A social capital perspective regarding available support: Informal HIV/AIDS carers in KwaNgcolosi, KwaZulu Natal

by

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DECLARATION

I hereby declare that this dissertation, unless otherwise indicated in the text, is my own original work. This research has not previously been submitted to any other institution for degree purposes.

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For Umar and Saaliha

with all my love........

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Abstract

South Africa has one of the highest country HIV/AIDS statistics in the world. The large number of ill individuals has created an unprecedented care work crisis in the country. In the absence of an adequate state supported care work response, the task of caring for people living with HIV/AIDS has fallen on community members. Under-resourced communities often do not have the capacity to engage in such intensive care work, and this shift has resulted in deleterious emotional, physical and financial consequences. This study sought to create greater understanding of the support available and accessible to friends and family members who serve as informal carers of people living with HIV/AIDS.

Methodologically, this is a qualitative study. Nine participants from KwaNgcolosi, a peri-urban area in KwaZulu Natal, were interviewed. A semi-structured interview schedule was directed to elicit participants' perceptions of the support that is available and accessible to them. Data was thematically analysed. Perceptions of support were understood in the context of the elements of social capital, namely trust, reciprocity, norms and networks, as well as the sociological strata in which these elements function, the bonding, bridging and linking levels.

Findings suggest that informal carers perceive low levels of support. Participants reported poor support from local community and extra-community members which include friends and family members, local political and traditional leadership and leadership at a governmental level. Low levels of social capital exist in the community evidenced by lack of reciprocity, norms that isolate the carer, mistrust, lack of control over resources, and weakened networks which inhibit the participants' pool of human resources. Stigma, discrimination and conditions of extreme poverty were major impediments to the availability and accessibility of beneficial social capital and thus the social support inherent in it. On the converse, the home-based carer (HBC) emerged as the strongest source of assistance to informal carers. The support reportedly received by the HBC

include emotional, instrumental and informational assistance. However, these contributions were insufficient, evidenced by the testimony from all participants that they were still experiencing extreme hardships in their care work.

The findings suggest that development, project and policy initiatives should focus on empowerment, greater involvement of all stakeholders ranging from individual community members to government policy makers, greater networking and participation and finally that there should be greater investment in the HBC and the informal carer in terms of resources and capacity building.

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Chapter one

Introduction

Introduction

HIV/AIDS has had devastating consequences for the people of South and Southern Africa. One of the most significant is the increasing burden of caring for the sick, particularly at home. Although the response to the epidemic includes initiatives at government and grassroots level, insufficient attention is paid to the experiences and effects of long term care of a sick individual from the perspectives of informal caregivers. Informal care within the context of this study refers to care work of a sick friend or relative of the carer who is not trained in clinical care. This research explored the perceived support available and accessible to informal carers of people living with HIV/AIDS (PLWHA) within the theoretical framework of Robert Putnam's Social Capital Theory.

This research is located within a broader study carried out in the same area by the Social Capital Project funded by the South Africa Norway partnership. The title of the project is "The role of social capital in promoting community based care and support for people living with HIV/AIDS in KwaZulu-Natal, South Africa", Project No. 180309/S50 Ethical clearance number: HSS/0174/08

This dissertation has been divided into six chapters.

Chapter one provides an outline to the study, briefly introducing the contextual background to the study, including HIV/AIDS in South Africa and the care work that is involved; it highlights the problem statement, significance and objective of the study; and briefly introduces the theoretical outline of the study, that of social capital.

Chapter two provides an overview of the social capital theory. This section discusses the definition of social capital; the bonding, bridging and linking levels of social capital; and the elements of social capital: networks, reciprocity, norms and trust. Economic

development and health outcomes are also considered from a social capital perspective, and finally the negative aspects of social capital are touched on. A working definition of social capital that contextualises it to a South African rural milieu has also been provided.

Chapter three considers the difficulties around HIV/AIDS care work specifically from the perspective of informal care providers, contextualised within broader debates around the value of care work, and provides finally a synopsis on social capital theory in the context of HIV/AIDS.

Chapter four presents the methodology used in the research. The study design, study area, sample, data collection procedures, data analysis, translation, ethical considerations and validity and reliability are discussed.

Chapter Five provides a combination of the analysed data and a discussion on the analysis.

Chapter Six presents the conclusion, and discusses the limitations of the study as well as recommendations based on the findings.

Background to the study

South Africa is facing a spiraling HIV epidemic (Pronyk, 2002). The UNAIDS estimates 5.7 million HIV infected people and an estimated 1.8 million AIDS related deaths (UNAIDS, 2007). These are some of the highest HIV/AIDS country statistics in the world. The KwaZulu-Natal and Gauteng provinces share the highest total of all South Africans infected: more than half of all South Africans infected live in these provinces (UNAIDS, 2007), with the overall highest statistic coming from KwaZulu Natal. KwaZulu Natal has a prevalence rate of 16.8%, and a prevalence rate of 37.4% among antenatal attendees, compared to a national prevalence rate of 10.8% and 28% respectively (Treatment Action Campaign, 2009).

Government interventions with regard to HIV/AIDS are generally large-scale, centralised and primarily preventative and treatment-based, focusing on responses such as behaviour change, voluntary counseling and testing, treatment of sexually transmitted diseases and other opportunistic infections, as well as anti retroviral therapy (Campbell, Nair & Maimane, 2007). Although vital, these interventions are largely individualistic and do not consider contextual effects. They have also been criticised for focusing very fixedly on the health care needs of patients (Ogden, Esim & Grown, 2006), and not sufficiently on the needs of their carers, an aspect of the HIV response that has not been given adequate attention. An estimated total of 1.2 million AIDS orphans, and over six hundred thousand AIDS-sick in South Africa (Treatment Action Campaign, 2009) places care work in an unprecedented crisis (Peacock & Weston, 2008). Whilst stakeholders are still in the process of experimenting with and developing the right HIV/AIDS policies and interventions, the immediate needs of the sick and dying has spawned organic, grass roots responses to the care work crisis. Community members, in particular women, are central to these responses (Peacock & Weston, 2008; Akintola, 2008a; Esplen, 2009).

Failure of government to adequately address this crisis, an ailing health care system and the commercialisation of health care, which makes privatised health care too expensive for the poor, means that in poor households care needs have to be met at home (Esplen, 2009). In addition, poor AIDS-related leadership does not bode well for the approximately 4.5 million pre-AIDS individuals (Treatment Action Campaign, 2009; Dageid & Duckert, 2008), or their carers.

Despite very little quantitative research conducted on the demographics of carers, there is evidence of this role being filled predominantly by women (Akintola, 2008a; Dageid & Duckert, 2008). Gender norms dictate that care responsibilities fall on women. That women take care of the ill is a norm prevailing in almost all societies, and across all socio-economic sectors (Esplen, 2009). However, in the context of a ravaging HIV epidemic, extreme poverty and gender relations unfavourable to women (Peacock & Weston, 2008, Esplen, 2009) these norms may have deleterious consequences. These consequences refer to the economical, opportunity, psychological and physical impacts of

care work on women. Whilst it is important to challenge these norms (Peacock & Weston, 2008; Pronyk, 2002), interventions do also need to address the immediate needs of caregivers, and improve the support systems available to them. An important first step in this regard is to understand what support is actually available and accessible to the carer.

This study is situated in KwaNgcolosi. KwaNgcolosi is a peri-urban area in the KwaZulu Natal province, a province in South Africa that has one of the highest HIV/AIDS statistics in the country. KwaNgcolosi is characterised by high unemployment, poverty, poor infrastructure and poor resources.

Care and Support in the Context of HIV/AIDS

Care work refers to the activities of an individual that serve others and their emotional, spiritual and physical well-being, and may include activities such as feeding and bathing young children, overseeing food production and preparation, or looking after the frail, elderly and ill (Esplen, 2009). Care work may be unpaid, such as caring for a family member, or paid, for example the services of a domestic worker, yet there are clear cost implications for the carer in terms of time, energy, resources and emotional well-being (GEMSA, 2009; Esplen; 2009).

This research focused on the carers of people living with HIV/AIDS. Care work in this context can be differentiated into primary care work, involving those that are directly involved in the immediate needs of the patient, such as cleaning, dressing, helping in the bathroom, etc (Peacock & Weston, 2008; Akintola, 2008a), and secondary care work which entails providing support to the primary care-giver (Akintola, 2008a).

HIV/AIDS care work can also be understood in terms of linked or unlinked care (Ogden, Esim & Grown, 2006). Linked care is that which is provided by individuals, whether paid or voluntary, who are linked to governmental or other-based support programs. Unlinked care takes place in relative isolation: carers are not linked to any formal support

base. Home-based care refers to those care activities that take place in the home of the ill person. It may be linked or unlinked, and may include clinical or non-clinical care.

Care work may be formal, referring to those employed to care for the ill; or informal, referring to those not in formal employment for their care work (Ogden et al., 2006). Within the context of this study, formal care work refers to paid care work but refers also to the care work of volunteer care providers, or home-based carers, and the community health workers. Informal carers are friends and family members of the sick, who are not formally trained to engage in care work, and whose care work is based on their relationships with the ill. This study focuses on family members and friends who assist the ill in the capacity of informal care workers. Whilst this does constitute home-based care, it is different from the home-based carer, as defined in this research. Home-based carers (HBCs) refer to the group of, primarily, women who volunteer their time to the families affected by HIV/AIDS and assist them with the palliative care of the ill. They are differentiated from informal carers in that their links with the ill are not based on relationship or friendship, and they usually receive some rudimentary training.

In an attempt to shift the focus of clinical health care from the formal health sector to the community, efforts by policy-makers included hospital-based outreach programmes (Ogden et al., 2006). However, these programmes were difficult to maintain, and currently home-based care is largely non-clinical, instead providing a range of care and support services to affected persons and families, and is provided by informal carers or the HBCs.

Care giving responsibilities include basic nursing care such as dressing of wounds, assisting them with basic hygiene care (LeBlanc, London & Aneshensel, 1997; Peacock & Weston, 2008; Akintola, 2008a), monitoring the patients' diet and medication (Akintola, 2008a; Esplen, 2009), and helping with their toilet needs (Steinberg, Johnson,

Schierhout, & Ndegwa, 2002). Caregivers also help with instrumental activities such as home care (housework, shopping, cooking, collecting water, care of children), transportation to health facilities and collecting medication and assisting with financial and legal affairs (Akintola, 2008a). Caregivers provide emotional support by listening to their patients, talking to them, showing love and concern, and otherwise tending to their emotional needs (Peacock & Weston, 2008; Lindsey, Hirschfield & Thlou, 2003).

Support for the carers refers to the assistance they receive in their capacity as carers. This may be emotional assistance (Orner, 2006), such as listening to the caregiver, and offering advice; instrumental assistance (Akintola, 2008a), such as relieving them of some of their own household or other chores, and; material assistance (Dageid & Duckert, 2008) in the form of money, material goods, infrastructure and housing, or food. Despite a relatively recent focus on the plight of informal carers, informal home-based carers face particular difficulties. They are the most under-served by basic public amenities such as sanitation and piped water (Steinberg et al., 2002), and are more likely to experience burn-out and injury, as well as increased vulnerability to illness and emotional despair (Ogden et al., 2006; Orner, 2006). Unlinked care providers may be most vulnerable to these conditions: they very likely have little information on the illness they are dealing with, receive no training, and no support from formal programmes, or concrete inputs such as gloves and medicine (Ogden et al., 2006).

Social Capital

This research was informed by the social capital theory of Robert Putnam (1994). Social capital theory asserts that collective action can be made easier through certain societal elements, namely social norms, norms of reciprocity, trust which gives rise to reciprocal relationships, and networks which facilitate interaction. It is a bottom up phenomenon with an emphasis on social relatedness that sees that the contextual needs of individuals and groups are addressed. Social capital inheres in relationships, and care work necessitates a relationship of sorts. Social capital theory is an ideal framework with which

to understand the experiences of care work. Its focus on social relatedness provides a useful lens with which to understand the social dynamics involved in care work, and the social dynamics that can be of assistance to carers. Although it is suggested that social capital can build a community's local resources, specifically in a HIV/AIDS context, this research did not make any suggestion of any benefits or deficits of social capital. Social capital was a critical framework with which to create an understanding of the perceived supports available to care workers.

Problem Statement and Significance of Study

There are presently over five and a half million HIV infected individuals in South Africa (UNAIDS, 2007). Although HIV affects all sectors of the population, it is the poorest that are most vulnerable to infection and for whom the consequences are most severe. The impoverishing impact of HIV/AIDS makes the consequences so much more acute because it is the economically active sector of the population that is most sick and dying. As more households in South Africa are affected by HIV/AIDS, there is a growing need for assistance with care and support. Increasingly households are faced with coping with the needs of sick members, including assistance with daily living, treatment and palliative care. Given the limited availability of formal, in-patient programmes, households rely on informal caregivers and home-based care programmes for assistance.

Informal home-based care providers are vulnerable to burnout, infection and illness, and emotional stress. They often do not have access to basic amenities, do not receive much support themselves, and may be ostracized and discriminated against due to the stigmatized nature of the epidemic. Many carers are themselves HIV infected and in need of care. Being in the domain of "women's work" care work is devalued and has often gone unrecognised, and so too care workers. The HIV pandemic has, however, strained the capacities of many under-resourced settings to provide care, and has brought to the fore many of the previously unacknowledged dimensions of care work, and these new insights challenge previously accepted ideas of the value of care work, and care workers.

Recognising the plight of care workers makes one aware of the huge input they are making in the HIV/AIDS response. As Ogden et al., (2006) suggest: "Making the carer visible, and bringing her into the focus of national and international HIV/AIDS policies, will enable these policies to provide a truly holistic continuum of care for those living with HIV and AIDS and their families" (p. 2).

Study Objectives

This research aimed to create an understanding of the support available and accessible to women who are caring for people living with HIV/AIDS, from the perspectives of the informal caregivers, and in terms of the different levels of social capital.

Further, this study sought to answer the following questions:

> **On a social bonding level:** how do caregivers perceive the accessibility and availability of support they receive from individuals in their immediate environment (family members, neighbours)?

> **On a social bridging level:** how do caregivers perceive the accessibility and availability of support from various groups and organisations, such as Churches and community-based organisations?

> **On a social linking level:** how do care workers perceive the availability and accessibility of support from government structures, businesses, and institutes external to the environment?

> What support would caregivers like to have available to them on all of these levels.

Chapter Two

Theoretical Framework

Social Capital Theory

Introduction

The concept of social capital has become increasingly popular in a wide range of social science disciplines. Despite disparate definitions and applications, Woolcock (cited in Martin, Rogers, Cook & Joseph, 2004) suggests that there is emerging consensus which summarises social capital as "the norms and networks that facilitate collective action" (p. 1). Intellectual and academic debate around social capital draws attention to the social relatedness of human beings (including factors linked to social relatedness such as norms and networks) and the manner in which this relatedness may shape their well-being (Edmondson, 2003). Adler and Kwon (2002) suggest that social capital can be understood as the goodwill that is produced by the fabric of social relations and that can be organised to promote action. Social capital cannot be understood in a linear fashion (Adler and Kwon, 2002). It comes into being from the interplay of a range of factors, each of which entails social relations that shape how agents react and these reactions are shaped by existing social capital. Social capital thus grows and is maintained in a self-reconstituting process that is difficult to quantify.

Social capital theory has informed studies on family (Putnam, 1994; Coleman, 1988), youth developmental issues (Raffo & Reeves, 2000), democracy and governance (Putnam, 1993), economic development (Evans, 1996; Woolcock, 1998; Woolcock and Narayan, 2000), and general problems of collective action (Pronyk et al., 2008; Adler and Kwon, 2002). Social capital has been useful in organisation studies; it has proven to be a

powerful factor in explaining career success (Burt, 1992); ability to find jobs (Granovetter, 1973); inter-unit resource exchange and product advancement (Gabbay & Zuckerman, 1998); reduction in turnover rates (Krackhardt & Hansen, 1993) and a strengthening of supplier relations (Uzzi, 1999). More recently, social capital theory has informed research into HIV/AIDS response.

Chapter two provides a theoretical grounding for the study: that of social capital theory. This section explores the definition of social capital, the bonding, bridging and linking levels of social capital as well as the elements of social capital: networks, reciprocity, norms and trust. Economic development and health outcomes are also considered from a social capital perspective. These dimensions of social functioning have important implications in the context of HIV/AIDS care work in under-resourced rural and semi-urban South Africa. Finally, the negative aspects of social capital are discussed.

Social capital's emphasis on organic functions of society provides an understanding of how under-resourced communities may find strengths in social structure in a manner that looks beyond the provision of material resources. KwaNgcolosi is characterised by fragmented social systems residual from apartheid and migratory labour practices, and with this is a lack of institutional and community networks that may facilitate HIV/AIDS care work. Social capital provides an appropriate theoretical framework with which to understand social problems in a fragmented society. In addition, social capital may provide an understanding of the vertical networks between communities and government, the deficits of which may be unsupportive to HIV/AIDS care work.

Definition of social capital

The popularity and the widely spread academic roots of the concept of social capital has led to it being used with a range of definitions. Edmondson (2003) argues that the reason why a shared definition of social capital remains elusive is because it takes on different forms in different settings. However common themes that run through the definitions are

those of reciprocity, networks, norms and trust that facilitate co-operation and co-ordination. The definitions of four theorists are considered in this review.

Pierre Bourdieu provided the first methodical analysis of social capital in current literature (Siisiäinen, 2000). His development of the concept of social capital is informed by his ideas of how social class and other forms of inequality are socially reproduced by the various "capitals" (Bourdieu, 1985). He defined the concept as "the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalised relationships of mutual acquaintance or recognition" (Bourdieu, 1985, p. 248). Bourdieu identified three aspects of capital each with its own relationship to class. Economic capital, cultural capital and social capital can be used to obtain resources that are critical to the pursuit of profit and the maintenance of social class position (O'Brien & O'Fathaigh, 2005). He emphasises conflicts and power functions in social relations that increase the ability of an actor to advance his/her interests. He states that social networks are not a natural given and is rather actively constructed through investment tactics oriented to the institutionalisation of group relations, which then functions as a reliable source of other benefits (Siisiäinen, 2000). The amount of social capital that one possesses depends on (1) the size of network connections that the individual can effectively mobilise and (2) the amount and type(s) of capital possessed by each of those to whom he or she is related (Portes, 1998). His theory recognises both the social relationships in which a person is embedded, and the sum and value of these social relationships, and in doing so has been praised by some scholars as being the most refined (DeFilippis, 2001; Portes, 1998). By considering how social networks and their institutionalisation serves to house power within actors of that group, Bourdieu's theory does recognize the potential negative of social capital: that of the exclusion of those that do not belong to these institutionalised groups to the sources made available to individuals that are members of a network (Siisiäinen, 2000; O'Brien & O'Fathaigh, 2005; Carpiano, 2005).

Robert Putnam has been one of the most influential social capital theorist within public health and community development (Carpiano, 2005). He defines social capital as referring to characteristics of social organisation such as networks, norms, and social trust that assist coordination and cooperation for communal benefit (Putnam, 1995). According to Putnam, social capital has three components: a) moral obligations and norms, b) social values, particularly trust and c) social networks, especially membership in voluntary associations (Siisiäinen, 2000). Putnam's theory has largely been formed by studying trends in regional governance in Italy (Putnam, 1994), and the decline of civic associationalism in America (Putnam, 1995). A key hypothesis of Putnam is that a community's capacity to amass social capital results in a well functioning regional economy and high levels of political integration (O'Brien & O'Fathaigh, 2005). Putnam has linked many social problems in the United States to declining stocks of social capital (Putnam 1995). Despite some opposing trends, the general conclusion is that social capital is being eroded with harmful effects noted in a loosening of bonds within the family and a decline in social trust and relationships within communities (O'Brien & O'Fathaigh, 2005). Accordingly, Putnam (1995) has directly linked levels of civic engagement and the capacity of communities to handle social and economic difficulties such as employment, poverty, educational non-participation, and crime. Putnam claims that networks of organised reciprocity and civic solidarity, are a precondition for, as opposed to epiphenomenon of, social-economic modernisation (Putnam, 1995).

According to James Coleman (1988) social capital is defined by its function. It consists of a range of diverse social entities, with two essentials in common: there is a social structural element inherent in these entities, and these entities facilitate social mobility within the structure (Coleman 1988). Rather than being lodged and accumulated within individual people or institutes, social capital is created and exists in the spaces between people, in "the structure of relations between actors and among actors" (Coleman, 1988, p. S98). As per Coleman's definition, social capital can be thought of as the creation of a myriad of everyday interactions between people that increase a society's resourceful potential. In this definition, Coleman highlights the intangible nature of social capital:

social capital comes about through changes in the relations among persons that facilitate action. Coleman (1988) identifies four important forms of social capital: a) obligations and expectations, b) informational potential, c) norms and effective sanctions, and d) the role of authority relations (O'Brien and O' Fathaigh, 2005). Although insightful, Coleman's contribution suffers from two shortcomings. First, Coleman does not provide an explanation as to what are the social bodies that facilitate individual goal achievement, nor where they come from. Second, his views suggest an instrumentalist course that analyses social structural forces only from an optimistic perspective (O'Brien and O'Fathaigh, 2005).

Francis Fukuyama (1999) explains social capital as an instantiated informal norm that promotes cooperation between two or more individuals. The norms that constitute social capital can range from a norm of reciprocity between two friends, all the way up to intricate doctrines like religion (Fukuyama, 1999). They must be instantiated in an actual human relationship: he asserts that while the norm of reciprocity may exist in potential, it is only formally actualised in dealings with friends. By Fukuyama's (1999) definition, trust, networks, civil society, and the like which have been associated with social capital are all epiphenomenal, arising as a result of social capital but not constituting social capital itself.

Levels of Social Capital

An important construct in the framework of social capital are the different levels of social capital: bonding, bridging and linking (Harpham, Grant & Thomas, 2002; Woolcock & Narayan, 2000). This differentiation allows for a clearer understanding of the concept, but is also important in its application. Recognising that different communities have more or less access to the different levels of social capital allows the argument that it is different combinations of social capital that are responsible for a range of outcomes.

