexivity is well known, widely practiced and recommended in qualitative research. It contributes significantly to validating the qualitative research process. After each interview, the interviewer made field and reflective notes addressing issues that were missed during the live interview. These issues were raised and discussed with the interpreter and addressed in future meetings with

the interviewees.

Dialogue and interview with the interpreter

The researchers' dialogue highlighted a journey of performance that went beyond the event of the interview alone. The interview was a dynamic course of interaction between all the parties (interviewer, interviewee and interpreter), each with particular intentions. The boundaries were flexible and permeable. Reflexive journal extracts illustrate this:

> Casper's [interpreter] translation is of a very high standard – she translated directly using the interviewee's "exact" words. Elizabeth [interviewee] seemed at ease with her and was clearly familiar with the process. My presence was sanctioned by Casper's or perhaps by the familiarity with researchers. My interview would have been more "bumpy" without the preliminary smoothing of the path.
>
> However, I still felt a little excluded from the process and therefore disempowered in tracking and following potential narrative leads. I wonder if it is possible to conduct narrative interviews with translation? The performance of the interview is certainly affected. How the interviewee positions herself is also influenced by her having to consider both the interviewer and interpreter as audience. Is the whole process too fragmented to contain a narrative …?
>
> TN Reflective Journal 24/04/2009 p. 2

Preconceptions on the part of the interviewer about how the process should unfold inhibited the interviewer's participation in the interview process. The realization that the interview process was dynamic and that holding on to such preconceptions would inhibit the process and ignore a noteworthy contributor led to active planned discussions with the interpreter.

> On the ride to S today, I briefed Casper (interpreter) in detail about what my intention is with the interviews, explaining that I was interested to hear the life stories of the women I would be interviewing today. I went on to explain my hypothesis about the two different types of interviews and the plan of piloting each style to assess which would be the most appropriate to generate the stories of home-based care volunteers. As usual, Casper listened intently and nodded knowingly. Her clarifying questions put me at ease that she understood my intentions. She expressed concern that we would get what we wanted with the life story style. I was happy to tell her that I was interested in whatever emerged and in the performativity aspect of the interviews.
>
> TN Reflective Journal 24/05/2009

Actively including the interpreter in the reflective process and acting on her insights enhanced the research process and the richness of the data elicited. This is supported by other scholars who have suggested that including interpreters in the debate on reflexivity and context generates valuable insight into the politics of location and identity, and contributes to the deconstruction of power in the research process. (Temple & Edwards, 2002; Temple, Edwards & Alexander, 2006; Gilbert & Sliep, 2009).

Reflexivity in the interview setting

Denzin (2001) argues that the interview is not a mirror of the real world or a window into the inner life of a person; rather, it is a miniature of the real world. "The interview is an active site where meaning is created and performed" (Denzin, 2001, p. 28). In introducing a third reflective interview, we presented the possibility for mutual collaboration in which the participant is enlisted as co-researcher. This practice acknowledges and applies participants' capacity to act as reflexive beings (Finlay, 2002). One of the interviewees mentioned that, to be a good home-based care volunteer one had to have "the mind of a mother." This metaphor was used reflexively as a generative metaphor to explore other interviewees' ideas about personal and group motivations and identity associations with their work (Barrett & Cooperrider, 1990; Naidu, 2011a).

> Gugu: yes that what it means, because when you are a mother you are like a chicken that protects its chicks. So if you are going to do this work you have to like that. You have to be like a chicken to the people you are caring for. When you arrive at the house they should feel that you have arrived, that you are going to protect them, they should feel warm in your presence.

Applying this metaphor in the reflexive interview seemed to have the dual effect of the interviewees' more in-depth realization of the nature and motivations of their work as well as creating a platform on which they were able to offer the interviewer a richer reflective picture of their experience. This represents an illustration of how performativity can create possibilities for constructing identity, subjectivity and agency where dominant discourses have blocked and complicated the visibility of marginalized voices.

Another interviewee commented that being able to talk about and reflect on her work and her own life story in such a way had led her to the realization that the performance was in itself beneficial. She expressed that she was inspired to use the method with the people that she visited.

> *Elisabeth*: Yes, there are things that I have thought about; there is a revival that I got from that personally as Elisabeth.
> *Interviewer*: What do you mean?
> *Elisabeth*: So the questions that you ask build me, and in some ways and they remind me as well of the life that we live here.
> *Interviewer*: What does that mean to be built?
> *Elisabeth*: It means that in terms of my personal story that I can go around telling people about where it all started and how it all came about like from my roots. So that for me is...now I am able to do that, so that is the process of being built.
> *Interviewer*: Is that important for you, Elisabeth?
> *Elisabeth*: It is and I saw it as a good thing to do and I think that it would be helpful for someone else as well if I sat down with them and asked them the same questions. I think that would clarify things for them as well.

These quotations are examples of positive performativity on a micro or interview level as a result of maintaining contextual reflexivity in the research process. Once insight and understanding are developed, decisions have to be made about the forms responsibility and accountability will take and these decisions must be translated into concrete actions. The HBCVs who participated in this study worked on a narrative theatre production, which was a method for communicating to the community. This feedback method had been agreed upon with the traditional leader. In this production the identity-based reflection initiated in the study and discussed in this article was taken a step further. The HBCVs performed a drama based on data and discussions. The drama was performed at a specially organized gathering of the community, researchers and government

officials responsible for AIDS care and support. This interaction has the potential to deepen understanding in and create opportunities to change attitude and behavior in both the HBCVs and the community members that witnessed the production (Sliep & Kezaabu-Kasimbazi, 2011).

Current position

Much of the discourse on qualitative methodology originates in the West; therefore, as South African researchers embarking on qualitative research in Africa, we are aware that this context carries with it some responsibilities. Amongst these responsibilities is the duty to maintain a constant awareness of the influence of context on emerging data. In order to keep context salient, ethics in practice (ethical reflexivity) and constant reflection on method (methodological reflexivity) must prevail. We labeled this practice 'contextual reflexivity. As far as we are aware, this article represents a new perspective in the literature by taking into consideration a specifically African perspective on reflexivity in context. Furthermore, we have offered some practical strategies and insights for keeping context in focus in an African setting.

In this article we showed how we created the space for HBCVs to acknowledge their legitimacy of voice and identity through social action inherent in a contextually reflexive interview process. This perspective emphasized the researcher's responsibility to maintain consistent methodological reflexivity and a focus on ethics in practice. Assuming a position that is contextually relevant creates the conditions for qualitative researchers to explore new dimensions and perspectives.

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Chapter 5

The social construction of identity in HIV/AIDS home-based care volunteers in rural KwaZulu-Natal, South Africa

The social construction of identity in HIV/AIDS home-based care volunteers in rural KwaZulu-Natal, South Africa

Thirusha Naidu*, Yvonne Sliep, Wenche Dageid

Abstract

Home-based care volunteer (HBCV) identity and how it is shaped was the main focus of the study. Fifteen HBCVs were interviewed about their work and personal life stories and then interviewed reflectively using a narrative interviewing style. Specific attention was paid to contextual meta-narratives and social field narratives in understanding the women's stories. Findings indicate that social field narratives of the women's stories were dominated by negative aspects of gender, poverty and socio-political factors. These were seen to coincide with the 'feminisation of responsibility' in this context effectively coercing the women into agency which manifested as their home-based care work. Meta-narratives influencing the women's lives were dominated by stories of communal motherhood, aspirations to service-oriented work and religious beliefs and commitment. The question of how it is possible for women who are seemingly constrained by oppressive narratives to voluntarily engage in community participation was answered in the women's personal life stories about being compassionate, hopeful, helpful and ambitious and having initiative. These characteristics collectively pointed to personal agency. Exploring connections between the different aspects of identity and context revealed that the women made sense of their community participation through their personal identities as strong and loving mothers. Connections between volunteer personal identity, agency and volunteer group identity were explored to make sense of the link between HBCV identity and volunteerism. The mother identity, encompassing personal agency (strength or power) and love (the meta-narrative of communal motherly love), was salient in influencing community participation of the group.

Keywords: HIV/AIDS care and support, volunteers, narratives, social construction of identity, context, agency

Résumé

L'identité des bénévoles qui procurent des soins à domicile (HBCV) et comment elle est façonnée était l'objectif principal de l'étude. Quinze HBCVs ont été interrogés sur leur travail et leur vie privée réflectivement à l'aide d'une entrevue de style. Une attention particulière a été accordée aux méta-récits contextuels et les récits sociaux de terrains dans la compréhension des histoires des femmes. Les résultats de la recherche indiquent que les récits sociaux de terrain de l'histoire des femmes ont été dominés par les aspects négatifs de genre, de la pauvreté et des facteurs socio-politiques. Ces derniers ont aussi coincidé avec 'la féminisation de la responsabilité' dans ce contexte contraignant les femmes dans des agences personnelles qui se manifestaient comme leur travail de soins à domicile. Les méta-récits influençant la vie des femmes étaient dominés par les histoires de maternité communale, les aspirations à un travail axé sur le service, les croyances religieuses et l'engagement. La question de savoir comment est-il possible pour les femmes qui sont apparemment contraints par des récits oppressifs à s'engager volontairement dans la participation communautaire a été répondue dans les histoires personnelles des femmes sur la compassion, l'espoir, l'aide, l'ambition et l'esprit d'initiative. Ces caractéristiques ont mis l'accent sur la responsabilité personnelle. En explorant les liens entres les différents aspects de l'identité et le contexte a révélé que les femmes donnaient sens à leur participation communautaire à travers leurs identités personnelles de mères fortes et aimantes. Les liens entre l'identité personnelle du volontaire, la responsabilité et l'identité du groupe de bénévoles ont été exploré afin de donner sens au lien entre l'identité HBCV et le volontarisme. L'identité maternelle, englobant l'initiative personnelle (la force ou la puissance) et de l'amour (récit narratif themeta de l'amour maternel communal était saillant en influençant la participation communautaire du groupe.

Mots clés: Soins et soutien du VIH/ SIDA, bénévoles, les récits, la construction de l'identité sociale, le contexte et la responsabilité

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Introduction

This article reports on an in-depth study into the contexts salient in the social construction of home-based care volunteer (HBCV) identity within a rural African context. Although volunteerism and volunteer identity have been extensively investigated in the West, there has been little or no research into volunteer identity and volunteerism in non-Western cultural environments. We focused specifically on the context of HBCVs who provide care and support for those infected and affected by HIV/AIDS. Home-based care volunteerism forms the mainstay of care initiatives available for HIV/AIDS sufferers and their families in Africa. The study followed an African-based approach to understanding African health-related issues. 'A cultural psychology perspective states that it is culture not biology that gives meaning to action by situating its underlying intentional states in an interpretative system' (Bruner 1991:34). The implication is that, in order to understand behaviour, motivation and intention, one has to do so in context.

Literature review and rationale for the study
Collectivism and individualism as a basis for understanding volunteer motivation

Volunteerism can, in its broadest sense, be defined as acts that are done on the basis of free choice or of one's own accord. Volunteerism has increased dramatically in the context of the HIV pandemic across Africa. Governments on the continent are ill-prepared and poorly resourced for the magnitude of care and support that is required. As a result, individuals and communities have responded by volunteering care and support services in areas of need, chiefly home-based care and support.

The social identity approach suggests that volunteers' interpretation of their personal identity as being consistent with the collective/group identity promotes internalisation of in-group norms, values and interests (Strumer, Simon & Loewy 2008). It is an approach that embraces all type of groups and is intended to be a general theory about inter- and intra-group behaviour. Social identity theory (SIT) sees group norms as expressing important aspects of group identity and group members are motivated to act consistently with them to attain a positive personal identity. Various psychological, economic and socio-political factors affect the nature of volunteering in different contexts (Tajfel & Turner 1986). Here we propose the norms of collectivism and individualism as the in-group norms that motivate individuals.

The constructs of individualism and collectivism proposed by Triandis (1995) have been useful in many contexts in the social sciences. People in collectivist cultures give precedence to group goals over personal and individual goals. They are likely to focus more on the context than on the content when making attributions, communicating and defining themselves as part of a group, giving less credence to internal than to external processes as determinants of social behaviour. People in collectivist cultures also define relationships with in-group members as communal, make more situational attributions and are more likely to be self-effacing. Collectivism and individualism are polythetic rather than dichotomous constructs encompassing a multitude

of cultural differences and variations but nevertheless seem to be important historically and cross-culturally. The four defining attributes of individualism and collectivism are (a) the definition of the self, which can emphasise personal or collective aspects or can be independent or interdependent; (b) personal goals that can have priority over in-group goals or vice versa; (c) the emphasis on exchange rather than communal relationships or the emphasis on rationality rather than relatedness; (d) the importance of attitudes and norms as determinants of social behaviour. Both individualism and collectivism may be *horizontal* (emphasising equality) or *vertical* (emphasising hierarchy) (Triandis 2001; Triandis & Gelfand 1998; Wang 2008).

African culture has been described as collectivist (Akande 2009; Mangena 2009; Mkhize 2004; Patel & Wilson 2004). This generalisation cannot be indiscriminately applied to all African communities and contexts, with urban contexts tending to be generally individualist even in traditionally collectivist contexts and the nature of collectivism and individualism being polythetic. Collectivist and individualist cultures may also be assessed on the vertical dimension (emphasising hierarchy) and on the horizontal dimension (emphasising equality) (Triandis & Gelfand 1998). The rural Zulu-speaking community at this study site can be described for the most part as traditionally and historically collectivist and vertical. Vertical collectivist groups see the self as different from others; there is communal sharing, authority ranking, low freedom and low equality and tendency to accept large differences in the relative status of men and women. Communalism of traditional societies with strong leaders is consistent with vertical collectivism. Traditional Zulu society has strict codes of conduct between different groups and is based on a hierarchical social system. Traditional leaders have significant power over community decision making and power at all levels of daily life (Masuku 2005).

Notably, research on volunteerism in individualist cultures places emphasis on examining personal motivation, personal values, personality traits, individual characteristics, individual benefits to the volunteer, psychological wellbeing and psychological commitment. Effective participation in volunteering is most likely to take place among the wealthiest, most educated members of a community (Borgonovi 2008). Research in individualist cultures suggests that volunteering has a positive effect on the mental health and wellbeing of volunteers (Borgonovi 2008; Crook, Weir, Willms & Egdorf 2006). Volunteers in individualist cultures are motivated to volunteer by virtue of their individual identity, the personal satisfaction they derive from their volunteer work, personal values and to some extent their expectation of others (Finkelstein, Penner & Brannick 2005; Ramirez-Valles 2003).

Evidence from collectivist cultures suggests that volunteering is viewed differently in these cultures. People might feel that they are obligated to volunteer because of socially constructed roles and spiritual beliefs (Akintola 2006; Songwathana 2001). In addition, informal helping behaviour may be seen as volunteering and more consistent with cultural practices within a particular culture (Patel & Wilson 2004; Ramirez-Valles & Brown 2003). This suggests that in predominantly collectivist cultures (such

as Asia, Latin America and Africa), the research focus should necessarily be different. Airhihenbuwa and De Witt Webster (2004) point out that in Africa, the values of the community and extended family have a major impact on the behaviour of the individual corresponding to the idea that in collectivist cultures, in-group needs have a greater influence on individual behaviour than in individualist cultures.

Volunteerism in AIDS care

Internationally, much attention has been given to research on volunteerism, specifically to topics such as the motivation to volunteer, stages in volunteer development, what promotes volunteer participation and persistence, volunteer role identity and collective identity (Davis, Hall & Meyer 2003; Grube & Piliavin 2000; Haski-Leventahl & Bargal 2008; Laverie & McDonald 2007; Planalp & Trost 2009; Strumer et al. 2008).

Rödlach (2009) observed that Zimbabwean HBCVs for people living with AIDS motivations included religious values; desire for prestige; empathy derived from witnessing the suffering caused by AIDS illness; the hope of securing care-giving support in the future; the hope of enlarging personal networks to include those with access to political and economic power; and the hope of receiving material benefits in the future. Rödlach (2009) noted that their concerns would be addressed by better integration with the national healthcare system at various levels as well as with community- and faith-based groups that could potentially stimulate positive commitment to care-giving. Glenton, Scheel, Pradhan, Lewin, Hodgins and Shrestha (2010) noted that female health volunteers in Nepal were motivated by a tradition of volunteering as moral behaviour and lack of faith in paid government workers and that context-specific incentives were most likely to result in low attrition and high performance. Maes, Shifferaw, Hadley and Tesfaye (2010) argue for the important issue of food insecurity among volunteer AIDS caregivers in Ethiopia, making the point that remunerating community health workers is a matter of the right to receive fair wages for one's labour and one which has implication for the understanding of social and economic costs and benefits of volunteerism. In a study on volunteer AIDS caregivers perceptions of rewards in a faith-based organisation in South Africa, Akintola (2010b) noted that volunteers experienced intrinsic and extrinsic rewards ranging from emotional and psychological self-growth to appreciation and recognition shown by patients and community members.

The South African government has acknowledged and is developing community-based care as the basis of palliative care for HIV patients (Campbell, Gibbs, Nair & Maimane 2009). Most research on home-based care in Africa has investigated the caregivers as a group and explored the burdensome, disempowered, gendered nature of the work. The women are usually related to their patients and are presented as oppressed and obligated to care for the sick. Seldom has a distinction been made between family caregivers and community volunteers who are not related to the patient. Minimal consideration has been given to the fact that there are women who volunteer for the work itself in addition to their personal and family obligations – an act that indicates initiative and choice to some degree. Moreover, there are many other women (and men) in this community who live under the same circumstances but do not volunteer. While volunteerism might be seen as a means of cheap labour that exploits impoverished people, especially women, it provides a method of identifying those who are willing to work and show the initiative to train and improve their skills base. Couching volunteerism as exploitation of the poor could obscure the impetus behind impoverished peoples' motivation to volunteer as well as opportunities for identifying community-initiated and supported development. The KwaZulu-Natal provincial government has recently embarked on a project identifying youth and HBCVs to be trained further to share their skills with others and be placed in formal government-supported ventures.

Rationale for the study

This study aimed to investigate the identity of women volunteers who provide home-based care and support to HIV/AIDS patients in the context of cultural and social capital networks within a rural community. An in-depth perspective of the social construction of identity in terms of group identity, role identity and personal identity and how these are related to community participation was taken. The study is a section of a larger project on the social capital around care and support in this community. Researchers in the study have established a relationship with the community and community organisations over time. Parts of the broader study include how study findings are disseminated to the community and implemented. The findings of this study are likely to be useful in informing recruitment, retention and motivation of home-based care and other community volunteers within community-based organisations and NGOs. Taking identity and personal motivations within a socio-culturally relevant context into consideration could contribute to increasing the interest in voluntary participation in home-based care by appealing to relevant socio-cultural identity and motivation factors in potential volunteers. Furthermore, the findings can be used to support current volunteers in ways that are relevant to their own motivation and personal goals.

Research methods

Study site

The community under study is situated approximately 40 km outside Durban, South Africa, and has a population of 12,285 (Statistics South Africa 2004). There is one clinic in the area, which provides a family planning service and primary health care, two community halls and four schools. Transport in the area comprises minibus taxis, as there is no municipally supported transport service. Only main roads are tarred and most homes are accessible on dirt roads and footpaths. Poverty and unemployment are extremely high in the community, with an average monthly income of between R500 and R2000 per household, and only 21% of community members have paid jobs. Most remunerative work can be obtained only outside of the community and many community members work away from home for extended periods ranging from days to months and years.

Ethical issues

Ethical clearance for the study was obtained from a university ethics committee. Informed consent was acquired from the interviewees to conduct the interviews after the interview process was

explained. Questions from the interviewees were addressed as fully and clearly as possible and interviewees could withdraw their participation at any time. Confidentiality of the interviewees was maintained by assuring them that their identity would be concealed in any presentation or publication of the data.

Study participants

The sample consisted of 15 women who were HBCV workers and belonged to a home-based care organisation called *Uthandolo-mama* (Love of the Mothers). The organisation was identified via its association with the overall study on care and support and social capital. The sample group of volunteers was identified through purposive and snowball sampling where individuals were referred by the group leader and a local community-based organ-isation. Participation was voluntary. The women were aged between 25 and 60 and had no formal employment. The partici-pants had all attended formal schooling and the highest grades completed varied from Grade 5 to Grade 12. None of the partici-pants had any formal training in nursing or care work, although three had experience caring for sick relatives. Of the group, all but four participants had participated in the informal employment sector as domestic workers or doing other types of 'piece jobs'. Nine of the women were married and all had one or more chil-dren. All the women spoke isiZulu as their first language and had some understanding of English. Most of the women were severely affected by the endemic poverty in the region. Of the group, nine participants received a small stipend of R500 per month, commonly known as 'soap money', which they used for transport to visit patients, attend monthly meetings and visit the clinic; calling ambulances, the clinic or other HBCVs for advice and support; and buying soap and other cleaning materials and sometimes food needed to care for the patients. Others received no money and sometimes used their own money or were given money by family members and neighbours to assist with transport, food and care supplies when care packages did not arrive.

The organisation involved in the study could best be described as a secular organisation as it had no formal association as a group with any church or other religious group. The organisation relied on material support provided by local government in the form of care packs (kits), although the latter was at best erratic. They did not enjoy regular association with any particular donor although they received intermittent support from the local community-based group who sponsored their garden project and worked on developing a formal management struc-ture, processes and record keeping so that the organisation could appeal for donor funding in the future. In the past, some members had been sponsored by corporate outreach programmes to attend home-based training. However, many of these women had left for work in formal care-giving positions. New members of the group had no training in home-based care and were instructed by existing members.

Data-collection method and procedure

The study employed a narrative qualitative research design (Creswell 2007). Data were collected through a series of narrative interviews conducted by the first author. Narrative interviewing (NI) is an approach that encourages and stimulates an interviewee to tell stories about significant events or experiences in her life and social context. The basic idea of NI is to reconstruct social events from the perspective of informants as directly as possible. We used a combination of the psychological approach in which the story is analysed in terms of internal thoughts and motivations, and a more biographical approach which attends to the person in relation to society and takes into account the influences of gender, class and 'family beginnings' (Denzin 1989:17). NI is motivated by a critique of the traditional question–response schema of traditional interviews in which the interviewer controls the flow of the interview by selecting the theme and the topics, arranging the questions and phrasing the questions in his or her language. NI directs the interviewer to avoid pre-structuring the interview. The interviewer is encouraged to use an everyday communication favouring story-telling and listening (Jovchelovitch and Bauer 2000).

The interviews were conducted in isiZulu and translated in situ by a first-language speaker fluent in English. Interviews were audio-taped and transcribed for analysis. Translations were ver-ified during transcription by a different first-language isiZulu speaker fluent in English. Each of the 15 HBCVs was inter-viewed three times, giving a total of 45 interviews. In the first interview, a constructivist interview style was employed. Ques-tions focused on the nature of the work and the social networks and resources that the HBCVs had access to and that supported their work. The HBCVs were encouraged to speak for as long and as freely as they preferred. The second interview employed a naturalistic approach and focused on the life story of the HBCVs. A generative question was asked to prompt the HBCV to tell her life story. Probing questions were asked once a coda (natural end to the interview) was indicated by the inter-viewee. The third interview was a reflective interview during which the HBCVs were encouraged to reflect on their work stories, life stories and the interview process. This interview was based on a set of reflective questions developed from the results of the first and second interviews. Connections between the different stories were explored. The NI approach was adopted throughout the interview process. An everyday inter-action style was used to encourage the interviewees to enter a storytelling/narrative mode to illustrate their responses to ques-tions. Potential stimulus questions were prepared ahead of the first interview; however, they were not rigidly adhered to and a conversational style was preferred. Interview 2 was initiated with the statement 'Tell me about your life story. Start wherever you like even as far back as you can remember including the parts about what lead you to become a volunteer'. The three-stage interview process was advantageous for a number of reasons. Firstly, it allowed for an action research approach to the interview process where information from the first interview was revisited and influenced the structure and content of the second and third interviews. Secondly, it facilitated the establish-ment of rapport in the interviewer, interviewee and translator triad allowing for stories to be built and cross-referenced across interviews, and thirdly it allowed the interviewees space and time across and between interviewees to become familiar and comfortable with the narrative interview style. The latter was an important issue as the women had been interviewed by other researchers in the overall project and other studies

previously and were accustomed to the traditional question and answer interview style.

Data analysis

The overall approach to analysis used was narrative analysis (Riessman & Speedy 2008). The first phase of analysis involved listening, making notes, reflecting and reading before and during the interview process across all interviews. The researcher/interviewer (first author) fostered a reflective process by keeping a reflective journal and through reflective conversations with the in situ translator and co-researchers (second and third authors). Relevant themes were identified based on reviewing the data in relation to dominant socio-cultural and historical discourses in South Africa, personal experience and relevant themes in the literature.

The second phase involved reading interview transcripts for context and incorporating narrative analysis strategies (Fraser 2004; Riessman & Speedy 2008; Zilber, Tuval-Masiach & Lieblich 2008). Two dimensions of context were considered central. The first of these, *meta-narratives*, are tacit (mostly unquestioned) precepts that exist in the communities or groups influencing ways of life, living and being a person. These stories tell how life should be lived and can be seen as cultural canons (Bruner 1991). The second was *social field narratives*, and refers to the socio-historical context within which a life was or is being lived and the larger social order, defined by both spatial (institutions and organisations) and temporal (historical events and figures) elements. Themes pertaining to socio-political, personal, cultural and traditional contexts alluded to by interviewees were highlighted and categorised according to the social field and meta-narrative aspects of context that they represented. Themes were based on relevant literature and representative indications in the women's narratives.

In phase 3, the interview transcripts were read for themes consistent with personal identity, volunteer role identity and group identity. Personal identity stories were those where the women told about their personalities and personal lives. Volunteer role identity stories were those where they told about themselves in their role as volunteers. Group identity narratives referred to stories about the identity of the volunteer group.

During phase 4, the data were coded and analysed in greater depth using NVIVO8 qualitative data-analysis software. During this process, further themes emerged and were coded. Immersion in the data during the coding process also alerted the researcher to the existence of 'meta-themes'. These can be described as themes that did not fall into any of the other categories but were consistently mentioned by the interviewees, e.g. love and strength. These meta-themes encompassed more than one theme. The emergence of these meta-themes was considered important for the next phase of analysis, which entailed making relevant connections between the data gathered. Throughout these first four phases, the authors crosschecked the relevance of the coding system and allocation of data to the various themes and narrative dimensions (e.g. meta-narrative, social field narrative or personal narrative).

In phase 5, NVIVO8 software was used to reflexively connect personal, role and group identity themes in the data in the light of context (social field and meta-narratives). Data were connected reflexively with field notes, reflexive journals and relevant literature to facilitate theory building around the social construction of HBCV identity. Co-researchers (first, second and third authors) held discussions intermittently throughout the analysis process to verify connections and expand possibilities for analysis.

Findings
Contextual narratives
Meta-narratives

The following meta-narrative themes were identified. They are presented in descending order of frequency.

(1) Motherhood
(2) Aspiring to service-oriented work
(3) Religious commitment and belief

Motherhood was a meta-narrative that featured strongly in the women's stories. They spoke of a mother's role in the community and stated that mothers or women that were considered mothers of the community (*omama*) should be treated with dignity and respect. Motherhood is seen as a desired status in Zulu culture and is one that is revered. Girls are expected to participate in childcare from a young age and a woman's position and status in the home of her husband is only solidified on her becoming a mother (Masuku 2005). Women of childbearing age, especially those that have children, are afforded status in the community and recognised within the group of mothers. Inherent in the women's idea of effective motherhood was the idea of strength or power associated with the role of mothering. Power was afforded by the traditional status associated with motherhood and multiple practical skills required in being a mother. This is illustrated in the following quote.

Interviewer: What does it mean to be a mother in a community? What do they stand for in the community?

Helen: I think it is important that it is Uthandolomama, because only mothers could do this, males could not do this, that is why it could not have been called Love of mothers and fathers. I don't see any men doing what these women do.

Interviewer: So does the community think that? Does the community think it is the fact that the name is Uthandolomama that makes it work, that a mother is a caregiver?

Helen: I think that the community can see it because they can see things that women are doing in this community, because it is the mothers that get up and do things in this community.

Other associations with the meta-narrative of motherhood included care, forgiveness, unconditional love and being someone who is compassionate and acts on compassion.

Mathilda: I think it is trying to show that mothers are the ones who show love for people. They are the ones who embrace us

when we have done wrong, they are the ones who are always there.

More recently, the power and status of mothers have come under threat as families crumble due to members leaving their homes to seek work and due to less investment in traditional values. In the past, the mothers (*omama*) in the community would have commanded respect by virtue of their status as mothers, but now they are relegated to maintain ancestral homes and care for the very young, the infirm and the aged.

Most of the women spoke of their *aspirations for service-oriented work*. They wanted to become teachers, nurses, social workers or police officers. In the past, black South Africans were prohibited by apartheid laws from obtaining higher education. Faith-based organisations and other NGOs offered vocational training in service-oriented professions. The highest possible aspiration for many black women in the years of apartheid was to become a nurse, teacher or social worker. Further, cultural precepts of care and civil service ensured that people who entered into these professions were admired in their communities. What was once set as a limit by apartheid laws slowly became an aspiration for many and one that was still evident in the narratives of the HBCVs interviewed.

Edna: I would say that it was something that I had even before I lived with my grandmother. Even when I was in standard one and we were talking about what we wanted to be when we grow up I always wanted to be a nurse and people asked 'so what would you do?' and I would tell them this is how I would look after my patients, this is how I would make the bed, I would wash them like this and give them injections like this. So I think that was even before I started caring for my grandmother.

Interviewer: so it must be quiet something that you have the chance to do that kind of work now?

Edna: yes even now I still have that, I dream about it now but not for myself because I didn't have that kind of education. And I have a child who has finished matric and I encourage her to become a nurse and she is like 'why do you keep pushing me in that direction because I am scared of sores and all that stuff?' I still want her to be a nurse because I didn't get the opportunity.

Many were motivated by their *religious commitment and beliefs* to care for others. The ideas that if one cared for others one would be rewarded and that strong faith would provide support through difficult times are strongly rooted in Christian religious doctrine. There is a worldwide trend in the positive association between religious commitment, faith-based organisations and volunteerism. Faith-based volunteerism represents one of the dominant motivations to volunteer in AIDS care work in this region (Akintola 2010a). Volunteers' comments highlighted community values espoused by religious teaching.

Nandi: And for us – people who are religious – I really think sometimes that God really tempted us when He said, 'Love

your neighbour as you love yourself'. Because some neighbours are really difficult to love, but you still have to be patient with them.

Olwethu: So I think that seriously the listening to other people and having faith in God help because I think with all the events of my life, if all those things happened at a time when I did not have a relationship with God, did not know God, things might have been really different.

Social field narratives

The following social field narratives were identified. They are presented in descending order of frequency (as reported by the women).

(1) Gender
(2) Lost educational opportunities
(3) Poverty
(4) Socio-political history

In addition to being identified as a theme, *lost educational opportunities* was also mentioned in relation to all of the other themes.

The participants' *gender* narratives were constructed through women's lives in relation to men in the community. Pregnancy, marriage and being a girl child were categorised within gender. The women's stories told of the absence of men literally and figuratively in their lives, either the physical absence through death or their absence as a result of polygamy.

Gugu:. . . And also it is the mothers who head the homes and there are not fathers for different reasons.

The women seemed to conduct their lives without factoring in the role of men. The traditional responsibilities of men in the community as hunting, warring and being responsible for cattle were all but obsolete. Women's traditional roles of caring for the family and taking care of gardens, sweeping, making beer and fetching water (Masuku 2005) continued to be a regular requirement for life in the area. The women related the absence of men in their role as both daughters and wives/partners. When men did feature in the stories, it was as absent fathers or as delinquent providers.

Jabu: I think that it is very important that there are mothers like us in the community who can do this kind of work, like there are these boys who live like orphans, because their mother died and their father lives on the other side of the village with another woman. So he is never there, I have to step up and take the role. Let all be parents to these children, because you can see that their father is not around. So I think that is very important thing to do, these children do not qualify for my programme, because they are not orphans, But since their father is not caring for them they might as well be, so I have to do this as a personal case, not part of my work. I mean if a child doesn't have a mother he is as good as an orphan, because the father will

almost always go after another woman and forget about the child.

When marriage was referred to, it was presented as leading to more difficulties in the women's lives. While marriage raised the women's status in the community (Masuku 2005), it placed more pressure in terms of work and responsibilities and severely restricted their independence and autonomy. In some cases, the women lived in extended families and their in-laws placed restrictions on them.

Cynthia: So I did my subjects bit by bit and then in the end I had to come back again and I finished the last subjects that I did in L, and that is where I got my matric. I got my results and I had passed but then I got married and then in my marriage I experienced oppression from the family. So I got married and I thought about going back to college but there was no one to talk to about that. And my husband said that my results were very bad and they wouldn't take me anyway, but I think he didn't want me to be educated like him. He didn't want me to be on his level.

Some participants, however, stated that they received encouragement from their husbands, who were supportive of their care work. However, it would seem that in these cases the possibility of a stipend which would supplement family income stimulated this.

Edna: Then I would go home and say to my husband 'You know I am sick of this I don't want to . . .' And he would say 'No just hold on, it might be . . . it will get better.' So I am holding on and I am hoping that if I get there then I will get paid and if there is more of this increment then I will also . . . ahh . . . benefit from that.

Evident in the women's stories of care work were *ideas about the role of men*. There was little expectation from the women that the men should participate in care work. It was explicitly mentioned that men were inept caregivers. In their descriptions of the work, there was the understanding that it was the kind of work that was best done by women. This is consistent with the cultural canons of gender roles inherent in Zulu culture. Women are responsible for caring and there should be no expectation that men should participate (Masuku 2005).

Gugu: Yes, I would say that it is the woman and if there is someone who is sick it is the mother who gets up and say, 'What is happening to the child?' So they are the ones who will respond first. It is not the fathers, the boys or the children, but it is the mothers who go see what is happening. So by the time the news spreads, it has already got to the mothers and then they go to the fathers if there is a really big problem and they say, 'Is there anything that you can do to help?'

Marriage is regarded as socially desirable within the Zulu culture. Traditionally, a person is not recognised as an adult person until marriage (Masuku 2005; Rudwick 2008). Most of the women participating in this study were married and related the stories of

their betrothals and marriages as part of their life stories. The idea of marriage or the aspiration to marry was seen as desirable, but marriage was not always presented as a desirable state.

Jabu: So I've had some challenges when my husband was having affairs and the children could see that and sometimes he would start a fight in front of them. I mean I asked him if we needed to have words we must go in the bedroom away from the children because when it happens in front of the children then the children can say, 'That's the one who started it; that's the one in the wrong'. And they take sides . . .

How the women viewed men and their relationships with men echoed the meta-narrative characteristic in South Africa, where relationships between the sexes, especially in rural areas, are paternalistic and permeated with the wider discourses of violence (Outwater, Abrahams & Campbell 2005).

In their stories, the women referred to *poverty* as significant. They had grown up in poor environments and as a result had to struggle to survive. Many had to leave school at an early age and missed educational opportunities that would have allowed them to improve their lives. They were also surrounded by poverty in their own lives currently and had concerns about feeding and educating their children and improving their own lives. The women were keenly aware of the effects of the poverty and that while they were considered poor by the economic standards of the country, the people they cared for were poorer still.

Asanda: . . . poverty and growing up poor, I think if one doesn't know that kind of suffering then they won't develop this kind of compassion of wanting to help people who are struggling. You cannot go through that and still look at someone suffering and not want to help them, and [what] other people do not realise is that by helping other people you might find that you also get helped in other ways, in more ways than you ever thought.

The *socio-political history* of the country has affected the trajectory of these women's lives.

The women spoke of how the political unrest of the late 1980s and early 1990s interrupted their lives. They related experiences where they had to leave the area to avoid persecution, where families were persecuted and they were attacked or assisted others that were attacked. Migrant labour had also affected the structure of families and many related stories of having grown up without a parent.

Bongi: so I went to school, I went to H to do my standard 9 and 10, but in 1989 I got a call while I was there and I umm/I got a message that it was urgent I was needed at home it was about my mother in-law/so I came, when I got to Pinetown I thought I should go my husband's work place to hear what this is all about, but then I decided to come here at home, but when I got there I found out that my husband had been shot and had died. So I stayed and he was buried, but then it was just . . . there was a lot of violence around that time and it was hard . . . if something like that had happened to you it was hard to relax, because there

was still a lot of violence going on around . . .

Jabu: We grew up with my grandmother. So my mother was a domestic. She didn't live at home. We used to see our mothers once a month when they brought groceries. We would wake up in the morning go to school. She really wanted us to get an education and she would tell about her own life. When she was raising our mothers her husband would was in J at work that she would sit and wait for him.

Stories of *lost educational opportunities* were dominant and all the women mentioned this in their personal narratives. The women attributed their being unable to complete their education to poverty, being disadvantaged as girl children and the socio-political situation in South Africa during their formative years. Political violence had disrupted many of these women's educational careers. All expressed the wish that they had continued school and spoke of ambitions that they had that had been frustrated by lack of education. The reasons for not being able to continue with their education included having no money for schooling because there was no income in the house, having to look after younger siblings, caring for a sick relative, political unrest, becoming pregnant and getting married. Many expressed the hope that they may be able to realise their dreams for self-improvement through their home-based care volunteerism. Here a woman talked about her industriousness and her continued hopes to improve her education and encourage her children to be educated. She poetically described education as 'the bread of today'.

Gugu: I live with my mother in-law and she is an old person and she asks, 'You keep going to these interviews. Are these interviews of yours promising, to go somewhere on particular doors and knock on your behalf? Because when you cry in mass you are bound to be heard'. And I think that if there was more money then things would progress and the children could study further, [] The bread of today is education, not money. So that means a lot of things would improve.

These multiple intersecting oppressions of gender disadvantage, poverty and socio-political history are consistent with that of the wider socioeconomic context of South Africa. This is clearly the dominant narrative of the HBCVs' stories. A question remains at this point: How is it possible that women who are seemingly constrained by these oppressive narratives are able to voluntarily engage in community participation? An indication lies in the personal, role and group identity narratives of the HBCVs. These alternative narratives present stories of hope, courage, strength, compassion and personal agency.

Personal life story narratives

The following themes were identified within personal life story narratives. The stories that the women told about their lives reflected their unique personal conceptualisation of self. The narrative themes are presented in descending order of frequency.

(1) Compassionate doer
(2) Hopeful helper
(3) Natural helper
(4) Ambitious initiator
(5) Emotional/constitutional resilience
(6) Socialiser

The *compassionate doer* encompassed the elements of having love for people and acting upon it. They have seen the suffering of the people and have taken the initiative to do something about it. While there are many people in the community that feel sympathy for those who are suffering, the compassionate doers were represented as acting on compassionate feelings. They would usually help neighbours and family members and have realised that helping is valuable and needed.

Interviewer: What makes you someone that wants to help someone?

Asanda: . . . compassion for other people. It seems people can feel it, because when you are sitting at home and someone rushes in because someone has been stabbed and you get up and you leave everything and you rush to their home and you organise transport for them . . .

Interviewer: Are there people like you in this community or did it start at some point – do you know?

Asanda: Some people do have the passion, some people don't, some people do have it, but they don't want to get up and act on that. So they will be talking about it and asking, 'Did you hear about this happening?', and you can see that they do feel sorry and they are sad about it, but they don't want to do anything about it. Some people have it, but they don't want to get up and do something, but they want to give something, that is how they help in a situation like that. Some people don't want to take action, because I ask them to come and they keep saying, 'You are doing such beautiful work', then I say come and we will do it together and they say, 'No, we cannot do what you are doing'.

The *hopeful helper* is the person who had joined the group of HBCVs in the hope that that it would lead to gainful employment. Some hoped that the stipend would supplement the family income, while others hoped that a portion of the stipend could be used to further their personal goals. Others in this category hoped that the volunteer work would lead to formal work as a caregiver in an established community care facility. Still others hoped that their help would lead to development in the community as more resources for HBCVs and patients were allocated by government.

Cynthia: My dream was to work in a hospital, but then I realised that I cannot be a nurse without matric. So this year I registered for ABET, but I haven't been committed to it. Like I would go when I felt like it and wouldn't when I didn't feel like it. But now I know that I really have to apply myself if I still want to reach my goal.

The characteristic of the *natural helper* also came to the fore. The women spoke of a natural predisposition they had to help others, which was evident from an early age.

Evident in the life stories were other aspects of identity, such as women who were *ambitious initiators*, future-oriented, decisive,

innovative and proactive and had an entrepreneurial attitude. Within the life stories were personal narratives that illustrated that these aspects of the women's identity go back as far as childhood. The lives of the people they cared for were severely affected by poverty, which the women were witness to on a daily basis. They made efforts to alleviate the worst effects of this by supplementing the patients' food with their own and using their own money for transport to government offices to apply for grants and pensions. In the following excerpt, the HBCV describes almost all of these traits.

> Gugu: I would say that I am a hardworking person. [...] I wake up at half past five in the morning and my children catch a taxi from the bus stop at about half past six and by the time they are gone I am already in the garden watering or doing whatever needs to be done. And that is before go out to households. As an organisation we have our own garden and having our own garden also means that we can share with other people whose situations I know are bad ...

Another woman told of how she had started a business to improve her situation. She wanted to be independent and self-reliant.

> Dudu: My problem is that I don't like asking for things, so when I ask and you tell me that you don't have the money it hurts, so I decided that well instead of asking and getting disappointed I should make my own money; that solved the problem.

An important aspect that was spoken about was having *emotional/constitutional resilience.*

This aspect refers to the ability to tolerate sometimes repulsive tasks involved in caring for the ill as well as having the emotional resilience to deal with death and dying on a daily basis.

> Irene: You must be very patient and you must not be easily disgusted, because there are a lot of things that people do sometimes, they cough and they have to cough up stuff and you can get a bucket full of these things that the person has coughed up. So if you are the kind of person that gets disgusted easily that means that you will never eat again.

Socialising was represented by the women's personal narratives of care for others. They talked about their love for people and the community in general. They had communal gardens and participated in *stockvels* within the group. They provided social support to each other by having personal friendships within the organisation. In these friendships, emotional support and advice about work and family were given.

Various personal influences shaped and nurtured these personal identity narratives. Mostly, these consisted of significant people in their lives who had helped mould and reinforce aspects of the care-giving identity. One of the volunteers described how her son commented on her strength in coping with a difficult marital relationship. Another young volunteer told of her relationship with an older female friend who provided support and encouragement for her work. Two women attributed their

volunteer care-giving to the support and encouragement of their husbands. Yet another woman remembered her mother's role as a helper and a caregiver in the community, which had inspired her own volunteer care-giving.

Discussion

Elucidation of the context provided the foundation for the understanding of the connections between the role/group identity of the HBCVs and their personal identity (Fig. 1). The examination of the context also provided insight into how the women in this study made sense of their volunteering and created meaning and purpose in their lives through volunteering (Naidu & Sliep 2011). A careful questioning process during the reflective interview (third series of interviews) uncovered the connections between the group identity, volunteer role identity and personal identity of the volunteers. In this discussion, we aim to render the different aspects of the HBCV identity explicit. The examination of HBCV identity represents a new direction in research in the area of home-based care. Most authors have focused their attention on examining various dimensions of the burden of care (Akintola 2010b). More recently, some authors have explored other areas such the needs, fears and motivations of HBCVs (de Saxe-Zerden, Zerden & Billinghurst 2006); human rights issues associated with volunteer care-giving (Kang'ethe 2010); how poverty and food insecurity impacts on caregiver well-being (Maes *et al.* 2010) and the perceptions of rewards among volunteers working in home-based care setting (Akintola 2010b).

In Fig. 1, we illustrate the relationship between the personal identity of mother and the group identity of the home-based volunteer of the particular group in this study in their particular context. Agency, mother and HBCV identity were the core identity elements of this group. We argue that agency is constructed on a contextual level by the social field narratives of poverty, gender, missed educational opportunities and the socio-political history of South Africa. Notably, all the women spoke with regret of their missed educational opportunities. They attributed their missed educational opportunities to marriage, pregnancy, being a girl child (gender), poverty and to the socio-political situation during their formative years. This is not an unusual set of circumstances for this cohort of women and their peers, as it is well documented that rural women in South African bear the brunt of gender, economic and socio-political oppression (Antonopoulos & Toay 2009; Coovadia, Jewkes, Barron, Sanders & McIntyre 2009). This set of circumstances has been implicated as contributing to the 'feminisation of poverty'. More recently, it has been argued that a more representative term is the 'feminisation of responsibility'. The latter describes a social context in which poverty, a lack of education, rural dwelling, a large household and the absence of men (due to death, illness, abandonment and migration) collude to create the conditions for poor, female-headed households to exist or for women to take increasing responsibility for financial and social well-being in the home and community (Chant 2008). A situation that might be construed as coerced agency.
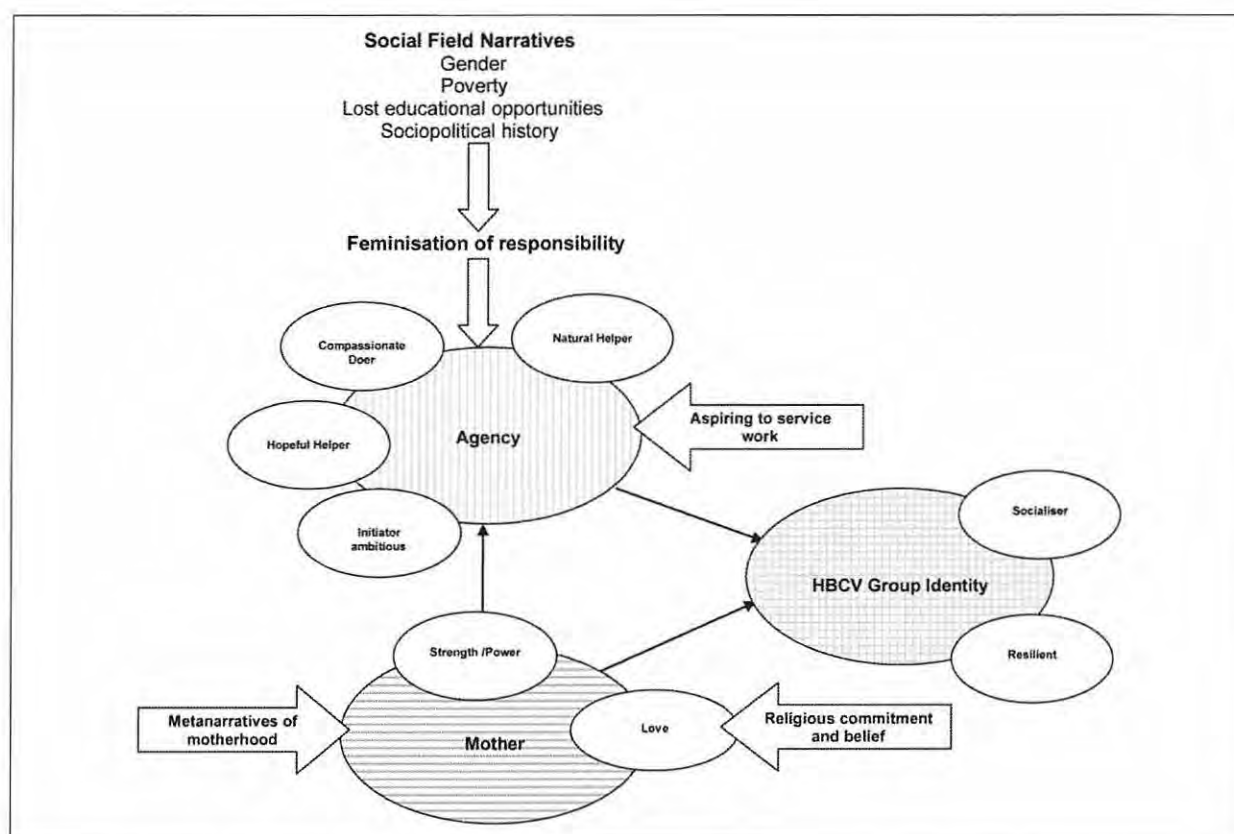
Fig. 1. Identity connections.

The HBCVs present themselves as having personal agency through acting on their compassion for others (compassionate doer), seeing their helping as a path to self- and/or community advancement (hopeful helper), being natural helpers in their personal lives and displaying initiative for themselves and others (ambitious initiator). The contextual meta-narrative 'aspiring to service-oriented work' supports agency in a contextually consistent form as it allows the women to have personal aspirations for self-improvement that are consistent with their personal identity and conform to cultural meta-narratives of women as mothers and caregivers.

The identity element of 'mother' was the most prominent. According to the women's narratives, the 'loving mother' role required one to multitask, be emotionally supportive, carefully mediate in family matters and be tactful and respectful of the rights of others, even those who are gravely ill. This was strongly influenced by communal meta-narratives of motherhood in the community as evident in the HBCVs' talk. Prominent in the women's stories was the contextual meta-narrative of motherhood. Mothers were represented as caring, nurturing, forgiving, protective and loving. They took initiative and make decisions for the best interests of people in their care. Mothers were seen as having power and agency as women by virtue of these communal meta-narratives. The dominant elements of the mother's role in this context were 'love' and 'strength/power'. The meta-narrative of 'religious commitment and belief' was associated with love, strength patience and

endurance. It is likely that this meta-narrative will have more and stronger reference points in the narratives of a faith-based group.

The group identity of HBCV was supported by two essential elements. These were, firstly, being someone that loved and care for people in general (socialiser) and, secondly, someone who was able to cope with difficult physical and emotional situations (resilience). The women specified that in order to fulfil the role of an HBCV, one had to have qualities that were consistent with a strong and loving mother, demonstrate personal agency and be interested in others (socialiser), but is also able to tolerate or endure the challenging physical and emotional situations encountered in home-based care (resilience).

Connections between agency, personal identity and group (HBCV) identity

The element of identity that connected agency and mothering was strength or power. Group members described their volunteer identity as having to have the 'mind of a mother' (*umqondo kamama*). Thus, they saw the role of an HBCV as requiring the love of a mother, the mind of a mother and strength or power (personal agency) as well as the agency encompassed by being a compassionate doer, hopeful helper, be an initiator and ambitious and a natural helper. All the women interviewed ascribed to and supported this as the overall group identity.

The following excerpt illustrates this:

Interviewer: If you had to tell someone that wanted to be a home-based carer what kind of qualities is required, what kind of person one needs to be, what would you say?

Olwethu: I mean people ask that question all the time. [...] In the organisation when someone wants to come and start to work with us we [...] sit them down and say, 'This work requires someone who has love, someone who can love people, it requires someone who can persevere. [...] Not someone who will say', 'No, not me, I'm not going to do that'. Someone who even when things get really tough [...] will speak the truth to other people, who can be honest with people, tell them in very constructive ways. Even if someone is sick that they can tell them the truth but still in a compassionate way so that the person can get stronger again. Someone who is courageous as well.

Interviewer: Can anyone be a home-based care worker?

Olwethu: So people try, some people will see other people doing it but [...] some of them just fail.

Interviewer: Some people, like some of your colleagues that we spoke to, said that it requires the mind of a mother. What do you think?

Olwethu: I think that my colleagues should have been more specific. It needs the mind of a strong mother. Mothers can have challenges of the home. Some people run away. Some mothers run away from home. So what I think it meant was that like you see that the mothers manage the home. They hold everything together in a home and that requires a lot of strength and I think that is what they meant. But I would have said the mind of a strong mother.

The volunteers' idea that strong, loving mothers were required for volunteering was the basis for naming the group *Uthandolomama.*

The identity elements of a compassionate doer, one who has hope for self- and community improvement (hopeful helper), a natural helper and a person with ambition and initiative, converge to define agency for volunteerism in this context. All of the latter elements are common to volunteer identity in general. Volunteers in most cases have a lifelong history of being helpful, are compassionate, take initiative and usually expect material, social, community, personal or emotional improvement from volunteering (Finkelstein *et al.* 2005). HBCVs in an African study experienced intrinsic rewards such as patience, love and feeling liked and needed. Acquiring skills, enjoying appreciation and giving pleasure to community members and patients were listed as extrinsically rewarding as volunteers in the same study (Akintola 2010b). Volunteering is evident in both collectivist and individualist cultures. However, volunteering tends to predominate among individuals that are more focused on others than is the general norm (allocentrics). They tend to be more cooperative and make relationships more intimate than idiocentrics who are

more self-oriented. On the basis of their personal histories as natural helpers and compassionate doers, the women in this group can be described as allocentric. People who are allocentric in collectivist cultures tend to be the most co-operative (Triandis 2001).

Also evident from the above extract and the one below is how the women make positive role identity associations with home-based care volunteerism. Invoking the Zulu cultural collectivist precepts of motherhood, *Uthandolomama* motivates women to work using skills they already have or are expected to have, as women and mothers. The fact that they would do this kind of work in their own homes with no payment could be what makes it possible for them to agree to work initially without payment.

Edna : How Uthandolomama is different from other organisations, is that we work ...I mean we work with other people, like we do good work in the community. When we get there, there is no one to help the sick person, we help them in every possible way, we wash them and we clean them, so that is how we are different from other organisations.

Strengthening in-group associations through comparison with outgroups

The positive identity associations of personal agency and the strong loving mother identity along with the role identity of an HBCV were reinforced through negative judgements about outgroups. The HBCVs described their work as being 'hands-on', while the community health workers 'only counselled'. Unloving mothers were disgusted by their children's illnesses and abandoned them to the volunteers, while women who were HBCVs were strong mothers, resilient and inspired by love. Men were seen as incapable of caring and usually causing more problems, while they as women were seen as natural caregivers. In a study by (Dworzanowski-Venter 2008; Dworzanowski-Venter & Smit, 2008) conducted in rural and urban care sites in South Africa, women were considered naturally emotionally fit to perform care despite men and women carers performing emotional labour techniques. Stigmatising male participation in care-giving perpetuates societal gender binary views by labelling care work as feminised (Dworzanowski-Venter 2008; Dworzanowski-Venter & Smit 2008). Campbell, Foulis, Maimane and Sibiya (2005) noted that stigma can serve as an effective form of 'social psychological policing', by punishing the breach of unequal power relations of gender, generation and ethnicity. Positive associations and negative judgements are simultaneously reinforced to maintain the status quo or discourage transgression of social conventions, norms or expectations.