Bonding Social Capital

Bonding social capital refers to the networks within homogenous groups. It specifically refers to trusting and co-operative relations between members of a network who are similar in terms of social identity - race, ethnicity, neighbourhood and community characteristics (Kawachi, Kim, Couts & Subramarain, 2004). Bonding views focus on collective actors' internal characteristics, as opposed to collectives' external ties. On a bonding level, the social capital of a collectivity rests on the linkages between individuals and groups in the collective that promote cohesiveness and facilitate the pursuit of collective goals (Adler & Kwon, 2002). Bonding social capital gives rise to in-group solidarity, which is described by Adler and Kwon (2002) as important for collective action. "Within-group solidarity", as referred to by Campbell et al., (2007, p. 351) is a powerful mobilising mechanism with which to challenge stigmas and discriminations. Within the context of HIV/AIDS, Campbell et al. (2007) suggest that the networks inherent in bonding social capital allows safe spaces for dialogue, promotes responsibility for the HIV epidemic, and empowers one with a sense of agency in relation to local strengths. Although having the potential to build strong ties, bonding social capital can also result in higher walls of exclusion (INFED, 2009). Higher levels of bonding social capital between HIV positive people and their carers can strengthen their support bases, however the same processes can exclude these very same from other social groups. For example discriminatory actions resulting from stigmas around HIV/AIDS can exclude those positive or with a positive individual in the households from belonging, for example, to a church group or parent-teacher body. Pronyk (2002) notes that the strong social cohesion in communities may increase the exclusion of those that are HIV positive, or those caring for AIDS patients.

Bridging Social Capital

Bridging social capital encompasses distant ties between homogenous groups (Franklin, 2004); it refers to the social capital generated by the networks between individuals in different groups. Bridging social capital may better facilitate access to resources external

to the immediate social group but still within the community or the community level, and in doing so engenders broader reciprocity. For example a local clinic can network with Church groups or with other support groups to increase support and understanding. Kawachi et al. (2004) suggest that bridging social capital can help explain the differential successes of individuals and explain the differential success of individuals and firms in their competitive rivalry: the actions of individuals and groups can be greatly facilitated by their direct and indirect links to other actors in social networks. Putnam (2000) suggests that bridging social capital is more encompassing than bonding social capital as by definition it incorporates individuals across communities. Although not specifically referring to bridging social capital, Granovetter (1973) does emphasise the potential benefits of bridging social capital in his discussion of "weak ties" (p. 1362). He describes weak ties as those that incorporate contacts between individuals at the periphery of that particular social organisation, who are able to move between groups and in this way transmit new ideas and knowledge. By the same token, "bridges" to individuals in communities external to a focal actor's community may open up channels for communication and information (Granovetter, 1973; Friedkin, 1980).

In KwaNgcolosi, and indeed most rural or peri-urban South Africa, bridging networks may refer to those networks between NGOs, Churches, clinics and possibly private sector. Through the processes of increased participation, greater networks which serve as sources of information exchanges and channels of communication, bridging social capital can increase the leverage of civil society to affect a more efficient response to the care work crisis. NGOs in particular may have the potential to fill in the gap left by government inadequacy. This potential may exist in NGOs because of their less bureaucratic structure, their closer affiliations with community members and their own networking with other institutes working in the same geographical area.

Linking Social Capital

Kawachi et al. (2004) suggest that what is missing from the bonding/bridging distinction is a clear exposure of vertical power disparity in social relations. In addressing this gap

Szretzer and Woolcock (2004) introduce linking social capital which they define as "norms of respect and networks of trusting relationships between people who are interacting across explicit, formal or institutionalised power or authority gradients in society" (p. 655). In KwaNgcolosi, linking social capital refers to networks between the community and political and traditional leadership, government structures and even large businesses. Often groups higher up in the vertical divide may be more heavily resourced, enabling access to a far wider range of resources than are available in the community or at the community level (Franklin, 2004).

Woolcock (1998) suggests that extensive extra-community linkages are essential for economic development in under-resourced contexts. Drawing on the early and contemporary studies of urban poverty and ethnic private enterprises, Woolcock (1998) further suggests that business groups in poor communities need to build and sustain linkages beyond their community so that i) individual financial benefit can be curbed when it undermines (or threatens to undermine) the economic prosperity of the group and; ii) entry into larger business and economic networks can be facilitated, as well as the merging of the business sector into larger social networks. In successful bottom-up development programs (development initiatives that emerge or take place at a grassroots level), linkages to broader extra-community institutions need to be created, and these are forged incrementally; a community's stock of social capital in the form of bonding social capital can be the basis for launching development initiatives, but it must be complemented over time by the construction of new forms of social capital, i.e., linkages to non-community members (Woolcock, 1998).

Adler and Kwon (2002) discuss the importance placed on external linkages, not just in terms of access to resources, but also in terms of the influence of extra-community linkages on the reality of those individuals at a community level. They discuss hierarchy as an important dimension of social structure that indirectly influences social capital by shaping the structure of social relations. Their discussion of hierarchy has highlighted the "top-down" role of such formal institutions as government structure and legal rules in initiating or inhibiting the emergence and maintenance of social capital and trust in civil society (Woolcock, 1998; Evans, 1996; Ostrom, 1994). Evans (1996) argues that the state

can act as a powerful facilitator of social capital when internal integrity (of the state) and external synergy (with actors in civil society) are inherent in the system. In similar vein, Adler and Kwon (2002), in their review of the literature, do suggest that market relations on a more global level can play a facilitative or an inhibiting role pertaining to social capital.

In the context of this study, linking social capital is that which is derived from government involvement. Governmental involvement has been largely preventative and playing a vital, albeit slow, role in rolling out ARV treatment and promoting media campaigns to increase HIV/AIDS education, amongst other projects. Whilst home-based care has been recognised as an importance alternative to hospital care, government has not adequately supported community's ability to respond to the increasing need for HIV/AIDS care and it has been suggested that government has rather shifted the responsibility of care onto individual community members (Ogden, 2006; Quinlan & Desmond, 2002). Government involvement may be hampered by a lack of clear policy guidelines, poor allocation of resources, transformational processes, and poor infrastructural support in communities (Campbell, Nair & Maimane, 2007; Nsutebu, Walley, Mataka, & Simon, 2001). In this context, government involvement is seen as the provision of resources and infrastructure. Their role in shaping social relations to promote beneficial social capital is limited. In this regard, Campbell et al (2007) notes that bureaucratic structure may hamper government's networks with civil society, including NGOs.

Elements of Social Capital

The literature on social capital consistently highlights four elements that have significance in the discussion of the social relatedness that promotes collective action and/ or well-being; that of networks, trust, reciprocity and norms. These four elements have been used to inform this study.

Networks

Social networks may be defined as the aggregate of social interactions, formed by the trust and reciprocity inherent in these interactions. Trust and norms of reciprocity are most likely to be effective in dense social networks.; frequent interactions with others build a basis for trust and norms of generalised reciprocity. Conversely, in a trusting community, there is likely to be more regular social exchanges (Putnam, 1994). Social networks also have the potential to facilitate social mobility and individual access to resources in the social, economic and political spheres (Franklin, 2004). Direct and indirect network ties allows an individual or group access to people who can themselves provide support, and to the assets those people have available through their own network ties (Granovetter, 1973; Coleman, 1988; & Burt, 1992).

Networks may be horizontal, bridging individuals with roughly equal status, or vertical linking individuals across stratified hierarchies and status positions (Putnam, 1994). Putnam's concept of voluntary association is one of the most important forms of horizontal interaction (Siisiäinen, 2000). These associations limits the potential for defection by increasing costs to a defector; encourage norms of reciprocity; allows for smoother communication channels about the trustworthiness of an individual, including reputation, and; finally they allow past successes at collaboration to smooth the way for future collaboration.

Solidarity can and does also emerge from weak ties, or at least weak ties that bridge otherwise unconnected groups: weak ties between various internally cohesive groups can add considerably to the degree of integration of the larger aggregate (Granovetter, 1982; Krackhardt & Stern (1988). Granovetter (1973) furthermore maintains that weak ties will provide useful, non-redundant knowledge.

Adler and Kwon (2002) state that an actor's network of social ties creates opportunities for social capital transactions, yet they do acknowledge as important the network's *ability* to provide resources, the lack of which does not equip individuals in a particular network to invest in social capital. Bourdieu (1985), in his discussion of social capital, forces us to consider not only the existence of community social networks, but also the resources

(potential or actual) possessed by the networks' and individual's ability to draw upon the network for those resources.

In South Africa, the "networking/ institutional context" (Campbell, Nair, Maimane & Sibiya, 2007, p. 508) of HIV/AIDS management refers to links between local communities, the government, private enterprises, NGO's and civil society networks. Campbell et al. (2007) suggest that not much is known on these networks, in particular the networks of home-based carers, and that an understanding of these networks will fill a contextual gap in the responses to the HI Virus.

Trust

Trust can be defined as confidence in the expectation or ability of an individual to act in a predictable manner (Putnam, 1994; Franklin, 2004). According to Putnam (1994) trust is an essential element of social capital. Social capital rests on the cooperation between various stakeholders or parties, and it is trust that lubricates that cooperation (Putnam, 1994). The literature on trust (Levine & Cross, 2004) provides considerable evidence that trusting relationships lead to greater knowledge exchange. When trust exists, people are more willing to provide useful information (Andrews & Delahy, 2000; Tsai & Goshal, 1998) and are also more willing to listen to and absorb others' knowledge.

Levine and Cross (2004) suggest that strong ties are helpful because they tend to be trusting. They propose that benevolence-based trust (described as trust with a strong affective component) and competence-based trust (described as trust with a strong cognitive component) mediate the link between strong ties and receipt of useful knowledge. Levine and Cross (2004) found that trust lubricates weak ties as well. They argue that when trust is low, weak ties will provide more useful knowledge than strong ties, and when trust is high, weak ties will also provide more useful knowledge than strong ties. Trusted weak ties may be even more helpful due to their added ability to provide nonredundant information.

Trusting in relationship can ease transactions in relationships: without trust, third party reinforcement and continuous monitoring, which is expensive and often impossible, may hamper positive collective outcomes (Levine & Cross, 2004; Lyon, 2000). Within the context of health systems, Gilson (2003) argues that trust promotes the cooperation that is vital to health production, and that a trust-based health system adds value to society. Similarly, Lazerson suggests that personal trust is essential to ensure high productivity in small firms (Putnam, 1993). Trusting relationships are based on the prediction that the person will behave in a way that is expected and this then rests on how well individuals know one another in society.

Social and institutional structures in rural and peri-urban South Africa may not encourage trusting relationships. Government structures may not be perceived as being "close to the ground", thus not allowing the kind of interactions and networking that may facilitate trust. Similarly, when traditional family systems are no longer in place, or migratory labour often displaces individuals, there is less opportunity to build stronger social relationships and trust between individuals, both on an institutional and individual level. Trust enables communal action (Putnam, 1995) and the absence of same may impede efforts at collective action for common good, which reduces the availability of care for those that are sick with AIDS, and the support for those that are caring for them.

Reciprocity

In some social structures, it is said "people are always doing things for each other" (Coleman, 1988, p. S102). This encompasses the idea of reciprocity that goes hand in hand with a discussion on social capital. Putnam (1993) cites reciprocity as one of the most important social norms. Taylor (as cited in Putnam, 1993, p. 172) characterises reciprocity as a combination of "short-term altruism and long-term self-interest". Putnam (1993) distinguishes between balanced and generalised reciprocity. The former refers to an equal exchange of items or favours, and the latter more to an expectation, or norm, that a favour granted now should be repaid in the future. A helper may help altruistically, but with the possibility that they will also receive help in the future. According to

Gouldner (1960), the stability of a social system depends, in part, on the mutually contingent exchange of gratifications, that is, on reciprocity as exchange. The norm of reciprocity then holds that people should help those who help them and, therefore, those whom you have helped have an obligation to help you. It is not only proper, but also expedient to conform with the specific status rights of others and with the general norm (of reciprocity).

The norm of reciprocity depends on two elements: trustworthiness of the social environment, which means that obligations will be repaid, and the actual extent of obligation held (Coleman, 1988). Social structures differ in both these dimensions, and actors within the same structure differ in the second. Whatever the source, however, individuals in social structures with high levels of obligations outstanding at any time have more social capital on which they can draw. The density of outstanding obligations means, in effect, that the overall usefulness of the tangible resources of that social structure is amplified by their availability to others when needed (Coleman, 1988).

Norms

Norms are standards of behaviour arising from expectations within communities without a legal or other formal basis, that provide a form of informal social control (Bullen, 2009; Putnam, 1994; Keefer & Knack, undated). They define what actions are considered acceptable or unacceptable, and can be seen as the basis of building and maintaining personalised trust: the employment of trust is on the probability that other agents will behave in a way that is expected (Lyon, 2000). Norms cannot be created at will. They are learned through processes of socialisation (Putnam, 1994) especially during childhood through institutes such as families, schools, religious bodies, and even civil society (Lyon, 2000).

Norms dictate what patterns of behaviour are expected in a given social context, and an infringement of those expected behaviours could incur social sanctions. Sanctions include loss of future benefits, damage to reputations, social pressure from members of the community as well as more formal forms of social control such as legal action (Lyon,

2000; Platteau, 1994). Individuals are pressured into keeping to norms by those around them. Platteau (1994) suggests a self-policing mechanism, whereby individuals internalise moral norms, behaving morally in order to avoid feelings of guilt and shame.

Keefer and Knack (undated) highlight the role of social norms in facilitating collective action, stating, "social norms prescribing cooperative or trustworthy behaviour have a significant impact on whether societies can overcome obstacles to contracting and collective action" (p. 2). The predictability of behaviour through norms allows for more trustworthy behaviour from individuals, which then facilitates cooperation and investments in social capital (Putnam, 1993; Keefer & Knack, undated). Fukuyama (1999) asserts that not just any set of instantiated norms constitutes social capital; norms should lead to cooperation in groups and therefore are related such virtues as honesty, honouring commitments, reliability and reciprocity.

However norms need not always have positive consequences. Carers of the ill should be females is a social norm, and as mentioned this norm may have harmful consequences for women. Norms such as those may hamper responses to HIV/AIDS, and a critical look followed by action may replace those norms with more effective ones that prescribe cooperative or trustworthy behaviour.

Social Capital and Economic Development

In 1942, Shaw and McKay hypothesised a link between inequality and the concentration of poor economic conditions and social disintegration through a breakdown of social cohesion and normlessness. Yet early policies for economic development has largely ignored this link. Early modernisation developmental theorists' held that only the adoption of the values, practices and resources of the West can establish the necessary preconditions for greater material prosperity. In discrediting the modernisation theory, world-systems and neoclassical growth theories have focused on the contribution of nation-states and transnational corporations (Woolcock, 1998, p. 183). Classical economists identified land, labour and physical capital (assets that generate income) as

the three basic factors shaping economic growth, and in the 1960's, the notion of human capital had been introduced to the discourse on economic development (Schult, 1963; Lucas, 1988).

Despite the hypothesised link suggested by Shaw and McKay (1942) decades earlier, the literature and policy interventions in economic development has largely ignored the contribution and consequences of social relatedness. Woolcock (1998) acknowledges that culture, power and rationality do play an important role in shaping developmental outcomes, but suggests that it is in and through social relations that outcomes are actually mediated. Woolcock (1998) further suggests that it is impossible to understand the prospects of development policies and projects without knowing the characteristics of social relations at the micro and macro level, how these levels interact with one another, and how this degree of interaction has emerged historically. Evans (1996, p. 1034) suggests a broader definition of the institutional bases of community development and economic empowerment in poor communities, one that considers micro-institutional economic foundations in relation macro-economic outcomes. Social capital provides a promising conceptual and policy devise by which to get beyond exhausted modernisation and world-systems theories and make potentially important contributions that complement orthodox development economic approaches by laying greater emphasis on social relatedness.

Research on social capital and economic development can be categorised into four distinct perspectives (Woolcock & Narayan, 2000): the communitarian view, the networks view, the institutional view, and the synergy view. The communitarian view equates social capital with such local organizations as clubs, associations and civic groups, and goes so far as to recognize the social assets of the poor that can be strengthened to promote economic development. The networks view considers bonding and bridging ties, and looks at social capital as inherent in the connections or networks between entrepreneurs, business groups and information brokers, and the contribution of these stakeholders in economic development. The networks policy, succinctly, is to decentralise, create enterprise zones and bridge social divides. The institutional view targets political and legal institutions to mediate between public and civil liberties, as

well as responsibilities and accountability. The synergy view combines the networks and institutional camps, bridging community networks and state-society relations. According to this view, social capital resides in the relations and networking between community groups, civil society, firms and states (Woolcock, 1998).

Woolcock (1998) and Narayan (1999) suggest that the combinations of the different dimensions of social capital (essentially what the synergy view proposes) that is tailored to specific circumstances and social, political and economic contexts, is likely to have the most productive developmental and economical outcomes. The synergy view suggests three central tasks in policy development (Woolcock & Narayan, 2000): to identify the nature and extent of a community's social relationships and formal institutions; to develop institutional strategies based on these social relations, particularly the extent of bonding and bridging social capital; and to determine how the positive manifestations of social capital – cooperation, trust and institutional efficiency – can offset sectarianism, isolationism and corruption. The synergy view to economic development looks to transform situations where a community's social capital substitutes for weak, hostile or indifferent formal institutions into one which both spheres complement one another.

A significant example of the social capital framework transcending both macro and micro levels is that of group-based microfinance institutions (GBMFIs), the most well known being the Grameen Bank in Bangladesh, where two million poor borrowers have been financially assisted, with a repayment rate of 97%. Despite failures, GBMFIs remain one of the most widely acclaimed success stories in recent efforts to alleviate poverty through small-scale income and employment generation (Besley & Coate, 1995).

The mediating benefits of social capital on economic development has been supported by research on social capital and violent firearm criminal behaviour. Kennedy, Kawachi, Prothrow-Stith, Lochner & Gupta, (1998) concluded that interventions aiming to reduce violent firearm crimes should not only target at most risk groups (including those steeped in poverty) but need to consider social relatedness which creates social contexts of huge financial disparities in income, reduced income and poverty. Also pointing to the mediating potential of social capital, Rose (1998) points to weak public institutions and

deep cleavages between authority and citizens in Russia, and how this can lead to political instability, corruption, rising inequality and ultimately capital flight.

Although social capital is still to enter policy framework, the importance of social relatedness has entered the discourse of economic development. Woolcock and Narayan (2000) conclude that social relations provide opportunities for mobilising other growth-enhancing resources and that prospects for development in a given community is shaped by the nature and extent of interactions between communities and institutions.

Social capital and health outcomes

It has been acknowledged for some time that social circumstances – including the availability of effective public hygiene, warm houses, accessibility to and availability of food – have noteworthy consequences for health (Edmondson, 2003). In addition, there is sufficient evidence that suggests that socially isolated individuals are at increased risk for poor health outcomes because of their limited access to resources such as instrumental aid, information and emotional support (Kawachi, Kennedy & Glass, 1999). Traditional understandings of the influence of social circumstances on health have been reductionistic, even if considered from a socio-political or economic perspective (Edmondson, 2003). However, there is currently an understanding of how social conditions influence health outcomes in a non-reductionistic way. It is suggested that the "sense of community", "community competence" or "community empowerment" contribute to public health (Sheill and Hawe, 1996, p. 241). Despite knowledge of the association between social conditions and health outcomes, it is only recently that public health has considered the influence of social capital on health outcomes (Harpham et al., 2002) and research findings suggest that households may derive protective benefits both from their own social networks and from the greater extent of shared networks throughout the community (Kawachi et al., 1999; Martin et al., 2004). Social capital has been shown to be of great importance for population health (Lindström, Merlo & Östegren, 2003).

Kawachi et al. (1999) suggest three credible pathways in which social capital influences health behaviour at the neighbourhood (bonding and bridging) level. First, social capital may influence the health behaviours of neighbourhood residents by allowing a more rapid diffusion of health information. The theory of diffusion of innovation (Rogers, 1983) suggests that innovative behaviours (e.g., use of preventive services) diffuse much more rapidly in communities that are cohesive and in which members know and trust one another. Social capital also encourages health outcomes by encouraging healthy norms of behaviour and sanctioning health-related behaviour (Lindström et al., 2003), including the facilitation of the prevention of crime (Kennedy et al., 1998; Kawachi et al., 1999; Putnam, 2000).

Second, neigbourhood social capital may allow increased access to local services and amenities Kawachi et al., 1999)

Finally, neighbourhood social capital may influence the health of individuals via psychosocial processes, by providing affective support and acting as the source of self-esteem and mutual respect (Wilkinson, 1996; Kawachi et al., 1999)

However, theorists warn against unrestrained gusto for the adoption of social capital in public health (Kawachi et al., 1999; Pronyk et al., 2008). Some of the criticisms aimed against the adoption of social capital in health promotion policies are that social capital may be viewed as a 'cheap' solution for solving public health problems (absolving government responsibility), or that there might be the tendency to view social capital as a panacea whilst ignoring its negative aspects. Pronyk et al. (2008) caution that the methodology in supporting a link to social capital and health outcomes may be compromised by the employment of diverse and unstandardised measurement tools. They add further that whilst a relationship has been found, the ability to draw causal inferences is limited (Pronyk et al., 2008).

Negative Aspects of Social Capital

The strong solidarity that bonds individuals in a tight knit community may have the effect of excluding others outside of this cohesive group (Portes, 1998). In addition, prior unequal distribution of other assets may lead to a situation where a dominant group's use of its social capital can considerably enhance its dominance by helping to exclude subordinate categories from the information, influence and solidarity benefits it has already accrued (Adler and Kwon, 2002)

Group or community closure may limit the economic advance of an individual by the demands placed on a focal actor by members of his/her group. In such cases, the social capital made available to claimants by their access to resources of those in their group is precisely that which limits opportunities for entrepreneurial furtherance (Portes, 1998)

Belonging to a group or community often necessitates conformity to the norms of that group (Portes, 1998; Kawachi et al., 1999). Social norms has been cited as a core aspect of social capital, but certain norms may inhibit the actualisation of individual potential.

Finally, Portes (1998) suggests that while social capital has been celebrated as public goods, it can also lead to public "bads" (p. 18). Mafia families, prostitutes and gambling rings and youth gangs offer many examples of how embeddedness in social structures can be turned to less than socially desirable ends (Portes, 1998; Martin et al., 2004).

Working definition of Social Capital

The definition of social capital used in this study is informed by Robert Putnam (1994). Putnam defines social capital as referring to characteristics of social organisation such as networks, norms, and social trust that make possible coordination and cooperation for shared gain. Social relatedness is considered in terms of the elements of social capital: trust, networks, reciprocity and norms. Within the context of this study, the four elements of social capital have been understood in relation to the bonding, bridging and linking levels. Social bonding is an important level to consider: in the semi-urban area of KwaNgclosi, the intimate social relations that occur on a bonding level may be the most

prominent. Social bridging has been considered to understand the connections that residents of this community have to others outside of their social groups, and how this might facilitate (or potentially facilitate) the response to the HIV epidemic. Social linking has been considered for a greater understanding of the links to powerful actors outside of the community that might aid (or potentially aid) the response to the HIV epidemic.

Conclusion

Social capital is a term whose utility is gaining in momentum and is being applied in a range of settings. Despite multiple interpretations of social capital by theorists, a common thread running through the various definitions are the elements of networks, reciprocity, trust and norms. Inherent in many definitions of social capital are the different levels, i.e., bonding, bridging and linking. More recently, and within the context of this study, social capital is being applied in a critical understanding the effects of the HIV/ AIDS epidemic, including an understanding of the support and upliftment for those that are ill and for those that are caring for the ill. Social capital has been used to inform studies on health promotion and economic development. Both these dimensions have significance in an under-resourced community with a high HIV/AIDS prevalence and poor structural capacity to counter the effects of the epidemic.

Chapter 3

Literature Review

Care Work in the context of HIV/AIDS

Introduction

Globally, 6.5 million of the 40.3 million HIV infected individuals are in need of care (VSO, 2006). In South Africa alone there are over 500,000 individuals in need of ARVs, and some 4.5 million pre-AIDS individuals (Treatment Action Campaign, 2009). Many more need treatment for opportunistic infections, palliative care, general nursing care and emotional support. Under-resourced health care systems in most developing countries cannot bear the burden of the care for these individuals, with the result that this task has fallen on those who have historically always seen to the care needs of families and communities: women and girls (Peacock & Weston, 2008). Yet this response to the epidemic is neither sustainable as HIV/AIDS care work increases and detracts from other productive activities, nor is fair to carers who are subsidising state health care with their own emotional, physical and caring labour (Peacock & Weston, 2008).

This chapter considers the difficulties around HIV/AIDS care work specifically from the perspective of family members and friends who serve as informal care providers. This chapter is contextualised within broader debates around the value care work, and finally provides a brief review of the research into HIV AIDS care work and social capital.

Care Work and Caring Labour

Care work describes a type of work that involves concern and personal attention to others, usually those that cannot perform care activities for themselves, such as the disabled, elderly and very young (Strazdins & Broom, 2004; Badgett & Folbre, 1999; Evers, 1994), but also for abled persons, such as spouses and adult children. Caring work

usually denotes such instrumental activities as assisting with personal hygiene, cooking, cleaning, and shopping (Boris & Klein, 2006). Care work may be paid (or formal), as in the teaching and nursing professions, or unpaid (informal) as in the care activities of a housewife (Joshi, 1992). Informal care is also the help that steps in when formal care fails, or to fill gaps between commodified formal care, such as child day care (Peacock and Weston, 2008). A source of informal care is usually female friends and relatives, particularly grandmothers.

Care work further describes an intrinsic motivation to perform those activities: it is often thought of as a "labour of love"; caregivers are expected to provide love as well as care giving activities. Hochschild (1983) relates the "labour of love" very closely to the sociological concept of emotional labour. Emotional labour, according to James (1989), refers to the skill and effort involved in the emotional regulation that usually accompanies care work. Equating it with other forms of labour, it can be understood as productive work, but with older understandings of the word labour, also "difficult effort, or "pain". It demands that the labourer gives personal attention, which means they must give something of themselves (James, 1989). Care-giving is thus an activity encompassing both instrumental tasks and affective relations: caregivers are expected to provide love as well as labour.

Caring work has been the concern of feminists for decades (Conrad & Doss, 2008; Boris & Klein, 2006; Badgett & Folbre, 1999; Ungerson, 1997). They argue that the assignment of care work is the interpersonal enactment of culturally specified roles, or gender norms (Peacock & Weston, 2008) that may have unfavourable consequences for women. Care work is expensive, no matter who the carer (Conrad & Doss, 2008; Strazdins & Broom, 2004; Ungerson, 1997). Time and energy is devoted to the care of others, at the expense of the caregivers earning potential and transportable human capital, placing carers in a weaker bargaining and advocacy position in the family and in society, and renders them economically more vulnerable (Badgett & Folbre, 1999). Gender norms which may devalue the feminine also function to keep men out of "women's work": they feel that it is beneath them, and the fear of being ostracized for doing "women's work" may prevent them from helping even when they feel they should (Conrad & Doss, 2008;

Peacock & Weston, 2008; VSO, 2006). These gender norms may also be underpinned at policy level, for example the lack of focus on paternity leave, or the difficulties of men accessing child care grants (Conrad & Doss, 2008; Peacock & Weston, 2008). The devaluing of "women's work" results in a devaluing of care work. There is a concentration of women in caring profession, such as nursing and teaching, and these professions are notoriously low paid and low status (Badgett & Folbre, 1999).

Caring labour, a term first developed and expounded by Scandinavian feminists (Badgett & Folbre, 1999), allows for an understanding of a market value of caring work, both paid and unpaid. The gendered debate on the market value of caring labour extends from Marxian and Weberian tendencies to locate caring labour in the family and the community, outside the sphere of modern markets, to feminists who assert that caring labour should be treated as a commodity (Badgett & Folbre, 1999; Ungerson, 1997). Support for the tendency to locate caring labour outside the capitalist organisation of work is given by the personal and emotional dimensions of care work, and its intrinsically rewarding value. It is argued that when care work is simply interpreted as a form of unpaid "work" (such as raising children), these personal and emotional dimensions are obscured. Feminists reject the idea that care work is necessarily more enjoyable and fulfilling than other types of work, and Hochschild (1983) goes so far as to treat the effort of emotional labour as a dimension of new forms of exploitation unique to the emerging service sector. The effort and time spent in care labour is obscured by the notion that this work is intrinsically rewarding, and comes naturally to women. In this line of thinking, the value and skill of care work is lost, and an accurate account of its toll on care workers is not considered.

A gendered economical lens is a useful way with which to view the phenomenon of care work, understand the concentration of women in this field, both formal and informal, to provide an idea of the value placed on care work and its relations to other forms of labour, and generally to contextualise care work within a broader, ongoing debate on the responsibilities, forms and consequences of care work. However, what remains as the focus of this review is the psychosocial experiences and consequences of care work,

particularly of informal carers of people living with HIV/AIDS in under-resourced communities.

The concerns expressed regarding care work are not new. But they have taken on a new urgency for two reasons. Firstly, the movement of women into the paid work force has left a gap in informal caring responsibilities (Esplen, 2009; Peacock & Weston, 2008. Concurrently, the need for care is rising: HIV/AIDS has placed care work, both formal and informal, in an unprecedented crisis (Esplen, 2009).

Care Work and HIV/AIDS

"When there is a sick or dying person in the house, someone quite literally has to care, whether out of love, duty or simply a lack of options" (Ogden et al., 2006, p. 2).

Over 350,000 AIDS sick in South Africa (Treatment Action Campaign, 2009) is greatly straining the capacity to respond to care needs (Ogden et al., 2006). The high HIV prevalence rate has resulted in unprecedented demands being placed on already weakened health care services (Ogden et al., 2006; De Jong, 2003; United Nations, 2004). In countries with a low availability of Anti Retrovirals, 50-70% of all hospital beds are being occupied by people with HIV infection (Opiyo, Yamano & Jayne, 2008; Haacker, 2001), and yet this is not even a true reflection of the total number of those that are positive (Ogden et al., 2006). These statistics are based on a formal diagnosis; for reasons ranging from stigma to lack of clinical care, the majority of positive individuals may remain undiagnosed (Ogden et al., 2006). Government resources have been strained to the point that it cannot cope, and the responsibility of caring for the ill has shifted to the communities, most notably women and girls (Dageid & Duckert, 2008; Peacock and Weston, 2008; Akintola, 2004; Ogden et al., 2006; Orner, 2006).

Early efforts at greater community involvement revolved around a principle of hospital-based outreach: hospital staff traveled directly to patients homes to provide care (Ogden et al., 2006; Osborne, van Praag & Jackson, 1997). This initiative was practically difficult and costly to maintain (Chela, 1995), and the resultant response was the mushrooming of

Non-Governmental Organisations (NGOs) and other groups to support affected families (Ogden et al., 2006). This effort also was limited as organisations did not have adequate funding, and their networks and strategies were often able to reach a small segment of the affected population, especially in areas with a high prevalence rate.

The World Health Organisation (WHO), in an initiative to offer a more pragmatic response to the HIV/AIDS epidemic, developed a "Care Continuum" framework (Osborne, 1996; van Praag, 1995). The continuum contains comprehensive HIV/AIDS related services, including counseling and testing, clinical management, nursing care and community-based social support; the provision of care extends from the individual/home to hospital, through various levels of care linked with discharge planning and referral networks, back to the individual/home (Osborne, 1996). The objective of this model was to support, create and maintain a holistic approach to care and support for persons living with HIV/AIDS. This framework locates the person living with HIV/AIDS at the centre of a wide range of actors who are dynamically linked, enabling them to receive clinical and non-clinical care (Ogden et al., 2006; Osborne, 1996; van Praag, 1995).

State support necessarily forms part of the care continuum. However, in South Africa, and indeed most parts of Africa, public health systems do not, or cannot provide home based care and the home based care organisations that are in existence are largely the initiatives of faith-based organisations, churches, community-based organisations and NGOs (Akintola, 2004). State funding is also limited. Although home based care organisations do receive governmental funding, these funds do not offer compensation to volunteers or family informal care givers. Also, this framework does not consider that many HIV positive individuals and the families remain "unlinked" (Ogden et al., 2006) (linked care has been previously described as referring to that care that occurs in relative isolation). Practically, the continuum of care is only achieved in "pockets of 'home-based care' programmes scattered across Africa" (Akintola, 2008a, p. 9), still leaving the majority of care responsibilities on the communities (Akintola, 2008a).

Community and Home-Based Care (HBC)

Community and home-based care is any form of care that is given to the sick within their homes and includes physical, psychosocial, palliative and spiritual interventions (Akintola, 2008a; VSO, 2006; Uys, 2003). The World Health Organisation (in Department of Health, 2001) define HBC as "the provision of health services by formal and informal caregivers in the home in order to promote, retire and maintain a person's maximum level of comfort, function and health including care towards a dignified death". A report from UNAIDS (2007) showed that 90% of care for people living with AIDS takes place in the home, with care provided by community caregivers, who are predominantly women (Opiyo et al., 2008; VSO, 2006; Homan et al., 2003).

Despite early efforts at formal home based care (Ogden et al., 2006), the majority of home care takes place by informal carers (Opiyo et al., 2008). Informal care workers are those that are not employed or receive any remuneration for their care work (Akintola, 2008a) and usually are family and friends of the ill, but also include volunteers (Akintola, 2008a; Blinkoff, Bukanga, Syamalevwe & Williams, 2001).

Home-based and community care is currently the key response to the HIV/AIDS pandemic globally (Campbell & Foulis; 2004). Home based care is associated with some benefits: those that are sick have the comfort of being cared for in their homes, by people that are familiar to them, and they receive the nurturing, and flexible care that is best given in a home. They also are able to undertake productive activities and contribute to the household as their symptoms alleviate (Ogden et al., 2004, Uys, 2001). Care providers also experience some of the benefits of home based care, most notably it may allow an entry point for survivors of the sick person to testing and counseling, it is less expensive than hospital care, and linked home based care offers opportunities for educating families and communities about HIV prevention and can help de-stigmatize HIV/AIDS, reducing the social isolation that HIV positive individuals and their families often experience (Campbell, Foulis, Maimane & Sibiya, 2005; Ogden et al., 2004). However, for most care givers, home based care proves to be a challenge, as a result of, or exacerbated by, inequitable gender relations, and poverty. Also, most home based care providers remain unlinked. Ogden et al. (2006) define linked care as that which enjoys

the support of other formal supports, such as NGOs, religious based groups or state interventions. Unlinked care is that which takes place in relative isolation, and may actually be suggestive of a more possible scenario, as a majority of HIV/AIDS sick may remain undiagnosed (Ogden et al., 2006). Unlinked care takes place together with other care activities that women engage in to sustain and look after their families, but as the burden of HIV/AIDS care is increasing, it is detracting from the available time and energy for other household chores (Ogden et al., 2006).

In South Africa there has been an increasing reliance on volunteer care givers. These individuals are trained to provide care and assistance to households afflicted with HIV/AIDS, but they receive no remuneration for their work (Blinkhoff et al., 2001). Volunteers are typically members of the same community who are conscripted to help and provide informal training for AIDS-affected families in carrying out care responsibilities in their communities (Akintola, 2008b). In the context of HIV/AIDS care it takes on a very distinctive form and meaning (Akintola, 2008b): volunteering has many of the characteristics of a full-time or part-time paid job, however, volunteers are not remunerated; volunteers' work is demanding, and often entails fetching firewood and water, cooking, cleaning patients, and even supervising patient's transport to hospital in wheelbarrows or relatives backs (Campbell et al., 2007); the time volunteering for HIV/AIDS care is usually beyond that spent in volunteering in other contexts (Akintola, 2008b). Volunteers form a crucial response to the HIV/AIDS pandemic (Blinkhoff et al., 2001). For example, volunteer care providers played a central role in the success of the Catholic Diocese HIV/AIDS and TB outreach programme in the Zambia's Copperbelt Province (Ntsutebu, Walley, Mataka & Simon, 2001).

Who are Home-Based Care Workers?

Home-based care workers refer to any person providing care at the home of the ill (Akintola, 2008b; Campbell & Foulis, 2004, Ogden et al., 2004). Despite a paucity of information on the demographics of caregivers, research does indicate that this role is filled primarily by women (Orner, 2006; Edoh, 2004; Steinitz, 2003). VSO (2006) reports

on the following statistics: three-thirds of primary caregivers surveyed in Southern Africa are female, one quarter of these are over 60 years old; a South African national evaluation of home based care found 91% of caregivers were women. Akintola (2008b) found all but one of twenty one of primary caregivers were women; and 36 of 38 volunteers working at a home based care programme in the Midlands Province of Zimbabwe were women. Even abroad women seem to be tasked with care work: in Thailand elderly mothers were primary caregivers for a large proportion of people living with HIV/AIDS (Knodel & Im-em, 2004).

In a study exploring the ways in which households cope with HIV/AIDS in South Africa, Steinberg et al. (2002) found the 7% care caregivers were less than 18 years of age (and the majority were females), and 23% were older than 60 years of age. Elderly carers are often ill themselves and may not have the capacity to care for their own adult children, and whilst younger child caregivers may provide love to the ill, they simply are too inexperienced for care work.

Challenges Facing Care Workers

Many community care workers often receive no, or inadequate training, which not only impacts on them as care givers, but also on the care they are able to provide (VSO, 2006). They are providing care for others in some of the harshest external environments. Steinberg et al. (2002) brings to awareness some of the difficult realities of caring for an individual with advanced HIV/AIDS. In the survey of 771 AIDS-affected families, 16% of those that were sick could not control their bowel and bladder movements; 17% needed help to and from the toilet and in and out of bed; about 19% could not wash without assistance; and just over 17% had to be helped to dress. They emphasised the fact that all of these problems were significantly compounded by insufficient access to even the most basic sanitation facilities: 30% of participants only had access to a communal tap or natural water source such as a river; only 20% had access to a flush toilet. Substantial proportions of both rural and urban households were still dependent upon pit or bucket latrines.

Volunteers face specific challenges. A study by Akintola (2008b) reports on some of these challenges. Volunteers face denial from potential patients and their families who fear that the presence of a volunteer worker will identify their home as an "HIV" home; they are often insulted by patients who often downplay the impact of their care work. In homes in which they were admitted, they are caught between the patients wishes not to disclose their HIV status, and families who demanded to know what was wrong.

The reality of the condition of some of their patients is a source of stress for volunteers. Their patients are often bedridden, cannot go to the toilet, soil their clothes, and experience extreme pain which they (caregivers) are helpless to alleviate. This leads to another source of stress: volunteers cannot administer to all of the needs of their patients, even though some of these are basic needs, and they are often left feeling incompetent. As a consequence they are left feeling discouraged, emotionally drained, and difficult to remain committed. In addition, volunteers often have little time, or opportunities to deal with their own problems for which they have no access to professional help (Akintola, 2008b). Despite the emotional and physical difficulties, all for no rumination, volunteers find it difficult to give up their roles as caregivers: there is an over-reliance on volunteers by family members of those that are ill (Akintola, 2008c), and volunteers often feel trapped in a sense of obligation in their roles as caregivers (Akintola, 2008b, Lindsey et al., 2003)

Impact of HIV/AIDS related care work in the context of rural South Africa

Economic costs

The costs and loss of income related to HIV/AIDS care is underestimated (GEMSA, 2009; Akintola, 2008a; Campbell & Foulis, 2004; LeBlanc et al., 1997), and is pushing more and more households further into poverty (Conrad & Doss, 2008). Women who have to stay at home to perform care work are less able to seek other forms of paid work (Peacock & Weston, 2008). Carer's already limited income is spent on care items and activities, such as gloves, medication, funerals and even clean water incurs considerable expense. In their survey, Steinberg et al. (2002) reported that on average households

spent a third of their income (34%) on medical related expenses. The financial cost to older carers is exacerbated by a loss of financial support from their adult children when they become sick (Knodel & Im-em, 2004), and becomes debilitating when they are unable to access grants or pensions. Care givers also incur transport costs, to travel to clinics or hospitals to get ARV treatment, or for the treatment of opportunistic infections. It is also costly to meet the dietary requirements for those that are ill and are using ARVs. Funerals are also are a huge expense to carry: Steinberg et al. (2002) reports that 55% of households that they had surveyed had to pay for a funeral in the preceding year and that, on average, they had spent four times the total household monthly income on a funeral (a mean average of R5,153).

One of the major economic costs that are not factored in an economic analysis of home-based care is the cost of women's unpaid labour (Esplen, 2008). This factor links to broader debates around the value of care work, and caring labour (Conrad & Doss, 2008). The care economy concept encompasses all aspects of care and home based care, but focuses on the economic benefits and costs of care (Ogden, et al., 2006). Specifically, the care economy concept describes the unpaid provisioning of, usually, home and community care (Ogden et al., 2006). The value, time and resources that are invested in care work often goes unrecognized, lost in the assumptions that that type of work is unskilled, and therefore does not factor into the market value of skilled labour. Yet the UN (UNAIDS, 2000) estimates that care work constitutes at least half of gross domestic product and more than half of private consumption. In the context of HIV/AIDS the economic consequences of unpaid care work become all the more severe. Caring labour has been stressed and stretched to limits by the care requirements of HIV/AIDS. Because care in this context extends from general care, it seamlessly falls into the domain of women and girls.

On a more concrete level, restraint by their care work on their employment opportunities means quite simply that women have less money, yet for more, if at least the same, amount of labour time and effort (Akintola, 2008c; Baylies, 2002). Suffering a loss of income weaken women economically, leaving them more dependent on their husbands, strengthening gender inequalities in the household and ultimately access to health care

and nutrition (Peacock & Weston, 2008). This affects whole communities: if women are unable to participate economically, the economy's productive potential is reduced (Conrad & Doss, 2008; Peacock & Weston, 2008), with deleterious consequences on their own health, and those of their families (Ogden et al. 2006)

Opportunistic and empowerment costs

Carers pay a high price in lost opportunities (Akintola, 2008c; VSO, 2006). Time taken for care work often means that women are unable to actively pursue income-generating activities (GEMSA, 2009, Peacock & Weston, 2008; Steinberg et al., 2002). Many caregivers who are in vulnerable employment, especially in the formal sector, are unable to take leave for care giving, and often have to leave their jobs involuntarily (Akintola, 2008c; Baylies, 2002). Even if they are working, care work is an extra load that steals from their leisure time, opportunities for literacy and skills building and the ability to advocate for their rights. This "voiceless ness" leaves their needs unheard by policy makers, usually men far removed from their circumstances (Esplen, 2009). Opportunistic costs are felt by children as well; girls in particular, as they are most likely to be removed from school to care for a family member (GEMSA, 2009). School enrolment in Swaziland has fallen by 36% since the epidemic hit the country, and enrolment for girls has fallen more precipitously than among boys (Desmond & Michael, 2000). An incomplete education means reduced ability to advocate, lower job opportunities, and more likely lower paying and lower status jobs (GEMSA, 2009, Peacock & Weston, 2008). It is also a risk factor for HIV infection, gender based violence and being in an inequitable relationship later (Wolff, Blanc & Gage, 2000).

Reduction in food security

The burgeoning care work around HIV/AIDS results in lost time for productive agricultural work (GEMSA. 2009; Wiegers, Curry, Garberto & Hourihan, 2006; Munthali,2002), particularly in countries and areas that live off the land. A survey

conducted in Kenya (Opiyo et al., 2008) showed that while men may be more involved in off-farm income-generation, women depended mainly on farming for income, and the loss of their productive labour had negative consequences for food security. This not only affects the food for individual families, but national economies as well, as women produce between 60 –80% of the food in most developing countries (GEMSA, 2009).

Reduced food security most likely will lead to nutritional deficits, which have physical, and mental health impacts, in addition to those placed by care work. That most caregivers are typically in their reproductive and productive ages has implications for income generation and food security: time, effort and labour needed for the care of PLWHA detracts from other productive activities (Akintola, 2008a).