Self-categorisation or self-interpretation processes are important in regulating social behaviour. An important distinction is made between personal identity and social or group identity (group membership). According to the social identity approach, self-interpretation in terms of group identity determines internalisation of in-group norms, values and interests. Group norms, values and interests are assimilated in the self and guide behaviour. The HBCVs displayed a strong sense of personal identity with regard to personal agency (personal identity narratives)

and mothering (meta-narratives). This aligned with the group identity of loving mothers reinforced group behaviour (community participation). Community participation is based on congruence among all three aspects of identity. This finding is consistent with that of Ramirez-Valles (2003), who noted that recruitment and participation in community work among women in Mexico were based on frame alignment of personal identity with group identity. Further support for this phenomenon is evident in a church-based home-based care group in Swaziland where religious identity, leadership and scriptural ethos emerged as part of HIV/AIDS care and demonstrated the synergies of tangible and intangible religious health assets (Root & van Wyngaard 2011).

The pivotal issue of gender in the area of HIV/AIDS globally and in South Africa in particular is one that warrants substantial and explicit consideration. Consequently, we chose to address gender and agency as issues for this particular group of women in a separate paper. While it goes beyond the scope of this paper to deepen this discussion, it is worth mentioning that the feminisation of HIV and AIDS on a biological and social level, in collusion with the feminisation of poverty, undermines the status and opportunities of women (Higgins, Hoffman & Dworkin 2010). Despite increasing support for the view that female-headed households are not necessarily poor, it has been noted that large household size, rural residence and lack of education, as is typical of the households of the HBCVs and their community, account for greater household poverty (Chant 2008).

A critique of this study might point to an apparent disregard or cursory treatment of the role of men. The role of men would need to be studied more fully but at this stage we offer three possible reasons for this notion. Firstly, where men were spontaneously mentioned, they were presented in a predominantly negative light. An SIT approach offers the idea that a negative assessment of outgroups enhances group identity and increases group cohesion. This is pertinent in this group that has established its group identity on a strong association with the core female identity of mothering. Secondly, vertical collectivist culture does not question status differences between men and women (Triandis & Gelfand 1998). In traditional rural Zulu culture where women have a lower status than men, in most arenas, the enclave of personal care giving is one that is dominated by women. Here they currently hold power and are possibly reluctant to concede this power especially in situations where there is the potential to receive outside attention for the work. Evidence to support the possibility of the latter comes from the work of (Dworzanowski-Venter 2008; Dworzanowski-Venter & Smit 2008) and Mbonu, Van Den Borne and De Vries (2010) who have noted instances where men have been actively discouraged from and even stigmatised for participating in care work. Thirdly, in this study, we did not specifically probe the women's ideas of men as poor caregivers, and as no spontaneous narratives of men as good caregivers were offered by the group, therefore we cannot speculate on the women's ideas in this regard.

In another study within the overall project which investigated the attitudes of people that did not participate in care and support, it

was found that men tended to favour providing support as demonstrating acceptance of the ill person visiting, talking and bringing required physical resources. Women referred to caring as bathing, feeding and cleaning the homes of ill people as indicative of support. Both men and women in this study perceived traditional gender norms and current social dynamics as barriers to men participating more actively in care (D'Almaine 2011). This implies that if the concept of care were extended, men may become more actively involved in care.

The implications of identity associations for volunteers and volunteering

Volunteers' personal identity and values (view of self as an individual), role identity as a volunteer and the group identity of the organisation were linked. The consistency between organisational values and member values is an important factor in increasing individuals' identification with the organisation. The perceived legitimacy of the organisation and the likelihood that the volunteers' self-concept will be linked to the volunteer role within the organisation are dependent on a balance and consistency between the two. A volunteer's self-esteem is increased if she perceives her role as being important to the success of the organisation. The role identity of a volunteer is related to the status of the organisation and the volunteer's degree of identification with the organisation. The higher the status of the organisation and the more strongly the individual identifies with the organisation's values, the more likely it is that there will be continued participation. The social identity approach suggests that volunteers' interpretation of their personal identity as consistent with the collective identity promotes the internalisation of in-group norms, values and interests (Strumer *et al.* 2008).

Social networking associated with volunteering contributes to the volunteer role identity and increases the likelihood of volunteer persistence (Grube & Piliavin 2000; Strumer *et al.* 2008). In addition, feeling respected by other group members and authorities and perceiving the organisation itself as being respected increases members' identification with and participation in the organisation (Strumer *et al.* 2008). Perceived individual benefits are important antecedents of the motivation to a volunteer. A crucial variable in community participation is power. Involvement in community networks is an aim of participation and leads to collective problem solving and increased community power and control. The process of empowerment and increased community power lead to the realisation in ordinary local people that they can influence their situation and effect change if that is their goal (MacPhail 2006).

In the case of the HBCVs in this study, the group identity was based on 'motherly love'. The group was called *Uthandolomama*, meaning the love of the mothers. It is significant to note that the word '*omama*' can be used for women and mothers interchangeably in Zulu. The women were told during recruitment that motherly love and caring were requirements for joining the group. This was presented as a primary motivation for the group's activities and all of the women interviewed understood and ascribed to it. A similar recruitment incentive was used.

Nandi: I thought like as a mother I love my children, so as a mother we love people, we have that love and we need to have that love spread around the whole community, because at home love is what works. So maybe that same love could be what makes things work in the community.

Nandi: The first thing that I tell them is that 'if you are going to work [...]with the community, you must be respectful. Think about what you say and make sure that it is respectful'. You must also respect yourself, and if you get to a person's house you must see that if there is a problem it is also your problem.

It would appear then that through their initiative to participate in care work, the women of *Uthandolomama* are, in some sense, reclaiming or reinvesting in the power associated with motherhood in this community. In assuming the opportunity to define their identity as a group, the women have connected it to their personal identities as motivated women, mothers who exercise their personal agency in their own lives. Volunteer work has created the opportunity to improve their perceptions of self personally and as women and mothers in the community.

Concluding note

The social field narratives of gender, poverty and socio-political context set the stage in Africa for women to suffer the worst effects of HIV/AIDS. The HBCVs in this study revealed alternative possibilities for how the seemingly inevitably negative dominant story can unfold. The personal narratives here offer clues as to how the women are able to offer comfort, hope and support to others in the context of discrimination, poverty and oppression. While much of the research on HBCVs in Africa has focused on the tremendous burden of care they assume, this study purported to shed some light on an alternative view. We have situated the understanding of identity in the African context to remain consistent with an African-based approach to understanding African health issues. Bruner's (1991) view of cultural psychology can help us understand people's health-related actions by situating intentional states (motivations and identity) in an interpretative system (culturally relevant framework). This study offers the idea that the motivation of HBCVs may at least in some part be identity-based. The social construction of identity in the group in this study appears to have an influence in activating women's community participation. This group based their organisational identity on an important aspect of cultural identity (the collectivist cultural view of mothering in the community) allowing women to activate personal agency through their confidence as compassionate doers, hopeful helpers, being initiators and ambitious and natural helpers as well as their personal identity as strong, loving mothers to participate as HBCVs. Identity status and norms were reinforced through negative attributions to outgroups which were typically men, community health workers and mothers who did not care. Further research is required to explore HBCVs' identity and the association with motivation to volunteer in various contexts with a range of home-based volunteer groups. This study has offered a basis for exploring identity as an important aspect of understanding the initiative to volunteer in the challenging context of poverty and HIV/AIDS home-based care and support.

Ethical clearance

Ethical clearance for this research was received from the University of KwaZulu – Natal Ethics Committee (Ethical Clearance Number HSS/0504/09D).

Authorship declaration

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Chapter 6

Generative metaphor in community-based action research: making culturally relevant connections

Abstract

This chapter describes a section of the social capital project concerned with the identity of HBCVs. The emergence of a generative metaphor umqondo kamama ('the mind of a mother') in the context of HBC work in rural African collectivistic culture is described. The generative metaphor was used to make new associations between HBCVs' identity and their work and to expand identity conceptualisations. Consideration is given to transforming tacit knowledge and cultural canons into generative metaphor in this context.

Women volunteers and unpaid care

Volunteerism in general across the world is decidedly gendered in nature (Gerstel & Gallagher 2001; Glenton, Scheel, Pradhan, Lewin, Hodges & Shrestha 2010; Petrzelka & Mannon 2006; Rotolo & Wilson 2007; Themudo 2009). This applies equally to paid care work and formal and informal volunteer work. Volunteer care work is the area in which this gendered division of labour is most distinct. Literature on HBC clearly documents the distinctly gendered nature of HBC in Africa (Akintola 2006; Chimwaza & Watkins 2004; Harding & Higginson 2005) and other parts of the world (Ramirez-Valles 2003; Songwathana 2001). Notably, this pattern has been most compellingly documented in parts of the world already considered having a poor socio-economic situation and poor quality of life for women. It has been argued that care work in and of itself disadvantages women. Caring for ill family and community members prevents women from finding gainful employment and contributes to further psychological, economic, social and physical stress in their already stressful lives (Chimwaza & Watkins 2004; Harding & Higginson 2005; Orner 2006). This especially applies to caregivers who are related to their charges (family caregivers).

The nature of care work provided by HBCVs encompasses what are traditionally viewed as menial, unskilled tasks most commonly 'women's work' in daily life. The work involves house cleaning, cooking, bathing the ill, assisting in access to medical care and providing psychosocial support. There is the assumption that this kind of work requires no training, special skills or personal qualities and that the caregivers are most often unpaid. Consequently, people who perform care work are most often those who have the poorest status in their communities by virtue of their age (very old or very young), socio-economic status (poor), gender (female) or education (poorly educated).

Generative metaphor

Modell (1997) notes that a metaphor is viewed as an emergent property of mind. In the use of a metaphor there is a juxtaposition of different domains resulting in a transfer of meaning from one concept to the other. The secondary subject of the metaphor organises perceptions of the primary subject, emphasising certain details and creating associations that lead to new ideas. In the case of our generative metaphor, the abilities and actions of the HBCV are the primary subject and the mind of a mother, the secondary subject. Metaphors act as filters that restrain some aspects of the association and elevate others (Barrett & Cooperrider 2001). By employing a metaphor, we are able to make sense of otherwise nebulous experiences. Metaphors according to Modell (1997) can be characterised along two axes: private/communal and foreclosed/generative. Private metaphors are those known only to ourselves, while communal metaphors are shared in symbol, myth or culture. Foreclosed metaphors are restrictive, and generative metaphors are open offering the potential for new ideas and possibilities

Schon (1979) regards metaphors as 'generative'. A metaphor is referred to both as a product (a perspective or frame, a way of looking at things), and as a process by which new perspectives on the world come into existence. Generative metaphors create a sense of imaginative play through which new meanings are created, transforming and increasing our understanding. Metaphors allow for a new organising schema on familiar and banal ideas in such a way that inestimable variations are/become possible. Lakoff and Johnson (1996) use the term 'mapping' in relation to metaphors, suggesting metaphors allow a meta-perspective in much

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the same way as a map would do in relation to physical geography. It offers an immediate mental picture where an explanation would be thin and inadequate. A generative metaphor facilitates the learning of new knowledge, creating the conditions for experiences that are outside the current frame of reference. Through a metaphor new perceptions of the world are possible and experiences of these new perceptions can be ordered and made sense of. Immersion in this experience, through active thought and experimentation, leads to the cultivation of new ideas and the expansion of cognitive frames (Modell 1997; Schon 1993; Winter 1989).

Metaphors can be constructive or destructive. In the generative form, metaphors can create new ideas; however, they also have the potential to sow panic or chaos. For example, the infamous "axis of evil" metaphor was created by the US Bush administration to initiate the Iraq war (Heradstveit & Bonham, 2007), The concept of generative metaphor has been used extensively in the corporate and business world to facilitate the crossing of the threshold to change and to break mental obstacles in order to progress. The aim of this chapter is to illustrate how a generative metaphor is employed to connect women's identity as mothers and their community participation. The research questions were:

1.   How do HBCVs view themselves in terms of identity?

2.   How can the generative metaphor elevate and thicken pre-existing positive identity associations with the role of the HBCV?

Methodology

An action research approach was adopted. The action research here involved creating the conditions for home-based care workers to think reflectively about their work and themselves

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in new/different ways. The action research perspective ensured that work was done collaboratively with the women understanding how their identity was framed and how they would in some way benefit or be improved by focusing on their strengths, hopes, dreams and aspirations. Narrative inquiry principles were actively applied (Freedman & Combs 1996; Moore 2008; Tomm 1986, 1987, 1988; White & Epston 1990). In keeping with the cyclical elements of action research (see Figure 11.1), three stages of interviewing were conducted, interspersed by observation discussion and reflection on the part of the researcher.

In the first set of interviews, the women's role identity as volunteer carers was explored through questions regarding the work. This served the dual purpose of gathering data about the work and evoking and re-affirming the salience of the volunteer role identity for the women. Participants had the opportunity to explain their tasks and role as volunteers to someone new (the interviewer); thus, empowering the women in their role as volunteers.

Observations, reflections and discussions during the second stage of interviews indicated that, whilst the participants had made some associations between their life stories and their role as volunteers, these associations were tenuous. A decision was made to include a further set of interviews that focused on making these associations explicit, in narrative terms, to thicken the narrative of volunteer identity. The appreciative inquiry process would facilitate this through a strategic approach and careful questioning.

The fifteen HBCVs in this study were each interviewed using semi-structured, biographical and reflective interviews. The interviews were conducted by the researcher (TN), at a community centre. Each of the interviews lasted between thirty and ninety minutes. The

researcher kept a reflective journal throughout the interview process, and observations, insights and reflections informed the interview process.
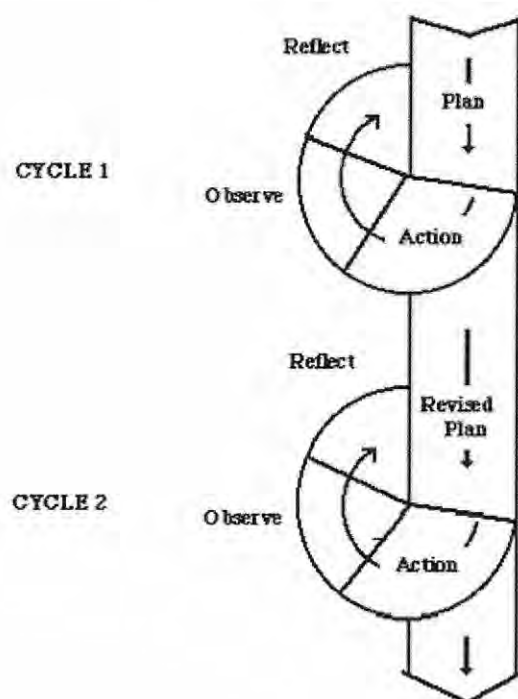
Figure 11.1 A simple action research model (MacIsaac 1995)

The women who took part in this study volunteered as part of a group who provided care services to community members who were too infirm to care for themselves. The women were approached through other researchers on the social capital project that had done preliminary work with the HBCVs. The group's leader contacted the women to arrange interviews. The participants lived in the community and were aged between twenty-five and sixty. None were formally employed. All had attended formal schooling and had completed between Grade five and Grade twelve at school. None of the group members had any formal training in nursing or care work, although three had experience of caring for sick relatives. Of the group, all but four

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had participated in the informal employment sector as domestic workers or doing other types of 'piece jobs'(a colloquial South African term for intermittent casual paid work). The women all spoke isiZulu as their home language and had some understanding of English. The women would begin by volunteering in the group for a period of six months or more after which they would receive a small government stipend as and when this was available.

Findings and discussion

Identifying the generative metaphor

During interviews and contact with the women, specific identity features were noted in their stories. An extract from the researcher's reflective journal illustrates this.

It would seem that, besides being a 'compassionate doer' Mrs T had many other traits that contributed to her being able to help others. Those close to her (her husband and her mother) were also strong-minded, proud and positive people who were industrious and innovative.

I was struck by the fact that the four women healthcare volunteers that I met seemed to be respectable and conservative matriarchs in the community. Their standards of dress and appearance conveyed this initially. Later it was also conveyed in Mrs T and Mrs N's stories about their lives. In my chance meeting with the two HBCV, this persona was also evident. The life stories of Mrs T and Mrs N conveyed the idea that they were aspirant people, ambitious, brave, unconventional and daring. The type that was willing to break the rules and take chances. Mrs N's life story reflected that she was always trying to improve her situation in life. (TN Reflexive Journal 24/05/2009: p. 8)

Vigilance was maintained for further indicators that would suggest the existence of an alternate identity perspective. I was in particular searching for identity perspectives that were neglected in the consciousness of the HBCV identity, but that would point to the reasons why and how it was possible for the HBCVs to do the kind of work that they did despite the hardship attached to volunteer care work. The search was for a 'sparkling moment' or 'unique outcome' (White & Epston 1990) that would indicate the existence of alternative identity stories concerning the HBCV's power and agency in their own lives.

During the process of inquiry, one of the participants mentioned that all one needed to be a good HBC worker was *umqondo kamama* ('the mind of a mother').

TN: What makes you as a person able to volunteer? Does it require a certain kind of people to be able to care for people?

Mrs M: I don't think it requires a particular type of person, just as long as you are able to go to people and give them information and help them. So, I really don't think it needs a special person it just needs a mind of a mother.

TN: And you don't think that is special?

Mrs M: The mind of a mother is very important, because it could help you go through small spaces, like enlighten people who don't know.

TN: I don't understand what it means when you say go through small spaces.

TN: Okay! Can you give an example of when you have done that?

Mrs M: When you get to a household and there is an old woman who cannot get up; maybe she has lost control over her excretion functions and when you get there, it is dirty. So, I

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would speak to the people around there who should be taking care of her. I would say: "This is not how it should be working ... she shouldn't be dirty like this and these are the effects." So, that old woman would be very pleased, and very grateful for saying things to make these children realise what they should be doing.

It appeared that this was an apt metaphor as it was consistent with the qualities observed in the participants during the initial interviews. The mother metaphor is consistent with the tendency for family metaphors to be used by those involved in care work (Berdes & Eckert 2007). Health professionals and caregivers are often reminded of applying ethical and humanistic practice by the phrase "treat patients as you would treat a family member". Berdes and Eckert's (2007) study reports on the geriatric residential care aides who express effective care for residents as they would to aged parents. In the context of South Africa, where the highest incidence of HIV is amongst young people, it is telling that HBCVs express the nature of their care through the metaphor of love and mothering. Notably, the group that the interviewed HBCVs belonged to in the community was called uthando lomama ('the love of the mothers'). This phrase was adopted as a generative metaphor.

The cultural, contextual and personal salience of the generative metaphor

By using an action research approach, the intention was not to make dramatic changes to how the HBCVs do their work. It done not merely to get the participants think about themselves in relation to the work but also to initiate a process of reflection. It was at the stage of repeated interviews that many of the women explicitly stated that the interview process had helped

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them and that they thought differently about their personal identity and volunteer work as a result of the interview process.

Reflecting on identity in terms of personal and socio-political histories and social networks, we anticipated a precipitated practice of creating positive ideas concerning the self and a foundation of hope. Considering that the women performed what is the most basic aspect of work within the care and support framework around social capital, it followed that they had little regard for their own skills in the work. They felt untrained and ill-prepared to perform the physical aspects of the work. In fact, their main requirement seemed to be training to enable them to perform the work better.

The use of mothering as the basis of this generative metaphor was especially fortuitous. It is a communal metaphor, one that is easily recognisable and transferable across cultures. The fact that the researcher is also a mother resulted in the use of the metaphor strengthening rapport around the shared role of motherhood. From a social constructionist perspective, it could be said that it is particularly because I considered the motherhood aspect of my identity salient that I was drawn to this phrase and applied it as a generative metaphor. The HBCVs accepted the salience of this metaphor for themselves to varying degrees and certainly as a collective as reflected in their decision to name their group Uthandolomama. The broader cultural framework within the context held distinctive ideas concerning the values, roles, etc. of motherhood (Masuku 2005). In Modell's (1997) terms, this would then be a communal generative metaphor. A metaphor is usually consistent with a value system that is coherent

with the its ontological stance. Within the cultural perspective of the participants (African collectivistic culture), motherhood is central to a woman's identity. From a collectivist view, motherhood is an inevitable role for all women in the community – a role they take on to varying degrees throughout their lives: mothering siblings, their own children and grandchildren (Masuku 2005). Older women in the community are referred to as omama. This is a collective noun meaning 'the mothers' and simultaneously reinforces the collectivist concept of motherhood. Children or younger people in the community are expected to afford the same degree of respect to all older women in the community as they would their own mothers. By the same token, older women should treat children with the same benevolence, care and concern they would treat their own children.

This metaphor allows for more meticulous examination of the concept it maps and the correlations between the mother identity and the home-based caregiver qualities or identity. The use of a metaphor is fairly common in care work. It is interesting to note that 'coming home' or 'home' is a metaphor that is often associated with palliative care (Dekkers 2009). This is a metaphor that is not out of place in this context where people literally return to their physical and ancestral homes to be cared for by their biological mother, a female relative all of whom are viewed as 'mothers of the community' (omama) in the terminal stages of illness. In a study by Berdes and Eckert (2007), nursing aides used metaphors associated with family relationships and attachment to describe their affective care and even contrasted it with uncaring families. The HBCVs in my study compared their caring to that of uncaring families, especially to uncaring mothers. Sharoff (2009a, 2009b) writes on the importance of the metaphor in nursing care work as creating possibilities for new meaning and providing new

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insight into the human spirit. In contexts other than caring, women have also attributed their volunteerism to an expression of their maternal nature (Petrzelka & Mannon 2006).

Conscientising the women around the value of their work can contribute to them furthering their own personal and group interests; thus, initiating advocacy and sensitising the women to an alternative perspective. The action researcher adopts the role of a catalyst, facilitating a novel method for perceiving a taken-for-granted idea, belief or situation. The generative metaphor of *umqondo kamama* (the mind of the mother)was identified and elevated during interviews by the interviewer; thus, making the connection that the participants had the talent, skill and ability to care for ill people that originated in their role as mothers and based on their ordinary lives. Despite the fact that this aspect of identity was generally taken for granted in the culture and therefore taken for granted by the participants themselves, it was also a role that took great skill to manage/juggle, as was illustrated in the stories of their lives. By turning the attention to a specific part of (individual and collective) identity (motherhood), the women are able to view it from a different perspective, e.g. through the eyes of family members and friends:

TN: What would your family say about the kind of person you are?

Mrs RM: They would describe me as the kind of person that I am [I asked what would that be] for example the mother-in-law sometimes she says to me – especially around sweeping the yard – when you die we will still see you in the yard with a hoe or with a broom ... [Mrs RM LAUGHS] ... because I sweep, I mean I sweep that side, I go outside and I pick things up. If I hadn't had the time to sweep the yard it is full of rubbish and I will be shouting and I would be

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like "Why does it have to be like this, just because I didn't have the time to clean up today does it mean it should be like this?" So she would describe me as that sort of person.

TN: So you are the type of person who takes control of things and makes sure that it is done properly?

Mrs RM: Yes.

TN: And everybody knows you like this?

Mrs RM: Yes, even my mother would tell you what kind of person I am. I am a mover.

TN: And what about your friends, would they think the same thing? Your friends and your neighbours?

Mrs RM: I think they would especially. People who come and visit at home, I don't sit, you won't find me sitting at home, because even inside the house I am always doing something. Like the dresser ... it doesn't sit in one place for the whole year, I move it at least twice a year. I move things; I re-arrange things all the time.

TN: Why do you do that?

Mrs RM: I think I am used to it and also that sometimes it is hard to clean places that you cannot reach.

The generative metaphor was suggested in each interview and all the women made sense of it and identified with it to varying degrees. Of significance is that metaphors in general resonate with what is familiar to the individual and what that individual relates to. According to

Obeyeskere (1990), culture is the process whereby the symbolic forms of the metaphor existing at the cultural level get created and re-created through the minds of people. There is an intersection of private metaphor and cultural symbol. Simply stated it allows the person to connect the known with the novel. The generative metaphor provides a tool that allows for ideas to be expanded beyond their initial presentation. The generative metaphor, if used constructively, can be simultaneously challenging yet respectful of current perspectives as illustrated in the following excerpt:

TN: And also someone said that one needs a mind of a mother to be a HBCV? What do you think that means?

Mrs RM: I wouldn't really say that you have to be a mother to do this; you just have to be someone who is hard-working, someone who is interested in helping people, because you can do that without being a mother. You can just ... because some people are not mothers, but they can give what mothers can give, you just have to have the love of helping people.

TN: Could it mean that the person meant you need to have the qualities of a mother even though you are not a mother yourself?

Mrs RM: Yes, that is what it means, because when you are a mother you are like a chicken that protects its chicks. So if you are going to do this work you have to like that. You have to be like a chicken to the people you are caring for. When you arrive at the house they should feel that you have arrived, that you are going to protect them, they should feel warm in your presence.

In the above quote Mrs RM uses yet another metaphor, that of a mother hen, to extend the mothering component of the HBCVs' approach to care-giving. In this example, Mrs RM

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connects the familiar and known of the motherly caring of the mother hen to the novel idea of motherly caring in HBCVs. She extends the facets of the metaphor of mothering to make explicit the qualities of protection, warmth and security commonly associated with mothering. In Mrs RM's de-construction of the metaphor she demonstrates her understanding of the metaphor and simultaneously expands the application of the metaphor in context, thereby extending the researcher's understanding of the contextual significance of the metaphor. In this process, the generative metaphor is used constructively. Each successive level builds on the previous one. Through the use of generative questions that were surprising, touched people's hearts and moved the spirits, the generative metaphor was established and encouraged (Bushe 2007). The central process of narrative inquiry as an intervention strategy is that it encourages transformation through critical responses to questions. The questioning process encouraged reflection by drawing attention to a salient aspect of identity (motherhood/mothering).

Thus far we have seen that the nature of care work is decidedly gendered. Care work in the context of HIV/AIDS disadvantages caregivers. Women caregivers view themselves as disadvantaged and make negative identity associations with their care work. This chapter explains how application of the generative metaphor *umqondo kamama* within an action research paradigm produced alternative positive identity associations connected to motherhood amongst home-based care volunteers. Examples from the HBCV's talk illustrate the cultural, contextual and personal salience of the generative metaphor and confirm the inventive properties of the metaphor as a means of connecting the known to the novel to create new and unexpected possibilities.

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Are generative metaphors omnipotent?

Generative metaphors can be powerful in the positive ramifications they generate, but like any tool they can be wielded destructively. What are the possible disempowering connotations of using the particular generative metaphor ' the mind of the mother' in this context? What ideas does the name *Uthandolomama* give on how people can access care and how care is viewed in the community? If caring is considered a mother's duty and responsibility in this context, then by the same token 'failing to care' in ways that are expected in the community can invite criticism towards mothers and the mothering role by the community. In fact, some of the HBCVs themselves commented on how the patients' own mothers had failed to care for them, thus necessitating the volunteers' intervention.

All the HBCVs cited uthando ('love') as being their primary motivation for volunteering. This, combined with the decision to call their group *Uthandolomama*, could conceivably have a disempowering effect on group and personal identity. The value construct of 'love' is a central element of both volunteer and mother role identities as constructed by the HBCV group within the canons of the broader socio-cultural and historical narratives of the community. Love in the context of motherhood – whilst it is passionate and unconditional – can also be selfless and self-sacrificing. The expectation is created for the HBCVs themselves, the community and new recruits that no external reward should be expected, and those willing to do the work needed to create their own internal sources of reward. The connotation of the name (*Uthandolomama*) is also likely to establish expectations within the community as to what to expect of the HBCVs, namely loving, caring and doing tasks for the ill that mothers are expected to do. Mothering is commonly understood to be an unpaid position, definitely financially and possibly emotionally. When children are at their most needy (very young or

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very ill), a mother's work is at its most demanding, both emotionally and physically. Based on interview data, it would seem that the name thus epitomises the philosophy of the group. Those who are not motivated by love cannot and should not do the work. In so doing, the work is simultaneously defined as unacknowledged yet beyond the resources of ordinary people requiring only those who are able to love unconditionally without the expectation of a reward.

Notably, a key feature of HBCV groups is that they consist almost exclusively of women. In cases where men are involved, they serve as supervisors and spokespeople for the groups. When men are active in the physical sense, it is usually in the role of caring for a relative – most often a wife and not, as in the case of women, caring for extended family members and community members. Aita, McIlvain, Susman and Crabtree (2003) note that in the case of the nurturing parent as caregiver model, empathy is central. By mapping the nurturing parent metaphor onto a political perspective, a viewpoint that emphasises a morality of empathy and justice, looking after people in need, and caring for the self and others emerges. The strict father model espouses self-discipline, accountability, and self-sufficiency. Mapping this metaphor onto a political perspective, results in a conservative idea of subscribing to a morality of strength, self-sufficiency and self-discipline. A blaming rather than a nurturing attitude to patients is cultivated in the context of the father metaphor. This perpetuates the international, cross-cultural stereotype of women as caregivers. The idea that women are the best caregivers, that they do the best job, and that they are naturally predisposed to caring roles, contributes significantly to excluding men from the process. In the particular case of *Uthandolomam*a, it is likely that, whilst the name may attract women to volunteer in the group, it is likely to have the opposite effect on male volunteers. Confronted by the implication that volunteering to care in this group requires a 'mother's love' many if not all

men in the community are likely to be discouraged from volunteering. In terms of Modell's (1997) axes of metaphors, *Uthandolomama* would in this case signify a communal but foreclosed metaphor, which could serve to reinforce the gendered nature of care work (Akintola 2006). Whilst there is substantial criticism around men being less involved in caring than women, the case in point might be illustrative of a phenomenon where women either consciously or inadvertently discourage men from participating in community care work.

Schneider (2009) explored the 'micropolitics' of a group of rural Mexican women's participation in local health groups. Their effort to reclaim control over health processes is a metaphor for claiming control over their lives. A parallel can be drawn to the HBCVs in this study as their participation in the social capital networks around HIV is based on their identity as mothers. Taking care of those in need, upholding standards in the community, educating, encouraging respect and exhibiting behaviour consistent with their status is seen by this group to be consistent with the communal ideal of motherhood. Evoking the role of mother as central is a way of reclaiming their status in the community. In the past, these women were disadvantaged by their motherhood, forsaking educational opportunities, fearing for the safety of their children as they worked away from home or missing job opportunities to maintain the family home. In the role of HBCVs, they are able to elevate their own status and the status of mothers in the community through their mothering skills. One of the women lamented the loss of respect for mothers and warns of dire consequences to those children who ignore a mother's advice:

Mrs VM: So sometimes I tell my children we were raised by women. One woman. There was no grandfather there. Our mothers were not there, but we were raised. We could have done whatever we wanted to but all of us who were raised by granny are married. So I say to them:

a mother and a father are raising you. You are very lucky yet you do not appreciate that you just go wherever you want to. People just govern themselves. I mean you come back and you say "Oh we were at H this weekend or we were in M" and yet you haven't told me that you were going to H or to M. What happens if you get hurt there? We could have done whatever we want with granny because she was a woman and she was old, but we respected her. These children don't respect what they have. So I talk to them a lot and sometimes I reflect and I think that being raised by Granny helped me a lot because I am in my home, there are bits of gravel here and there, but I am there and I tell them because now they are grown they can see things and I tell them, I say "Can you see that there are problems within this house, but I am still here?" Granny used to say, "You don't just live like that you can build a house a home as a woman just by yourself you can do that. There doesn't have to be a man for there to be a warm home." So yes, I tell them that if you listen to me you are also going to turn out to be strong women and strong men who are going to build strong homes, but if you don't then you'll end up roaming the streets and just be nothing.

As in Schneider's (2009) study, the women in this rural area have responded to the call to service to address healthcare gaps in their community in a context where government resources are non-existent or inadequate at best. Most significantly, in both instances, both groups of rural apparently disempowered women use traditional skills and resources that were previously ignored, taken for granted or even devalued. As in Schneider's study, an important aspect of women's participation relates to their need to feel as if they are contributing to society. All the HBCVs expressed that their motivation to volunteer was based primarily on love and the wish to serve the community. The women's participation in volunteer care-giving offered them the opportunity to transform their lives by engaging with a community of people

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who have suffered in similar ways, through poverty, loss of a family member to AIDS, or other reasons.

According to Finkler (1985), the transformative effect of women's community health work constitutes a powerful aspect of personal transformation. Interaction with peers and community members in similar situations affords the opportunity for seeing universality in their experience. Through extending their role from mother to health promoter, these women gain a foundation from which to build a new sense of identity and purpose. Becoming a mother immediately restricts participation in the workforce. Every traditional mother role and task a woman chooses to adopt (breastfeeding, being a stay-at-home mother, etc.) intensifies this. By making the association with the role of mothering and the skills required to be a home-based care volunteer this metaphor becomes transformative.

Schneider (2009) notes that rural Mexican women were empowered by their community work, but there was still a lack of critical consciousness to extend the positive effects of the work to a political level and to empower peers. According to Freire (1970), mere engagement in the work is not enough to raise critical consciousness. Rather, reflection through dialogue with others is required to raise critical consciousness. The transformative process of narrative inquiry served in this case to make connections between previously unconnected ideas. Using a metaphor facilitated the process. For a metaphor to function as a mapping tool, it must be communal and it has to appeal to commonly held notions of what a the particular concept it refers to means. Metaphors allow for serendipitous discoveries, and invite a deconstructive approach to language in the understanding of everyday life (Aita et al 2003; Sharoff 2009b). This was supported by the home-based care workers as they were all able to deconstruct the metaphor and make an association to some degree.

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How do generative metaphors ultimately feature in community-based research?

Metaphors are naturally embedded in language, and language is the medium of qualitative analysis. It makes sense then to incorporate metaphors within the investigative tool of interviewing in qualitative research. This methodology has potential for enhancing the values and ideas that shape practice but which may otherwise be elusive. A metaphor holds the possibility to bridge cultural and cognitive divides. In some contexts, the use of metaphor and other linguistic tools is part of everyday speech. This is true of the isiZulu language. Storytelling and metaphorical language plays an important role in Zulu culture. These practices provide tools through which to convey deeper insights, generate new ideas and sensitive information without contravening social taboos.

Metaphors facilitate the juxtaposition of dissimilar or unrelated ideas and create conditions for unimagined possibilities to emerge. Using metaphors encourages creative thinking, breaking away from old styles of thinking. The use of metaphors as a natural human tendency facilitates collaboration in the research process. The narrative quality of metaphors allows for a story of meaning to be conveyed in a few words or a phrase. The use of metaphors in research contexts facilitates the understanding of complex ideas and bridges the divide between conceptual frameworks. It could serve as a cultural conduit for co-researchers from different backgrounds and perspectives. Power and the power of metaphorical frames arise from their ability to concurrently focus and marginalise, keeping an idea just outside from direct perspective so that it may be associated and enhanced by a seemingly unrelated other. The use of a metaphor suspends reality to a degree allowing for imaginative navigation through the realms of possibility.

However there should be some caveats to the use of metaphors. If overused and over-applied, metaphors could restrict the development of new ideas in the area. Such metaphors could lose meaning and momentum to generate innovative thought. In this way, metaphors become clichés. They can often be inappropriately transferred from one context to another and lose meaning or become destructive if they are too far removed from the original meaning. Metaphors can be situational specific and culturally idiosyncratic, so whilst they work effectively in one context they may be destructive or meaningless in others. The danger exists that, if strongly biased to one idea, a metaphor can exclude participation and restrict new possibilities.

Conclusion

Feminist consciousness-raising happens in more subtle ways than directly addressing unjust sectors of society and talking itself is a form of consciousness-raising (Gallin 2002:61-78). Introducing drastic and unsustainable changes can create false hope and possibly leave people worse off that they would have been without intervention. It can also make people and communities overly dependent on outside help. Campbell, Gibbs, Nair and Maimane (2009) state that evaluation of the reasons why changes introduced to HBC workers failed to empower them suggests that sweeping changes are more likely to be in keeping with cultural precepts of researchers rather than of participants. Many researchers make the mistake of training and educating people on how to make, what researchers envisage as, positive changes to their lives. However it is a well-established idea that knowledge and awareness do not inevitably prompt people to change. Rather, consciousness-raising is required.

In this case, the application of a communally relevant metaphor allowed researchers to initiate a subtle change process. The incorporation of a generative metaphor that emanated from the participants' ideas created the conditions for participants to make connections between the social and personal identities and their role identity as volunteers that were culturally relevant and resonated personally.

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Chapter 7

Understanding the agency of home-based care volunteers: establishing identity and negotiating space in AIDS-home-based care in rural KwaZulu-Natal, South Africa

Understanding the agency of home-based care volunteers: establishing identity and negotiating space in AIDS-home-based care in rural KwaZulu-Natal, South Africa

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In traditional Zulu communities, caregiving is rooted in compassionate and hardworking personal identity precepts and the traditional identity expectations of women. Home-based-care volunteerism in the community represents the performance of this identity. Data from a series of interviews with 15 home-based care volunteers (HBCVs), in a rural community in KwaZulu-Natal Province, South Africa, is used to illustrate how HBCVs promote the notion of women as paid home-based caregivers, with a recognised space in the care and support system regarding HIV and AIDS. Home-based-care volunteering also represents the attempt by women to be seen, heard and recognised in the hope that it will lead to self-improvement and the improvement of their families. Volunteer motivations vary from altruism, to volunteering as a means to be recognised and increasing the chances of self-improvement. We propose that home-based-care volunteering may be viewed as a form of agency in response to a lack of recognition, support and acknowledgement for AIDS caregivers and their patients. The continued lack of support for HBCVs over a long period undermines the work and the basis of the HBCVs' identity or the aspects of identity on which the motivation for the work is based.

Keywords: community care, cultural aspects, gender, narrative research, poverty, research methods, women

Introduction

Attention to women's issues in HIV and AIDS discourse has been hard-won. Women's struggle for recognition has obscured the complexity of the effects of HIV and AIDS on women's lives. Structural forces such as gender, poverty, and the socio-political circumstances in a country such as South Africa result in women being affected differently by different social aspects of the disease. In the arena of HIV prevention and infection, the responsibility for negotiating safer sex is disproportionately placed on women and rationalised by their biological vulnerability to HIV infection and their socioeconomic vulnerability to the effects (Higgins, Hoffman & Dworkin, 2010). Initially, research on HIV and AIDS was dominated by a focus on the biological aspects of the virus. Later, as research developed, social connections were associated with the spread of the disease. In the early stages, exclusive attention was given to white male homosexuals (Strebel & Lindegger, 1998). The effects of HIV and AIDS on the health and lives of women received attention only after women staged protests at the Eighth International Conference on AIDS in Amsterdam, The Netherlands, in 1992 and at other forums in the early 1990s. Women's visibility in the global trajectory of HIV and AIDS impacts had been largely ignored and not substantially deconstructed.

Once attention was given to women in the mainstream global discourse on HIV and AIDS (i.e. the literature on HIV and AIDS), the focus was dominated by a storyline of women's powerlessness against the HIV epidemic (Fourie, 2006; Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009; Higgins et al., 2010). Socio-cultural and structural forces add momentum to the impact that HIV and AIDS has on women's lives and futures. Globally, women are most commonly disadvantaged in the socio-political and economic arenas. Notably the highest incidence of HIV and AIDS occurs in developing countries where poverty and related socioeconomic burdens also impact most significantly on women. Higgins et al. (2010) refer to this 'vulnerability paradigm' as a phenomenon that has constructed women as more affected by the HIV pandemic due to biological differences in susceptibility to HIV infection, reduced sexual autonomy, and men's sexual power and privilege.

Much of the work around women's issues in HIV and AIDS has focused on prevention and women's power in sexual relationships (Strebel & Lindegger, 1998; Wingood & DiClemente, 2000; Wojcicki & Malala, 2001; Türmen, 2003; Hoosen & Collins, 2004; Pettifor, Measham, Rees & Padian, 2004; Dworzanowski-Venter & Smit, 2008; Campbell, Gibbs, Nair & Maimane, 2009; Mbonu, Van den Borne & De Vries, 2010). In South Africa, the neglect of women's issues (during apartheid and after 1994) as a result of structural forces such as poverty, socio-historical influences and gender disparity (Maree, 2003; Meer, 2005) has disadvantaged women in the era of HIV and AIDS. Campbell et

al. (2009) found that empowering laywomen to facilitate home-based care for AIDS patients in a rural South African community did not translate into increased agency around negotiating condom use with their partners or asserting themselves with male leaders. Campbell *et al.* (2009) suggest that glimpses into the agency offered to women, even by unsustainable or failed projects, could result in benefits that are not immediately or easily identifiable but which are likely to manifest in the long term. Higgins *et al.* (2010) propose that the vulnerability paradigm can mask women's power and agency. The point emphasised here is that a lack of sexual agency does not necessarily equate to a general lack of agency for women. In this article we indicate how home-based care volunteers (HBCVs) exercise agency through HIV/AIDS-related caregiving based on their personal and socially constructed identity as caregivers.

Some authors (Holland, Ramazanoglu, Scott, Sharpe & Thomson, 1990; Strebel & Lindegger, 1998; Maree, 2003; Meer, 2005) have suggested that women can and do exercise agency against male-centred discourses through the construction of alternative positions. The approach of construing women as powerless perpetuates stigmatisation and obscures the everyday decisions and actions in which women are engaged. The tendency to speak of women as powerless does not account for the range of coping strategies and social networks which women have constructed to deal with daily life challenges (Campbell *et al.*, 2009). The danger in this argument is that as long as women are seen as powerless, the actions they take will be seen as reactions to men's actions and choices. The consequence is that women are judged in relation to men and become defined in terms of their functional significance to men instead of by their own significance (Wingood & DiClemente, 2000).

Women can and do demonstrate agency against the structural forces of poverty and gender around HIV and AIDS; thus a focus on the 'vulnerability paradigm' can mask women's activism. AIDS care and support is one area in which women dominate. Much of the attention in the area of care and support has been characterised by the 'burden of care' that is imposed on women. This has drawn much needed attention to the fact that the majority of those who care for HIV and AIDS patients in developing countries are women, and that they are overwhelmingly and diversely burdened by the care duties. Moreover, the majority of female caregivers are related to the people they care for and may be compelled or obligated to provide care due to poverty and the traditional expectations of women as caregivers. Nevertheless, there is another category of caregiver: the HBCVs. These volunteers are mostly women who have *chosen* to participate in home-based care as a result of recognising the need from their own previous experience of caring for sick relatives, observing the effects of HIV and AIDS on the community, and acting in response to a compassionate identity (altruism) (Naidu, Sliep & Dageid, 2012). They can be distinguished from the category of family caregivers by the fact that they are not compelled to offer caregiving, and from others in the general community in that they recognise and respond to a community need. Volunteer home-based care is a phenomenon that few researchers have explored (cf. Rödlach, 2009; Akintola, 2006).

We propose that agency as displayed by women in the context of HIV and AIDS home-based care may not be easily recognisable to the casual observer but may manifest more subtly (cf. Hollander & Einwohner, 2004). This offers glimpses of agentive potential which, if left unsupported, could dissipate. One study showed that women's belief in their efficacy as caregivers was strong despite being unable to exercise agency in their personal and sexual relationships with men (Campbell *et al.*, 2009). Dworzanowski-Venter & Smit (2008), while concerned with female caregiver sexuality and condom-usage negotiation, suggest that these women do possess a degree of agency. They argue that "our Ekurhuleni caregivers continue to preach without being able to practice safe sex *to the degree* that they would wish" (Dworzanowski-Venter & Smit, 2008, p. 78). It is likely that contextual issues such as stigma and gender power differentials constrain women's ability to act (agency). Agency in one area of life does not imply agency in other areas.

Resistance is a reaction to a current unfavourable situation. Resistance is not necessarily a conscious reaction and may even be passive or avoidant. Agency, on the other hand, can be a conscious, planned and empowered reaction to a current unfavourable situation. Advocacy takes agency a step further as it is a conscious, planned and empowered action on behalf of the self and others against current and future unfavourable situations. In this article we give credence to the view that in South Africa the HIV and AIDS trajectory of impacts represents, on some levels, the confluence of the effects of the history of women's oppression and the epidemiology of the disease in the country. We explore how, despite vulnerability, women as HBCVs display agency in the context of AIDS care based on their identity as women volunteers.

Identity and agency

All human interaction is performed within the context of a pre-existing social structure that is governed by a set of norms and laws. However, the structure and rules are not permanent and external, but sustained and modified by human action through reflexive feedback. Social agents' regular interaction with a system of norms is described as structuration; reflexivity refers to an agent's ability to consciously alter his or her place in the social structure (Giddens, 1984).

Identity theory suggests that those who are marginalised generate 'resistance identities' and use these to build a new identity that redefines their position in society and thus seek the transformation of the overall social structure (Hall, 1990; Castells, 2009). This would include activism through the mobilisation of movements, at community, national, and international levels, aimed at social change. Recent work on the nature of identity has emphasised its constructed and constantly changing character (Hall, 1990; Somers, 1994; Kraus, 2006; Hammack, 2008). This has made it possible to begin to theorise changing constructions of identity in relation to both the experience of oppression and stigmatisation, as well as resistance to it (Castells, 2009). Castells (2009, p. 8) has distinguished between *legitimising identities*, which are "introduced by the dominant institutions of society to extend and rationalise their domination [over]

social actors," *resistance identities*, which are "generated by those actors that are in positions/conditions devalued and/or stigmatised by the logic of domination," and *project identities*, which are formed "when social actors, on the basis of whatever cultural materials are available to them, build a new identity that redefines their position in society and, by so doing, seek the transformation of the overall social structure."

It has been widely documented that care for AIDS patients is usually administered by a female relative or a female community caregiver, which exposes the women to physical and emotional stress and can have serious negative effects on finding employment outside the home (Chimwaza & Watkins, 2004; Harding & Higginson, 2005; Akintola, 2006; Dworzanowski-Venter & Smit, 2008). It might be argued that in taking on a caregiver role, volunteer caregivers support rather than resist the dominant structural constructions of women as natural caregivers. However, Hollander & Einwohner (2004) contend that resistance is a complex construct that is socially constructed, and even in resisting power some individuals and groups may simultaneously support and resist the structures of domination that compel the resistance to begin with. A particular activity may constitute both the resistance and accommodation to the different aspects of power and authority. Home-based care is an example of this phenomenon.

We suggest that in moving caregiving, and HIV and AIDS caregiving in particular, out of the home and into the public realm, HBCVs demonstrate the initiative associated with agency. Shifting the context from female relatives caring for HIV and AIDS patients in their homes to volunteers visiting patients at their homes introduces the element of agency. While family home-based caregivers (mostly women) are hidden and 'invisible' and expected to care, the HBCVs' identity represents a choice to care, resisting government's neglect of care and support initiatives for HIV- and AIDS-affected people in rural areas. HBCVs are more visible in the community than family caregivers, and their volunteerism constitutes activism in response to the need for the care and support of HIV and AIDS patients that has been neglected by government. Implicit in this neglect by government is the expectation or presumption that female relatives should provide home-based care for HIV and AIDS patients. Furthermore, HBCVs use the social action of volunteering to attract attention to their position as unemployed rural women. They are willing to embark on self-improvement strategies in the hope that their efforts will be recognised and they will be offered formal employment in government and non-governmental AIDS-care organisations, allowing them to work and contribute to their personal and family's wellbeing.

In South Africa, poverty and the socio-cultural and economic impacts of apartheid have, along with the migrant labour system and the resultant disintegration of rural families, had a significant impact on the course of women's lives (Coovadia et al., 2009). In this study, we looked at women's narratives of identity in the context of their home-based-care volunteering. We paid specific attention to how women 'narrate voice and visibility' in the context of volunteer home-based care. We illustrate, through women's

narratives, how they make sense of their personal experiences and understanding of poverty and undertake to claim space for their identity as HBCVs in the context of HIV and AIDS care. They undertake this on the basis of the cultural materials available to them, which in this case are women's identities as caregivers, in order to construct a new (resistance) identity that moves towards redefining their position in society. The new identity or position that HBCVs aim to achieve is that of paid home-based caregivers who have an acknowledged place in the system of HIV and AIDS care and support.

Methods

The study employed a qualitative design. Narrative inquiry and analysis were chosen as research methods in order to focus on how people make sense of their experiences through stories. This approach allows for the expression of identity to be visible to the researcher as it emerges during the construction of a narrative during interviewing (Somers, 1994; Kraus, 2006; Hammack, 2008). The narrative approach to research views meaning-making as contextual and relational. The research situation is viewed as constantly evolving, and the account of it (the research story) is formed in the interview relationship. Dialogues are multi-voiced and polyphonic because they are socially embedded and contain many, and sometimes opposing, voices and discourses (Mishler, 1986, Gubrium & Holstein, 2002; Riessman, 2007; Tanggaard, 2009).

The participants

The participants in the study were 15 female HBCVs from a resource-poor rural community in KwaZulu-Natal Province, South Africa. The volunteers belonged to a community-based organisation founded by women who had responded to the need for home-based care in the community. They ranged in age from 26 to 58 years and had an average of 8.5 years of formal schooling. Some had previously cared for family members with AIDS. The women engaged in the care work for altruistic reasons and to gain recognition or experience for better jobs in the future, such as working for government and non-governmental organisations involved in AIDS care. The services provided by the HBCVs included washing, feeding, cooking, cleaning, providing emotional support, and advocating for those who are too ill to care for themselves and who lack appropriate family support.

Data collection

Each participant was interviewed three times. The interviews were translated *in situ* by a Zulu speaker and tape-recorded and transcribed for analysis. The first interview focused on the nature of the caregiving work, the second interview was a personal autobiographical narrative, and the third was a reflective interview. The names used here are pseudonyms.

During the first interview, the researcher asked specific questions about the nature of the home-based care work allowing the participants space to construct their responses and assume the desired positioning. The researcher controlled the interview by directing the content and nature of the conversation. The second and third interviews

were intended to create space for alternative possibilities of identity to emerge and be assumed as storylines. The second interview was unstructured, with the only condition being that the participant should talk about her life story. The intention was to offer space for the interviewee to present a preferred perspective of herself as part of a self-affirming process. Typically, unstructured interviews are conducted before structured interviews. However, the reverse was done in this study. The participants had previous experience with structured interviews about their work by other researchers in the overall project of which this study formed a part. It was decided that beginning with a familiar interview type and structure would facilitate rapport. Discussion with the translator indicated that this sequence would be more comfortable for the interviewees. Moreover, the second life-story interview required that a greater degree of rapport be established before starting such an interview. It would have been presumptuous to expect the participants to reveal their personal life-stories at the first meeting.

The third set of interviews was introduced to further encourage a reflexive perspective. According to Hermans (2001), positioning and repositioning allow the individual to take the initiative and respond to familiar situations in new ways. This may be accomplished in three ways. First, a new position can be introduced into the system, prompting a reorganisation of the self. Second, positions may move from the background of the system to a more prominent position. Here, the positions are already part of the system but they become accessible as the result of a reorganisation of the self. Third, two or more positions may support each other or develop some form of collaboration so that they form a new sub-system in the self. Positions that have a common purpose or orientation can meaningfully go together as an alliance. In this case, the women's roles as mothers in their own families and helpers within the community were evoked and associated with their role as volunteers (Naidu, 2011). The voices of family members were solicited by asking the participants to relate what they believed family members would say about their work and personalities. The specific questioning techniques used here were adapted from narrative therapy where 'remembering conversations' evoked the voices of fictional, historical, significant others as well as alternative, past and future aspects of the self to discover alternative perspectives to dominant negative or oppressive stories (White, 2007).

Data analysis

Dialogic performance analysis was used to analyse the data. This is a broad, varied and interpretative approach to oral narrative that makes selective use of thematic and structural methods and adds other dimensions. It analyses how talk among speakers is interactively produced and performed as a narrative. The analysis requires close reading of the contexts, including the influence of the investigator, the setting, and social circumstances on the production and interpretation of the narrative. Performance analysis of a narrative text needs to be grounded in the analyst's understanding of the context (Riessman, 2008). While it is common practice in narrative analysis to use one interview/text as an exemplar for a group, we decided to implement

a collective analysis using data from all the interviews to illustrate concepts and ideas. In this way, the polyphonic/multi-vocal nature of narrative would be more authentically represented through various voices of the women.

In comparison to thematic approaches that interrogate 'what' is spoken and 'how,' dialogic performance analysis pushes the boundaries of what is and what is not considered in narrative analysis, focusing on 'who' an utterance may be directed to, and 'when,' 'why' and 'for what purposes' (Riessman, 2008). The investigator becomes an active presence in the text. Dialogic/performance analysis is concerned with how social reality is constructed in interaction and how identity is dialogically created. This analysis assumed a narrative approach within a post-structuralist framework. This approach subsumes the destabilising elements of time, space and relationality into the central core notion of identity (Tanggaard, 2009). Dialogic/performance analysis allows the researcher to maintain an ontological perspective of identity. This "avoids categorical rigidities by emphasising the embeddedness of identities in overlapping networks of relations that shift over time and space" (Somers, 1994, p. 607).

To facilitate immersion in the data, the data was first analysed thematically using NVIVO8 software. Second, the themes that contained the most references in the text were analysed further, using structural analysis. Structural analysis focuses on where and when specific themes or ideas are mentioned, as well as the order of presentation of ideas and topics within these themes (Riessman, 2008). The manner in which interviewees constructed arguments and narratives to convey their ideas and convince, collaborate with, or correct the interviewer was carefully noted.

At a third level, dialogic performance analysis was applied. The interview data were analysed for double-voicing/ventriloquating, even triple-voicing, whereby re-accentuating the voices of others provided speakers with a mechanism to establish positions for themselves (see Bakhtin, 1981; Wortham, 2001). The style of language (e.g. confident and purposeful or vague and hesitant), the use of disclaimers, and apologetic and submissive language were documented (see Riessman, 2008). The use of sub-narratives to support or explain opinion or the main narrative idea suggested conviction of ideas. Topics, spontaneously raised and repeated, were considered significant, as well as those that were raised despite what the interviewer was asking. Turn-taking and topic management in the conversation were also taken into account. Special attention was paid to comments, ideas or narratives that were conveyed to external audiences (i.e. those other than the interviewer and translator) whom the interviewee believed the information would be conveyed to.