Physical and Emotional Costs

The emotional and physical exhaustion that accompanies the care of AIDS sufferers, especially if carers are sick themselves, underlines and runs through all of the above mentioned impacts on carers (Homan et al., 2005; Akintola, 2008a; Campbell et al., 2007; Peacock & Weston, 2008). Carrying fresh water over long distances, or transporting the ill to health care facilities places huge physical demands on carers (Peacock & Weston, 2008; Steinberg et al., 2002). It is estimated that it takes about 20 – 80 litres of water to provide care every day to an AIDS sick individual. In developing countries where running water is a scarce resource this may have to be carried from rivers, wells or public standpipes located far away from dwellings (UNAIDS, 2007). Carers in very rural and isolated areas may not have easy access to transport facilities, including public transport, and it is not uncommon for those that are too ill to walk to be carried, or pushed in a wheelbarrow to clinics (Steinberg, et al., 2002).

Carers often experience negative consequences to their own health. They are at increased risk for exposure to HIV, or if they are already HIV positive, they are more vulnerable to opportunistic infections (Peacock & Weston, 2008). As many older, and younger care providers are "invisible" to authorities, they are not targeted for information and support services (Ogden et al., 2006), making them more vulnerable to possible infection. Older

caregivers themselves need care with afflictions of age, such as strained muscles, arthritis, high blood pressure, diabetes, as well as hearing, vision and mobility problems. They may not have the emotional, physical or financial capacity to care for others, and are actually at a stage of their lives where they expect to be cared for by others.

The stigmatised nature of the disease adds to the care burden of carers (Campbell et al., 2005). They often are socially isolated as they are associated with a disease that has many negative social undertones (ibid), and it is often assumed that they have the disease as well (VSO, 2006). Because of the stigmas associated with HIV, patients often are cared for in "secret", and carers then do not have access to support, if it is available, and have very little or no opportunities for training (VSO, 2006). Volunteers experience the stigmas associated with the disease in a similar, but also unique way (Akintola, 2008b). Volunteers often cannot identify those that are need of care, they have to serve as advocates of those that are sick in communities that have reduced tolerance, and their ethical commitments to confidentiality places them in a conundrum between the sick and their families (Akintola, 2008b; Russel & Schneider, 2000)

The Role of Social Capital in HIV/AIDS Care Work

HIV/AIDS poses a challenge to public health, not just in terms of the extent of its devastation, but also in the inadequacy of normative public health initiatives to curb its spread. Pronyk (2002) argues that dominant approaches to the epidemic are trained by our scientific and epidemiological understanding of the disease, and interventions are accordingly targeted at individuals within prescribed risk groups. These interventions include the active promotion of condom use (Pronyk, 2002; Campbell et al., 2007), education programmes aimed at risk reduction (Pronyk, 2002), voluntary counseling and testing (Campbell et al., 2007), STI management, and more recently, ARV treatment (Pronyk, 2002; Campbell et al., 2007). However the rising prevalence rate of the epidemic has not only prompted researchers to investigate the social context of the epidemic (Barnett & Whiteside, 2002; Tawil, Verster & O'Reilly, 1995, Gregson, Terceira, Mushati, Nyamukapa & Campbell, 2004; Campbell et al, 2005) but has also

spawned research into how best to facilitate a community to respond effectively to the HIV epidemic (Paruk, Petersen & Bhana, 2009; Campbell et al., 2007; Campbell & Foulis, 2004).

The past two decades has seen a multi-disciplinary attempt to understand health related problems, including HIV/AIDS prevalence and treatment, from a contextual perspective. In this effort, an emerging theme is that of social capital (Norris & Inglehart, 2003). The cohesion and solidarity that necessarily goes hand in hand with high stocks of social capital may make available opportunities for the exchange of information which would have the potential to influence community norms around gender relations, sexual negotiation and communication (Campbell, Williams & Gilgen, 2002; Pronyk, 2002). In addition, individuals in communities with high stocks of social capital have a higher chance of serving as role models for health-promotive behaviour, such as engaging in safe sex, remaining in monogamous relationships or deferring sexual activity until a later age (Pronyk et al., 2008). Networks characterised by an easy flow of information may also serve to reduce discrimination around HIV/AIDS, creating a more accepting environment for the ill and their carers. Further, communities with high stocks of social capital are better equipped to take collective action to make their needs heard, particularly in under-resourced communities where high levels of social capital may be the only source of leverage (Pronyk, 2002).

With specific reference to HIV-AIDS care work in the context of rural and semi-urban South Africa, Campbell and Foulis (2004) suggest three key challenges facing care providers, that of "providing effective care; lobbying for the recognition of the needs and interests of carers and their patients, and finally, equipping the survivors and their carers to reconstruct their lives once the epidemic has run its course" (p. 5-6). They suggest that the mobilisation of multi-stakeholder collaboration at a local, national and international level is vital in promoting the bonding, bridging and linking social capital needed to deal with the challenges facing care providers.

Home-based care and the networks that arise from the organisation of home-based care workers is an important contextual resource in the HIV/AIDS response at a community level (Campbell & Foulis, 2004). The links between HBC are recognized as networks at

the bonding and bridging levels. These networks hold huge potential in addressing many of the issues facing the ill and their carers over and above the instrumental and palliative care that they provide. It is argued that home based care provides a medium for support and education about HIV/AIDS amongst local families and communities, creating first hand awareness of the dangers and effects of HIV/AIDS. It has been argued that these functions of the HBC played an important role in reducing HIV transmission in Uganda (Low-Beer and Stoneburner, 2003).

HBC groups may also provide the leverage to potentially activate the invaluable support derived from linking social capital (Pronyk, 2002; Campbell & Foulis, 2004; Campbell et al., 2002). In an idyllic situation the mobilization of HBC groups could enable local people to wield an influence on wider government policies and interventions. Mobilisation of HBC groups may also generate community solidarity, having the potential to strengthen communities' abilities to address other challenges to their health and well-being. Campbell and Foulis (2004) suggest that small groups of local involvement may form the basis of wider social associations through which otherwise isolated people might have access to more powerful social actors in communicating their requirements and wellbeing.

Pronyk (2002) does note that the reverse may also be true: strong social cohesion in communities may increase the exclusion of those that are HIV positive, or those that are caring for AIDS patients. He suggests that those adverse aspects of HIV/AIDS, "death, disability and discrimination", may further compromise vulnerable communities systems of care and support (Pronyk, 2002, p. 13). It is important to note that social capital is not put forward as a panacea, but rather as a resource that, as any other, has huge potential when used correctly, but that also has huge potential to be abused.

Whilst HBC networks are recognised as important resources, much remains to be known on the contextual response to HIV/AIDS care work. Campbell and Foulis (2004) conclude that despite research that has identified much of challenges facing home based carers, and that has indicated the type of support they need, the community and social contexts most likely to provide them with this support still need to be explored. Social

capital provides a useful framework for understanding the contexts that are likely to promote the needed support.

Conclusion

The care of those that are sick with HIV/AID is a critical issue in Sub-Saharan Africa. Currently, state attempts to address the care work crisis is failing many, particularly those in rural, outlying areas, or areas that are under-resourced. These are the areas that have the lowest potential to provide effective care in the absence of adequate state support. Care work adversely impacts on carers in terms of their own emotional and physical health, and also by reduced income, reduced food security, and reduced opportunity for personal furtherance. Despite these challenges, the organic response of home-based carers and their organisation has proven to be an invaluable resource to many carers. Social capital has the potential to play a role in community and social attempts to address the needs of those that are caring for people living with HIV/AIDS, with particular reference to the mobilisation of HBC networks.

Chapter Four

Research Methodology

Introduction

This chapter presents the methodology used in the research. The study design, study area, sample, data collection procedures, data analysis, translation, ethical considerations and validity and reliability are discussed.

Study Design

The research was a qualitative, explorative design. The dimensions of perceived support to caregivers within the KwaNgcolosi area were not known, and a qualitative design allowed the researcher to explore these dimensions in terms of feelings, experiences and social situations as they are most likely to occur in the community. A central aim of this research objective was to understand the data in its specific context, and a qualitative paradigm allowed this understanding to emerge.

The sample of nine women were purposefully selected; they were identified with the help of the HBC who was assigned to their area. The basis of selection was on their care giving activities of a family member or friend, being women, and tenure of care giving activities, namely a minimum of six months. Data was collected through in-depth interviews over four days. The data was transcribed, thematically analysed and coded. Validity was ensured through close adherence to the data. Validity was also strengthened through the transcription of the data: transcriptions from isiZulu to English ensured that meaning and information was not lost in the translation. Dependability was ensured by, once again, close adherence to the data, and the inclusion of the data into the discussion.

Study Area

This research was conducted in KwaNgcolosi, a peri-urban area in KwaZulu Natal. KwaNgcolosi is situated on the banks of the Inanda Dam. The area is breathtakingly beautiful, however the beauty belies the daily hardships faced by the members of the community. The area is characterised by poverty, high unemployment rates, and poor infrastructure. Although KwaNcgolosi is under-resourced in terms of amenities and infrastructure, the area is located within close proximity to developed and wealthy neighbourhoods. KwaNgcolosi has a high HIV prevalence rate. Clinics are available in the area; however, community members do not have easy access to hospitals.

Study Sample

The sample used in this research were purposefully selected, based on their residence in the KwaNgcolosi area, and their informal care work of friends or family members that are HIV positive. Participants were aged between 20 and 67 years, with the average age being 34 years. They were identified by the Home Based Carer (HBC) assigned to their specific area. A criterion for identification was the care of a sick family member or friend for a minimum of six months. The span of years that participants had been engaging in care work is between 1 year and 8 years. Another criterion is that participants were all women. Whilst men and women may be involved in care work, research suggests that it is primarily women who are responsible for the care of PLWHA. This study focused specifically on female carers because of their increased vulnerability: they are already disadvantaged by gender inequalities in a heavily patriarchal context which sees them economically and symbolically more vulnerable than men (Peacock & Weston, 2008; Esplen, 2009). This research also focused on women who were caring for friends or family members on an informal basis, rather than volunteer workers or HBCs. This band of care workers are rather more disjointed and isolated than the HBCs and volunteer care workers in the area, who meet regularly. With many of the participants, their only link to any kind of formal support group was through the HBC. This link to the HBC differentiates this sample from unlinked carers.

All but three of the participants responded in isiZulu (the interview was facilitated by a translator). The translation made the interviews possible as my isiZulu, and the participants' English was too poor to allow a conversation. However, with the three participants who were fluent, and thus interviewed, in English, I found the conversation to flow smoother and be more focused. Efforts to ensure that essential information was not lost in the translation included briefing the translator on the content of interviews and research, and requesting that translations remain as literal as possible. A further check on the accuracy of translation, which strengthened the validity of the research, was done during transcription: translations back and forth were checked by a transcriber fluent in English and isiZulu.

Data Collection Procedures

Collected data was the perceived support available to participants in their capacity as carers. The data was obtained through interviews with participants using a semi-structured interview schedule. Participants were interviewed at their homes accompanied by the HBC assigned to their area, and with a translator. Participants appeared comfortable in this setting. All the interviews were recorded, with prior consent from participants, and later transcribed. In addition, notes were taken during the interview of any outstanding information or perceptions. Interviews were between 30 minutes to one hour and 15 minutes.

A semi-structured interview schedule and open-ended questions allowed a free range of responses to emerge from the participants about their experiences and perceptions of the kinds of support available to them in their capacity as informal care givers. The interview schedule was used as a guide to ensure that the key objectives of the research were met, but was followed with exploration and following of leads as they emerged. Questions in the interview schedule were general, tapping generally into perceived support within the various levels of Putnam's social capital theory, therefore further exploration was an essential component of the interview. I attempted further to allow an uninhibited response by avoiding leading questions, not interrupting, and allowing the participant space and

time in which to think about their responses and answers. At certain points, closed ended questions were used to keep the interview focused, and to elicit concrete details. Examples of such closed ended questions were enquiries about the health state of the patients, usually conducted at the beginning of the interview. Open-ended questions were used to elicit uncensored responses on particular areas. For example, care givers perceptions of support on a social bonding level included questions such as "who is (available) to help you look after her (participant's patient)?" (Participant 9, page 4). The participant's response gave an indication that people could not be called upon for help, because confidentiality may not be maintained. Further prompting with closed ended questions explored issues of trust and stigmas.

All participants were Zulu speaking, and most could not speak English. The interview was thus facilitated by a translator.

The Role of the Translator

KwaNgcolosi is a predominantly Zulu speaking area. All of the participants spoke isiZulu as a first language, although three were fluent in English as well. The translator, who is fluent in isiZulu and English, facilitated communication between the interviewer and the participants by converting questions into isiZulu, and isiZulu responses back into English. The translator adhered to as strict a translation as possible, preserving valuable information, and ensuring it did not get "lost" in the translation. The translator allowed for a smoother conversation, which may otherwise have been disjointed. The translator quickly acclimatized herself to the content and thrust of the research, and this was also a valuable aid in ensuring that my explorations were understood, and that information was not lost.

The translator served a valuable role not only in the translation of the conversations, but also in my understanding the nuances of the language, as well as the customs that I had to be sensitive to. The translator has done considerable community development work in this specific geographical area and this added to her expertise and value as a translator.

Data Analysis

The data was thematically analysed. Thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). Thematic analysis was used for its flexibility, which allowed the inclusion of social capital into the analysis as a critical framework.

Thematic data analysis (or any qualitative analysis) is not a linear process, but a recursive one in which reference has constantly been made to the data, and the data is read and re-read to ensure a refined and accurate analysis. As suggested by Braun and Clarke (2006) there is movement back and forth through the different phases of analysis.

Braun and Clarke (2006) suggest a 6 phase model of thematic analysis, which was used as a guide to analyse the data for this research. These are guides, and therefore do retain a degree of flexibility in its application. However, I stayed as close to these guidelines as possible.

Phase one: familiarisation with the data

The interviews were conducted in person, and familiarity with the data began at that early stage. The data was read a few times before coding, and a few times during coding. This helped to ensure that the themes that did emerge were relevant to the data sets.

Phase two: generating initial codes

Codes were formed during early readings, but were committed to paper during later readings. Data was coded manually, using electronic word documents, in which I "cut and paste" the data into various codes. The codes were informed by the levels and elements of social capital, as well as any other significant data that appeared in the data sets.

Phase three: searching for themes

This phase begins when all the data has been coded. During the phase the different codes are rearranged and sorted to form overarching themes. The emergence of themes was also informed by social capital theory and specifically the stated study objectives.

Phase four: reviewing themes

This phase involves refining the themes, and omitting or altering if necessary. There were two levels that were followed during this phase: during level one all the collated extracts were re-read for each theme to ensure that they did indeed support the theme; and level two ensured that the individual themes accurately reflect meanings in the data set as a whole.

Further reviewing and refining was done at this phase, as themes were changed, or codes were converged into new themes.

Phase five: defining and naming themes

During this phase a narrative is written of the theme. As with all other phases there is continuous referral to the data sets. Naming is providing a concise but inclusive heading to the theme that immediately allows the reader to know what the theme incorporates.

Phase six: producing the report

This phase involves the final analysis and write-up of the report. As Braun and Clarke (2006) suggests "it is important that the analysis provides a concise, coherent, logical, non-repetitive and interesting account of the story the data tell – within and across themes" (p. 93). The write-up provided evidence of the themes through vivid data extracts.

Ethical Considerations

The most outstanding ethical consideration is the expectation from many participants that this interview with them may lead to some change in their situation. It was very difficult for me to have to explain that this research was for academic purposes. I did explain

though, that it may contribute to a broader pool of knowledge that would create more awareness around the issues and challenges involved in caring for someone who is very ill, and that potential benefits may be long-term.

For many participants, the HBC is the only source of communication and relief from their daily burden. Some participants expressed some relief at having being able to talk to someone about their difficulties, and it was a concern to me that they were possibly left with many emotions that were stirred in the interview, that may not have been contained during the interview, and with no follow-up sessions to help them work through some of what they were feeling.

Confidentiality is yet another ethical concern, especially considering the stigmatized nature of the disease. Confidentiality was assured, both in writing in the consent form, and in private. Voluntary participation, and the right to withdraw from the study at any point was also pointed out.

Validity and Reliability

Validity

Golafshani (2003) conceptualised validity (and reliability) as 'trustworthiness, rigor and quality' (p. 604). To ensure a valid research, I closely adhered to the transcripts, and provided an honest and accurate account of the participants' experiences and perspectives.

Validity was also ensured during the transcriptions of the data. The transcriber is fluent in English and isiZulu, and checked that meanings were not lost or altered during the translation

Reliability

Reliability refers to the degree to which results are repeatable. Qualitative researchers believe that individual behaviours and opinions are not stable, unchanging entities, and that these will change in changing contexts (Terre Blanche, Durrheim & Painter, 2004). Qualitative research thus rests more on the idea of dependability rather than reliability

(Terre Blanche et al., 2006). Dependability refers to the degree to which the reader can be convinced that the findings did actually occur as the researcher claims, and within this study this is achieved by providing a rich and detailed account of the transcripts (Terre Blanche et al., 2006).

Conclusion

A qualitative research design was used in this study. This type of research method allowed for a rich, detailed account of the experiences of care work, and the perceptions of available and accessible support, from the perspectives of female carers of PLWHA. A semi-structured interview, with the use of open-ended questions allowed the researcher to explore these dimensions in terms of feelings, experiences and social situations. The study sample consisted of female carers of a friend or family member who are ill with HIV/AIDS. Nine participants were interviewed, the data transcribed and analysed, and the results of the analysis reported in this dissertation. Data was thematically analysed, using the levels and elements of social capital theory as a critical framework. Ethical considerations were noted, and validity and reliability ensured.

Chapter Five

Analysis and Discussion of Results

Introduction

Chapter five provides an analysis and discussion of the results. The results were analysed according to the different levels of social capital: bonding, bridging and linking levels. Themes were elicited according to these levels, and understood in relation to the elements of social capital: networks, norms, reciprocity and trust. This chapter reports on informal caregivers' perceptions of support on a bonding, bridging and linking level. Poverty, stigma and discrimination, and certain social norms are discussed as weakening social capital. The home-based carer (HBC) is discussed as a source of emotional, instrumental and informational assistance that ultimately serves to increase stocks of social capital in the community. Finally, this analysis reports on the caregivers' perceptions of what support should entail. These are discussed within the bonding, bridging and linking levels.

Poverty Weakens Social Capital

This research found the effects of poverty to be extreme, and hampered the creation of beneficial social capital. These effects are discussed on the bonding, bridging and linking levels: poverty affects the extent to which individuals in social networks are able to provide assistance; the contextual effects of poverty increase the burden of caring on the carers through, for example, transport costs and difficulties in transportation; and the problems of poverty are not addressed sufficiently at a governmental level.

Poverty and Social Bonding

Poverty coalesces with stigmas and misperceptions of the disease to sustain the participant's isolation: individual community members may not have the resources to help carers or they may conserve money and/or energy for their own struggles. Poverty

influences the support of the carer because it reduces the individual's networks' *ability* to provide assistance or for the carer to reciprocate. KwaNgcolosi is a community known to be steeped in poverty, with basic survival necessities such as food and medication being unavailable in many households, which inhibits the potential of householders to be of assistance to others.

I wish the kids could get the porridge...if they could get that porridge, because sometimes there isn't enough money for everything (Participant 5, 5, 115-116)

some of them do not work they are suffering, some people do not go to hospitals to collect the treatment, because they don't have money to go there (Participant 9, 10, 255-258).

The networks that are potentially available to carers in relation to their HIV/AIDS care work are not utilised due to a lack of reciprocal actions (also due to a lack of trust, discussed below). Reciprocity refers to the expectation that a favour bestowed will be returned (Gouldner, 1960). This lack of reciprocity is due to an inability (due to poverty) of the networks to initiate or broadly reciprocate acts of assistance. Thus, social mobility and individual access to social, economic and political opportunities and resources to the community members of KwaNgcolosi, in the context of HIV/AIDS care work, are hampered by inadequate social networks which are created and maintained so, in part, by the effects of poverty. This is suggested by the following extracts:

so what I think in my case personally is that my neighbour is also very troubled she lost her daughter who was feeling ill and her child...she had a baby so she has to look after the baby/I don't think its anything personal when she doesn't look my way when I'm having a hard time, 'cause she has a lot of troubles of her own (Participant 3, 5, 107-111)

in my family there is a lot of people, so it happens like this people are caring for their children, but they are always supportive, so I cannot rely on them, we cannot rely

on them....because they are caring for their families, for their children and mothers, you
know (Participant 9, 10-11, 265-270)

Poverty and poor social networks may also be spuriously related to sustain a networks'
inability to engage in collective action and may exacerbate poverty among the previously
poor (Akintola, 2008a). Poverty reduces the strength of one's social networks, and thus
one's pool of human resources that can be called on for assistance. The absence of
greater support from the community increases the burden of care onto the carers. This
may then relate to reduced opportunity costs: in a situation where there is an
unavailability of greater support, family members may have to be pulled out of school or
care work may hamper employment opportunities, undermining the development of their
own human capital, and may ultimately lead to a reduced ability to advocate for their
rights and make their needs heard (Esplen, 2009; Peacock & Weston, 2008). Some
participants had indicated that this is indeed the situation:

this child has had to get out of school, I made her to stop going to school, because
if I am not here who would stay with her, so she had to stay here at home (to look after
patient) (Participant 3, 2, 35-38)

so I used to work, but I had to stop, because it became clear that the child is not
taking her medication and we have to go back to hospital they would check that the
tablets did not balance/so I had to come back and make sure that at 7 in the morning she
takes them and at 7 at night she takes them/I cannot go and look for work now, 'cause I
want to be there and make sure that doesn't happen (Participant 7, 3,55-60).

Poverty and Social Bridging

This discussion considers the role of local leadership in the community in buffering the
effects of poverty on the care providers.

Adler and Kwon (2002) state that an individual's network of social ties creates
opportunities for social capital transactions, yet they do acknowledge as important the
network's ability to provide resources, the lack of which does not equip individuals in a

particular network to invest in social capital. Ability refers to the "competencies and resources at the nodes of the network" (Adler and Kwon, 2002, pg26). Bourdieu (1985), in his discussion of social capital, forces us to consider not only the existence of community social networks, but also the resources (potential or actual) possessed by the networks, and the individual's ability to draw upon the network for those resources. In KwaNgcolosi there is a clear inability of the networks to provide assistance, based on poverty and their own struggles with daily living. Theorists are divided as to whether ability should be considered a source of social capital or a complement to social capital; the former suggesting that social capital theory loses some of its utility when the resources of networks are not considered, and the latter suggesting that incorporating resources makes social capital theory too broad. No matter what the theoretical placement of ability into social capital theory, the data in this research does suggest that a lack of resources is a significant impediment to accessing beneficial social capital.

Also on a social bridging level, transport difficulties (problems in accessing transport and the cost of transport) and related poverty weakened social capital by increasing the strain experienced by carers. Transport problems were mentioned by almost all participants. The difficulties revolved primarily around transport costs and inadequate transport, either because the public transport points were too far or because their roads were inaccessible. Inability to meet transport costs talks about the poverty of the community, and poor road quality talks about the apathy of local leadership and/or government in developing infrastructure.

there is a lot of money that get spent, especially on transport, because when she is sick and needs to be taken by car to the clinic the people charge about R200 to take her to the clinic/if it happens at night then we are in trouble, because it is hard to find cars at night (Participant 3, 3-4, 74-77).

Roads must be closer, make transport easier, even if you want to do something you cannot because the roads are not here. (Participant 3, 8, 194-196).

sometimes there isn't money to take her to the clinic/like today she going to the clinic, but its been two days since she went out of her ARV's, but because there was no money to go to the clinic she couldn't go (Participant 7, 1, 10-20)

and we also went to the clinic, so if we had to go from home to the bus stop, of which it is a long distance and we don't have a car yes that was the toughest thing/maybe they would say we must come tomorrow and then it's the following day, the following day, that was the worst thing; (transport) was the biggest one and still it's the biggest problem (Participant 9, 2, 35-38;40).

Despite these difficulties, there were no participants who reported that they could not or would not take the ill to the clinic or hospital for medical attention. By some or other means, they would get the ill to the help that they need, although this was done at considerable cost and difficulty. One participant had to transport her mother in a wheelbarrow to the taxi point:

the taxis do not go in to our home (it is very isolated), so we need to travel and it's a long distance from my place to the bus stop/more especially to someone who is very sick, it is very, very difficult, sometimes we need to take a wheel barrow or something, because she cannot move for herself, yes it's the toughest thing (Participant 9, 2, 43-47)

Inadequate transport facilities translate to an increase of the burden of care on the carer. When faced with a situation such as this, one questions whose responsibility is it to ensure good infrastructure; why are informal carers of this community not supported in a way that eases daily difficulties (such as transport); and why also are the ill cared for at home when they clearly need hospital attention (if someone is too sick to walk and needs to be transported in a wheelbarrow, they are likely to be in need of care in a hospital). Similarly, in highlighting the inability of a social network to provide assistance (as discussed above), attention is drawn to the role of those in the community who have the resources, monetary and political, and can create contexts that would relieve carers. This draws attention to the function that should be fulfilled by the organisers of society, which includes but is not limited to local political and traditional leadership. In this regard, it is

significant that there is no mention of local leadership in the participants' responses to the perceived help that they are currently receiving. Participant 8, pointing to the necessity of leadership involvement, suggested that more workshops need to be held in the area, acknowledging the workshops run by Sethani at her school, but also mentioning that for workshops to be held outside of the school the councilors need to show greater involvement.

Campbell & Foulis (2004) question the utility of emphasising AIDS-related home care when the environmental context that patients are discharged into cannot support them. Whilst they specifically mention food and water being lacking in their article, this research points to inadequate transport facilities and the related poverty, which significantly increases the cost of care, physical, financial and emotional, on the carer. Commenting further on the necessity of government involvement, Campbell et al. (2005) found that the lack of local leadership, resources and infrastructure accompanied lack of action in peer education programmes in schools in a rural KwaZulu-Natal town. A school principal participating in their study suggested that an adequate response to the problem of HIV/AIDS in schools cannot be addressed without counseling and welfare backup.

This discussion suggests that carers can be facilitated in their care work by addressing infrastuctural and other contextual support that makes their daily lives easier. It draws attention to a criticism aimed against Putnam's social capital theory – that it is excessively "bottom-up" and there is insufficient attention being paid to "top-down" processes, both in their ability to promote or impede the creation of social capital (Woolcock, 1998; Evans, 1996; Ostrom, 1994).

Poverty and Social Linking

Grants

All participants reported receiving some money from the government in the form of disability grants, child care grants, or pension. This was money that was intended for other people in the carers immediate family, including in some cases the ill, but that the carers did report on as a source of monetary support. It is very noteworthy that the carers

themselves were receiving no rumination for their work in their capacity as carers. They were spending of their time and labor without any financial recognition for their work. Insufficient monetary funds emerged quite strongly in the data, indicating quite clearly that despite the fact of receiving grants, this was inadequate.

she does receive grant and it takes one year and it will end this year, so by next year she won't get it and since she is not receiving any parcels that means by next year she will have no support and since there is no one working at my house that is going to be a problem (Participant 9, 8, 200-203).

Also, participant 5 mentioned that she does not have access to the grants because her sick children "are not sick enough". Technically, that is correct – her family has not reached a debilitating state of sickness. Yet they are sick enough to warrant her full attention (even if employment opportunities did exist in the community, she still does not have the ability to work because she herself often gets sick and she has to care for her two sick children and husband).

so I really don't see and I really don't get what the government is doing, because we are sick and the children are sick, we are told we do not qualify for the grant, because we are not that sick yet/I mean like we are sick, we have the same sickness its just that we are not at that level of being sick, but we are also taking other medication and for all medication we need to eat before you take medication and I don't know what…where we should get the food from? (Participant 5, 10, 262-268)

Anti-Retro Viral Treatment

Six of the nine participants reported that their patients are being treated with ARVs (this information was not elicited from one participant). The patients who are not treated with ARVs are not so because their CD4 count is not low enough for it. Yet of the 6 participants, five of them were still having to actively care for their patients as the ARVs did not bring them back to their original state of health. The carers of the two participants

who are not on ARVs (because their CD4 count was not low enough) still reported much difficulty in caring for them.

The primary medical input (as reported) for these patients was the ARVs, and this in itself is inadequate. It is hard to differentiate, in this context, between help for the carer from help for the ill. ARVs and proper medical attention directly relieves the carer, and lack of same further burdens the carer.

Despite concerns that the main medical input did not translate into complete relief for the carer and the ill, it should be noted that there was general consensus that medical attention was sufficient, and participants did not have complaints regarding the care provided by clinics and hospitals (apart from access to because of transport difficulties, discussed above).

Primary input from government is perceived as inadequate

The discussion on grants and ARVs summarises the main input that participants' reportedly received from government. However, both are inadequate in addressing the needs of the ill that may influence the impact on the carer, and more importantly, there is no input from government in addressing their particular concerns in their capacity as carers. Much has been written on government's apathy in responding to the care work crisis. A VSO policy brief (2009) noted that most national governments have failed to respond appropriately to this crisis. Ogden et al. (2006) and Quinlan & Desmond (2002) have criticised government for "downloading" the burden of care onto communities and individuals; and Campbell et al. (2007) note that government participation "has been disappointing" (p. 358). Ntsebu et al. (2001) observe that there should be greater government health services involvement and that, in Zambia, there has been very little material, financial or technical support from the Zambian and other African governments. Recommendations for government involvement include meeting monetary requirement for health care (VSO expressly states that Heads of States should meet the Alma Ata declaration of allocating 15% of national budgets to health care); the implementation of effective policies to protect community caregivers (VSO, 2009; Ogden et al., 2006);

moving beyond policies that focus narrowly on health needs and improving sanitation, hygiene, clean water as well as addressing economic and psychosocial factors which may influence health outcomes (Ogden et al., 2006; Quinlan & Desmond, 2002); and the utilisation of public health care facilities which could be used as outlets for supporting HIV/AIDS home care (Nstebu et al, 2001). Nstebu et al. (2001) do note that lack of government involvement may be explained by the lack of an adequate home care model that may be applicable to resource strapped government, and lack of government technical expertise or motivation for developing and implementing HIV/AIDS home care. Campbell et al. (2007) suggest further that government involvement is hampered by transformational processes, lack of resources, heavy work loads, low salaries, limited skills, a large volume of social regeneration projects, and finally bureaucratic red tape that inhibits public servants involvement in "non-standard activities" (p. 358). Despite this, a central theme running through all these discussions is that the HBC and NGOs cannot do it alone. For an effective response greater involvement from government is imperative. An important conclusion in much of the literature is that the key to an effective response to HIV/AIDS care work is the active participation and networking of the various stakeholders, ranging from individual community members to government policy makers.

Criticisms have been aimed at the global community as well, these focusing on lack of sufficient funding (VSO, 2009) and inappropriate response to debt relief. The contribution of the global community might also point to global economies that perpetuate poverty and even more broadly, their influence in the conceptualisations of care work that sees this work being undervalued and thus overlooked.

Stigmas and Social Norms that Weaken Social Capital

One's positive HIV status, or the association with an HIV positive individual, contributes to the weakened networks on a bonding level. This appears to be related to HIV/AIDS related stigmas and discrimination which are still rampant in the community, creating a climate of mistrust, denial and fear, a lack of reciprocity and a situation of isolation and exclusion of the carer and their ill. Social norms that suggest that individuals must "take

care of their own" further isolate the ill and their carers. These conditions impeded the creation of positive social capital.

Stigma and Discrimination

Shame

A very superficial analysis points to the suggestion that association with HIV/AIDS socially isolates the carer.

so my husband died and her boyfriend you know when you get sick people don't want to be associated so he doesn't come anymore/so its me, her, her daughter and her other two small children (Participant 3,3,55-57)

because there are people who are like right now they are not coming to visit us here as usual, they are not coming here because…I am not sure, but I think they are not coming here because they think we are all HIV positive (Participant 8, 10-11, 258-261)

A slightly deeper analysis indicates that there is much shame associated with being HIV positive. This feeling of shame comes from those affected themselves and arises in them as a result of community perceptions of the disease. But it also extends to affected individuals and their families from the community. The shame associated with being HIV positive inhibits open disclosure of a positive status, which then affects the extent to which carers can expect help from others or whether they would disclose their status and seek out help.

so there is a lot of shame associated with this kind of disease, especially with the parents if they have a sick child and they think if they tell you, the person will start laughing at the family (Participant 5, 8, 190-192).

it depends…sometimes I feel like if people want to know they must know (what is wrong with my mother)… but I hate hearing people gossiping about that, it also breaks your heart, I think she feels the same way (Participant 9, 5, 119-122).

HIV positive individuals, their families and care providers are in this way ostracised and isolated. The apparent conclusion is that being HIV positive, or being associated with someone who is HIV positive, significantly weakens the participant's social networking.

Misperceptions

Misperceptions fuelled the negativity with which a positive status is associated. Many respondents cited a lack of knowledge about the disease by the community in general as leading to misperceptions. According to Bond, Chase and Aggleton (2002), the main causes of stigmas were identified as ignorance and misinformation about how HIV is transmitted and what it means to be HIV positive. Malcolm, Aggleton, Bronfman, Mane and Verral (1998) confer, suggesting that fear, ignorance, lack of knowledge and denial about HIV/AIDS has led to reactions which have had tragic effects on individuals, families and communities.

it actually affected me a lot, because in our knowledge you only get this if you behave badly and you don't behave in a particular way/yes it did come to me like because she had behaved badly, she has not listened to me, if she had listened to me she would not be lying on that bed today like that, but then I wouldn't say it to someone who is lying in bed. (Participant 1,3, 76-80)

I wish for everybody in the community to just learn and be educated and to understand about this disease, because sometimes the home based carer would go like to the house with a sick person with the aim of helping with the washing and all of that and the person would totally refuse 'cause they think that they are there to see them and then go around and tell people about their health (Participant 5, 8, 214-219).

Mistrust

Trust is an essential element of social capital (Putnam, 1994). Social capital rests on the cooperation between various stakeholders or parties, and it is trust that lubricates that cooperation (Putnam, 1994). Literature suggests that inhibitions on disclosure of one's

status or the status of one's ward are strongly related to mistrust. Mistrust of community members stem primarily from fears of gossip, creating a bad name (reputation) and being ridiculed, shamed or ostracised. These fears are referred to as perceived stigma (Scambler & Hopkins, 1986). Perceive stigma creates a mistrustful climate in the community, and this limits the extent to which the existing networks can be called upon for assistance, limiting reciprocity, and ultimately inhibiting the creation of social capital.

Participants reported that trust was lacking in the community (at least in relation to an HIV status):

I would like to see a more understanding community, that cares, people who are not talking things on other people's backs (Participant 8, 10, 245-246)

maybe it would be too heavy for them (to know my family is HIV positive), how they would respond, maybe they would talk about it everywhere/so that's difficult, so that's why the home based carer is the only person I can trust (Participant 4, 5, 119-122)

no I don't trust them (neighbours), because you know sometimes when you have a tiff with people, they would like shout most confidential information about you for the world to hear/so no I wouldn't trust them (Participant 6, 5, 99-111).

As stated earlier stigmas creates mistrust within the communities and networks. As discussed, perceived stigma refers to the *fear* of stigmatisation. Yet participants also reported enacted stigmas (Scambler & Hopkins, 1986), or that they were actively discriminated against and this contributes significantly to inhibitions to open disclosure.

It's very painful, because they call me names, they say everything that they want to say (Participant 8, 12, 307)

so it is difficult to tell other people, because sometimes you tell other people and you are really concerned and they make a joke out of it and...I mean because I used to look after her kid if she wasn't around I would take her baby and bring it back home, but when I went to the neighbours they wouldn't even touch the baby, because they could see

that the mother was sick, so they wouldn't even want to touch the baby (Participant2, 5, 113-118)

A complete discussion of stigma and discrimination in terms of social capital theory draws on the definition of networks. As mentioned networks refer to the interactions or ties between individuals that is propped up by norms of reciprocity and trust. Stigmas still do exist in the community and fears of same, both perceived and enacted, create a climate of mistrust. A network or tie can be said to contribute to the creation of social capital if trust exists in that relationship. Reponses from participants indicate that they perceive trust to be lacking. In summary, mistrust that is created by stigma inhibits disclosure. This inhibition has far reaching consequences, the most destructive possibly being that the virus will continue to be passed on because of the fear of the consequences of disclosure. In terms of social capital theory, inhibitions on disclosure suggest that individuals cannot draw on existing sources of assistance, and they are increasingly isolated and ostracised.

It is of particular interest that participants do not discriminate against their patients. Further, the indication by participants that ignorance drives the behaviour of others attests to their knowledge of the disease. This suggests a change in the values and norms around HIV/AIDS responses, as suggested by one participant in a study by Bond et al. (2002, p. 354) "So many people close to you are dying that you cannot always run away and have to offer care and spiritual support". A second possibility is that participants of this research are connected to the networks of the home-based carers. In being part of these networks they have access to their knowledge and information. The perceptions of carers that are unconnected to the home-based carers have not been elicited, and these may indicate otherwise. In terms of social capital theory, this illustrates the benefits of bridging and bonding social capital. Relationships at the community level that connect individuals to other groups as well as individuals in their immediate vicinity serve to empower those at an individual level and in potential has benefits for the community as a whole.

Participants did not report more extreme acts of discrimination, to either themselves or to others in the community. However, literature indicates that these do exist. Active

discrimination were reported by Bond et al. (2002), Steinberg et al. (2002), Blinkhoff et al. (2001), Lindsey et al. (2003), amongst many others. Malcolm et al. (1998) note that individuals may choose to withdraw and isolate themselves to protect themselves from discrimination. This may be the case of the participants of this study who did not report significantly on active discrimination. Malcolm et al. (1998) also note that as consciousness is raised on discriminatory actions and there are more severe legal restrictions on HIV/AIDS discrimination, both in the public and private sphere, HIV/AIDS discrimination may become more subtle, and thus less accessible to debate and transformation.

The shame associated with being HIV positive, or being associated with an HIV positive individual relates directly to stigmas held about the disease. Likewise, misperceptions and misinformation contribute to the creation and maintenance of stigmas. Yet HIV/AIDS related stigmas are born from much more than shame and misinformation about the disease: meanings and explanations for sickness, ideas about disease transmission and sexual behaviour, and fears associated with illness, disease and sex are implicated. Alonzo and Reynolds' (1995) summary of HIV/AIDS related stigmas include these aspects, but involve more. HIV/AIDS related stigmas arise because of its association with deviant behaviour; the perception of individual culpability; perceptions of HIV/AIDS that are tainted by religious beliefs as to its immorality and/or thought to be contracted via a morally sanctionable behaviour; the perceptions of its contagion, and thus it is seen as a threat to the community; it's association with an undesirable and an unaesthetic form of death; lay person misperceptions; and the negative views of health personnel.

HIV/AIDS stigma and the associated discrimination are impeding efforts to provide adequate care and support for the sick (Brown, Trujillo & Macintyre, 2001; Bond et al., 2002). This has been recognised for some time now, as evidenced in the literature on HIV/AIDS stigma and discrimination. A lack of complete success in preventative intervention has resulted in more attention being placed on the social constructs of the epidemic, including the role that stigmas are playing in blocking preventative measures and in providing adequate care (Campbell et al., 2005; Hayes & Vaugham, 2002).

However the complexity of the role of stigma defies simple measures to reduce its effects: the experienced or perceived stigmas may not be the same over the trajectory of the illness (Alonzo & Reynolds, 1995); HIV's association to socially undesirable behaviours, such as promiscuity, sex work, homosexuality, and injecting drug use, and the stigmas existing are layered over existing attitudes to these behaviours; and finally it is argued that the social function of stigmas is to feed into and maintain existing power differentials (Parker & Aggleton, 2003, Malcolm et al., 1998; McGrath, 1992). In regard to the last point, an important observation of Campbell et al. (2005) is that in the context of poverty and disempowerment, the "othering" of less desirable members of the community may constitute a symbolic resource that can serve to enhance a person's self-esteem. In other words, those who are HIV positive are stigmatised in an attempt to maintain self-respect in a context where material access to that respect is not available. Considering the above, it is insufficient to say that stigmas still exist in the community. It is imperative to understand *how* stigmas survive in the community, and answering this question might point one in the direction of further research. Ideas and perceptions of sickness, disease transmission and sexual behaviour need to be viewed in a broader social and cultural context (Parker & Aggleton, 2003). While Parker and Aggleton (2003) call for a more adequate conceptual framework that considers stigmas as a complex social construct to think about, analyse and inform interventions to counter them, Bond et al. (2002) recommend that efforts to reduce stigmas should focus on policy interventions, empowerment, and generally expanding on partnerships and education.

Social Norms

Social norms that weaken networks through their isolating effects

Norms are described as standards of behaviour arising from community expectations and that provide a form of informal social control (Bullen, 2009; Putnam, 1994; Keefer & Knack, undated). They are communally created and learned through a process of socialisation (Putnam, 1994). They define what is considered acceptable and unacceptable in a given social situation. Norms generally serve a productive function in

society; however they can be problematic when inflexible. Within the context of this study norms appeared to hamper the ability of the community to respond effectively and adequately to the HIV epidemic. That participants would not approach others for help appears to be rooted in the way that the community exists and functions. The expectation that one does not ask for help if one does need it does not provide the carer with the human resources that they need to support them in their care work. It is possible that the expectation of help may exist, as respondents did indicate that they do need and want the help of others and that they likewise would like to provide assistance, but they may not necessarily elicit or offer that help. In this way social norms existing in KwaNgcolosi serve to isolate care workers and hamper their care work.

(neighbours don't help me), because I don't like going outside and asking people for help….we are not the same in this world we are very different people, so I don't want to go out there and ask people from outside, because people talk I will be the one who suffers when they start talking about me and they are saying why isn't she doing it for herself (Participant 6, 3-4, 70-77).

so neighbours don't look at you when you have a problem, in (this) area (there are) few people who help when you have a problem (Participant 3, 5, 104-105).

nothing much you can do with people, as people are not the same, don't watch out for each other until it happens to them and then they realise what it's like. Don't dwell on what they do but concentrate on your plans to do what you have to (Participant 3, 8, 203-206).

if people were more willing to receive help, like if I went and offered to help…people are willing to helping the community, so they must be willing to receive the help (Participant 5, 11, 300-305).

Lack of community and neighbourly support runs counter to the norm of reciprocity, or the expectation that a favour conferred will be repaid, and its existence may be better understood when the norm of reciprocity in slightly unpacked. The norm of reciprocity depends on two elements: trustworthiness of the social environment, which means that

obligations will be repaid, and the actual extent of obligations held (Coleman, 1988). Social structures differ in both these dimensions. Both these dimension have already been discussed with regards to KwaNgcolosi: stigma and discrimination create a climate of mistrust; and poverty limits the ability of community members to engage in acts of reciprocity. Putnam (1994) claimed that reciprocity is one of the most important of social norms, and that the outstanding obligations, incurred through reciprocity, means that the overall usefulness of the tangible resources of that social structure is amplified by their availability to others when needed (Coleman, 1988). The expectation (or norm) that individuals in the community "must take care of their own" serves to isolate the carer by reducing the strength of their networks. As mentioned, networks are built on the reciprocity inherent in them.

Social Norms and Stigmas

Norms dictate what patterns of behaviour are expected in a given social context, and an infringement of those expected behaviours could incur social sanctions. Stigmatisation has been put forward as the sanctioning of non-normative behaviour. Stigma has been defined as "an attribute that is significantly discrediting" (Goffman, 1963), and as "an attribute used to set the affected person or group apart from the normalised social order, and this separation implies a devaluation" (Gilmore & Somerville, 1994). Stigmatisation is thus more a devaluing of an attribute, and a devaluing of persons based on their association with that attribute. Social exclusion and isolation from stigmatisation are thus based on deviance from culturally determined normative behaviour. In other words, the basis of stigma may not necessarily lie with an objective idea of deviant behaviour, but rather what is considered deviant behaviour in a specific historical and cultural context. Alonzo and Reynolds (1995) suggest that when individuals do not meet normative expectations because of attributes that they hold that are different and/or perceived as undesirable, they are reduced from acceptable to unacceptable. The discrepancy between what is desired and what is actual damages their social identity and leads to unacceptance, from society and from themselves (p. 304).