Findings and discussion

In the women's narratives it was evident that the context of poverty had a major effect on their personal and group activities and experiences. This narrative followed a similar trajectory as that well documented in the literature. The issue of space was important and strongly reflected in the narratives, featuring elements of the broader context of

care in the country as well as the participants' specific and personal contexts. The next section presents some of the women's comments on poverty and space in the context of the personal and group identities of HBCVs. This is followed by a discussion on ways of acknowledging and enhancing the voice of HBCVs in this context.

The context of poverty and the motivation to volunteer

Notably, time was a salient element in the women's narratives. Narratives connecting poverty, traditional values, and personal identity depicted a change in traditional values over time. Collectivism and sharing were referred to as important values in the past. The women indicated that although poverty already existed in the past, people survived and coped due to reciprocal community support and a belief in traditional values. One elderly HBCV talked about reliance on traditional collectivist values and reciprocity in the past tense, comparing it by implication to the current predicament that people find themselves in as a result of the abandonment of traditional values:

> Asanda: ...So we were poor and we continued to live like that, but the difference was that back then people used to give each other stuff. We use to share things, like we used to go to my uncles to fetch maas [sour milk] and there was also another house that we could go to if we wanted some sour milk. We would bring that back home and we would eat that. Sometimes you will be walking and someone would call you in and say here's some mielies, here's some sweet potatoes, people would...give each other food like that.

The participants referred to two major contextual (socio-historical) changes between the situation in the past and in the present. First, there was the collapse of the apartheid system and the establishment of a new government. In the past, black people in rural areas of South Africa had no government support and relied on community support in times of need, thus ensuring that collectivist values remained relevant. Migrant labour practices applied chiefly to men while women were forced by apartheid laws and tradition to remain at home. More recently, women have also started migrating out of rural communities as job opportunities become far more available to them as previously disadvantaged women. The latter situation has contributed further to the disintegration of the family in rural areas, often leaving elderly women to maintain homes and raise children. Second, the HIV epidemic has placed further stress on care and support resources in rural communities (Coovadia et al., 2009):

> Bongi: My times and these times are quite different. When I look at today's times, it's like a time of suffering. Even though things were difficult when we were growing up, we never lacked food, there was plenty of food. But in these times, there is no food. People need food and they are sick, but they need food before they can take their medication.

The women's emphasis on poverty and traditional values recreates a representation of the context that determined their reflexive social action (volunteering). Poverty, the advent of HIV and AIDS, the lack of government care and

support for HIV and AIDS patients, and the breakdown of traditional values create the context for reflexive social action in the form of volunteer home-based care. Significantly, personal experiences of poverty and the expectation that the government would begin to pay HBCVs was also evident in the women's accounts:

> Irene: So I thought that — Well, I need to do something, which will make sure in the long run we always have something to eat.... So I spoke to Nandi and asked if I could join and what I needed to do to join, and she said, yes, I could join. Although, at the moment, I am still volunteering totally, I am not getting paid and my husband has since found a job. But it is not very stable. But there is hope with this that there is going to come a point where I can make sure that there is something on the side.

The women acted on the personal identity elements of being compassionate and hard-working as they participated in care and support initiatives for people with AIDS (Naidu et al., 2012):

> Interviewer: What did you think qualifies you or what makes you able to do this kind of work?
> Jabu: I would say I have a heart, I have compassion, I feel sorry for people.
> Ompilo: I would say it is love, the love that I have inside, the love I have for my people who might be sick with HIV.

Through investing themselves in care work, the HBCVs resist the legitimising identity of women as caregivers in the home by installing alternative ways to represent their identity as caregivers (resistance identity). In this case, the alternative is volunteering for an essential service through which they attract the attention (positive and negative) of powerful stakeholders, such as community members, government agencies, researchers and activists. This represents an instance when social actors, on the basis of whatever cultural materials are available to them, build a new identity that redefines their position in society, and, by so doing, they seek the transformation of the overall social structure (Castells, 2009).

Group identity and individual identity and space

'Performance' regarding space varied, as space was performed in two expressions: 1) physical space for an office, garden or hospice/care centre; and, 2) legitimate space in the health system.

Physical space for an office, garden or hospice/care centre
Around the time the interviews were being conducted, the issue of a physical space for home-based-care volunteering was salient. First, the food garden the group of participants had planted to provide supplemental nutrition for the households they visited was under threat as it was in another community group's space. Second, they had not been allocated official office space by the community as was the case with other groups. Third, payment was being demanded for space to establish a care centre which had initially been offered free of charge. The group had no resources to pay the amount that was required. The expression of this claim for space of a hospice or care facility was

overt, distinct and consistent across all the interviewees, suggesting planning preparation or coaching. The researcher was perceived as an audience, who, if she could not provide help on this issue directly, could certainly convey the message to those who could. However, the performance, linguistically, was contrary in many of the women. In their talk, the women did not seem personally invested in claiming space. The narrative performances suggested that they perceived the claim to space to be beyond possibility and in the realm of the ideal. Talk about claiming space was typically expressed in vague and wistful terms:

> Bongi: *...So what I thought about after we had spoken is that it would be really great if there would be a place that was built to bring in all those people who are sick, because most of them don't get all the necessary medically related stuff. They don't take medication when they are supposed....*
>
> Cynthia: *...It is the promises that actually keep me going. They said* — Well do with the kit that you have, if there is something that you don't have tell people to go to the clinic. *They also promise us that one day we will have enough sponsors and we will get a hospital, we will get better conditions to do our work. So it is that hope.*
>
> Nandi: *Now the group already knows which households need more than others, but we have a problem because we don't have a place of our own here, so they told us that we are going to have to go because they want the crèche. And the other place, where we have the garden, the owner wants R8 000 for that. So we don't have the money and we don't have space, so I don't know how we are going to work.*

As a group, the women had begun a food garden to supplement the nutrition of the people they visited. The leader and others campaigned for donations to supplement their kits and to obtain other supplies. They participated in a *stokvel* (savings club) within the group to supplement their personal income and to contribute to improvement in their own homes and lives. This ostensibly implies there was a solid sense of group identity. As women, they had learnt to rely on and take care of themselves and others with no expectation that others would take care of them or even notice them. This attitude generalised into one of taking care of patients. The attitude was one of 'can do' and 'make do.'

Three elements of the women's performance around group identity indicated instability associated with group identity. First, the women did not place significance on the caregiving work that they did as something that required special skills, talents or disposition until this idea was outlined by the interviewer (see White, 2007). Second, there was no formal acknowledgement of the work within the health-care system and the group relied on erratic support from government agencies and various funding sources. Third, the way in which HBCVs positioned themselves relative to others in the HIV/AIDS care and support networks indicated that they perceived their role and position as subordinate within the greater network. Nevertheless, the group identity had the potential to garner support and recognition for the volunteers to a far greater degree than is available to family

caregivers. The elements affecting the stability of group identity are related to the fact that 1) women's care work is taken for granted and undervalued, 2) there is no formal acknowledgement of the work, and 3) HBCVs are considered on a bottom rung in the care hierarchy. The instability displayed with regard to group identity is reflective of the lack of contextual support for this identity.

A structural analysis of the transcripts indicated that the HBCVs' talk about space mirrored how they perceived their right to claim physical space for their group's work. Conversation about claiming space was inserted in 'gaps' in the interviews. Moreover, this topic was introduced in some interviews only when the interviewer deliberately presented an opportunity for the HBCVs to cover anything that had been excluded from that interview, usually at the end of the last interview. The assertion here is not that the HBCVs saw the issue of having a space of their own as unimportant, but that they did not perceive their identity as HBCVs as sufficiently powerful to secure such a place.

Legitimate space in the health system
The HBCVs' ideas about having a care centre or hospice also evoked future possibilities for their identity as caregivers. In such talk, the women entertained the possibility, however remote they currently perceived it to be, that they would one day achieve legitimately recognised roles in a space allocated to them:

> Cynthia: *Yes, it would really be nice if the government could work with us, that we be known to the government, so that they can give us things to use. We carry these bags with us when we do home visits; sometimes people ask you* — What have you brought me? *They expect something and all you have then is maybe a few diapers or maybe pain killers, or whatever, and you don't have anything for them to eat, because that is what they need.*

The volunteers' work was stigmatised by the community, their own family members and the family members of the people they cared for because of its association with HIV and AIDS. The narrative performances here were characterised by ventriloquating/double-voicing (see Bakhtin, 1981; Menard-Warwick, 2007) to convey the words of family and community members. Yet, they continued to do care work because it holds the promise of personal development:

> Interviewer: *What do you think other people would say about you and your work as a home-based care worker, for instance your family?*
>
> Dudu: *So my family doesn't have a problem with it per se. But other people do say* — Oooh, this kind of work that you are doing. I mean like really...I wouldn't do it, I wouldn't stand to look at other people's dirt — *and that sort of thing. I mean it's true it's sometimes disgusting, but you get used to it. You get used to it.*
>
> Interviewer: *What would they say about the kind of person you have to be to do that kind of work?*
>
> Dudu: *So, I think from what they say it's like you have to be really, really poor to do this kind of work, which is not necessarily true because it's just about* — do you want to do it? Do you have love for doing

it? Do you want to do it? Because if you are going to be repulsed by it, then you're not going to do it. You have to want to get over that repulsion.

In contrast to group-related narratives, the participants' personal narratives were performed confidently, with enthusiasm, determination and energy injected into the talk. These narratives were rich and there was little hesitation in giving examples. There were few disclaimers in the talk, little vague third-person and remote third-person talk. The narratives were also supported by sub-narratives that supported and enriched their main thoughts. The participants established a personal space as individuals which set them apart from others (community, family members) and the narratives devices they use illustrate this. This aspect of identity was performed decisively and confidently. The women were self-assured in their individual identity as caregivers and claimed the space for it in their talk, confidently supporting it with narrative devices.

Narrative performances on claiming space: personal and group identity

Performances of gender occur in most human interactions, and are always to some extent constrained by the social context, including factors like ethnicity and social class (Menard-Warwick, 2007). In this instance, gender is reflected as a social construct in which caring is construed as women's work. Thus, this aspect of identity is socially reinforced and the HBCVs' performance is simultaneously replicating and perpetuating the female caregiver role. The participants drew on past performances of their identity as mothers and the social construct of communal mothering in Zulu culture. While acknowledging the constraints on gendered performances, a number of authors (Blackburn, 2003; Eckert & McConnell-Ginet, 2003; Pennycook, 2004) point to such identity performances as a potential force for individual and societal change. This was evident in the women's performances as they referred to group identity. These performances tested the boundaries of women's caregiving, which has been traditionally confined to the home and immediate community.

The group identity tests the notion of caring as promoting agency in women. In assuming the role of HBCV, the women created an opportunity for their voices to be heard both as individuals and as members of the group. The role of HBCV could garner attention from government, non-governmental organisations, and researchers (as with this study) due to their visibility in the community. This is in contrast to family home-based caregivers who typically become isolated as a result of their caregiving duties. Moreover, the group's activities would suggest to potential supporters and investors methods for how AIDS care in the community might be supported. The social circumstances created by the HIV epidemic and a corresponding lack of support from outside the community resulted in caregiving becoming a commodity and one through which the women may develop and be recognised by associating their care services with agency. This is possible only through mobilisation as a group. As a group, HBCVs can gain greater visibility and voice than they would as individuals — and certainly more recognition than female family home-based

caregivers. Women volunteer their services as caregivers in home-based groups, established within communities, in the hope that this will lead to formal employment as caregivers or at the very least that they will qualify for a stipend after a period of volunteering. This has already happened to some degree. In July 2011 a group of volunteer caregivers were given government-paid positions as 'community caregivers.' The first expressions of this agency are tentative as they transgress a traditional gender performance, which is unpaid caregiving by a female relative in the home. Coovadia *et al.* (2009) stress that the will of the people, expressed through resistance to oppression or mobilisation against failed policies in democracies, is the best investment for a healthy future. By moving the tradition of women's caring outside the home and into the public realm, the HBCVs are transgressing the assumptions that care is confined to the home and carried out by female relatives and that caring for AIDS patients is stigmatised.

According to Somers (1994), modern theories of universal agency have rendered many realms of human activity inexplicable. In the past, women, non-Westerners and minorities were frequently defined in social analysis as irrational, anomalous or deviant from modern social action. Somers (1994) contends that as long as we continue to conceptualise others as sources of external constraint we are forced to label such relational and institutional-oriented goals as 'backward looking' and 'reactionary' or 'evidence of social control.' Home-based-care volunteering has been labelled 'oppressive' and 'burdensome' as the work is judged in relation to gender and power relations in the community (Somers, 1994, p. 633). Care work is viewed in the realm of women in the community; therefore, it is deemed to be less important, easy and unskilled, and is accordingly undervalued. Ironically, it is the only area in which women can call themselves dominant and therefore they may be reluctant to relinquish it to men. In fact, women may actively discourage men from a caregiving role, providing examples they have witnessed in the community, currently and in the past, as evidence that men are not capable of caring. Superficially, this appears to perpetuate a *legitimising identity* of women as caregivers. However, including the fact that the caregiving is voluntary introduces an element of resistance. The participants saw voluntary caregiving as an opportunity to be noticed and gain recognition — ultimately in the form of paid work and an acknowledged space in the care and support network:

> Jabu: *I think that it is very important that there are mothers like us in the community who can do this kind of work…. I mean if a child doesn't have a mother he is as good as an orphan, because the father will almost always go after another woman and forget about the child.*

Women's undermining of men's participation in caregiving has been noted in studies in other parts of Africa (Mbonu *et al.*, 2010). The lack of power as caregivers is linked to the lack of power as women. Whereas women may perceive themselves as having personal power, their performances relating to group identity in which they position themselves as less powerful suggest their identity as HBCVs is nascent or emergent. Even though there are glimpses of this

identity, it is not yet a fully formed aspect of their identity. This is characteristic of resistance identities and is associated with an absence of support from structural forces (e.g. government).

The traditional female roles of mother, wife and nurturer are highly valued in traditional Zulu culture, and women attain status through marriage and having children. However, women's identity within caregiving groups is not as actively, widely and overtly supported. In effect, group-based caregiving as offered by HBCV groups may be discouraged by community members and their own families (as illustrated above) and caregivers may be stigmatised due to the association with HIV and AIDS. This dissuasion is due to the stigma associated with HIV rather than to stigmatisation of the caregiving itself. Furthermore, the fact that the women do the work without payment supports a common notion that they 'must be desperate' to do this kind of work (Parker & Aggleton, 2003).

Hearing the voices of home-based care volunteers

Women are cast as powerless within the dominant narrative of women as caregivers. In the context of HIV/AIDS care and support in poorly resourced contexts across the world this relegates women to an apparently thankless and weak role. Evidence from the HBCVs' narratives in this study suggests that the picture is far more complex on the ground. Home-based care workers who receive little official and community status and recognition seek spaces to express their identity and the importance of their role.

The narrative performances recorded in the study were variable in their force, efficacy and eloquence. In some areas, the performances were confident and show evidence of being well-structured and well-planned. In other areas, the performances were hesitant, vague, apologetic, nascent and not yet supported by broader narratives, as yet unpractised by the narrator (e.g. claiming space for the work). Wojcicki & Malala (2001) associate agency with resistance and recognise that women's power operates in the spaces around wider power relations. This hesitant type of performance supports the assertion that 'home-based care volunteer' is an emerging identity. As mentioned earlier, expressions of 'resistance identity' offer glimpses of agentive potential, which could dissipate if left unsupported or not facilitated. We propose viewing women's caregiving groups as a potential site for developing HBCVs' agency in the context of HIV and AIDS. For example, the results of this study and related work with this HBCV group were used to stage a narrative theatre production and photo-comic presentation with the intention of taking the results of the work back to the community (Sliep & Kezaabu-Kasimbazi, 2011). Here the HBCVs performed their experiences of providing volunteer care in the community at a large gathering of community members, researchers, and local government representatives. Two of the themes that the HBCVs chose to express were 'competing for resources' and the 'lack of communication between government, community and organisations.' Indeed, small group initiatives in communities are generally where women have the potential to be most powerful and to express their voices outside of the home. Thus, the study participants expressed agency

through the identity of volunteer home-based caregiver, which was supported and facilitated via a narrative theatre production. Through the process of preparing and staging this production, which was supported and facilitated by the researchers, the HBCVs had the opportunity to explore their identity and role as volunteer caregivers. The expression of this in the community gathering was a step towards building a new identity (project identity) that could redefine their position in society, and, by so doing, seek the transformation of the overall social structure.

This adds weight to the view that, in order to impact significantly on the nature and value of care work, structural changes that influence wider narratives are needed. Interventions and empowerment strategies that are envisioned as having an effect on individuals and groups are unlikely to have a significant and enduring impression — as individuals inevitably subscribe to, perform, and perpetuate existing grand narratives. Unquestioning acceptance of established norms confines people to being subjected to them, regardless of whether the said norms are oppressive, stifling, harmful or otherwise restrictive. For the desired changes to occur, corresponding structural changes must simultaneously occur to support and develop emerging 'disruptive' narratives and associated identities. In the absence of corresponding supporting structural or wider discursive changes, emergent disruptive/alternative narratives are ignored and suppressed, and the associated resistance identities are extinguished. Anti-apartheid revolutionaries understood that emergent black identities in opposition to the Nationalist government's construction of black identity would soon be crushed under the dominant machinery of apartheid narratives. They canvassed support in the wider global community and created underground movements that offered structural support and created associated grand narratives that supported these emergent identities.

Studies that include women affected by HIV and AIDS tend to make broad recommendations about improving structures, policies and programmes to protect women from contracting HIV. These studies recommend addressing socioeconomic and literacy issues (Buseh, Glass & McElmurray, 2002) or analysing cultural effects (Songwathana, 2001). While these issues are carefully investigated and outlined, recommendations tend to take the approach of talking *to* women, *at* women, or *for* women — instead of *with* women. These recommendations are broader in their scope and would, in general, require some interpretation and adaptation before they can be applied practically. Moreover, it seems that current research frequently asks women about issues on an individual level (most studies employ the method of individual interviews) and then translates the findings into recommendations for women on a broader structural level. What is missing is a perspective on women in collectives or small groups. For instance, does what women want for themselves as HBCVs relate in any way to what researchers see as important issues to address and to improve the conditions for women in general in the context of HIV? Do women affected by HIV and AIDS share researchers' and theorists' concerns for these broader issues, or do they cooperate in research initiatives because they cannot refuse an opportunity to

have their voices heard? It would seem that the gap that women's agency tends to occupy in the informal infrastructure around HIV is not adequately addressed in research. Issues pertaining to women's groups, such as home-base care groups and community women's forums, have been largely left unattended, except for a few isolated studies (e.g. Akintola, 2006; Campbell *et al.*, 2009).

Conclusions

In participating in organised voluntary home-based care, women resist the 'legitimising identity' of women as natural and traditional caregivers and generate the 'resistance identity' of HBCVs in response to the South African government's neglect of HIV/AIDS care and support in rural communities. In this article we provided evidence that in laying claim to physical space (e.g. in the form a local hospice) and space in the formal care network (in the role of home-based caregivers) for AIDS care, HBCVs seek to reshape their identity and redefine their position in the social networks around HIV/AIDS care and support, thereby counteracting the assumption that care by female relatives and volunteer (unpaid) care by local women is unquestionably acceptable. We propose that the volunteer home-based care groups initiated by women create the context for the emergence of a resistant identity associated with women's caregiving and the opportunity to be recognised and demonstrate agency by resisting unpaid care by women in communities. This allows women a chance to explore new aspects of identity with the potential for self-development.

South African women as HBCVs are unique in their performance of identity in the wake of the history of apartheid as well as in the continuing context of poverty and the marginalisation of women's concerns. While South Africa is commonly regarded as one of the best-resourced countries in Africa, factors such as competition for resources between small groups associated with HIV/AIDS care, HBCVs' interrelational struggle for identity and place, coupled with the government's failure to distribute resources equitably, create tensions between groups competing for resources and informs the identity perspectives of the group members. Women's experience of a socio-political history of poverty and gender- and race-based oppression in South Africa provokes agency and activism stemming from a historical mistrust of the government's handling of resources. Women's groups perform agency to assert their identity perspectives and exercise responses to personal and community challenges. The existence of home-based care groups provides the government with an opportunity to invest in the initiative demonstrated by women who participate in voluntary caregiving. Through support of these groups, the government could assist in providing HIV patients with home-based care while simultaneously creating space in which women can explore emergent aspects of identity contributing to their own empowerment and self-development.

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Chapter 8

Am I a poet-researcher?

(Autoethnographic realisation of legitimacy of voice: a poetic trail of the forming identity of a researcher while completing a study of volunteers providing home-based care to AIDS patients in a in rural setting in KwaZulu-Natal, South Africa)

"Performance helps me see" (Madison 1999)

Abstract

In my work in a rural South African community, autoethnographic poetic reflection highlighted the trail of my experiences in realising my voice as a researcher. Here I illustrate how I employed poetic reflection during my doctoral work with HIV and AIDS home-based care volunteers. The method addressed how issues of space, witnessing and projecting voice were implicated both in the process of realising my identity as a researcher and HIV/AIDS care volunteers realisation of their identity as valuable contributors to the HIV/AIDS cause. I propose that autoethnographic reflection through poetry can help researchers to consciously acknowledge and creatively apply their subjective positions and experiences within the research environment in ways that are beyond the scope of standard academic prose. Poetry can be a valuable, creative and generative medium for autoethnographic engagement, facilitating creative thinking and meaning-making more generatively than prose. This allows the researcher to breach new and innovative conceptual territory.

Introduction

In this article I present my experience of using poetry as a reflective tool to facilitate my personal insight as a researcher and how this process contributed to the results of my research. I present poetry as a reflective medium that allowed me to assimilate and process swathes of emotion-infused data. Poetic reflection offered a means to 'drift' in- and out of the data on a reflective rather than an analytical level without completely losing touch with the content of the research.

Postmodernism is imperative in ethnography for the latter to remain contemporary and relevant in diverse global contexts. Poetry as a medium of documenting autoethnography attends to this through merging conceptual, cognitive and emotive aspects of human experience. It allows for audiences to concurrently participate in the researcher's experience and make subjectively meaningful interpretations by appealing to the audience as hermeneutic beings. Autoethnographic poetic reflection encourages links between the personal and political that can lead to novel understandings about the shared humanity of researcher, participant and audience thereby reducing 'othering' in research.

Qualitative researchers acknowledge that interpretive acts of meaning-making are always located in contextually unique social environments, times, and places. Their intention is to render these contexts visible through depth and richness in the descriptions of human talk about experiences behaviour (Clarke et al. 2005). Such researchers are interested in "metaphoric generalisablity", referring to how qualitative data resonates with the essence of human experience and how it also fully resonates with an engaged audience (Furman, Lietz, and Langer 2006). Concerns about the unexamined power of the researcher, as exemplified

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positivist researchers' exclusive responsibility to determine objectivity, led to an emergence of feminist versions of reflexivity. These aimed to reframe power balances between participants and researchers where the voices of participants are seen as equivalent to the voices of researchers in data representation (Hertz 1997). In this vein, persistent emphasis came to be placed on community, relationality and the democratic involvement of participants (Lincoln and Reason 1996). Qualitative researchers no longer question the need for reflexivity in qualitative research, but question what form reflexivity should take. A more explicit focus on the reconstructed nature of researchers' reflexive accounts is required. Acknowledgment of narrative reconstruction in developing reflexive accounts creates ethical research. This should include the explicit admission that the researcher's role cannot be fully captured in data production (Bishop and Shepherd 2011). Researchers need various competencies, and participants need emerging competencies in this type of research environment. Amongst these are interpersonal, political, emotional, moral and ethical competence, intellectual openness and creativity, and spiritual qualities. Building on these ideas, (Denzin 2003:216) challenges qualitative researchers to engage a new movement in qualitative inquiry, described as "a radical ethical aesthetic" in which researchers move from the personal (the reflexive relational) into the political (reflexive activist), by employing emotional critique to political action. (Finley 2003) proposed that arts-based inquiry in the form of poetry, narrative theatre, creative writing, etc. could be the catalyst for movement into the radical, ethical aesthetic. I found that the medium of poetic reflection addressed the issues of voice, identity and reflexivity, for me as a researcher.

Richardson and Adams-St. Pierre (2008) regard writing as itself a method of inquiry, as a way of discovering and knowing, not simply a way of telling. In presenting writing as

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constructional, they envision writing and the writing process as a multi-textual space where various voices dynamically contend for positions. This is a space where that which is 'partisan, partial, personal and perhaps even political' can find illustration without necessarily approaching imposed, resolute but inauthentic clarity. A consciously reflexive position facilitates researchers' attempts to engage with and empathetically appreciate the private, emotional experiences of research participants. In the process of reflection, researchers have typically shared intimate and personal reflections of their own as they interview and observe study participants.

Autoethnographies situate personal experience within social and cultural contexts and invite provocative questions about social agency and socio-cultural constraints. According to Jensen-Hart and Williams (2010), good autoethnography is a distinctive method of garnering knowledge within inter-subjective realities, which concurrently creates critical reflection. Denzin (2006) submits that ethnographic research practices are not innocuous but performative, pedagogical and political. This means that rather than being inert ethnographic research practices influence the contexts in which they seek to document describe or understand by recreating those contexts, teaching about them and influencing and being influenced by them on a political level Ethnographers enact the world in writing and talk, through performances that are messy and instructive. They teach readers about the world and their views of it using moral and political methods. Autoethnography challenges, contests or endorses the official, hegemonic ways of seeing and representing the other through this enactment. As a critical methodology, it endeavours to disrupt and deconstruct cultural and methodological practices performatively for the benefit of a "more just, democratic, and egalitarian society" (Denzin 2006:422).

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Poetry may be preferable to other forms of representation for some kinds of knowledge and useful for seeing beyond the conventions of sociological representation (Richardson 2002; Clarke et al. 2005; Furman, Lietz, and Langer 2006; Prendergast 2009;Leggo 2011)). Piirto (2002) has argued that, through poetic representation, the field of social science representation is transformed through individual researchers pushing the boundaries of their domain. The convention of using standard prose as a representational form for interview material is simply one possible literary technique and not the singular legitimate medium of knowledge representation (Richardson 2002). Poetry is not bound by the rules of grammar that limit expression, despite its use of linguistic symbolism. The use of elements, such as metaphor and other symbolic imagery, enables access to deep, unconscious material that may only available in the symbolic manifestations of poetry. It allows for the expression of deep-seated symbolic material, and the development of a distinctively personal voice that communicates the idiosyncratic realities uncovered in the autoethnographic process (Kempler 2003).

The intersection of poetry and autoethnography falls within the description of evocative autoethnography. Autoethnography usually stems from researchers' emotions, or connects emotions to research in some form. In writing authoethnography, the researcher/poet must call on issues that are personally resonant issues whilst concurrently reflecting on research processes and outcomes. Saunders (2006:504) maintains that poetry is a form of research in that it is tangible, an aesthetic object, "made in language". The silences within poems stir the memory and kindle the unconscious by saying just enough, to allow the audience to connect with the provocative space central to the issue. It is the skilful juxtaposition of silences and words in poetry which gives poetic work meaning. This is what makes poetry emotionally evocative for the audience. Audience members experience poems

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as hermeneutic beings who construct understanding in distinctive ways that contribute to their enduring and coherent identity (Berry 2006). Poetry seeks to examine the meaning-making opportunities in everyday life by means of close examination through an alternative creative lens.