In the context of this study, stigma has been discussed as hampering adequate care for the ill, and support for their carers. Also discussed is stigma as a complex social construct that needs to be researched in its own rights. This discussion is suggesting further that social norms need to be examined in an attempt to shed some light on the manner in which stigmas exist in this community, or in any community. Social norms in the context of social capital theory has largely been cited as an element that enhances a communities stock of social capital. However, this discussion of stigmas and social norms suggests a downside of social norms, namely its role in the maintenance of stigmas. A study undertaken by Li, Liang, Lin, Wu, & Wen (2009) highlighted the importance of understanding social norms and personal attitudes in studying HIV-related stigma and called for the incorporation of existing human capital into future HIV stigma reduction programs. Rectifying misconceptions and misinformation in relation to HIV/AIDS will go some way in reducing the effects of stigmas, but if the argument that stigmas represents the enactment of complex social processes is accepted, then much more needs to be done to reduce stigmas, including a restructuring of the perceptions of many common social norms.

The Home-Based Carer (HBC) as an important resource that Strengthens Social Capital

The home-based carer emerged in the data as possibly the strongest resource that the carers can rely on. The functions of the HBC are often thought of as assistance to the ill. This study has suggested that the HBC provides much assistance to the informal carer, and that this assistance includes, but extends, instrumental care of the ill. The informal carers relationship with the HBC is regarded as a network strengthened by poverty because in the absence of other available sources of help, the HBC steps in to provide help to the carers in caring for the ill. In doing so, the HBC are creating links between themselves and the informal carers, providing them with respite and knowledge. This relationship has been considered to have been strengthened by stigmas as well. The existence of HIV/AIDS related stigmas inhibits disclosure of one's status or the status of

one's ward, as has been discussed above. The informal carer's relationship with the HBC is one in which these stigmas do not play out.

The HBC provided emotional, instrumental and informational support to the informal carers.

Emotional support

In the HIV/AIDS literature, emotional support often refers to moral, spiritual and psychosocial support that is provided to the ill by the carer. It can be said that this is the same support that the HBC offers the informal carer. The HBC went some way in helping the informal carer "carry their emotional burdens" and this support from the HBC was possibly the strongest that emerged in the data in relation to the HBC. This by no means undermines the instrumental support received, but rather highlights the emotional burdens carried by the informal carers. The HBC assists the informal carer emotionally by being supportive, offering advice, being welcoming and open to participants, listening to them, and providing an avenue of release for the carer from their daily burden of caring, simply by their presence.

so I will say that she (HBC) is very supportive, because I mean one time when my CD4 count went low and I was really worried about that and I discussed it with her and she reassured me and she spoke to me and then I felt better (Participant 5, 6,152-154).

so I really don't think that there is anyone that I can go to, 'cause I'm quite new in this area, but I come from Estcourt, so when I arrived she welcomed me in her...in everyway...I mean I come to her...then I discovered that she was doing work that was around caring for people in these ways/so to me she has been a mother, like someone I can talk to, if I go to her and she cannot help   me with a problem or trouble that I am experiencing, then I know that it is because she cant, not that she doesn't want to (Participant 4, 4, 78-84).

she comes and asks us how we feel, that is what she is doing sit with us laughing, talking…….its very nice, sometimes it is very nice meeting someone who is not a member of your family, coming to your family and sympathise, sitting and talking about things and not about your ills sometimes, but general knowledge, its open…..if someone is coming to my place and talking generally, it helps me not to stress, to think about one thing (Participant 9, 13, 331-344).

The psychosocial impacts of care work are well documented (Ogden et al., 2006; Orner, 2006; Forster, 2000; Catalan et al., 1996). This consequence of care work needs to be addressed to ensure not only the well being of the ill, but also the emotional health of the carer, and their families. The informal carer fulfils roles in addition to that of caring for the ill; if her ability to cope is stretch, it may have consequences for the family as a whole, the community, and even for nations (GEMSA, 2009). The HBC is then fulfilling a vitally important function by taking care, in part, of the emotional needs of informal carers.

Instrumental support

The HBC was an invaluable source of instrumental support, assisting with cleaning, bathing and cooking. For many participants this was the only instrumental assistance that they did receive. Although this role of the HBC did not emerge as strongly as their role in providing emotional support, the relief that they provide informal care providers cannot be undervalued.

so I will say that it is enough, because even when I have to go away I ask her (HBC) to look after the house and the kids/she is the only person whom I can trust, 'cause she knows how sick she is/even when I'm away she sees that it is getting bad, she will call me to say that it is getting bad and if she has the money she will take her to the clinic or something/so she is the person that I can go to and talk about my problem, I look at her and liken her to my mother, 'cause she is the one who is around here whom I can turn to (Participant 4, 3, 67-73).

so my mother in law used to help us, but she died....so the only other person that I talk to now is the home based carer... like that time when I had an operation for myself, she would come and help me...help me with the kids help me wash them (Participant 5, 5, 104-112).

the only person who can help is the home based carer, because she comes and she gives her a bath or even bath the baby (Participant 6, 3,58-60).

sometimes she (HBC) comes here and I am by myself she helps me look after my mother, like sometimes she would cook or sometimes she would put on gloves and wash her (Participant 7, 3, 69-71).

when I am alone she (HBC) comes, she cooks and she helps by washing my mother (Participant 7, 3, 77-78).

This discussion raises the question of who is caring for the carer (the HBC). Although a discussion of the support of the HBC does not form part of this research, the support to them would influence the ability of the informal carer to continue providing emotional and instrumental support to their own patients. In addressing this issue Akintola (2008b) suggests recommendations and future research that might suggest ways to provide respite to women who are overburdened by care work, and also highlights the necessity of assessing the capacity of families to care for the ill before releasing them into home-based care. Campbell et al. (2007) suggest more broadly, that understanding the HBC networks will fill a contextual gap in the care work response; in understanding the existing network, one can find ways to strengthen it.

Trust and Reciprocity

so she (HBC) is the person that I can go to and talk about my problem, I look at her and liken her to my mother, 'cause she is the one who is around here whom I can turn to (Participant 4, 3, 71-73)

What is it about the informal carers' links to the HBC that allows them (HBC) access to their homes, thoughts, and troubles? The relationship that exists between the HBC and the informal carer is one in which stigmas, perceived or enacted, is absent. Participants can rely to such an extent on the HBC because this is a relationship that they can trust. The literature on networks in general suggest that networks may provide social support, self-esteem, identity and perceptions of control for an individual (Cattell, 2001). Social capital literature states further that trust is an essential element in these networks (Putnam 1994). The HBC networks are more likely to provide these (social support, self-esteem, identity and perceptions of control) to informal carers in a context where they are isolated and ostracised, and cannot approach others. The trust inherent in this relationship allows for the activation of support (and information, discussed below), mutual interaction which would further strengthen this relationship, and may provide the leverage to further increase the informal carer's support and knowledge base by the HBCs links to other stakeholders.

The network between the HBC and informal carers is one characterised by generalised reciprocity. Generalised reciprocity refers to the expectation, or norm, that a favour granted now will be repaid in the future (as opposed to balanced reciprocity, referring to an equal exchange of favours). The trust and reciprocity inherent in the relationship with the HBC, and the "outstanding" favours from her, increases the pool of resources available in the community.

Informational Support

On a bridging level, the HBC provided access to information and knowledge of HIV/AIDS. The assertion by some participants that the community needs to be informed

on HIV/AIDS attests to their knowledge of the disease. That this knowledge comes from the HBC is explicitly stated by some participants, and a fairly safe assumption may be that this knowledge gained by other participants is also due to their networking with the HBC.

the home based carer comes and she reminds me/so she reminds me about a lot of things and the she also speaks to my mother to tell to stop drinking, but my mother still swears at her when she comes to say that (Participant 7, 3, 65-67).

there is this mother (HBC) who comes to tell us about HIV, they teach us and they talk to her and they talk to us, they teach us how to look after her (Participant 8, 5, 103-104).

Despite much time and resources spent on media and other campaigns to increase HIV/AIDS awareness (Brown et al., 2001), the data in this research, and the literature in general, indicates that stigmas due to misinformation and misperceptions are still rife. For example, despite three decades of research, theory and interventions, certain members of the community will still not hold a baby whose mother was sick with HIV/AIDS:

the neighbours they wouldn't even touch the baby, because they could see that the mother was sick, so they wouldn't even want to touch the baby (Participant 2, 5, 113-118).

It is not only stigmas that are influenced by a lack of HIV/AIDS knowledge. Participants reported that community members did not care for their ill in a manner that ensures their own safety.

the mother is helping them, washing them, look after them, they don't put any gloves on/so I think that the support groups are really needed, for more information especially for the older people, to teach them how to do things and how to take care of themselves from the disease (Participant 5, 8, 200-206)

The HBC belong to networks or relationships that bring in new information and knowledge to the community. The primary importance of this finding, however, is not

that this knowledge is available, because as stated media campaigns have attempted to reach even rural communities, but suggests rather that the HBC provides a more efficient *manner* of disseminating HIV/AIDS related knowledge. Diffusion of innovation is defined as "the process by which an innovation is communicated through certain channels over time among the members of a social system" (Rogers, 1983, p. 11). The HBC may provide these channels of communication, having access to the homes of affected families, and more importantly, holding their trust. This puts the HBC in an ideal situation to "diffuse" new information into the community by teaching and engaging community members in critical dialogue.

The HBC are able to diffuse information and innovation because of their own networks with institutes and organisations outside of the immediate community (bridging level social capital). These institutes include but are not limited to NGO's, faith-based organisations and universities. An example of such a network is the KwaNgcolosi HBCs' relationship with the Narrative Foundation, a non-profit organization that runs independently in the area that not only provides capacity building to the HBC, but also connects them to other organizations within the area. The Narrative Foundation is in turn related to the University of KwaZulu Natal (UKZN). This relationship allows innovative ideas to enter the community and also provides a platform to highlight the social situation of the carers of KwaNgcolosi in the political, academic and civil society spheres. These networks or relationships can be considered weak ties (the strength of a tie defined by Granovetter (1973, p. 1361) as a "combination of the amount of time, the emotional intensity, the intimacy, and the reciprocal services which characterise the tie"). Granovetter (1973) stated that weak ties have the potential of bringing in new and non-redundant sources of information into a community that may otherwise be characterised by strong networks which, despite the obvious benefits, tend to be exclusionary.

Despite the indications that the HBCs are possibly one the most important resources available to informal carers, the fact that the carers are still experiencing extreme hardships in their care work brings one to the conclusion that that the help they are receiving from the HBC is still by far inadequate.

Discussion on the role of the HBC

Formal HBC networks have been set up in an attempt to address the care needs of patients ill with HIV/AIDS, and to assist families in caring for the ill. However, poor government involvement and general lack of resources has led to these HBC programmes being powered primarily by volunteers, organised by NGO's and faith-based organisations. At the time of writing, Akintola (2008c) reported that there is no accurate data on the number of care organisations in South Africa, nor the proportion of volunteers, leaving a somewhat blank slate on extent of involvement of the HBCs and the level of dependence by community members.

On a theoretical level, the importance of the HBC has been recognized. Campbell and Foulis (2004), in their review of the international health promotion literature, identify three forms of participation that are important for promoting health and well-being: grassroots participation in the delivery of formal health services; community participation in public-health projects; and finally high levels of grassroots participation in local community organisations and groupings. They suggest that the HBC networks have the potential to incorporate all three forms of participation by being trained and offering rudimentary nursing; providing a catalyst for education and counseling among community families; and finally by strengthening networks that may have the potential to provide the leverage to mobilise for collective action that would have the benefit of addressing immediate needs but also to strengthen a community's sense of solidarity which might strengthen the communities abilities to address other challenges to their health and well-being.

In their conceptualisation of a "health-enabling community' in the context of HIV/AIDS, Campbell et al. (2007) placed emphasis on collaboration and participation, building of skills within the community, and the networking resources, both within the community creating greater solidarity or bonding social capital, and external to the community, building bridging social capital. In this regard, the HBC are playing an important role: they have links to each other which can serve as sources of support, knowledge and

experience; they are linked to the informal carers; and they are linked to "outside" sources.

This theory highlights the valuable, multi-level, role that the HBC can potentially play in the response to the HIV epidemic. Referring to an earlier description, networks has been defined as the aggregate of social interactions, formed by the trust and reciprocity inherent in these interactions, and that has the potential to facilitate social mobility and individual access to resources in the social, economic and political spheres (Franklin, 2004). In the absence of productive, supportive networks in the context of poverty and stigmas, the HBC arise most profoundly as a means to counter the community's problem of "weak" networks.

The help from the HBC is arguably the main source of assistance to the informal carers (Campbell et al., 2007, Akintola, 2008b). However it is still lacking, as suggested in the data of this research and supported by existing literature. Not all needs are met by the HBC and the HBC serve more as a complement to household caregivers than as a substitute. The HBC can increase their outreach and influence with greater involvement from government (Campbell et al. (2007), Akintola, (2008a), Nstebu et al., 2001).

This discussion echoes the assertion by Campbell et al. (2007), that the institutional context of the HIV response needs to be further investigated, and in particular the links of the HBC. The findings of this study support this assertion, and adds further that currently the contributions of the HBC are insufficient. The organisation of these networks and investment in terms of time, resources and knowledge may prove to be the most effective way to respond to the HIV/AIDS care work crisis in rural South Africa. In this regard, a study by Waterman et al. (2007) found that the HBC, working mostly at an individual and community level, did have some success at reducing stigmas in a rural Zambian community. Their potential in effecting other changes related to HIV/AIDS response, care work and otherwise, should be investigated

Care Workers Perceptions of what Support for the Carer Should Entail

Perceptions of wanted support generally point to improved support on a bridging and linking level, but with a view to greater independence on a bonding level. Participants' reports of essential support that is required includes monetary assistance. Assistance in monetary resources is understandable and may even be expected considering that adverse effects of poverty emerged strongly in the data: this is a very desperate and immediate need of the participants, and indeed of the community as a whole.

> *I'd like help with money, like sometimes she doesn't have the money when she runs short of food and baby food and even in the house they do run out of things...I would like it if they could help in terms of money (Participant 2, 6, 141-143)*

> *with regards to the medical help the only thing that she gets is the food and for her. That is not where it should end, they should look at the situation and see what else they can do, like if they give food as well as treatment or to give money as well as treatment that's what should make it better (Participant 4, 6, 163-166)*

Participants also mentioned education, employment and self-subsistence opportunities (farming), as well as the structure of support groups with the explicit intention of creating greater awareness: these participants are not looking simply to "receive" but are looking for opportunities to be more independent and self-sustaining.

> *if they could fence like a small area here so that I can have a vegetable garden and have food to eat (Participant 6, 8, 206-207).*

> *the thing that I...the only thing that I need is to study and then after the study I can get work, if I could find a job, that is something I need (Participant 9, 15, 393-395)*

> *if I could find a job, if I got a job it would make it much easier to care for my friend (Participant 2, 7, 183-184).*

> *it is not as if I never think about work, about going to work although that would make things seem much easier, but then I start to think about what about this child - who*

will I leave her with when I go to work... its not that I don't want work or that I cannot find work, I can find work, its just that even if I do find work in a place that is not   close by so I will have to be not here (Participant 4, 8, 201-207)

(I would like more) job opportunities, because we are poor (Participant 6, 10, 245).

if I can find a job, if they can open the door for opportunity, that is the thing I am praying for/'cause if I was working things could be better, I would not go to someone and say please I need money to take my mother to the hospital, I need money to go collect treatment, so yes if I was working (Participant 9, 9, 217-221).

so my wish is that there can be more support groups in the area, especially with the mother's, the older woman who have children that are sick, 'cause sometimes you can't just make up that this person is HIV positive, but the mother is helping them, washing them, look after them, they don't put any gloves on/so I think that the support groups are really needed, for more information especially for the older people, to teach them how to do things and how to take care of themselves from the disease (Participant 5, 8, 200-206).

A conclusion that may be drawn from the responses of participants is that they may appreciate interventions that might allow them an improved ability to take care of themselves. This relates strongly to literature on empowerment. The term empowerment was initially understood on an individual level, relating to the intra-psychic world of the individual and referring to greater feelings of control and actual control. Education, employment and self-subsistence farming do suggest that members of this community are looking for opportunities to be more self-sustaining.

However, later constructions of the term and its application to health promotion literature prompted a more critical understanding: individual empowerment needs to take place in the context of transformative changes that addresses contextual inequalities. Perkins (1995) defines empowerment as a "construct that links individual strengths and competencies, natural helping systems and proactive behaviours to social policy and

social change". Rissel (1994) differentiates between psychological empowerment and community empowerment. Psychological empowerment refers to greater feelings of control that individuals have over their lives. Community empowerment includes raised levels of psychological empowerment within individual community members, a political action component that includes the active participation of individual members, and the achievement of some redistribution of resources favourable to the community (Rissel, 1994).

There are many definitions and conceptualisations of the term empowerment. A complete discussion of this does not fall within the realms of this research. What remains important is the central theme that community well-being and health are directly related to individual members' perceptions of control, or psychological empowerment (Rissel, 1994); this control should work in coalition with raised levels of consciousness (Campbell & Murray, 2004); and includes a socio-political aspect which involves the active participation of community members as well as a redistribution of resources (Rissel, 1994; Rappaport, 1981). Empowerment is an important dimension of this discussion because, as mentioned, this talks to the perceived needs of the participants. It is important also to address the sustainability of an intervention – grassroots participation and strengthening of local resources will ensure that the correct needs are identified and met. Yet another reason for its importance is because it provides a vehicle with which to address some of the contextual problems that hamper care work, these including but not limited to gender and class inequalities, poverty, and apathy in leadership. Psychological and community empowerment is useful also for its transferability: as community members, and the community as a whole, are empowered in one aspect, their ability to address other issues affecting their lives is strengthened. Campbell et al. (2007), drawing on Wallerstein's (in Campbell et al., 2007) conceptualisation of empowerment, elaborate on six strategies that serve to empower individuals and the community as a whole: building knowledge and skills; creating safe social spaces for dialogue; promoting ownership and responsibility; building confidence in local strengths, and agency to mobilize these; and strengthening bonding and bridging relationships.

Although community psychology and public health literature has written extensively on empowerment in general, and particularly community empowerment, there is a paucity of information on community empowerment in the context of HIV/AIDS, addressing issues particular to the epidemic such as stigmas, social inequity (on multiple level: gender, class and age) and care work. Studies, however, by Pronyk et al. (2006) and Paruk et al. (2009) not only incorporated empowerment terminology in their studies related to HIV/AIDS, but further demonstrated how to translate the rhetoric on empowerment into viable, practicable actions.

Pronyk et al. (2006) report on a study and intervention based on microfinance – a development method that provides loans to poor households for income generation. This intervention, and microfinance in general, aims to alter "the context in which ill-health occurs" (p. 1973) by structural interventions in risk environments characterised by underdevelopment, lack of economic opportunities, inequalities in the distribution of power and resources and gender inequalities. Microfinance aims specifically to reduce poverty, empower participants and improve health. Their Intervention with Microfinance for AIDS and Gender Equity (IMAGE) study found that a structural intervention can have health and social benefits through the empowerment of women through microfinance. This study also goes some way in supporting the argument that, even in the short term, shifts in social and economic vulnerability is achievable – these are often thought to be achievable in the very long term and therefore not addressing the immediate needs required by an adequate response to the HIV epidemic. Paruk et al. (2009) similarly report on their AmaQhawe Family Project that aimed to address some of the contextual environmental influences on individual behaviour (related to HIV/AIDS) through the individual empowerment of parents and the strengthening of collective empowerment. Their study found that increased social networks through empowerment initiatives facilitated the development of social capital, which parents could draw on to protect their children against high risk behaviours.

The emphasis on the redistribution of resources (as suggested by Rissel, 1994) once again highlights the conclusion the any initiative requires the inputs of those who do hold more power (and thus more resources, monetary and otherwise). In this regard, Campbell et al

(2007) conclude "…it is a myth to regard the mobilisation of grassroots community participation as a cheap way of delivering services and addressing social problems in deprived communities, and that those seeking to implement such approaches need to recognize that they are extremely resource intensive to initiate and maintain" (p. 361). In discussing the role of social capital in community development, Wakefield and Poland (2005) suggest that a discussion of social capital should run parallel to conceptions economic and political structures and includes an emphasis on the redistribution of resources. They argue that social connections are contingent on, and structured by, access to material resources, and suggest that a narrow focus on social cohesion and relations does not factor broader influences on social relations. They suggest a construction of social capital that highlights a critical consciousness of social justice.

Summary of results and conclusion

Summary of Results

Participants reported conditions of poverty, personally and in the community in general, which impeded their access to support and assistance. The difficulty in accessing support was due to an inability of participants' social networks to provide this assistance, which relates directly to a lack of resources. Restrictions on reciprocity reduced the strength of one's social networks, limiting carers access to support from those in their immediate environment. In addition poverty and poor networking appeared to be spuriously related: as the ability to call on social networks was reduced (due to a lack of trust and poverty), participants and their families had more of a burden to carry, increasing opportunity costs as family members have to leave work and school.

Poverty further added strains on the carers by impacting on their mobility. Mobility was affected by inaccessibility of roads, and poor transport infrastructure in general as well as an inability to meet transport costs. This translated into added burdens on the carer as their ill had to be transported (to the clinics, hospital, etc) at considerable cost and difficulty to the carer. This questions the role of those that should be addressing the

community's infrastructure and in general ensuring an environment that is supportive to informal carers and the ill.

The effects and conditions of poverty are not addressed adequately at a governmental level. The main contributions by government (as reported) were the provision and ARVs and grants. Whilst most participants' patients were receiving ARVs, and at least one member of the family was supported by government grants, either pension, child care or disability, these were insufficient: some participants were still having to care for their family members despite being on ARVs; other patients were not on ARVs because they were "not sick enough" despite actively needing care by their care providers; and as mentioned, the community is still steeped in poverty and some participants reported not having food in the house, despite receiving a grant.

Stigmas and discrimination, still rampant in the community, create a climate of mistrust, denial and fear, a lack of reciprocity and a situation of isolation and exclusion of the carer and their ill. Participants found themselves increasingly isolated and ostracised, either in response to enacted stigmas, or in anticipation of acts of discrimination. Misinformation and misperceptions of the disease lead to and perpetuate stigmas. However, stigmas arise from much more that misinformation. Failed preventative initiatives has prompted research into the social construction of HIV/AIDS related stigmas, and points direction to HIV/AIDS's association with socially undesirable behaviour (such as injecting drug use); the suggestion that stigmas evolve during the trajectory of an illness; and finally stigmas social function to preserve dominions of power in a community. Stigma is a complex social process that requires further research in it sown right in order to disentangle.

Social norms, generally considered as beneficial to the creation of social capital, can actually hamper community members' ability to access help. The norm that one must "take care of their own" makes it difficult for community members to solicit help if they do need it. This norm, which could be said to be lacking in reciprocity, is better understood against the backdrop of mistrust and poverty: reciprocity rests on a relationship characterized by trust, and an ability to actually reciprocate. Both these aspects are lacking in KwaNgcolosi due to poverty and HIV/AIDS related stigmas and discrimination.

Social norms may also play a role in the social creation of stigmas. Stigmas has been put forward the sanctioning of non-normative behaviour. Social exclusion and isolation from stigmatization are thus based on deviance from culturally determined normative behaviour.

The home-based carer (HBC) provided much needed emotional, instrumental and informational support to the participants. They emerged as possibly the strongest resources provided to the carer. Yet the inputs of the HBC are clearly insufficient as participants still reported extreme difficulty in their care work. It is significant that the community's strongest help is still insufficient. Yet the HBC are ideally placed in the community to effect much larger grassroots changes, and it has been suggested that the organisation of these networks and investment in terms of time, resources and knowledge may prove to be the most effective way to respond to the HIV/AIDS care work crisis in rural South Africa.

Participants' reports of what support should include monetary assistance, land and resources for farming, education, employment opportunities and support groups with the explicit intention of passing on HIV/AIDS related information. These perceptions suggest interventions that may serve to empower individuals and the community.

Conclusion

This study concludes that caregivers perceive a low level of support. Low levels of social capital exist in the community, evidenced by lack of reciprocity, norms that isolate the carer, mistrust, lack of control over resources, stigmas and discrimination, and weakened networks, which inhibit the participants' pool of human resources. This is countered somewhat by the functions of the HBC, but their current input is not great enough to strengthen the community's ability for collective action, including a strengthened response to the care work crisis.

Participants' perceptions of support were elicited on a bonding, bridging and linking level. On a bonding level, poverty reduced the actual ability of community members to

provide support to the caregivers. Stigmas were also major impediments, creating a climate of mistrust that further isolated and ostracised the carer. Social norms that dictate that community members should not ask for help also reduced the likelihood that individuals will elicit that help. The HBC was the strongest resource available to the informal carer. Her input overlapped over the bonding and bridging levels. She offered informal carers emotional and instrumental support. This was outstandingly insufficient though, evidenced by the data which suggested that participant's were still experiencing extreme hardship in relation to their care work. The HBC played a role in teaching and educating the participants on various aspects of HIV/AIDS, and participants attested to the knowledge gained by the HBC. Transport difficulties, both the cost and inadequacies of, were cited as a major obstacle to participants. The ill had to be transported to the clinics or hospitals, often at considerable cost and difficulty to the carer. This highlighted the responsibility of the organizers of society in ensuring proper infrastructure to ease the daily burdens of carers (such as transport), but more broadly questioned the utility and justice of releasing patients into home care when the environment could not support the carer or the ill.

An important element that runs through this discussion is the role of higher authoritative structures in facilitating or impeding access to help and support. Poverty, stigmas, transport problems, and even social norms have the potential to be altered with sufficient and well-identified inputs from government structures. Difficulties that might impede governments' involvement have been noted, but the general consensus is that grassroots initiatives need the support of government resources. In other words, bottom-up and top-down structures should work in coalition. Greater networking and participation of all stakeholders is a proposed way in which these difficulties can be overcome.

Critical reflections of the terms empowerment and social capital convey the important message that any community development initiative should consider the broader social, political and economic contexts that shape it. Understandably, these are not easily amenable to change, and in the immediate term the pressing needs of carers need to be addressed. However it has been suggested that critical consciousness forms a vital

component of empowerment, and it is recently suggested that this critical consciousness should extend to discussions on social capital.

Chapter Six

Conclusion and Recommendations

The HIV/AIDS epidemic has set off a care work crisis in South and Southern Africa. The unprecedented number of the ill has strained the capacity of formal health facilities to cope, with the result that this responsibility has shifted to individuals in communities. Yet this response is not sustainable as under-resourced communities are battling to cope under the strain. The demands of care work - monetary, physical and emotional - are playing a huge role in perpetuating the difficulties that are already experienced by members of under-resourced communities. These concerns have prompted much research into the impacts of care work on informal (and volunteer) carers, with a view to conceptualise the most efficient response to the care work crisis.

Social capital theory has been used in this research as an analytical tool with which to understand the perceptions of support available to informal carers, from the perspective of the carers themselves. Social capital's viability as a theoretical framework for this research comes from its emphasis on the social dynamics inherent in any gathering of people. It draws attention to the social relatedness of human beings (including factors linked to social relatedness such as norms and networks) and the manner in which this relatedness may shape their well-being (Edmondson, 2003). The concept of social capital runs parallel to ideas of other forms of capital, but rather than being lodged and accumulated within individual people or institutes, social capital is created and exists in the spaces between people, in "the structure of relations between actors and among actors" (Coleman, 1998, pS98). Despite the lack of a uniform definition of social capital, the literature consistently points to four elements, that of trust, norms, the norm of reciprocity and networks; as well as the sociological strata on which these elements function: the bonding, bridging and linking levels.

This research was situated in KwaNgcolosi, a semi-urban town in KwaZulu Natal. This area is characterized by poor infrastructure, high levels of unemployment, steep poverty levels and a high HIV prevalence rate.

Much of the data was presented on a spectrum of networks: those social relations that support the carer, and those that do not; as well as factors which inhibit or facilitate access to human resources.

The HBC emerged as the strongest source of support to the informal carer. They provided much needed instrumental support by helping the carer with daily chores such as bathing the ill and cooking for the family. They offered emotional support by offering advice, being welcoming and open to participants, listening to them, and providing an avenue of release by their presence. Whilst not undervaluing other ways in which the HBC assists, the emotional support from the HBC emerged most strongly in the data and attests to the emotional difficulties involved in care work. The HBC also offered informational support, disseminating AIDS related knowledge to the families that they were caring for. The value of the knowledge gained by the carers is highlighted by the fact they themselves have called for support groups to pass this knowledge on. This function of the HBC has been discussed as an extremely efficient and effective manner of creating more AIDS related awareness. Their intimate relations with, and placement in the homes and lives of participants would allow for the "diffusion" of information, allowing more AIDS related information to reach community members, where extensive media campaigns have been unsuccessful. The help offered by the HBC, despite being reported as the strongest source of support, is still insufficient, evidenced by reports that participants are still experiencing extreme hardships. However the value of her work, both actual and potential, is not lost and there should be greater investment in the HBC in terms of resources, time, knowledge and skills.

Lack of knowledge leads to misperceptions, which drives stigmas and discrimination in the community. These have been found to exist in the community (despite media campaigns as mentioned above). Perceived stigmas and fears of discrimination, or enacted stigmas, have created a climate of mistrust, which inhibits open disclosure of one's status, or the status of one's ward. The carers' pool of human resources may be

diminished in a situation where the carer does not want to solicit help from others for fear of the reaction that they might receive. But even in the absence this inhibition, simply being associated with HIV/AIDS isolates and ostracises the carers from others in the community. Stigmas arise from much more that misinformation, however. It is a complex social process that is shaped by meanings and explanations for sickness, ideas about disease transmission and sexual behaviour, and fears associated with illness, disease and sex. It has been suggested also that stigmas function to preserve existing power differentials in society, and that the stigmatisation of others serves as a source of self-esteem in an under-resourced environment where material access to that respect is not possible. The conclusion is that there still is a greater need to create awareness (the HBC having a potentially much greater role to play in that regard), and that stigmas as a complex social process deserves more research in its own right.

Social norms, generally discussed in the literature as being beneficial to social capital, has played a role in further isolating participants. That participants would not solicit help from others appears to be rooted in the way that the community functions. These norms can be regarded as lacking in reciprocity: reciprocity rests on the trust that is inherent in a network, and the ability of that network to reciprocate. KwaNgcolosi is lacking in both these dimensions (with regard to HIV/AIDS care work).

Poverty has been cited as a major impediment to accessing support from others. Poverty limits the ability of social networks of participants (and participants themselves) to broadly reciprocate acts of assistance. Networks are built on trust and reciprocity; both of these are missing in KwaNgcolosi (trust due to stigmas, and reciprocity due to poverty). In the absence of adequate networks from which to draw support, social mobility and individual access to social, economical and political opportunities and resources, in the context of HIV/AIDS care work, to the community members of KwaNgcolosi are hampered. Poverty and poor social networks may also be spuriously related: poor social networks limits the participants' pool of human resources, placing a greater strain of the carers themselves and this might translate to opportunity costs as family members are removed from school and employment. This then inhibits the creation of their own

human capital. This would have the effect to obstructing their own growth, as well as reducing their ability to advocate for their rights and make their needs heard.

Poverty, and related difficulties with poor infrastructure, has also been cited as a major impediment to accessing help. Participants reported transport difficulties, both the cost of, and the inadequacy of due to poor access to roads. However this discussion relates to the increased burden of care onto the carer, rather than poor networks. This does not however downplay the difficulty. It rather points attention to the role that should be played by local leadership. It has been noted that to effectively transfer care from the public outlets to the home, the informal carers need to be supported and current literature questions the utility of transferring patients to home care when the contextual environment cannot support them or their carers.

The role of higher authoritative structures, in this particular case that of government, has also been discussed as lacking in the response to the care work crisis, and in particular in addressing the conditions of poverty. The major inputs from government structures, as reported by participants, are the provision of grants and ARVs. Yet, participants still reported extreme and debilitating poverty (some participants not having food in the house); and carers were still having to actively care for the ill despite 6 patients of participants being on ARVs. These efforts are not sufficient in addressing the needs of the ill. Although addressing the needs of the ill ultimately supports the carer, there has been no reported contributions that support the participants in their capacity as carers: this vitally important function that they are fulfilling has not been officially acknowledged by government. Lack of government involvement may be explained a lack of skill, technical expertise, motivation due to low salaries and heavy work loads, lack of resources and lack of an adequate home care model on which to place interventions. Yet a grassroots initiative cannot adequately respond to the care work crisis alone, and the support of government is imperative. Active participation of all stakeholders and greater and more efficient networking has been proposed a way in which to counter these difficulties.

Informal caregivers' perceptions of what support should entail include such structural support as monetary assistance, education, employment, land and resources for farming and the structuring of support groups to create greater awareness. Monetary support might be expected, considering that poverty is steep in the community and this is a desperate and immediate need of the community, one related to survival. The other suggestions put forward indicate that community members are looking for opportunities for empowerment. Empowerment refers to the increased ability of individuals to control one's their social, political and economic functioning. Psychological empowerment, referring to increased levels of individual control, is separate from, yet is an important component of community empowerment. Community empowerment refers to a community's increased levels of psychological empowerment, but also includes raised awareness, or a critical consciousness of broader social, economic and political influences that shape social reality. Community empowerment asks for active participation of community members, as well as a redistribution of resources. Empowerment is an important dimension of this discussion because it relates to the perceived needs of the participants; it ensures greater likelihood of the sustainability of a project; it provides a vehicle with which to address some of the contextual problems that hamper care work; and it is transferable – empowerment in one aspect can be transferred to address other social difficulties. Likewise, social capital should include a critical discussion of the broader social, political and economical structures that influence the distribution of resources and shape social relations.

Limitations and Challenges

1. The interviewer was not of the same racial and ethnic group as the participants. She also did not speak the local language of isiZulu. The unfamiliarity of the interviewer to the participants may have inhibited them in their responses. However, this inhibition was not readily apparent as participants spoke about some difficult topics and revealed much personal information suggesting that the differences of the interviewer may not have hampered their responses much. This difference may also have been countered somewhat by the presence of the

translator who was from the community, and necessarily spoke isiZulu. Her presence may have eased the relations between the interviewer and the participants. She also alerted the interviewer to the subtle nuances of Zulu culture.

2. Much information may have been lost in the translation. The interviewer's interviewing skill could have been honed in to be able to follow the thread of conversation through translations. This deficit could have been countered by with follow-up interviews. However, the skill of the translator, and her quick immersion into the content of the interviews countered the limitations of the interviewer.

3. The Home-Based Carers assigned to the participants' area were present for all the interviews. There exists the possibility that her presence may have influenced the participants' responses, and that they may have commented differently on the role of the HBC were she not present.

4. This research may have benefited from more participants. Only nine were interviewed. However there was saturation in terms of the themes that emerged, and further interviews may merely support the themes that did emerge.

5. The participants interviewed were those that were linked to the HBC. The perceptions of unlinked carers may yield different themes. This is significant considering that most community member may remain unlinked. This research may then be unrepresentative of the entire community, and is more representative of linked caregivers.

6. It was a challenge to neatly delineate the discussion of the perceptions of care and support into bonding, bridging and linking levels. For example, in discussing the poverty experienced by participants and how this hampers their access to support, one does need to be mindful of the macro economic structures that serve to create and perpetuate poverty on a micro level. Also, when discussing stigmas, which is enacted on a bonding level, again one does need to take cognizance of the hierarchical structure of power that stigmas seek to maintain (if we accept that argument).

7. Likewise, it was a challenge to delineate the elements of social capital. The crux of social capital rests on the balance between trust, reciprocity (this being a social norm) and networks. These concepts are interrelated, and a discussion to delineate them does not do justice to the complexity of the interplay of these social dynamics that ultimately create the structure of social capital

Recommendations

The results of this research indicate that informal carers perceive a low level of support. This is due primarily to the effects of poverty, stigmas and discrimination and an inadequate response from government and local leadership. The following recommendations serve to address these issues.

Research recommendations

1. This research elicited important themes that warrant further attention. Possibilities for future research include a quantitative analysis of the elicited themes. This may ensure greater representativeness of the data. A second possibility is triangulation with data, quantitative and qualitative, from other research projects from the greater social capital framework within which this study is situated.

2. Future research can further explore the role of the HBC. This research has pointed to trust and reciprocity as increasing the acceptance of the HBC in the families that were interviewed. Future research may elicit other aspects of this relationship. This knowledge could have a bearing on future policy and research.

3. Future research could explore the perceptions of unlinked carers. As mentioned, the participants in this research are linked through their connections with the HBC. The perceptions of unlinked carers will not only ensure greater

representativeness but may point to other needs that are not expressed by linked carers.

4. The extent and effects of stigma in the KwaNgcolosi community should be investigated. Whilst much has been researched into HIV/AIDS related stigmas and discrimination, the research and literature reviewed suggests that this construct of stigmatization is complex and multi-layered. Whilst there are universal attributes to these stigmas, the socially constructed nature of it indicates a more nuanced understanding specific to particular communities.

Project Recommendations

1. Explore joint projects, or just greater networking, with other stakeholders in the community. Possibilities are the Church and Sethani, these being mentioned by participants. Community leaders are others that may be involved in projects and networking. Interventions should be sensitive to crossing the bonding, bridging and linking divide.

2. Explore interventions that strengthen food production and income generation. One possibility is subsistence farming; this talks directly to discussions with one participant who said that she would like land and resources for farming. Such interventions may promote individual and community empowerment. This is also an intervention that is sustainable and can address the concerns over the lack food and money mentioned by many participants.

3. Future projects can promote the mobilisation of the HBC groups and networks to:

   - Create greater awareness and disseminate AIDS-related information

   - Generate critical discussion which may include community members' perceptions of their needs.

- Run support groups that can incorporate points one and two above, but that may also be a source of psychosocial support to the carers.

4. Future projects could include the screening of and possible treatment of depression and anxiety disorders. Whilst the psychological and emotional impacts of care work do not necessarily indicate a depressive and anxiety disorder, it is likely that these conditions may exist in some community members. If untreated, these may have debilitating effects on the carer, the ill and their families.

Policy Recommendations

1. Care workers are not formally recognized by government. They may be acknowledged on a theoretical and rhetorical level, but currently there are no policies in place that support them in their capacity as caregivers. Policy recommendations are that 1) the informal (friends and family members) and formal (HBC and Community Health Workers)) carers receive some monetary remuneration for the care work and; 2) there is greater provision for their skills training and capacity building (an added benefit is that these are transferable skills)

2. There should also be investment into the HBC in particular as this study suggests quite strongly that in their relationship with the families of informal carers and the ill is great potential to effect greater change.

3. The caregivers' ability to care for the ill should be assessed before AIDS patients are released into home care. These should include the infrastructural support available to carers, and should include such details, as whether they have running water, how far away are the carers from public transport points, clinics and hospitals. Their financial ability should also be assessed, as well as the physical ability of those that would actually be caring for the patient (for example, are the carers elderly grandmothers or school going children; what is the state of physical health of the carers, etc.)

4. Policy interventions should move beyond a needs-based approach to community development; interventions to empower should identify and strengthen social relationships and formal institutions and the interactions between the two, particularly on bonding and bridging levels, with a specific view to generate positive manifestations of social capital that is context specific.

Conclusion

The concept of home based care by friends and family members of those that are suffering with AIDS is indeed a romantic one that has many merits. But this romanticised notion may not be a just one when individuals and communities are burdened beyond their abilities to cope by their care work. This study sought to understand the perceived support available to carers of people living with HIV/AIDS, and concluded that caregivers perceive low levels of support. Social capital, used as a framework with which to make sense of the perceptions of support, provided important indicators of the social dynamics that are accessible and available to caregivers. Low levels of social capital exist in the community, evidenced by a lack of reciprocity, norms that isolate the carer, mistrust, lack of control over resources, stigmas and discrimination, and weakened networks which inhibit the participants' pool of human resources. This is countered somewhat by the functions of the HBC, but her current input is not great enough to strengthen the community's ability for collective action, including a strengthened response to the care work crisis. This research has strongly suggested that much more needs to be done to support and empower the care giver and that greater involvement from government and other influential stakeholders is imperative. Effectively attending to the care work of people living with HIV/AIDS in rural South Africa requires that all stakeholders involved, ranging from individual community members to government policy makers, combine and share resources and skills in a communal effort to provide care.

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APPENDIX A

Consent Form: English

Dear Participant,

This interview and research is part of my studies that I am completing with the University of KwaZulu Natal, which would allow me to practice as a psychologist. During this interview I hope to understand the kind of help that you have available, and would like to have available, in caring for an HIV positive person. The interview will be about an hour, and during this time I will ask you a few questions on your experiences in caring for a friend/ family that has HIV/AIDS. There are no right or wrong answers to these questions, but please feel free to provide as much detail as you wish. I understand that some of the things we will be discussing are very private, but I would like to assure you that only my supervisor and myself would know your name, and that of your family and friends. The results of this study may be made public, however, your confidentially and anonymity, and those of whom you may mention, will be maintained. This interview will be recorded, but no-one other than myself and my supervisor will be able to access recordings. If you have any queries after this interview you may ask either myself, or you may contact my supervisor at the University of KwaZulu Natal, Professor Yvonne Sliep (031-2607982)
Your participation is highly appreciated
Thank you,

Fatimah Dada (076 667 2684)

Informed Consent
- I hereby agree to participate in the above mentioned interview and research project, of my own free will and under no duress or obligation
- I understand that I may withdraw from this study at any time
- I understand the purpose of this interview
- I understand that this research is for academic purposes
- I understand that my name, and the name of anyone else that I may mention, will remain confidential, and will be known to this researcher and her supervisor only
- I understand that if the results of this research are made public, my name or that of my family and friends will not be revealed
- I understand that my participation in this research is voluntary and that I will not receive any money, food or other gifts

Signature of Participant   **Date**

_____   _____

APPENDIX B
Consent Form: isiZulu

Mhlanganyeli othandekayo,

Lokhu kuxoxisana nocwaningo kuyingxenye yezifundo zami engiziqedelayo esikhungweni sezemfundo ephakeme yaKwaZulu Natal, ekwiyisona esingivumelayo ukuthi ngisebenze njengesazi kwezokusenza kwengqondo nemicabango yomuntu. Kulokuxoxisana ngiyathemba ukuthi ngizoqonda uhlobo losizo onalo olukhona, futhi engizothanda ukuthi lubekhona ekunakekeleni umuntu onegciwane lengculazi. Ukuxoxisana kuzoba yisikhathi esingange-hora, futhi kulesisikhathi ngizobe ngikubuza imibuzo emibalwa olwazini lwakho ekunakekeleni umngane noma umndeni onegciwane lengculazi nesandulela sayo. Azikho izimpendulo ezikahle noma ezinge-kahle kulemibuzo, Ngicela uzizwe ukhululekile ukunika imininingwane eyanele ngendlela othanda ngayo. Ngiyaqonda ukuthi ezinye zazinto esizobe sizixoxa ziyizimfihlo ezinkulu, Kepha ngizothanda ukukuqinisekisa ukuthi yimina kanye nomhloli wami kuphela abazokwazi igama lakho, nangomndeni wakho nabangane. Imiphumela yalesisifundo ingavezwa ngaphambili kwabo bonke abantu, nokho, ukuba yimfihlo kwakho nokungashiwo igama kanye nalabo ongase ubasho kuyolondolozwa. Lokuxoxisana kuyoshicilelwa phansi, kepha akekho noyedwa oyokwazi ukuthola okushicilelwe ngaphandle kwami nomhloli wami. Uma unemibuzo emva kwalokuxoxisana ungayibuza mina noma uxhumane nomhloli wami esikhungweni sezemfundo ephakeme saKwaZulu Natal, umfundisi omkhulu wasenyuvesi uYvonne Sliep (031-2607982)

Ukuhlanganyela kwenu kuyabongeka kakhulu.