In the process of qualitative research, it often happens that once the data are collected and sits as a mass of recordings, the researcher is typically apprehensive about commencing the analysis process. In qualitative research, most especially in the analysis and interpretation stages, it is difficult to generate new ideas and ways of looking at the data when had been involved in the process for an extended period. Poetic reflection can offer direction by at once offering the researcher a means of consciously addressing apprehension and beginning to process initial impressions of the data. At later stages, when the researcher is immersed in the data, poetic reflection can be used to access different perspectives and impressions on the data as various dimensions emerge. The latter ordinarily becomes increasingly difficult as the researcher becomes more familiar with the data. Poetic devices such as metaphor, imagery, personification, etc. can stimulate different levels of thought and facilitate creative thinking. Kinsella (2006)suggests that reflection on practice rooted in poetic form (poetic reflection) can illuminate tensions, highlight previously silenced experiences and generate new interpretations.

Context and orientation to the study

Current national HIV policies or strategies do not address many central aspects of HIV/AIDS care and support. Volunteers commonly provide the bulk of much needed

psychosocial and physical care services and support. Family and community members, volunteers , particularly women, whose contribution to the HIV/AIDS response often goes unrecognised and unsupported, meet most care and support responsibilities (UNAIDS, Global Report 2012).

In South Africa, most home-based care volunteers are unemployed women in the community who care for AIDS patients who are in an advanced stage and others who are unable to care for themselves. Volunteers are not related to patients and commitment is evident when one realises that there is limited access to running water and electricity in the community and daily household chores might include fetching water from a communal tap, collecting firewood and tending to the family food garden in addition to cooking and cleaning the family home before tending to patients. Local government gives some of the women a stipend of R600-R1200 ($70-$140) a month, referred to as "soap money". Most of this is spent on transport for minibus taxis (the only available public transport) in the hilly community, where houses are widely spread over a large area. Home-based care volunteers (HBCVs) regularly use the money that they are paid to buy food, soap and other necessities that their patients cannot afford. Volunteers own family members may also contribute to their 'work'. In the AIDS care and support hierarchy, home-based care volunteers occupy the lowest rung. As such, the women have been all but invisible as a group and up to now remain so as individuals. The women participating in community-based AIDS care and support act out of altruistic sentiment and communal cultural expectations, and hope to possibly gain access to paid work and have the opportunity for self-improvement through recognition they receive during the course of the work (Akintola 2010).

Little is known about HBCVs' identity and their reasons for volunteering. The aim of the broader study was to understand the social construction of identity in home-based care volunteers. In this study, fifteen home-based care volunteers were interviewed in three successive interviews. As the work progressed, I realised that there was a need to create the space for volunteers to tell about their work, their lives and themselves in ways that facilitated legitimacy and awareness of their identity. In this presentation, I will illustrate how my journey of realisation towards developing a legitimate voice as a researcher paralleled the women's realisation of a legitimacy of voice as home-based care volunteers and how our voices collectively contributed to the quality of the research.

Poetics and space

Physical space and self-development

I wrote my first poems on a three-hour train journey from Stoke-on-Trent to London. I had just attended the 3rd International Narrative Practitioner Symposium where I first encountered, narrative research presented in creative forms. There were visual presentations, songs, short plays, videos and poems. On that trip, I wrote, in my ever-present reflective field notebook, the beginnings of my first poems. Later I came across a poem reflecting on the "intergeneric world of poetry and inquiry" written on the Vancouver Island ferry (Prendergast, 2001). This sparked the idea that space was implicated in the poetic process, especially in the case of research poetry. The physical space created by travelling and the train journey had manoeuvred me into a poetic space. My encounters with the creative representation of the narrative practitioners at the conference facilitated a cognitive space for poetic expression.

22/06/2009 to 24/06/2009

Attended the 3rd Narrative Practitioners Conference

Interesting how widely accepted and known narrative is here in the UK. It is easy to engage with researchers who understand the intricacies of narrative research. What I learned most profoundly here is how the findings, outcomes, understandings of narrative and indeed qualitative research can be presented in creative and different ways. In some instances they can only be presented legitimately in this way.

Writing the poems served the purpose of situating emotions that were bubbling under the surface of my psyche waiting for a legitimate place. When I wrote the first research and reflective poems, I was merely mimicking what I had seen and heard at the conference. Through poetry I practiced autoethnographic reflection. There were many times in the process that I encountered information, ideas or processes but did not really hear them until a space had been created for them. My doctoral supervisor would suggest an article to read or area to consider. I would not hear her until days, weeks or months later when I was ready for the idea. The seed for this article was one of them.

The association between my own process and the experiences of the home-based care volunteers in my study occurred to me whilst road-running, giving myself space outside of work and writing to explore a different aspect of myself and work on a different side of my life. I considered whether those home-based care volunteers had the task of self-development in conjunction with the new information they encountered to enable them to confidently express their ideas and intentions. Would their experiences include elements of self-doubt similar to my experience as a emerging researcher? The extract below documents my initial

consideration for creating space within the interview process for interviewees to reflect more spontaneously and creatively about their work and lives.

The interview had to be halted often for interpretation. This interfered with the flow of the interview and I felt placed an inordinate amount of control with the interviewer. This effect could be counteracted with an opportunity for the interviewee to give a more flowing account. Interpretation in this account could be for broad understanding and the interpreter would interrupt the interviewer far less often. The interviewer would at this stage make fewer clarifications other than those that have to do with the content of the life story and would make no attempt to make connections between ideas of uncover meaning.

****Need to substantiate this with evidence from different interviews.

As mentioned previously, connections could be explicitly elicited in a third follow-up interview

Reflective field notes 14/05/2009

While interviews were being conducted, the issue of a physical space for HBCV work was in contention. A food garden that the group had planted to provide supplemental nutrition for their patients was under threat as it was in the space of another community group. They had not been allocated office space by the community as other groups had. Space to establish a care centre that had initially been offered free of charge was was then reoffered at an unaffordable rate. The latter was a particularly important issue for this group of volunteers. Impressions of the women's interviews suggested that they perceived the claim to space to be beyond their capabilities. The HBCVs' conduct in the interviews suggested that they saw the

issue of having a space of their own as important, but that they did not perceive their identity as HBCVs as sufficiently powerful to secure or demand such a space.

Ensuing conversations with the HBCVs aimed to facilitate space for the exploration of identity in context. I hoped to arrive at an understanding of how the women made sense and meaning of their lives and work in what seemed to me to be intolerable physical conditions, lack of support and invisibility. I realised from my own experiences, that an enthusiastic audience who provided witness to one the telling of one's story contributed greatly to validation and affirmation of that story. The enthusiastic audience was an important element of establishing and acknowledging my own identity as a researcher, and I decided to acutely aware and reflective in my position as a witness to the stories of the HBCVs. The group of HBCVs had discussed their work with other researchers previously so I added the life story and reflective interview to scaffold a connection between their work (landscape of action) and their personal identity (landscape of identity) (White 2007). I adopted an attitude of seeing the HBCVs as experts in their own lives, listening in a non-judgmental and accepting way that encouraged HBCVs to reconnect parts of themselves (personal narratives) that they had not considered as important but were significant in the home-based care work (Weingarten 2003). I used a questioning style that served listening, promoted the development of alternative meanings, and which was non-judgemental and accepting (White and Epston 1990;White 2007).

Dialogical space and identity construction

I was intrigued by how the construction of identity is a constant interplay of what is perceived as self-determined and the influences of audiences and context. Dialogue with my

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doctoral supervisor elevated my research and reflective process. In this relationship too there was constant interplay between supervisor–student convention and the 'academic rebellion' that I had to embark on to develop new frames and paths for exploration for myself as a researcher. In the poems below, I consider the issue of how context and audience shape performance and the performer's identity. This realisation is simultaneously liberating and oppressive. One is compelled to act within the boundaries of what is recognisable to others in order to be recognised as a person. However this compulsion can be stifling sometimes, perpetuating a dominant, tyrannical norm. This cycle of performativity is breached only through decisive rebellion in thoughts words or action. Those who choose to enact this rebellion risk losing identity within contemporary and traditional frames, when they venture to explore or assert new possibilities for identity. Yet, even in this rebellion, the other, whether real or imagined, is still essential for dialogical impetus to witness, corroborate and support the emergence of new frames. The dialogical self approach to understanding identity contests the notion of identity as a fixed duality and conceives of identity as socialised, historical, cultural, embodied and decentralised (Hermans 2003).

Sawubona means "I see you"

Sawubona

Yebo, Sawubona

Ninjani

Ngikhona ...

I see you

Yes, I see you (two)

How are you?

I am here

You see me

So, I am here

I see you

So you are here

Salutations, breathed on the wind

Condense, on touching ear, mind and spirit

Sound-shifting across familiar melodies

Abiding ancient rhythms

Voices draped perilously on the breeze

Plucked by deft thoughts

Woven into colourful exchange

Lacing round communal yarns

Conversation settles on unsteady wings

Vivid ideas take flight,

In the air amid minds

Connecting past and present people

Spin-storying over time(s)

Performing tentative designs

Skilful sewing fashioning ties

Stitching the banner of 'I'

As I became more captivated by research poetry, I became more daring about how I used it. I started to write what I call 'transitional poems'. These poems occupy a space between traditional presentation of research data and poetic representation. I would classify this type of poetry as consistent with Piirto's (2002:434) description of "poetry that has no issue of quality or qualification in the exercise, or in the execution. It is simply a means of alternative expression and alternative seeing". Writing the transitional poems quelled my anxiety about writing 'perfect poetry' that fulfilled poetic criteria whilst allowing me to

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harness some crucial reflective ideas before they dematerialised. Moreover transitional poems allowed me to bridge the space between the emotional and the cognitive. In order to convey the emotional ideas inherent in the data without sacrificing poignancy, I could safely indulge in the transitional poem where I could engage with data, a reflective idea or with the relevant emotion of a poem first. Transitional poems facilitate dialogical reflection and promote critical agency. The transitional poem below is one that developed towards the poem above. Here I was grappling with the notion of collectivist aspects of identity. As we strive to be seen, recognised and acknowledged as a right of our existence in the social world, there is the implicit responsibility of reciprocity in this recognition.

To be a person in this world you must ...

To be a person in this world you must

See others

Others must see you

To be a person in this world you must

Sing others' songs

Others must sing your songs

To be a person in this world you must

Dance others' dances

Others must dance your dance

To be a person in this world you must

Hear others' voices

Others must hear your voice

To be a person in this world you must

See(k)

Sing

Dance ... Listen

Notably, the African philosophical concept of Ubuntu commonly articulated in the isiZulu phrase *Umuntu ngumuntu ngabantu* (a person is a person because of people) corresponds here, reinforcing the idea that every aspect of human identity is always defined relative to the identity of other human beings. To authentically inhabit an identity it is imperative that one is witnessed and acknowledged in one's performance of that identity. According to (Weingarten 2003), witnessing includes the element of remembering. If someone witnesses another by remembering qualities or aspects of their lives that they have neglected, but which have bearing on current circumstances, that witnessing will produce a greater sense of wholeness in the other then previously held. Witnessing also incorporates

non-judgmental, accepting listening and questions that serve and promote the development of alternative meanings (Weingarten 2003; White 2007).

Witnessing

Witnessing as a qualitative researcher

These researchers maintain that Witnessing is a consequence of using qualitative methods that require the direct presence of the researcher in the process of research (Stein and Mancowski 2004). In working with marginalised groups, qualitative researchers are often among the few to witness the study participants as informants. Witnessing and validation by others leads to a legitimate sense of self and a resonance with valid discourses or the self-confidence to challenge counterproductive discourses. Alternatively, qualitative researchers may help elicit prior experiences of being powerless, reveal unguarded narratives and reveal the workings of an oppressive system in their work with dominant groups. Witnessing can be transformative for both the researcher and the research participants in marginalised or dominant groups (Stein and Mankowski 2004).

In my conversations with the home-based care volunteers, I saw that my (and other researchers') witnessing offered a means for acknowledgment and affirmation of their work. At a practical level, the home-based care volunteers recognised the witnessing aspect of interviewing as a method for drawing attention to their needs and a way of gaining material resources.

Asanda: It's helpful to talk, it helps because sometimes we do what we do and we don't know what other people think about it, so if there is a possibility that someone will hear about it and do something to what we do and how we do it. And also just to have someone to

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listen even though they are not going to do anything or help you in anyway but just listening. Sometimes we are out there and we start doubting what we do, ask ourselves is it relevant is it contributing towards anything and we are sometimes not really sure.

Being witnessed and acknowledged offered catharsis and inspiration to continue with the work.

Asanda: *It felt like I had gained something even though I did not have anything tangible. It felt like a big weight had been lifted off my shoulders.... Talking helps and it makes me not sit and not do anything, but it makes me work even harder and move on from that. ...Sometimes when you really need to talk you might have to call someone who is not so close by to you and that is limiting. But to have someone that you don't know who is interested in listening to what you have to say, you can say and talk about anything and that makes me ... it makes me feel good.*

Research ap(plea)cation

Represent me as

I represent you

Stand up for my rights

Go where I cannot

Speak for me

Make them hear my voice

Represent

In the poem above, I considered my responsibility as a researcher to authentically represent the voices of the participants in research output. In fact, as my voice as researcher became stronger there was the risk that it would obscure the participants' voices in my representation of them. The process of acquiring a legitimate researcher identity involved my having to make various applications to funders and review boards for funding and ethical clearance of the study. I questioned how this process moved me further from the essence of what the participants had to say and how I would represent it. Standardised data representation methods distance or alienate the researcher from the voices of participants and the participants from how their words, thoughts and feelings are represented, particularly if the participants belong to disempowered or marginalised groups. Very few, if any, research participants are able to understand research reports or publications about the results of studies in which they participated. Stein and Mankowski (2004:22) submit that part of the assumption that qualitative research serves is to reveal or amplify the voices of participants and this should be incorporated in what they refer to as 'the act of knowing'. This is the researchers ethical obligation to create publicly accessible representations of knowledge gained by conducting qualitative research. It embodies the reflections and understandings of the researcher about the social contexts and lives of research participants and can be represented through a various activities, e.g. writing, teaching, speaking, organising, depending on research and action goals. Poetry represents a valid example of the "act of knowing" in qualitative research. This is particularly apt because research poetry represents a resistance to academic prose and offers the opportunity for people to simultaneously connect with the content, context and emotional connotation of the research, mediated by the researcher/poet's reflective voice. The latter is significant in that it is possible for the researcher's voice to be manifestly evident in poetry

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contrary to positivist academic prose where it is often the researcher's/writer's aim to eliminate subjectivity from writing.

Witnessing: Validation of self and other through dialogue and authentic representation

In the initial stages of my work I constantly doubted, at a 'rational' level, the legitimacy of the research methods that I was drawn to and which were, on a visceral level meaningful to me. The intuitive attraction to the creative aspects of the work and the assurance from my doctoral supervisor that this research direction was indeed legitimate and had many vociferous supporters ensured that I persisted despite doubts. I began to realise that being part of the research community that heard and understood my voice gave me confidence to explore my ideas further and present them in more creative and authentically representative modes. A poem conveys this.

(Poet)ry B-rated

Of all the names I've called myself

Of all the selves I would've liked to be

A poet was not a role I thought I'd fill

A poetess less still

To be judged with those that scribble

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In dog-eared, well-thumbed notebooks

With pencils past their prime

Was not a goal of mine

Scratching sentiments of love won and lost

Extolling virtues of those dead and past

Sprouting language in bursts of fire

Was not the course of my desire

Then bewitchingly, sleight of word

Entranced this stolid mind

Materialising magical refrain

Past logic's dense domain

Scratchings not works of literary merit

Tethered thoughts unfetter

Finding in poetic identity

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A peaceful synchronicity

In considering the legitimacy of my voice as a researcher, I shared common ground with the home-based care volunteers. I had embarked on work that was personally significant and meaningful to me but I constantly doubted myself and adhered to superficial exploration of the work and my own perception until I experienced validation from like-minded researchers, my doctoral supervisor and the acknowledgment of my work in an academic journal. The HBCVs had also embarked on work that was necessary and personally significant whilst striving for legitimacy of voice as a group. Their voice and interests were not supported by larger social and political discourses and structures but gained some ground through the interest shown by researchers like myself, their patients and community members.

Poetic representation creates the space for alternate expressions of life along with the opportunities for critical attention to knowledge claims about them (Richardson 2002). As I struggled with my right to represent the women's voices, poetic expression redeemed me through its very form and style. The necessary silences, spaces, implication and impression of the poetic form created a respite between the women's voices and my representation of their voices in which I hoped an audience could relate to the material through the vantage point of a personal repository of experience In this way, it seemed to be a more respectful, authentic and genuine means of representation.

Projecting voice: Making the personal political and the political personal
...Performance ethnography, of which poetic reflection is a form, offers more than a tool of liberation. It is a way of being moral and political in the world and represents striving for an

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ethical position and authenticity in research (Denzin 2003; Stein and Mankowski 2004). Performance ethnography represents a form of action research in that it is a triple process of doing, thinking and being. Action research combines the process of developing theory and practice through making creative connections and playing with interactions between emerging concepts and different arts-based media generally, and poetry in particular (Elliot 2009). Poetry writing as a form of enquiry knowing can be used as a medium to make conceptual breakthroughs in writing action research and as a means to reflect on and distil writing experience (Richardson and St Pierre 2008; Barrett 2011). The concept of civic participation is redefined within the spaces of this new performative, cultural politics and radical democratic imagination, transforming the personal into the political.

Writing space writing self

In my space, I write

My space writes me

With my words, I speak

My words speak me

Hearing my words,

You hear me

Knowing that

You hear my words

I become me

"I write what I like" *

I write what I am

I write what I will be

I write me

*From South African black consciousness leader Steve Biko's writing about claiming identity from fear, oppression and denial (Biko, 1978).

Hiley (2006:561) proposed that there has been a "great silencing" of poetic voice such that we are less likely to acknowledge the everyday, practical value in realising that reflective practice and poetic expression are linked, and that expressing our "selves" in texts animates our words and actions. I questioned whether my identity as a woman from a marginalised group affected my ability to believe confidently in my own voice as a researcher. In all dealings with the world, women must take an apologetic stance for success and sacrifice other aspects of their lives to achieve it. Sometimes, they must even make excuses for why they want to achieve or ask permission for participating in worldly activities that do not pertain to supporting their own homes and families. Even in the absence of discernible external criticism, internalised self-criticism is present, fostered by generations of defined gender roles and the real and imagined transgressions and consequences thereof. My own experience of finding space in my life and from my family and my full-time work as a therapist to do my

doctoral research is resonant in this. Even as I wrote this I questioned my own authority to assume this position. Do I have the right to say this out loud, present it in academic article?

Tacit tyranny

Someone said "To be born a woman is a curse"

Not me ... being a woman means

You never have to think, who you should be.

That's luck!

No chance of losing the key to your identity

You don't even have to hold on to it.

Just ask

Your ask parents, man, children

If that fails

Don't panic

There are a hundred others

Willing to say

Where you should go,

What you should do

Who to be

Be warned ...

There are those who will ask

Who is she? Who does she think she is?

Remain calm,

They will move, ahead of your response

Don't try to be yourself or someone else

There's no way you'll succeed

Enquire, confer, consult, apply ...

Just don't think for yourself

Thinking, you could change the world

Change what is important, Alter the rules

What will happen then?

How will you deal with that?

What happens if one is silent? One is insidiously deflated. Like the air escaping from a balloon in a slow almost imperceptible leak.

Silence?

> *Silent summer sun*
>
> *sliding slow,*
>
> *stealthy, somnolent.*
>
> *Seeing secret schemes*
>
> *searching soundless sights*
>
> *surveying sinister spectacles.*
>
> *Suppose such scenes*
>
> *showed signs*
>
> *strange, serious, scary ...*
>
> *Should YOU, staring,*
>
> *sympathise?*

Every real poem is the breaking of an existing silence. The question to ask of any poem is "what kind of voice is breaking silence, and what kind of silence is being

broken?"(Rich 2001:150). In the poem above, I question: What happens when good people are silent? I thought about this on a visit to the Apartheid Museum in South Africa. The South African governments both old and new have each been defined by and guilty of two major and deafening silences. The former against ignored voices of the people opposing Apartheid and the latter ignored the voices of the people asking for HIV and AIDS treatment and that HIV and AIDS be acknowledged as real conditions (Fourie 2006). Poetic reflection offers a medium through which the practitioner can represent an experience as well as the reactions and interpretations of it (Willis 1999). 'Self-reflexivity unmasks complex political/ideological agendas hidden in our writing'(Richardson and Adams-St. Pierre 2008:475).

The women's actions through volunteering as caregivers speak out against the silences represented by a lack of caregiving resources for people afflicted with HIV and AIDS. However, in breaking the silence, they risk sanction for transgressing boundaries.

To speak up and deny silence requires courage, strength and hope. In performing home-based care work, the home-based care volunteers act on the silences about how people living with HIV and AIDS should be cared for and supported. Their resistance through the performance of care is both personal and political. In talking to the women, I aimed to clear a space for reflection on action. I hoped the women would reflect on their work and themselves and move towards imaginative possibilities, for understanding their work and lives. Poetic reflection facilitated my imagination. Performance autoethnography dialogically introduces itself into the world aspiring to social change through stimulating conflict, curiosity, criticism and reflection and promoting meticulous "ethical grounding" in a commitment to combat racial, sexual and class discrimination (Denzin 2003: 261).

Found poetry in the voice of one of the participants illustrates self-reflection, reflection on action, dialogical reflection and the validation and affirmation of identity inherent in the acknowledgement of one by another (Prendergast 2009).

I think that through …

I went back I started thinking

It makes me work even harder

It inspires me to do even more.

Sometimes I feel like I am not doing well

But talking helps

It makes me feel happy to be able to talk

I realised that in talking

You could blame yourself

And forgive yourself

And then move on from that.

It does help a lot to talk.

But, to have someone

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Who is interested in listening,

That makes me ...

It makes me feel...

Good.

This 'found' poemencapsulates the women's response in essence. The understanding of self and other can be attained through a reflective, creative process that circumvents a traditional social science representational methodology. It is person-centred and requires that the researcher engages with the personal world of the self and others. Poetic reflection and interpretation allowed me to realise that the use of poetry could be helpful in understanding the life experiences of research participants and oneself and arrive at new realisations. This final Haiku conveys that.

Reflective alliance

A drop of oil floats

On a puddle in sunlight

Iridesen(s)es!

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Chapter 9

Reflective release: Two poems about doing qualitative research with AIDS home-based

care volunteers in South Africa

Reflective Release: Two Poems About Doing Qualitative Research With AIDS Home-Based Care Volunteers in South Africa

Thirusha Naidu[1]

Abstract

These two reflective poems emerged from my research on home-based care volunteers caring for terminally ill AIDS patients in rural Kwa-Zulu Natal, South Africa. I found myself overwhelmed by the emancipation offered by qualitative research, particularly when compared with the strict confines of the positivist paradigm that dominates clinical research and practice. My being "left to my own devices" was at once liberating and daunting. Later, when interviewing home-based care volunteers who care for people living with HIV/AIDS, I felt overwhelmed again, this time in a different way. The caregivers were like me in uncharted territory, their work neglected in government policy and practice. The poems granted me an avenue for reflection that helped me assimilate the diversity of experience and emotion with which I was confronted. Giving all of it space in the form of these poems allowed me to get on with the job of research.

Keywords

Reflective practice, research poetry, AIDS home-based care volunteers, South Africa

Qualitative Ride

Roller-coasting into the valley on a now
"first world road"
Freewheeling down
Foot by the brake
Am I in control?

Dented barriers where others have crashed before
Spasm'ed thighs threaten to relinquish their hold
Chickens, goats, cows, "extraneous variables,"
"Confounding" the route

Eyes on the road
Forget the brake
GPS aside
Enjoy the ride!

Who Cares?

At home to die
Acquired Immune Divisionsy Syndrome
(Sic)k
Who cares?

Blue sky, green hills, brown hut
Dusty chickens, washing line
Bandaging heat
Hot wet, stop death
Who cares?

Bad blood, no gloves, no touch
No food, no love,
No bed, no care,
Who cares?

Wash, rest, soft words
Cool drink, warm touch
Who cares . . .

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The last section of the drive to the research site was a long, winding, precarious road down a hill, into a valley. It had been a dirt road (now tarred) that I had driven years previously as an undergraduate student learning about community psychology.

I kept reflective journal to document the data-collection process and "ground" me. It did not seem to be enough to help me absorb the impact that the AIDS pandemic has had on the people of South Africa. Migrant labor had split families, and AIDS brought family members back home. Idyllic rural African backdrops belied the daily struggle of home-based care volunteers who are sometimes the only support for people living with HIV/AIDS in rural South Africa.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interests with respect to the authorship and/or publication of this article.

Bio

Thirusha Naidu is a practicing clinical psychologist and is currently working on her PhD in narrative research on AIDS home-based care volunteers at the University of Kwa-Zulu Natal. She holds a postgraduate certificate in narrative research from the University of East London (U.K.) and postgraduate diploma in health promotion from the University of Kwa-Zulu Natal. She is developing an interest in narrative medicine and autoethnography in research and clinical practice.

Chapter 10

General discussion and conclusion

10.1. Preamble to closing insights

The conclusion chapter comprises of two main sections. The first section is a discussion of the distinctive contributions of each paper to the body of research on HIV and AIDS home-based care in Africa. Each paper takes a slightly different but related approach to the subject and represents a separate contribution. The second section presents the overall contribution of the thesis as an integrated whole. A summary of key findings, recommendations emanating from the study and limitations of the study follow.

10.2. Original contributions of the articles

The systematic meta-synthesis of qualitative literature on the topic provided a comprehensive overview of HIV and AIDS home-based on the African continent. It provided systematic substantiation for the proposal that researchers have succeeded in providing a basis for the argument that the subplots of "poverty", "women as caregivers" (gender) and "stigma" around HIV and AIDS co-exist to create a support structure for the "burden of care" narrative. This burden of care narrative has come to dominate the story of home-based care in Africa. Government and stakeholder collaboration is proposed as a means to alleviate this burden. This review highlighted the necessity for prospective researchers to consider alternative directions in this narrative to obtain solutions to the problems and to provide more detailed information in the area. Investigation by means of both quantitative and qualitative research is warranted to obtain a richer picture of the phenomenon of home-based care in Africa. Specifically, more investigation is required into how the subplots of "poverty", "stigma", "women as caregivers" and "stakeholder and government collaboration" influence home-based care collectively and independently. More recently, researchers have begun to

investigate areas other than those that thicken the "burden of care" narrative. It is likely that alternative possibilities to relieving the "burden of care" on women in Africa may be uncovered in this way. Following from the idea that the "burden of care" narrative around HIV and AIDS care has been substantively established, the study reported in this thesis aspired to explore a different view on the issue.

This view was influenced by the lack of research on the "micropolitics" in HIV and AIDS home-based care, which looks at the everyday and detailed aspects of the phenomenon (Schneider, 2009). Moreover, there is a dearth of research on volunteer caregivers exclusively in Africa. The current study therefore focused on the social construction of home-based care volunteer identity with the intention of obtaining an in-depth understanding of what makes it possible for impoverished rural women to offer care voluntarily. Bearing in mind that most research on volunteerism has been conducted in the West and very little work has been done on volunteer identity in Africa, it was imperative to ensure that the research process was contextually and ethically relevant to the context in which the study was conducted. The emphasis was on viewing context as important to understanding all aspects of the research process from community entry, ethics, data collection and analysis to interpretation and researcher reflexivity. "Contextual reflexivity" comprising ethical and methodological reflexivity was developed and used in the process of gaining access to the community, collecting and interpreting data. "Contextual reflexivity" represents a novel approach to ensuring that the influence of context is consistently accounted for in relation to emerging data in qualitative research. This approach may be applied to other research projects for similar purposes.

HBCV identity was found to be multidimensional and contextually determined. It incorporates elements of personal, socio-cultural and historical aspects that were operational in the context to result in the home-based care volunteer identity and the performance of that identity. Insight into the social construction of home-based care volunteer identity could help to understand the kinds of people who are likely to volunteer, the areas of health care where they work and the way volunteerism may be supported in ways that value volunteers' social personal, collective and role identities so that volunteerism persists.

In one interview, a participant used the term *umqondo kamama* to describe how home-based care work required "the mind of a mother". This metaphor was incorporated into ensuing interviews with other participants to determine whether it was resonant within the group as a whole and to enhance reflexive capacity. Generative metaphors have been used fairly extensively in organisational psychology with good results (Barrett & Cooperrider, 1990). Generative metaphors as a technique to enhance interaction during interviewing have not been explored fully in community research. As illustrated in this thesis, this fairly simple and undemanding technique offers the opportunity to enhance the level of communication and understanding in qualitative interviews and creates opportunities for new insights and shared understanding in the interview process.

In this study the 'mother' identity was observed to be an important aspect of the collective identity of the HBCVs. On the group level the HBCVs' motivation to volunteer was based on identification with the collective mothering identity in Zulu culture. In Zulu communities even those who have not given birth to their own children may be considered mothers of other family members' children and children in the community. These women would have similar rights and responsibilities. Mothering is communal rather than dyadic and

the roles and responsibilities of motherhood may be generalised to contexts other than biological mother-child relationship. This is likely to be relevant to the ethos of *Ubuntu* where affording the role of mother to all women of child-bearing age and some of the responsibilities of mothering to younger women and girls establishes female identity elements about communal roles and expectations. To be recognised as a mother one must behave like mother and to behave like a mother one must be recognised as a mother. Given the significant but gendered association of mothering with being a woman in Zulu culture it is not surprising that women perform and generalise the positive associations that are linked to love and care in mothering to caring for people with HIV.

This performance of identity is not without issue and it is likely that men and those women in the community who do not identify with the dominant social identity of mothering may be likely to experience difficulties or conflict as discussed in relation to agency in Chapter 7. Ridgeway and Correll (2004) consider that hegemonic cultural beliefs about gender and their impact in "social relational" contexts are the essential elements that reproduce and alter the gender system. When gender is salient such as in the case of mothering and care, cultural beliefs about gender serve to bias behaviours, performances, and evaluations of otherwise similar men and women in systematic ways. As discussed in chapter 7 introducing the identity of mother and its gender associations serves to exclude men and women who do not identify with the mother role from caregiving thus restricting group identification and consequently available caregivers. According to Amartya Sen's (1985) capabilities approach which focuses on the being and doing, an agent is someone who acts and brings about change and whose achievement can be evaluated in terms of his or her own values and objectives. From this perspective the HBCVs work is based on their capabilities as

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mothers. HBCVs do home-based care work based on their identification with the communal mother role and its associated capabilities.

This thesis introduces the idea that volunteer home-based care represents a form of agency where "agency" refers to the capacity to make choices and to act upon them (Burr, 2003). From this standpoint, home-based caregivers' volunteerism involves questioning and negotiating of contextually imposed identity precepts of women as de facto caregivers in the family setting. The assertion presented is that, the volunteers accept some aspects of contextual identity precepts such as those that view women as more capable of offering care than men, for example. On the other hand, they question, modifiy and renegotiate the assumption that female relatives should assume the role of traditional and natural caregivers by caring for relatives living with HIV and AIDS. The home-based caregivers' agency and individuality manifested in volunteerism could become part of the impetus towards a multitude of options offered in the world. The viewpoint presented in this thesis is a counterpoint to the dominant perspective of home-based caregivers as merely over-burdened and oppressed women who are forced to care for sick relatives. The distinction between family caregivers and home-based care volunteers adopted in this thesis allowed for the consideration of home-based care volunteers as different from family caregivers in many respects. This represents an alternative approach to dominant research narratives on home-based care.

Researcher reflexivity was an important connecting thread in this thesis. Detailed documentation of the researcher's reflective practice contributed to overall methodological rigour. The specific contribution made by this aspect of the study is the example that reflective practice through poetry and other creative media can be used as a valuable

generative medium for auto-ethnographic engagement facilitating innovative thinking and meaning-making, more generatively than prose.

10.3. Discussion: overall contribution of the thesis

Volunteer identity is an area that is distinctly under-represented in the research on volunteerism in general and is to this researcher's knowledge not evident in the research on HIV and AIDS home-based care. The current study has demonstrated that female home-based care volunteers' motivation to volunteer is based on their identity and the context within which that identity unfolds or is performed. The rural women appeal, through volunteerism, for recognition of the care they provide and the means through which they choose to provide that care. The HBCVs, whilst strained by challenges, are proud of the contribution they make and see themselves and their group as providing an essential service to the community that few other people are able to offer. The HBCVs pride themselves on the fact that their willingness to work is based on their personal identity as kind, caring and hardworking people along with their enduring "love" for helping others. The women are influenced to volunteer by a combination of socio-historical, cultural and personal conditions that occur in the context of HIV and AIDS and overwhelming poverty. This accumulation of circumstances in conjunction with the lack of government resources to provide adequate care and support for HIV and AIDS has produced the conditions for the identity of HBCV to emerge.

The HBCVs in this study did not ask to be relieved of the care duties that they had voluntarily assumed but rather appealed for acknowledgment and recognition of the unique role that they play in HIV and AIDS care and support at community level. HBCVs wanted to be supported in ways that are meaningful to them and which are consistent with their personal

and organisational vision. This request for acknowledgement was twofold. Firstly, they requested space, from which to conduct their work and, secondly, for their work and by implication their role in care and support networks to be recognised as important within the formal health care system. This type of request is not new. The HBCVs initiative to provide care in response to the overwhelming need for care and support around HIV and AIDS in the community, highlights the fact that care from outside the home has become a crucial element in the community-initiated care and support around HIV and AIDS. This emphasises the fact that family caregivers alone cannot cope with the burden of care which is slowly debilitating families and communities. HBCVs choice to offer care distinguishes them from family caregivers who are cloistered and overburdened by care demands. The HBCVs initiative is validated by the largely positive response that HBCVs receive from the community.

HBCVs render the *ubuntu* principle visible in home-based care through their volunteerism such that it could be witnessed in this way by researchers, community members, government and policy makers. This visibility and attention that HBCVs have drawn to the phenomenon of home-based care offer inspiration for others to learn from their example and to offer support in ways that are personally resonant and meaningful. The cultural precept of *ubuntu*, personal identification as competent caregivers and the association with the auxiliary group identity of the home-based care volunteer organisation reinforce support for the HBCVs to persist in volunteering.

The home-based caregivers define themselves within the group and as individuals by performing work that is personally meaningful and gratifying, thereby enabling them to deal with the challenges that they encounter competently. Their affiliation to a volunteer organisation, the identity of which is resonant with their own identity as "mothers of the

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community", provides support and solidarity. They are empowered, validated and feel needed and see themselves as crucial to the service that they provide. It offers a sense of meaning and purpose in their lives to realise that skills that are usually taken for granted in women and mothers are crucial skills in home-based care work. These skills, together with the personal and organisational meaning attached to the work, encourage persistence in their volunteerism. Through this personal and organisational identification with the work the women are empowered in the performance of the work. They maintain that the work is difficult and requires special traits and skills and they are empowered by the belief that they are uniquely experienced to perform the work.

The HCBVS in this study wanted to be recognised as personally suited and experienced to perform this kind of work. They wanted to be valued as uniquely capable to provide home-based care and thus deserving of space in the formal health care system. They appealed for space, in other words, physical spaces in which they could care for others and spaces in which they can be seen and heard and recognised within the health care system. This was not evident on initial contact with the HBCVs but emerged only after extended engagement. The interview process used in this study facilitated this by taking a different approach to the traditional question–answer format. The three-stage interview process used extended interviewing of HBCVs further than had previously been done by adopting a multifaceted approach to interviewing. This was an approach that focused on the stories that the women told about their worlds, lives and experiences as female HBCVs. The process created space for home-based care workers to have their stories about their work, lives and personal reflections on these stories witnessed by interested and committed witnesses in the form of the researcher and interpreter. The process offering a dialogical space to talk and be

witnessed allowed the women to convey the value they saw and held personally and in their work and simultaneously be validated and acknowledged by the researcher's presence and interest. As one women said when asked about her reflections on the interview process,

> *I went back. I started thinking. It makes me work even harder. It inspires me to do even more.*

It has been suggested that the burden of care imposed by HIV and AIDS on communities is so great that it must be expeditiously relieved. However, a deeper examination reveals that simply not enough government resources exist to alleviate this burden of care satisfactorily. For example the introduction of ARV treatment has introduced hope and optimism into the realm of care and support as people are now able to live with HIV infection as a chronic condition. The HBCVs are not compelled to deal only with death but are able to work with helping people live with the condition. Nevertheless in poverty-stricken rural areas, issues of poor uptake associated with accessibility and poor nutrition create a host of day-to-day problems for the HBCVs and the people they serve. The contention in this study is that if the voices of HBCVs are not heard and attended to with any degree of seriousness, the impact of HIV and AIDS is likely to continue unabated in rural contexts. The latter will not be due to a lack of treatment but to inadequate distribution of resources that support treatment including home-based care.

In this study, deep engagement with HBCVs led to the realisation that incentives outside of monetary compensation are highly valued and can contribute significantly towards creating and sustaining viable community-based care. HBCVs in this study were people that volunteered to care in ways and within groups that were personally meaningful to them.

Considering that the South African government cannot successfully sustain the HIV and AIDS care and support needs, a viable option may be an arrangement where people are recognised and supported in what they do in ways that are meaningful to them, taking into account personal, social and contextual circumstances under which care is provided. In this study, repeated contacts and varied approaches to interviewing and encouraging dialogue with HBCVs generated a varied perspective on the issue.

There needs to be greater investment of resources in creating momentum around existing community-driven initiatives, as these are more likely to be sustainable in the long term due to the personal investment of community members such as the HBCVs. Financial resources should be invested in innovative ways of supporting community-initiated care initiatives. Simply stated, this would involve investigating existing community care initiatives and supporting them through empowering strategies. Since there are minimal resources available to provide care and support, it is useful to consider what the reasons for volunteering to care are. This study demonstrated that in- depth engagement on all levels from contextual, community and participant engagement to personal reflexive engagement offered an understanding of the home-based care volunteers that could provide innovative options that are resonant with community initiatives.

Recent changes in policy have created uncertainty regarding lay health workers' categorisation as volunteers or full members of the health system (Daniels et al., 2012). The introduction of the national government endorsed community caregiver (CCG) programme by the KwaZulu-Natal government, which aims to incorporate orphan caregivers, home-based caregivers and youth workers does not take into account the specific types of care that volunteers provide and the conditions under which they will start and continue to volunteer.

Government intervention appears to be aimed firstly at offering more stipends to lay health care workers based on the assumption that this will provide an incentive to initiate and sustain volunteerism without evident consideration of personal work preferences and aspirations. Secondly, the policy aims towards creating a cadre of general workers who is able to adapt to a variety of social and health needs in a community. Based on the HBCVs' perspective, their intention is to secure a legitimate space in the health care system of the country and their view is that tasks that they undertake require a specific or special type of person. It seems that government policy initiatives for lay health workers and the workers' own aspirations are discordant. Schneider and Lehmann (2010, p. 66) caution that "national policy initiatives aiming for coherence through one approach to lay work and "flattening difference" could result in the inadvertent raising of expectations without addressing underlying problems."

I suggest that socially constructed identity comprising social, personal and meta-narratives sustain participation in volunteer care. Home-based care volunteers consider the tasks of home-based care as requiring a "special kind of person". The proposed all-inclusive category of community caregiver does not make allowance for the particular skills and identity factors that make it possible for the volunteers to perform home-based care work and makes the assumption that anyone can and will do this kind of work. Moreover, the current stipend is very small and the fact that women are willing to accept this amount attests to the impact of poverty on their lives. Taking into account that gender is so closely linked with home-based care implies that many issues unique to women are resonant in home-based care, not the least of which is the feminisation of poverty. Even the "burden of care" narrative supports the idea of all female caregivers as inherently and contextually disempowered. Consequently suggesting that volunteer home-based care represents a form of agency is an idea that may be

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considered radical and even counterproductive. Most researchers investigating home-based care in Africa recommend greater stakeholder and government involvement in alleviating the burden of care on women and communities. The generalist approach to lay health worker policy does not take this recommendation into account. Superficially, it could seem that the salary offered to lay health workers provides an adequate incentive. This represents a partially accurate but restricted view that, due to poverty and unemployment, people may be willing to do whatever they have to secure paid employment. The results of this study have suggested otherwise. In fact, in-depth engagement with the HBCVs indicated that it takes a special type of person with special qualities and life experiences to perform the challenging tasks required in home-based care work. Volunteers perform care work because it is work that is personally significant to them and it is aligned with personal, social and contextual meaning.

The gendered nature of home-based care in Africa has been widely acknowledged. However, there is little evidence in the literature regarding collaborative consultation with the women regarding how support for home-based care work should be provided and which forms of intervention it should take (Akintola, 2006; Daniels, Clarke & Ringsberg, 2012). In general, the literature on home-based care advocates for intervention by government and other stakeholders to alleviate the burden of care on women. However, there is little clear and definitive direction on how this should take place. It would seem somewhat presumptuous for external parties to intervene at their discretion without consulting with those who have borne the weight of the burden for so long. It might be argued that, while the home-based care volunteers are adept at providing care, they may lack the skills and experience required to transpose these activities into action at a broader community and policy level. However, it

remains necessary to consult with those "at the coalface" as it were to ensure that intervention and support are context-dependent and relevant to those participating in care and support.

The need for care and support for PLWHA is so great that women in communities volunteer personal resources to invest in this area. This research report offers the contention that home-based care volunteerism represents a form of agency highlighting that the current situation where families and community members provide care is untenable and damaging to communities in the long term. This notion only became evident following reflective interviewing, prolonged exposure and personal reflection by the interviewer/researcher. Moreover, volunteers' personal, group and socio-historical identity element plays an important role in volunteerism. Policy initiatives that do not take these issues into account and refer to current community trends and practices in policy development and implementation, run the risk of possible failure. The community caregiver policy is an example of incidental as opposed to transformational leadership disregarding academic and community views (Daniels et al., 2012; Ige and Quinlan, 2012; Schneider & Lehmann, 2010).

The tacit assumption behind the changes in policy is that people who were previously volunteering would now work more willingly based on the promise of payment. There is also the possibility that paid employment will attract more prospective caregivers who would be willing to work for the payment. Volunteers are more motivated to work than paid workers due to the element of free will and choice inherent in volunteering as compared to paid work, especially where work circumstances are difficult and uncomfortable. The intention is not to suggest that the "burden of care" should continue to lie unchecked on the shoulders of impoverished women nor that home-based care volunteers should have complete discretion as to which form stakeholder and government intervention should take. Essentially, a more

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detailed examination is required through various combinations of broad and detailed approaches to research on what makes it possible for women to assume this seemingly insurmountable task. It is realistic to assume that female relatives may not have a choice in the matter. However, this view is countered by many who choose not to offer care and support to family members who live with HIV and AIDS, let alone volunteer to care for strangers. Therefore, careful consultation is imperative with caregivers and communities to develop and implement policy that is resonant with the needs and aspirations of home-based care volunteers and those to whom they provide care and support. This consultation does not have to result in meeting needs inevitably, as this is not always possible. Rather, it can take the form of listening to experiences, collaborating and supporting,

10.4. Summary of key findings

This study made use of a range of tools and methods of analysis underpinned by a social constructionist framework and a narrative methodological approach. This approach allowed for a thread of narrative to be maintained in the entire data collection framework and for comprehensive perspective on the data to be developed. Various types of interviews were used in the data collection process with the connecting element being the focus on the narrative element overall. This narrative approach also prompted understanding of the literature and allowed the researcher to gain an overall perspective of the phenomenon of home-based care in Africa. The data from interviews was analysed using various narrative analytical methods allowing for different aspects of the data to become evident thereby offering new insights that would not have been possible with thematic analysis alone. A reflective journal and field notes were invaluable in keeping track of data and emerging ideas and allowed for associations between the former and latter to made in meaningful way.

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Finally the use of research and reflexive poetry offered new perspective and a new depth of understanding and meaning that would possibly would not have been achieved without this tool.**10.5   Recommendations**

Participation in volunteer care work is influenced by a complex interaction of social, personal and contextual elements. Care and support are likely to be influenced by varying series of personal, contextual and socio-historical factors. Research providing insight, such as the insight into home-based care volunteer identity provided by this study, has the potential to deepen understanding on specific aspects of volunteer caregiving, community health care work, orphan and child caregivers and youth workers and lay health care work in general. Such insights may be utilised in a range of ways from initiating, supporting and developing HIV and AIDS caregiving to providing relevant information for policy development.

In general, the area of home-based care requires deeper investigation into the relationship between gender and care on a variety of dimensions, e.g. cultural, socio-economic, historical and policy. Policy research in this area could focus more intentionally on how government and stakeholder collaboration in alleviating the burden of care can be implemented in such a manner that care is provided and female caregivers benefit from participation in care in ways that are satisfactory to them. The manifestation and impact of stigma within home-based care is another important aspect that requires more detailed investigation. The role of poverty at a macro and micro level must be investigated to the degree that directions for potential solutions to the impact of HIV and AIDS and poverty on the phenomenon of home-based care in Africa become more evident.

Policymakers must take the perspectives of people on the ground into account when developing and implementing policy, and home-based care is no exception in this regard. Despite South Africa's reputation as a well-resourced country, there is significant competition for resources between small groups associated with HIV/AIDS care. HBCVs' inter-relational struggle for identity and place and a shortage of government-distributed resources fosters tensions between groups in competition for resources and inform the identity perspectives of the group members. A socio-political history of poverty and gender- and race-based oppression in South Africa provokes agency and activism stemming from a historical mistrust of government. Home-based care groups offer government the opportunity to invest in the initiative they show via voluntary caregiving. Government could, through support of these groups, assist in providing HIV patients with home-based care while simultaneously creating space in which women can explore emergent aspects of identity contributing to their own empowerment and self-development.

The burden of care narrative has done much to attract attention to the overwhelming weight assumed by impoverished female caregivers in the realm of HIV and AIDS care. However, the "burden of care" narrative has created the implicit suggestion that these women should be relieved of their burden through the intervention of outside parties such as NGOs and the state. Little attention has been paid to the conditions that make it possible for these women to volunteer despite their own challenges as a result of similar social and contextual factors as the people they help and support. Indeed, little attention has been paid to the reasons for offering volunteer care in the context of poverty. In this study, a consideration of context offered richer insight into the understanding of the social construction of home-based care volunteer identity. Future research in this area must take due cognisance of contextual

factors that influence participation in volunteer care. It is recommended that a broad perspective of context be adopted, as this is likely to offer a comprehensive picture of phenomenon of home-based care volunteerism.

Innovative approaches to research and dissemination of research results are required in the area of HIV and AIDS home-based care. While there is relevant research that is being conducted in the area of HIV and AIDS caregiving and volunteer caregiving in particular, very little of this research is accessible to community members who participate in this research. Researchers call for greater stakeholder and government collaboration and involvement in alleviating the burden of care. However, government communicates at a policy level while in the realm of HIV and AIDS home-based care, most stakeholders consist of community-based groups and NGOs and individuals who communicate at a grassroots level through community meetings and public forums. This creates a communication chasm. The communication chasm is sometimes narrowed and at other times widened by academics and the media who may attempt to bridge this divide by highlighting and discussing relevant issues in academic journals and policy documents. However, these methods have restricted accessibility because of the specialist language they employ and the environments in which they are published. Alternative methods of collecting data and disseminating research findings must be considered for communicating research findings to communities, consulting with community members on policy issues and communicating grassroots issues to policymakers expediently. Some such dissemination methods include creative non-fiction (Caulley, 2008; Cheney, 2001; Gutkind, 2005), research poetry (Barrett, 2011; Furman, Lietz, & Langer, 2006; Richardson & Adams St. Pierre, 2005), narrative theatre (Sliep, 2004; Sliep & Meyer-Weitz, 2003) and film

documentary. These methods offer channels that have the potential to give voice to the voiceless and for presenting rapidly changing policy issues in an accessible ways.

10.6. Limitations of the study

The following represent some possible limitations of this study.

The study emphasised an understanding of the context in which the study was conducted, which makes the results less applicable to other contexts. However, the methods used to obtain a comprehensive understanding of context in Chapter 3 may be applied to obtaining an understanding of other contexts in which similar studies may be conducted.

The study focused on one group of home-based care volunteers. While this offered the opportunity for depth of meaning to be attained, the study results cannot be generalised to other community-based home-based care groups. The perspective on lay health worker identity in general would benefit from applying the method used to explore the social construction of home-based care volunteer identity to groups in other communities and other categories of lay health workers with some adjustment.

Interview data was collected using interpretation and translation from isiZulu to English. While precautions were taken to counteract the effects of translation and interpretation, some possibility of data being lost or misinterpreted remains.

The definition of a volunteer in the context of home-based care is contentious both in international literature and literature on home-based care in Africa. The arguments vary based on whether family caregivers offering care constitute volunteers or whether they are coerced into caregiving, and the answers vary depending on context and culture. Moreover, whether

voluntarism involves payment or not is also an issue in debate (Wilson, 2000). Some paid community health workers refer to themselves as volunteers based on the fact that they do not have a formal place in the health system (Schneider et al., 2008). In this study, we restrict the definition of volunteer to those who offer care to non-family members in the community and who may or may not receive a stipend. This definition restricted the range of potential participants to those who conformed to this definition of volunteers and excluded those home-based caregivers who might have defined themselves as volunteers. Nevertheless, the definition confined study participants to members of a volunteer group and extended the understanding of how personal volunteer identity is supported by the volunteer organisational identity.

The thesis makes use of the of the publication format for presentation. The papers represent some defined perspectives on the data rather than offering an exhaustive overview of the data collected. I chose take an in-depth perspective of selected views of the data whilst giving due consideration to context, reflexive research practices and innovative methods of data presentation instead. Given the richness of the data collected several possibilities exist for exploring the data. Some of these were evident in the analysis done thus far and are currently being pursued. These include an exploration of stigma and discrimination as experienced by home-based care volunteers and an analysis of the home-based care volunteers life stories from a discourse perspective around issues of gender care and power.

10.7. Conclusion

This section covered the contributions that individual articles comprising this thesis have made to the research on home-based care volunteerism and the contribution made by the

thesis as a whole. The overall contribution of the thesis concerns the assertion that the conditions under which people choose to volunteer are closely related to what they hold as personally meaningful. Home-based care volunteers' choice to offer care represents a form of agency defying the assumption of female family members as de facto caregivers. HBCVs want to be supported in providing care in the way that they have chosen offer that care. Government initiative to create a generalist category of caregivers does not take the personal incentive demonstrated by the connection between volunteerism and identity in volunteers to care into account. Considering that government resources for HIV and AIDS are overstretched, other alternatives to supporting care that are less resource-dependent are essential. It is important for government and policy makers to consider using the momentum of community initiatives such as that created by the strong identity associations in home-based care volunteerism in this study to plan government intervention in care and support. This type of alignment is likely to garner community backing and to sustain and develop initiatives as these initiatives would be based on and driven by existing community precepts. Simply stated, government support of existing care initiatives is considerably more empowering for individuals and communities than initiatives that seek to alleviate the burden without sufficient and sustained consultation with those concerned.

In facing the HIV and AIDS pandemic, every voice no matter how small and seemingly insignificant has a contribution to make. Acknowledgment, validation and respect are the keys to dialogical engagement. It is incumbent on the powerful to recognise, clear and protect space for all voices to be heard, for it is in the most unexpected places, from the quietest voices, that the answers to the big questions may be found. In practice this means

seeing, striving to understand and listening to people closely from an open and respectful position.

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APPENDICES

APPENDIX A: INTERVIEW ONE

GENERATIVE QUESTION FOR HOME BASED CARE VOLUNTEERS

I am doing some research on the work that home based care volunteers, like you, do on a daily basis for people living with HIV/AIDS. I am interested to hear about your experiences of being a home based care volunteer. I am also interested to hear what kind of person one needs to be to do the work of an HIV/AIDS home based care and support volunteer.

EXMANENT QUESTIONS

1. How did you get started taking care of HIV/AIDS patients in their homes
2. How long have you been doing this kind of work
3. What does your work entail What does your daily work in caring for the patients involve?
4. What are the barriers to conducting your work effectively?
5. Is the work important to you personally , if so why?
6. What are the factors, besides those you are responsible that help you to carry on this kind of work?
7. What kind of person is best suited to do the kind of work done by a home-based care volunteer in this community?
8. Do you have to do this kind of work or do you have the choice to?
9. How do people in the community respond to you and your work?
10. What is the attitude of patients their patients and their family members to you and your work?
11. What do the people that work in organization involved in care and support of HIV/AIDS think about you and you colleagues and the work that you do?
12. Which of the different groups and people working in the care and support of HIV/AIDS patients in the community assist or facilitate your work the most?
13. Do you find there are groups or people in the community who disturb/hinder the work that you do in caring and supporting AIDS patients at home?

APPENDIX B INTERVIEW TWO
LIFE STORY INTERVIEW

Please tell us please about your life from as far back as you can remember, from your childhood?

APPENDIX C: INTERVIEW THREE

HBCV REFLECTIVE INTERVIEW

1. What did you tell you family about the interviews OR what will you tell them?

2. From you life story and your work story I have heard that you are a hard working, committed, concerned about your future and that of your family, good at making quick decisions entrepreneurial, innovative ambitious? Would you say that this is true of you?

3. What would your family the person closest to you or good friend say about you as a person – the kind of person you are?

4. Would they and your friends agree with this idea of the kind of person you are?

5. What kind of qualities do you need to have to be a HBCV
6. Can anyone be a home based care volunteer?
7. Someone said you need the mind of a mother to be a HBCV – What are your ideas on what this means?
8. Do you agree?
9. What are you ideas on why the group is called *"Uthando lomama"* Would you say it is good name? Why?

APPENDIX D
CREATIVE NON-FICTION: BEARING THE BURDEN – AIDS AND HOME-BASED CARE IN SOUTH AFRICA

Abstract:

After many years of relying on home-based care volunteers (mostly impoverished women) to provide palliative care to those dying of AIDS-related illnesses in rural communities the South African government has created the position of Community Care Givers to attend to this desperately needed service. The position is one that combines the tasks previously done by volunteer home-based caregivers, youth workers, orphan care givers and community health workers. A researcher considers the practicality of implementing the policy supporting this issue considering nuances of volunteerism in AIDS care in Africa and the logistical challenges to providing care and support in rural communities in Africa.

Bearing the Burden of HIV/AIDS home-based care

MaNdlovu's forehead glistened, evidence of her walk from her home in the valley to our meeting point at the community centre on the hill. We had arranged to meet to discuss her work as an AIDS home-based care volunteer and group leader in her rural community A vividly colored scarf wound expertly around her regal head heralded her status as a married woman. We stumbled through an isiZulu-English greeting scattered with unnecessarily wide smiles, nodding heads and punctuated by the mercifully calming ritual of three-clasp Zulu handshake. Over her shoulder, deep in the valley, the waters of the dam defiantly reflected flashes of the sun's brilliance into the cerulean African sky. The impossible beauty of the surroundings belied that the fact that the region effectively represented one of the highest concentrations of people living with HIV and AIDS anywhere in the world. The pastoral setting and hushed resilience of the people in the community could lull one into the misconception that nothing was amiss in this idyllic corner of the world. A curious goat chanced a nibble at my precious set of notes. MaNdlovu sprang into action shooing the offending animal aside with a practiced sweep and a loud exclamation of,

"*Ai suka!*" before resuming her seat and nodding pointedly for me to continue.

" Uhmmm, I'm interested to hear about the work that you do caring for sick people here in your community…", I began tentatively.

MaNdlovu's broad shoulders floral-encased heaved heavenward with a slow, measured breath. Her voice implicitly commanded attention and inspired immediate respect like the matriarch of her namesake, the elephant clan,

"We are losing children, we are losing our husbands. We are the ones who carry the burden of this whole thing that is happening. The husbands die, the children die, the parents of these babies die. The grandparents have to look after the grandchildren."

The South African government has devoted a large percentage of the health budget to HIV and AIDS treatment and prevention in recent years. There is much to be compensated for after a poor track record by politicians. A cynical view would see the death-grip that AIDS pandemic has on South Africa as having thrived on the political inertia of successive administrations beginning with the Apartheid regime. The Mandela administration, occupied with the task of nation-building, was silent about HIV and AIDS. This silence and the social and political upheaval in the country, during the transition to a democratic state, created the ideal conditions for the spread of HIV. Former president Mandela publicly apologized for this and encouraged his successors to do better. Shockingly, Thabo Mbeki and his minister of health Manto Tshabalala-Msimang maintained a long-term denial that HIV caused AIDS and failed to provide essential anti-retroviral treatment. This rampant political disregard for science, popular sentiment and civic pressure contributed meaningfully to South Africa's notoriety as the country with the highest number of people infected by HIV in the world. Since those dark years, the South African government has fully acknowledged the existence of HIV and its relationship to AIDS. Resources and attention is poured into massive prevention and treatment campaigns. The issue of care and support has lagged disappointingly behind. However in addressing the mammoth task of HIV and AIDS prevention and treatment, the issue of care and support of those living with AIDS, especially in the end-stage of the syndrome, has fallen by the wayside.

Home-based care volunteers represent a group of women who care for people living with HIV and AIDS-related conditions at their worst stages and do so under the most trying of circumstances. I wanted to know what made women, who had very little in the way of material possessions, volunteer to provide the seemingly thankless and frankly risky service of caring for terminally ill from AIDS related diseases. These 'mothers of the community' as some liked to call themselves fed, bathed, cooked for and cleaned the homes of people who were at their most vulnerable point in their lives. I met with many inspiring women on my visits. For example Buhle's, jovial, easy-going manner shrouded her intense passion as she spoke about the stigma she confronted daily,

"Sometimes I see that some people get locked away in houses, I tell people, You don't lock them like that in the house, because once you do that they start feeling not so needed and wanted. The only way that they see to get out of this is to die. That is not the way they need to be thinking or feeling".

"Do people listen?" I questioned.

"Some do and some don't", she replied, "Anyway, what can they do with those that are sick? There is no place to care for them here."

"The clinic is not enough?'

"No. It would be good if we could have one place in the community where people who are sick could stay to be looked after by people like us, the home-based care volunteers. We have to walk long distances, the roads are bad, so then we don't have enough time to see everyone.

Buhle's laconic response made perfect sense to me and I was left pondering why in fact this was not the case. Most of what I had encountered described western volunteers as people from privileged or advantaged groups who were keen to 'give back' by supporting those in need. From this perspective the home-based care volunteers did not fit the mold. The phenomenon of home-based care is alarmingly common throughout Africa and in much of the developing world affected by HIV. Impoverished women care for their children, siblings and husbands who return to their rural homes from cities after contracting HIV and becoming ill from AIDS related diseases. In most communities local women band together to provide volunteer services to people that are too ill to care for their selves. All over Africa the burden of care is borne by women like MaNdlovu and her ilk. Where AIDS has threatened to deplete the socio-economic resources of a country, such as South Africa, the battle against the spread of HIV infection is far from won. In the face of the continuing onslaught of HIV and AIDS in the country Government must diversify resources. However minimal time, attention and resources are afforded to care and support as compared to prevention and treatment which are considered primary. A reconsideration of this trend is needed if the country is to emerge victorious in the fight against HIV and AIDS. The MaNdlovu's of Africa represent an essential service ignored and neglected by the South African government, without them many South Africans would suffer a slow, painful and lonely demise.

A chorus of women's voices singing in isiZulu, wafted over a warm breeze mingling strangely with the smell of fresh cow dung.

"The caregivers are struggling but they continue. Some people discriminate, some people keep laughing but we continue. Hold on tight, it's going to be alright. We will work together"

The spirited voices of MaNdlovu's volunteer colleagues working in their group food garden on the slope outside the community center as a cow contently mooed about her contribution of fertilizer. Reminded of another important note MaNdlovu continued,

"The community looks at us with varying eyes. They say you have to be really poor to do this kind of work, which is not necessarily true, because it's just about do you want to do it? Do you have love for doing it?"

The food garden that the volunteers tended provided nutritious food, essential for their 'patients' to take with the anti-retroviral treatment. Each woman gave some time in her day

outside of her own family commitments to water, weed and sow this precious patch of ground. Over the following months I met many more of MaNdlovu's colleagues both young and old.

All the volunteers held hope in common. In what seemed to be a hopeless context people abandoned to the mercy of a dreaded pandemic turned inward and found reasons for to be hopeful. Mbali provided an enlightening perspective on the inevitability of encountering death in her daily work,

"Listening is also part of a conversation. Even with the sick people I talk to them. I comfort them to the point that they die - because some die. I should not be the one who confirms it for them".

"What is your reasoning for this?" I probed, genuinely mystified.

"I am there to give them hope to give them hope for the future or a tomorrow." Her calm and restrained presence conveyed that in her hands this unimaginable task was possible, even sensible.

 "What is that inspires you to continue your volunteer work, when there seems to be little interest from the government?" I asked as MaNdlovu as I gave her a ride into the city one day on an appeal errand to a donor organization she had heard about.

"I do have hope that one day things will get better, that our organization will grow." MaNdlovu explained patiently. Her apparently endless optimism extending well beyond her own organization and colleagues to the sluggish machinery of government, "Maybe the government will give us more support, she offered convincingly, "At that time we might be able to help the people, with those problems those huge problems that we cannot seem to fix right now."

I began to understand that the volunteers work was based on altruism. They were proud that the demanding work that required a special type of person. The women distinguished themselves from the government paid community care-workers as being more 'hands on'; from child caregivers by working with sickest and most needy people in the community and from youth workers by dealing with hope in the face of death. The youth workers were young people who organized the local youth and youth from international volunteer organizations to work on youth-related community development projects. The home-based care volunteers wanted to be recognized by government for their unique work that required a unique type of person. They wanted be offered some form of recognition and compensation from government. All this seemed reasonable to me but I wondered, given historical trends, whether this would really happen.

A few months later was I invited to a 'taking back' session in which the results of the overall research project were presented to the community in the form of a narrative theatre production. The main players were the home-based care volunteers who collaborated with

researchers to produce a CD, photo-comic and drama (http://www.youtube.com/watch?v=ziW1VMphfqw) enacting the central findings from different researchers involved. Outside the big, hall deep in the Valley, people gathered. Men and women, young, old dressed in Sunday best or as they pleased. Perhaps it was the unprecedented arrival of the government officials that ignited the atmosphere with anticipation. Granted, they were not of the caliber that arrived in shiny black cars but perhaps those, detained by more important obligations, sent their deputies instead? It was after all a few weeks from local election time and savvy politicians would not want to be seen as uninterested in 'their peoples' causes.

The home-based care volunteers performed their well- rehearsed parts depicting the everyday struggles they encountered in their work around stigma and discrimination, the burden of care, lack of awareness, apathy, lack of communication between government community and organizations, the competition of resources. For a moment after the performance a hushed stillness filled the room, only the eternal sounds of people calling to each other across the Valley and the interminable mini-bus taxis whooshing past on the nearby gravel road precluded total silence. Slowly people began to raise their hands or stand up to say what the production meant to them what they learned or what it had reminded them of about the services that home-based care volunteers provided in the community. The government officials listened with a tight-lipped smugness. Finally one spoke in a shrill, confident voice, her scarlet-encircled lips formed each word deliberately, "The community will be happy to learn that the government has created a new category of health worker called the 'Community Care Giver'. This worker will provide all the services provided by home-based care volunteers, child caregivers and youth workers and other community volunteers and will be paid in the region of R1000 ($125) by government" This was not news to the audience as word of this new development had been brewing for weeks prior to the gathering. The government official sat down smoothed her skirt and patted her hair into place. No doubt her report would assure her superiors that they could depend on votes from the region.

Out of the corner of my eye I saw Andile, a youth worker's, perpetual smile wane as he wrinkled his nose in disgust, "Eish!, he hissed under his breath, "They just dumped everyone into one basket. I can't look after sick people. That work is too scary for me. There's going to be problems!" An ominous prophecy, or the regular resistance to change? It was difficult to say so early in the game.

At our next meeting, few weeks later, MaNdlovu resignedly reported, "Yes, my sister they have all left now" Amavoluntiya have gone for the money that they will be paid a salary as Community Care givers. Who can blame them? Everyone must eat."

"What are you keeping yourself busy with now?"

"Oh, many more have joined us to volunteer. They have hope that they too will one day be paid workers. We are still the ones that are cleaning, feeding and cooking for those who are sick. We will always be here. As you have heard, it is a special kind of person who can do this type of work."

The previous group of Home-Based Care Volunteers have started work as Community Care Givers in the community along with previous groups of Child Caregivers, Youth Workers, Community Health-Workers and others. A new group of Home-Based Care Volunteers have joined as the "mothers of the community". The Community Care Giver Management Policy Framework is in its sixth draft and the policy has not yet been finalized after the last local government elections. Community Care Givers are expected to offer a package of service that includes but is not restricted to home nursing, basic health screening, health education, nutritional advice, following up on chronic treatment, supporting long term drug regimes for HIV and TB. They are expected to visit 3 houses a day and have at least 60 households under their care. This might achievable on paper until one recognizes that the women (and they are mostly women) have to walk long distances between household as public transport is not available and privately owned transport is relatively expensive. The policy does not give any indication of how Community Care Givers will obtain the supplies they will need to carry out the work. This is likely to be a problem given that in the past home-based care volunteers, child caregivers and other groups to have had difficulty with this issue in the past. Nevertheless it is encouraging that government has at last sat up and paid attention to volunteers' initiatives to care and support for people living with HIV and AIDS in the end-stages of the syndrome. The question arises: Will the newly branded Community Care Givers cope with the many aspects with all they are expected to achieve? MaNdlovu would say, "It will take a special kind of person".

APPENDIX E: PARTICIPANT BIOSKETCHES

PSEUDONYM	AGE	CHILDREN	EDUCATION	MARITAL STATUS	PREVIOUS EMPLOYMENT	TYPE OF EMPLOY.	DURATION
Asanda	53	8	7	Widow	yes	Domestic	2
Bongi	48	3	12	Widow	yes	Restaurant - cook	5
Cynthia	52	7	12	Married	No	N/A	0
Dudu	35	2	11	Single	No	N/A	0
Edna	41	5	7	Married	No	N/A	0
Funeka	44	3	5	Married	yes	Domestic	5
Gugu	42	3	8	Married	No	N/A	0
Helen	45	4	8	Single	yes	Domestic	6
Irene	43	5	10	Married	No	N/A	0
Jabu	52	6	8	Married	yes	Domestic	3
Khanya	40	2	10	Single	yes	cashier	9
Lungi	38	3	10	Single	No	N/A	0
Mathilda	28	1	10	Single	No	N/A	0
Nandi	56	2	10	Divorced	yes	Shoe Factory	8
Olwethu	47	7	7	Married	No	N/A	0

APPENDIX F: CONSENT FORM ENGLISH

INTERVIEW CONSENT FORM

Thank you for taking the time to consider participating in this research project. You will need to be aware the following information before you agreed to be interviewed.

1. I (Thirusha Naidu) am conducting this project as part of a course in research methods at the University of Kwa-Zulu Natal (UKZN).
2. The project is about people who do voluntary work caring for people affected by HIV/ AIDS.
3. You will remain anonymous and will be identified within the research by a pseudonym.
4. The information you provide will be kept confidential and will be made available in full only to the research supervisor (Prof. Yvonne Sliep - UKZN).
5. Excerpts of the interview may be used in academic presentations and publications, always excluding information that could reveal your identity.
6. During the interview you are free to speak to speak as long as you want to and ask any questions at any time.
7. You may choose to withdraw from the process at any time.
8. You do not have to answer questions that you don't wish to.
9. The interview will be recorded. You have the right to review the tape and transcription of the interview and make changes, corrections and comments should you wish.
10. You are entitled to a copy of the interview and transcript.
11. If for any reason you find that during or after the interview you feel that you need emotional assistance as a result of confronting issues discussed, please contact the researcher and you will be assisted.

Thank you
You may contact me on the following:

Thirusha Naidu
University of Kwa-Zulu Natal
Health Promotion
School of Psychology
Cell: 0837893032
Naidut10@ukzn.ac.za

The above information has been explained to me and I understand it fully and I willing to participate in the interview.

_____   _____   _____
Print Name   Signature   Date

APPENDIX G: CONSENT FORM ISIZULU

IFOMU ELINIKEZA IMVUME YOKUBUZWA IMIBUZO

Ngiyabonga ukuthi uthathe isikhathi sakho, ubambe iqhaza kulolu cwaningo. Kuzofanele wazi lokhu okulandelayo, ngaphambi kokuba uvume ukubuzwa imibuzo.

1. Mina (Thirusha Naidu) ngiqhuba lephrojekthi njengengxenye yezifundo (mayelana nezindlela ezahlukene zokwenza ucwaningo) eNyuvesi yaKwaZulu-Natali (UKZN).
2. Le phrojekthi imayelana nabantu abenza, ngokuvolontiya, umsebenzi wokunakekela abantu abane HIV/Aids.
3. Igama lakho angeke lidalulwe; kulolucwaningo uzokwaziwa ngegama ekungelona elakho.
4. Ulwazi ozosinika lona luzogcinwa luyisifuba kanti luyodalulwa ngokugcwele kuloyo owengamele ucwaningo (uProf. Yvonne Sliep) kuphela.
5. Iziqeshana zengxoxo yethu kungenzeka zisetshenziswe emibikweni ngezifundo kanye nasemibhalweni ethile, kodwa ngaso sonke isikhathi kuyoshiywa ngaphandle leyo mininingwane engase idalule ukuthi ungubani.
6. Ngesikhathi ubuzwa imibuzo, ukhululekile ukukhuluma kangangalokho okufisayo, kanye nokubuza imibuzo nanoma ingasiphi isikhathi.
7. Ungahoxa kululuhlelo nanoma ingasiphi isikhathi uma ufisa.
8. Awuphoqelekile ukuphendula imibuzo ongafisi ukuyiphendula.
9. Izingxoxo zizoqoshwa. Unelungelo lokulalela okuqoshiwe kanye nokuyifunda uma isibhalwe phansi ingxonxo, futhi ungaguqula, ulungise, noma uphawule ngalokho okuyobe kuqoshiwe noma kubhaliwe.
10. Kuyilungelo lakho ukuthola ikhophi yale ngxoxo.
11. Uma ngabe uzwa sengathi udinga usizo/ ukululekwa ngokomoya ngenxa yezinto okhulume ngazo, ungaxhumana nomcwaningi ukuze uthole usizo.

Ngiyabonga. Ungathintana nami ngalezizindlela:

Thirusha Naidu
University of Kwa-Zulu Natal
Health Promotion
School of Psychology
Cell: 0837893032
Naidut10@ukzn.ac.za

Imininingwane engenhla ngiyichazeliwe futhi ngiyayiqonda ngokugcwele, futhi ngizimisele ukubamba iqhaza ekubuzweni imibuzo.

Igama	Signature	Usuku

APPENDIX H: DATA ANALYSIS REPORT OF NVIVO NODE STRUCTURE USED IN REVIEW PAPER

Node Structure
Oslo Review
2013/03/12 07:06 PM

Hierarchical Name	Nickname	Aggregate	User Assigned Color
Node			
Nodes			
Nodes\\Care defined as ...		No	None
Nodes\\Chronology		No	None
Nodes\\Chronology\Epiphanies		No	None
Nodes\\Chronology\Epiphanies\AIDS care as home based		No	None
Nodes\\Chronology\Events		No	None
Nodes\\Chronology\Events\sociological events		No	None
Nodes\\Plot		No	None
Nodes\\Plot\Action		No	None
Nodes\\Plot\Characters		No	None
Nodes\\Plot\Characters\caregivers		No	None
Nodes\\Plot\Characters\civil society		No	None
Nodes\\Plot\Characters\community		No	None
Nodes\\Plot\Characters\faith based groups		No	None
Nodes\\Plot\Characters\government		No	None
Nodes\\Plot\Characters\Health workers		No	None
Nodes\\Plot\Problems		No	None
Nodes\\Plot\Problems\burden of care		No	None
Nodes\\Plot\Problems\poverty		No	None
Nodes\\Plot\Problems\stigma		No	None
Nodes\\Plot\Problems\women as caregivers		No	None
Nodes\\Plot\Resolution - Stakeholder collaboration		No	None
Nodes\\Plot\Resolution - Stakeholder collaboration\community as caregivers		No	None
Nodes\\Plot\Resolution - Stakeholder collaboration\community consultation on care		No	None
Nodes\\Plot\Resolution - Stakeholder collaboration\Government needs to become involved		No	None
Nodes\\Plot\Resolution - Stakeholder collaboration\The impact of home based care		No	None
Nodes\\Plot\Setting		No	None
Nodes\\Role of mother as caregiver		No	None
Nodes\\Themes		No	None
Nodes\\Three Dimensional space		No	None
Nodes\\Three Dimensional space\Continuity		No	None
Nodes\\Three Dimensional space\Interaction		No	None

APPENDIX I NODE SUMMARY & SAMPLE REFERENCES - 'HOPEFUL HELPER'

Hopeful helper   Summary

Name	In Folder	References
H1 LUCIA MDIMA	Internals	3
INTERVIEW C2 MRS MBAMBO	Internals	1
INTERVIEW D1 BAZINI BHENGU	Internals	2
INTERVIEW D2 BAZINI BHENGU	Internals	2
INTERVIEW E1 THOLANI MABASO	Internals	3
INTERVIEW E2 THOLANI MABASO	Internals	1
INTERVIEW G1	Internals	1
INTERVIEW I1 BUZANI NENE	Internals	2
INTERVIEW J1 VIRGINIA MHKIZE	Internals	1
INTERVIEW K1 SITHEMBILE GCWENZA	Internals	1
INTERVIEW M1 PURITY MZIMELA	Internals	1
INTERVIEW N1 THANDI LANGA	Internals	2
INTERVIEW O1 SIZAKELE NYOKA	Internals	2

<Internals\H1 LUCIA MDIMA> - § 3 references coded [20.32% Coverage]

Reference 1 - 5.08% Coverage

H1: our work is about sick people who are sick and are home bound, we go to visit them and if they need washing we wash them and if they need changing of diapers we do that and we help them with medication if they are taking any. So that is what the work is basically about.

Reference 2 - 8.30% Coverage

H1: I was looking for a job and I would say to everyone that if they do hear of anything please let me know. So I spoke to Thandi and she heard that I was looking for a job and I said what is it that you need to have do you need to be educated or what and she said no. she said you just need to have a heart for sick people and be patient with them and not be disgusted by sickness and then you will be alright and I said yes I would love to do it.

Reference 3 - 6.95% Coverage

TN: I want to ask one last question and that is do you have any hope that your work as a HBC will improve you or will improve your life in a way?

H1: yes I see my life improving, because at the moment we are not making much and that with time we are going to get more funding and we are going to get more money and is I have more money, my life will improve in some way.

<Internals\INTERVIEW C2 MRS MBAMBO> - § 1 reference coded [5.58% Coverage]

Reference 1 - 5.58% Coverage

C3: well some of it was for financial gain as she did say that we were going to volunteer for a year and then get the stipend. So I thought that this could be a way to compliment what he was bringing home. And then there was the possibility that once I was in there were opportunities of getting a better job. Like be called to work in hospitals or at the clinic and work as cleaners or counselors and then I would more likely be in line to be employed because of my experience.

APPENDIX J: EXAMPLE OF DIALOGICAL PERFORMANCE ANALYSIS

Care Centre in the Valley : Group Agenda

TN: is there any other question that you want to ask me today?

A2: so it is not really a question, but a request, you know sometimes when we are working and we are working with people and we think we know and we want to do something and we can't/like sometimes we wish like there was a house a home somewhere where we can bring all of them together and look after them there, like we see the kind of conditions they live in their homes and we will change shifts/like some people will look after them during the day and some of them will look after them during the night, or if there was a car that would take the sick people to the clinic, they would know that if there is a sick person can the car come and take the person to the clinic and that sort of thing/also I think especially for the older workers they...the older home based carers they are not like the younger ones, like I think we feel this thing even more, like the person would be so worried about their patient that they end up getting sick themselves, they lose their appetite and they are all stressed out and they come and tell you that I am so worried about that one and you try to comfort them, but you can see that it does get to them/so can you ask, ask anywhere for us like people can they help with those sort of things.

TN: if you remember the last time we spoke Mrs. N we spoke about your work in HBC and you told me about your life. What did you think about those interviews, what did you think about that after you left us?

B3: so what I thought about after we had spoken is that it would be really great if there would be a place that built to bring in all those people who are sick, because most of them don't get all the necessary medically related stuff they don't take medication when they are supposed to because none remembers or reminds them to take it. So they keep changing the times. But if all the sick people were together it would make it much easier for people to be on track and getting the best care.

....

B3: for example there is this one person that I am working with and she got really sick and then she went blind. She lives with her granny and the granny is quiet old. But she is dead now, the young person. She would try to take her medication but the pills will spill on the floor because she was blind and there was no one to pick them for her. She took the medication whenever the granny remembered and there was no one to cook in the house because she is the young one and now she is sick. She was supposed to be the one help the granny but she was sick. So if there was place like that, then that could have been avoided.

Comment [T1]: Most presented the idea of the hospice after I asked specifically if there was anything more they wanted to say.
They then presented if as an "off the cuff idea" whimsically as if by the way – perhaps to give me a chance to take it up and build on it?
A hope/dream?
Look at this across interviews it was clear that the members had discussed this strategy as their responses were similar and pitched at a similar point in the interview.

Comment [T2]: Non-specific vague tone to the language "wish"
Too much to hope for

Comment [T3]: Supporting narrative used to gain create allegiance and strengthen support and understanding. Presents the idea of a space in abstract form and thickens and reinforces the idea with a narrative account - in this case on e that is illustrative
Followed by...

Comment [T4]: A DIRECT request to the interviewer

Comment [T5]: Wish terms – Hopeful yet tentative.

Comment [T6]: Using a narrative to support and strengthen

Comment [T7]: Reinforces with a personalized narrative

APPENDIX K: EXAMPLE OF CONTENT ANALYSIS FOR THE CONCEPT OF WITNESSING

These excerpts made me consider to how being witnessed validates identity.

Asanda: It felt like I had gained something even though I did not have anything tangible. It felt like a big weight had been lifted off my shoulders.…. Talking helps and it makes me not sit and not do anything, but it makes me work even harder and move on from that. …Sometimes when you really need to talk you might have to call someone who is not so close by to you and that is limiting. But to have someone that you don't know who is interested in listening to what you have to say, you can say and talk about anything and that makes me … it makes me feel good.

Excerpts from Reflective Journal

20March 2009

I feel like I am putting in so much effort and not getting much reward. I feel disconnected and don't have the energy to connect…(with the work and other aspects of life)

10 April 2009

Paper accepted at Keele Narrative Practitioners conference now I have to find some funds to get there! I was hoping getting this paper accepted might be a stepping stone to getting a traval grant…also need to apply for the PhD scholarship. It is almost as if I will not feel validated until I get some kind of (financial) support. It will certainly be good motivation for me to keep the momentum going

On reflecting on the above and the similarities between my own concerns about being validated as a researcher and Asanda's need to be heard and recognised. I wrote the poems on p180 and 177 respectively.

APPENDIX L: AUTHORSHIP DECLARATIONS

AUTHORSHIP DECLARATION

Naidu, T. & Sliep, Y. **The storyline of home-based HIV/AIDS care in Africa: A narrative meta-synthesis of qualitative research.** Submitted to *Social Science & Medicine*

Thirusha Naidu conceptualised, planned and prepared successive drafts and final compilation of the article.

Yvonne Sliep participated in planning and conceptualisation of the article and commented on successive drafts of the article.

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                            UKZN

Name & title (print)   Place   Date

Signature

Second Author

Prof. Y. Sliep   Howard College   27/11/2012
                            UKZN

Name & title (print)   Place   Date

Signature

AUTHORSHIP DECLARATION: Naidu, Sliep &Dageid

Context & The Social Construction Of Identity In Hiv/ Aids Home Based Care Volunteers In Rural Kwa-Zulu Natal, South Africa

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Thirusha Naidu conceptualized and designed the research outlined, conducted interviews, analysed data and prepared successive drafts of the manuscript. Yvonne Sliep supervised the conceptualization and design of the research, participated in the data analysis, writing and revision of the manuscript. Wenche Dageid contributed to the data analysis and participated in the revision of the manuscript.

Ethical clearance for this research was received from the University of Kwa-Zulu Natal Ethics Committee (Ethical Clearance Number HSS/0504/09D).

I declare that the above statement is an accurate reflection of my participation in compiling the above named paper for submission to the SAHARA Journal
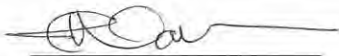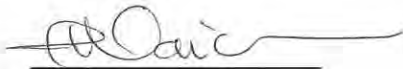
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AUTHORSHIP DECLARATION

Naidu, T., & Sliep, Y. (2012). **Understanding the agency of home-based care volunteers: establishing identity and negotiating space in AIDS-home-based care in rural KwaZulu-Natal, South Africa**. *African Journal of AIDS Research (11)*2 143-152.

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