Ngiyabonga

Fatimah Dada (076 667 2684)

Ofundiswe kahle ovumayo

- Ngiyavuma ukuhlanganyela kulokuxoxisana nocwaningo olushiwo ngaphezulu, ngokuthanda kwami ngaphandle kokuboshwa noma ukuphoqwa.

- Ngiyaqonda ukuthi ngingase ngihoxe kulokhu kufunda noma yingasiphi isikhathi.

- Ngiyayiqonda inhloso yalokuxoxisana.

- Ngiyaqonda ukuthi lolucwaningo lungelenhloso yemfundo ephakeme.

- Ngiyaqonda ukuthi igama lami, kanye negama lanoma ngabe ngubani engingamusho lizoba yimfihlo,futhi lizokwaziwa kuphela ngumcwaningi nomhloli wakhe.

- Ngiyaqonda ukuthi uma imiphumela yaloucwaningo yenziwa ukuthi ibonwe abantu bonke, igama lami noma nalelo lomndeni wami nawabangani angeke avezwe.

- Ngiyaqonda ukuthi ukuhlanganyela kwami kulolucwaningo kuwukuzithandela nje futhi angeke ngithole mali, ukudla noma yiziphi izipho.

Signature of Participant   **Date**

_____   _____

APPENDIX C

Interview Schedule: English and isiZulu

Interview Schedule:

These question hope to elicit the perceived support available and accessible to caregivers on a bonding, bridging and linking level. A broad first question begins, followed by another that shifts the interview to support for the caregiver. Beyond that questions aim to elicit further information by the participants.

1. Can you tell me about some of your experiences of caring for a family member/ friend that has HIV/AIDS and is very sick?

1. **Ungangitshela yini ngolunye lolwazi lwakho ukuthi ungalinakekela kanjani ilunga lomndeni noma umngani oguliswa kakhulu yigciwane lengculazi?**

2. Can you tell me a little about the people that are in your life that are available to help you with any problems you might be experiencing whilst you are caring for an HIV positive person?

2. **Ungangitshela yini okuncane ngabantu abasempilweni yakho abakhona ukukusiza nganoma yiziphi izinkinga ongase uhlangabezane nazo kulapho unakekela umuntu onegciwane lengculazi?**

3. *If respondent does not elaborate on question 2:* Would it be possible to explain little more about them and the kinds of things that they help you with?

3. *Uma umuntu ophendulayo engachazi ngokucacile embuzweni wesibili (2)* **: Ngakube kungenzeka yini ukuthi uchaze ngaphezudlwana ngokucacile ngabo nangezinhlobo zezinto abakusiza ngazo?**

4. Do you think that the help you receive or hope to receive for your own problems might make caring for your family/ friend easier? *If respondent does not elaborate:* can you explain that in a little more detail?

4. **Ngakube uyacabanga yini ukuthi usizo olutholayo noma othemba ukulitholela izinkinga zakho ukuthi lingenza unakekelo lubelula emndenini wakho noma emnganeni wakho?** *Uma umuntu ophendulayo engachazi ngokucacile* **: ungakuchaza yini lokho ngemininingwane kakhudlwana?**

5. Can you tell me a little about whom you would like to receive help from with any problems you might be experiencing whilst you are taking care of your family member/ friend?

5. Ungangitshela yini okuncane ukuthi ngubani ongathanda ukwamukela usizo kuyena nanoma yingaziphi izinkinga ongahlangabezana nazo kulapho unakekela ilunga lomndeni wakho noma umngane wakho?

6. What kinds of activities would you like help with? *If respondent does not elaborate:* can you explain that in a little more detail?

6. Yiziphi izinhlobo zemisebenzi ongathanda ukusiza ngazo? *Uma umuntu ophendulayo engachazi ngokucacile :* **ungakuchaza yini lokho ngemininngwane kakhudlwana?**

7. Can you tell me about any groups, organisations or institutes that you may go to for help with problems you may experience whilst you are caring for your family member/ friend?

7. Ungangitshela yini nganoma yimaphi amaqembu, izinhlangano noma isikole esikhulu ongayela kusona usizo mayelana nezinkinga ongase uhlangabezana nazo kulapho unakekela ilunga lomndeni wakho noma umngane wakho?

8. *If an affirmative to question 7:* Can you tell me a little about what help you might be able to receive from them.

8. U*ma ephendula embuzweni wesikhombisa (7):* Ungangitshela yini okuncane ngokuthi yiluphi usizo ongase ulwamukele kubona.

9. What might make it difficult for you to approach these institutes for help?

9. Yini engase yenza ukuthi kubenzima kuwena ukuthi ukhuluma nalezinhlangano ngosizo?

10. Can you tell me about any government structures in your community or outside your community that you may approach for help with the problems you might be experiencing whilst caring for an HIV positive person?

10. Ungangitshela yini nganoma ngabe yiziphi izikhungo zikahulumeni emphakathini wakho noma ngaphandle komphakathi wakho ongakhuluma nazo ngosizo ezinkingeni ongase uhlangabezane nazo kulapho unakekela umuntu onegciwane lengculazi?

11. *If an affirmative to question 10:* Can you tell me a little about what help you might be able to receive from them

11.*Uma ephendula embuzweni weshumi (10) :* **Ungangitshela yini okuncane ukuthi yiluphi usizo ongaluthola kuzona (izikhungo zikahulumeni).**

12. What might make it difficult for you to approach these government structures for help?

12.Yini engase yenze ukuthi kubenzima kuwena ukukhuluma nalezikhungo zikahulumeni mayelana   nosizo?

13. What would you like to see change in your life to make it easier for you to look after for your family member/ friend?

13. Yini ongathanda ukuyibona ishintsha empilweni yakho ukuze kubelula kuwena ukunakekela ilunga   lomndeni wakho noma umngane wakho.

14. What would you like to see change in your community to make it easier to care?

14. Yini ongathanda ukuyibona ishintsha emphakathini wakho ukuze kubelula kakhulu ukunakekela?

APPENDIX D

Transcript of Interview

Interview 9

Location: Wushwini

DATE: 09-06-09

TIME: 14:00-14:45

INTERVIEWER: Can you tell me who you are caring for?

RESPONDENT: for my mother.

INTERVIEWER: How old is she?

RESPONDENT: she is 40.

INTERVIEWER: Can you tell me a little bit about what kind of sickness does she have, what is happening to her physically in her body?

RESPONDENT: it started by shingles and she got sick and she was losing power…and then she started drinking ARVs.

INTERVIEWER: When did she start the ARV treatment?

RESPONDENT: it was last year…in…early last year, I can't remember when.

INTERVIEWER: How long was she sick before she began ARVs?

RESPONDENT: she was not used to be sick all the time, sometimes today she is fine and tomorrow she is sick, but then it become worse, worse.

INTERVIEWER: And how long has that been going on?

RESPONDENT: now I can say that she is better, I don't know whether its…yes its treatment.

INTERVIEWER: Ok so before she began treatment how long was she sick?

RESPONDENT: maybe a year and a half.

INTERVIEWER: And you say she is better now?

RESPONDENT: yes she is better than before.

INTERVIEWER: Is she able to do things for her self now?

RESPONDENT: yes sometimes.

INTERVIEWER: Sometimes, but most of the time you have to do things for her right?

RESPONDENT: yes.

INTERVIEWER: Ok so tell me about the things that you do for her.

RESPONDENT: sometimes when she don't have power and she couldn't walk, I go and cook for her, wash things for her, but she can manage feed herself.

INTERVIEWER: But when she was sick before the ARVs she could not feed herself?

RESPONDENT: yes.

INTERVIEWER: What other things do you have to do for her, you cooked, you washed, you fed her when she was very sick?

RESPONDENT: and we also went to the clinic, so if we had to go from home to the bus stop, of which it is a long distance and we don't have a car yes that was the toughest thing/maybe they would say we must come tomorrow and then it's the following day, the following day, that was the worst thing.

INTERVIEWER: So transport was the biggest problem?

RESPONDENT: it was the biggest one and still it's the biggest problem, yes.

INTERVIEWER: Can you just explain a little bit more about the transport problem?

RESPONDENT: since that we live in this area, the taxis do not go in to our home, so we need to travel and it's a long distance from my place to the bus stop/more especially to someone who is very sick, it is very, very difficult, sometimes we need to take a wheel barrow or something, because she cannot move for herself, yes it's the toughest thing.

INTERVIEWER: So you had to put her in a wheelbarrow and take her to the bus stop?

RESPONDENT: to the bus stop yes.

INTERVIEWER: Would it had been possible to get transport to…

RESPONDENT: yes if I ask for the taxi…if I ask the taxi to come to my home then you have to add money, more money, so we don't rely on the taxi since we have no neighbour who don't have cars, you know so it hard.

INTERVIEWER: So then do you get someone to come to your home, with them requiring more money?

RESPONDENT: yes, of which sometimes we don't have that money.

INTERVIEWER: Ok so you've had to cook, wash, feed her at certain times although she is able to feed herself now and the transport is one of the biggest challenges in looking after your mother/have you had to maybe help her bath and go to the toilet?

RESPONDENT: sometimes yes, sometimes…since we don't have toilets inside the house, you need to go outside for a toilet of which it's a distance/and then sometimes she needs to go to the toilet in the night, you know its bad.

INTERVIEWER: Is there anything that you would like to add to that?

RESPONDENT: about?

INTERVIEWER: About what your mother has being going through and what you have had to do to help her?

RESPONDENT: she's been…I can't…but then what I can say is that she is…oh besides that it also a distance for her from my place to the hospital, not the clinic, but to the hospital, because she is getting her treatment from St. Mary's Hospital, so that's…sometimes she cannot afford it, you know, that's what irritating these days.

INTERVIEWER: Has it ever happened that, because you cannot afford the transport that you were unable to go pick up the treatment?

RESPONDENT: you know what we do is, we go to someone that w know we can borrow money, that is what we do when she doesn't have money.

INTERVIEWER: So you always make sure that you go to the hospital?

RESPONDENT: yes, we make sure, we always make sure that she gets the treatment.

INTERVIEWER: Are there any other problems that you have been experiencing?

RESPONDENT: since…according to my knowledge a person who is taking ARV's needs to eat healthy, healthy food, of which they don't want to…what you call…they don't give…they do not sponsor in the hospital/sometimes they get a…other people get parcels, food parcels of which she doesn't get…that's what's irritating.

INTERVIEWER: Why doesn't she get the food parcel?

RESPONDENT: I don't know, she asked, but she did ask for it and they refused to give it to her…it's a hospital problem, I don't know…according to my knowledge it should be done like that/because I was once taking the TB treatment and I was getting the food parcel at the clinic and other stuff for a person who got TB and for a person who got ARV's…

INTERVIEWER: Ok now I understand a little bit about the difficulties in taking care of your mother, who is there to help you look after her?

RESPONDENT: (couldn't hear part of the response), but then she didn't know about the HIV, she doesn't know that she is taking the ARV's, she cannot keep a secret.

INTERVIEWER: Ok why do you want to keep it a secret?

RESPONDENT: for her, that is what she likes, she talks about it, but she is still like, you

know she doesn't just talk to anyone/even in my home my granny is a drunk as well.

Ok so your granny might tell a lot of people?

RESPONDENT: yes, even if she doesn't want them to know.

INTERVIEWER: And why would your mother not like other people to know?

RESPONDENT: I didn't ask for that, I took what she told me, but she don't…I mean don't people to know, but the thing is she didn't want someone to tell people about her/she wants to tell people herself.

INTERVIEWER: Is it like she doesn't want people to be talking about her?

RESPONDENT: yes, that's what's the…

INTERVIEWER: What does she think people would say when talking about her?

RESPONDENT: I think it breaks her heart.

INTERVIEWER: What will break her heart?

RESPONDENT: because she has had two years with HIV.

INTERVIEWER: How do you feel about people not knowing your mother's HIV/AIDS status?

RESPONDENT: on my side feel…it depends…sometimes I feel like if people want to know they must know, but if someone else is asking what is wrong with your mother, she must know/but I hate hearing people gossiping about that its also breaks your heart, I think she feels the same way.

INTERVIEWER: Would it make it any different in your life if more people did know about your mother's status?

RESPONDENT: it won't make any difference, the thing is it will break my heart you know…it will break my heart to hear people speaking about my mom and judging her she has gotten this, because of 1, 2, 3 and 4.

INTERVIEWER: These people that you say will be talking about your mother, who are these people in your life?

RESPONDENT: just people.

INTERVIEWER: Ok would you say its family, neighbours?

RESPONDENT: neighbours, mostly the neighbours.

INTERVIEWER: Ok do you receive any help from your neighbours?

RESPONDENT: no.

INTERVIEWER: But would you like to receive help, I just want to clarify that it is different when someone helps your mother, if a family member or a neighbour comes to help look after your mother/it can be very difficult with you as well, so I really want to know, does anyone come to help you as you are helping your mother?

RESPONDENT: no, in the family…in the neighbourhood no not these neighbours, but the family does.

INTERVIEWER: Ok I will ask you about the family just now, but since we are talking about the neighbours, would you like any of the neighbours to help?

RESPONDENT: yes I would like some of the neighbours to help, like with the transport…

INTERVIEWER: So you would like help with practical things?

RESPONDENT: yes that's the thing, only with the practical things, because…

INTERVIEWER: Is there any other kind of help that you would like to receive from your neighbours?

RESPONDENT: just practical things.

INTERVIEWER: Do you think it night help to be able to talk to some of the neighbours?

RESPONDENT: about her status?

INTERVIEWER: About her status, but what I want to ask is will it make you feel better if you were able to talk to someone about the difficulties you are expecting as you are caring for your mother?

RESPONDENT: I do have friends that I talk to, so I don't think it is a wise thing to talk your problems to every person, 'cause you never know what people think about yourself or about your family/I guess if I got a problem I will go to my friend and speak to my friend.

INTERVIEWER: So would it be that maybe you do not trust a lot of people?

RESPONDENT: yes that is the thing, I do not trust them and according to our beliefs yes.

INTERVIEWER: What are some of those beliefs?

RESPONDENT: like witchcraft.

INTERVIEWER: Then someone might then say that is, because of witchcraft that your mother is ill and they might not want to help because they think there is some kind of evil…?

RESPONDENT: some evil magic, yes.

INTERVIEWER: Ok well maybe tell me about the friends that you do talk to and the kind of help that you get from them?

RESPONDENT: first it is my boyfriend and then my other friend, my boyfriend help in financial and practical…so he is the first person I go to/and my friend they help me like emotionally, so I talk to my friend when I wan to feel like calm, when I want to feel better when my mom don't feel like talking then I go to my friend, and she gives me advice and she tells me that my mother is going to get better, but financially and physically it I my boyfriend.

INTERVIEWER: So you are getting some support from your friends, how does that help you…you mentioned that it makes you…ok can you answer the question I won't answer it for you…how is it helping you as you are caring for your mother, what kind of…how does it make you feel?

RESPONDENT: if someone is helping me, or are you asking about my friend?

INTERVIEWER: You say that your friend helps you by listening and understanding, so how does that make caring for your mother easier?

RESPONDENT: if someone is your blood, its bad, its your heart and soul, you can't even sleep, you can't even eat, sometimes you cant even eat so its becomes very hard/so if someone comes to you and be close like a friend and speak and comfort you it makes you feel better/it does and thinking about myself sitting the whole day in the yard you know, and stress…its stressful so its better if you got a friend that you can cry on their shoulder/it makes me feel better, since it is my mom you know a very, very close person.

INTERVIEWER: Is there anyone else that you would like to get that kind of help from?

RESPONDENT: the government.

INTERVIEWER: Ok so lets talk about the government, what do you think the government should be doing?

RESPONDENT: I think the government must give grants or what…

INTERVIEWER: Are you not receiving grants at the moment?

RESPONDENT: she does receive grant and it takes one year and it will end this year, so by next year she won't get it and since she is not receiving any parcels that means by next year she will have no support and since there is no one working at my house that is going to be a problem.

INTERVIEWER: Ok so you feel the government should do more to support you with the grants?

RESPONDENT: yes and the parcels.

INTERVIEWER: So its money and food?

RESPONDENT: yes.

INTERVIEWER: What else, is there anything else that government should be doing to make your life easier and here again I just need to clarify that the government could be doing things to make your mom's life easier, because they are already providing

ARV's/but what I want to know is what should the government be doing to make your life easier?

RESPONDENT: my life, personal.

INTERVIEWER: You personal…because right now it is quite difficult, because you have to care for your mother.

RESPONDENT: ok how can I put this…but then…if I can find a job, if they can open the door for opportunity, that is the thing I am praying for/'cause if I was working things could be better, I would not go to someone and say please I need money to take my mother to the hospital, I need money to go collect treatment, so yes if I was working.

INTERVIEWER: So now there is three things that you would like government to do, it's the food and the money and a job and you feel like the government is not providing these things.

RESPONDENT: I feel like he isn't and I think he…that the government don't even care…how can you, you know not care for a person who I really sick, he might not care for me, but for someone who is ill he must care, he must take good care for them/even those people who are working in the government office they don't have time, they don't care if you are ill or what, they talk in their way, they don't care.

INTERVIEWER: Have you had some experiences with them?

RESPONDENT: yes.

INTERVIEWER: Tell me about them.

RESPONDENT: sometimes when I went to hospital and the nurse is forward, but others they are good especially if you are there to take your results, the problem persons are the nurses they always…I don't know how I can, but they are the problem/they don't care if you are ill, not all of them, but most of them.

INTERVIEWER: Would you like to see some changes the way help is?

RESPONDENT: yes.

INTERVIEWER: Ok so can you tell me a little bit about that, but also tell me in terms of

how it would make your life a bit different as someone who is caring, it can make your moms life a bit different, because she is ill, but how would it make your life different…I'm interested in what happening with you?

RESPONDENT: if they can employ someone who knows how to treat other people, because it is irritating if someone close to you, who is your blood like your mom, someone talking like hell to her its really, if they can maybe fix that thing it can be better.

INTERVIEWER: What about the health care that is provided?

RESPONDENT: the other care?

INTERVIEWER: The actual care that is provided, do you think it makes it easier for you to care for your mother?

RESPONDENT: I think they…according to my mom you know, if I was a government, I would do something like, I would send them…the treatment you know so they don't have to go to the hospital/some of them do not work they are suffering, some people do not go to hospitals to collect the treatment, because they don't have money to go there/so if they can try to do that that could make my life easier.

INTERVIEWER: Coming back to your family you know, I had asked you about friends an family and you mentioned that your boyfriend is very helpful and that you have friends that you can talk to and talking to them makes it easy for you/and then you said something about family and I said we will come back to that just now, so tell me about the kind of help that you get from your family?

RESPONDENT: in my family there is a lot of people, so it happens lie this people are caring for their children, but they are always supportive, so I cannot rely on them, we cannot rely on them.

INTERVIEWER: Why can you not rely on them?

RESPONDENT: because they are caring for their families, for their children and mother's you know.

INTERVIEWER: Is it a case where they have they own things in life they need to deal with and they cannot help you with your things?

RESPONDENT: exactly, but not all of them, but there are some.

INTERVIEWER: So the people in your family do help, can you tell me who does?

RESPONDENT: it is my cousin and my aunty they just…sometimes they come and maybe say I am going somewhere fro an interview or something or whatever, maybe I ma forced to be there, I phone my aunty and I ask her to come and look after my mom I need to be there/so they come, that help, I can cal it help, she never refuse and also my cousin she always phone asking…and if it takes her to come she comes if it takes her to help financially she does.

INTERVIEWER: So there are family members that you can rely on?

RESPONDENT: yes.

INTERVIEWER: Is there any other kind of help that you would like to receive from family members?

RESPONDENT: if they can like be working together.

INTERVIEWER: Working together, what do you mean by working together?

RESPONDENT: everything if someone is ill all must come to see what they can do, yes they don't need to wait for me to phone them, I have to call them every time, every time, everyday and come and see for their own, not for me to phone them, but they must see for themselves, so if they can do that it can mean a lot.

INTERVIEWER: But at the moment if you do need help can you call your family or somebody in your family to come help you?

RESPONDENT: some people.

INTERVIEWER: And you would usually get help from that person?

RESPONDENT: yes.

INTERVIEWER: I know that the home based carer comes quite often to help, can you tell me about the help you are receiving from the home based carer?

RESPONDENT: what am I going to say…?

INTERVIEWER: It's ok to be perfectly honest, nobody is going to get offended, honesty is quite important.

RESPONDENT: my home based carer she doesn't come at all, but sometimes Sis'Sthembile does come.

INTERVIEWER: Ok so you have got your own home based carer?

RESPONDENT: we do, like every house has their own home based carer, but she don't come at all.

INTERVIEWER: Why do you think she doesn't come?

RESPONDENT: I don't know.

INTERVIEWER: Have you asked her?

RESPONDENT: no she knows she must come, why should I ask her, why should I follow her for her job?

INTERVIEWER: What is stopping you from going to her and asking her?

RESPONDENT: because that is her job, she must do what she must do, I cannot follow a person, I cannot keep following her, she knows what he must do and she must do that/if she doesn't want to do her job that's her story, a long as y family becomes healthy each and everyday, that makes me happy, its like I don't care about someone who don't care, if she don't come that means she don't care.

INTERVIEWER: Can you tell me what you would like her to do?

RESPONDENT: I would like her to come and work as she do, but I don't know what she must do exactly.

INTERVIEWER: Ok if you don't know what she must do exactly, then you can tell me what you would like her to do, what you think a home based carer should be doing?

RESPONDENT: coming to a sick person asking what she can do, if it calls for her to go to the clinic and collect treatment, do that, because sometimes they cannot travel from

their places to the clinic, so if she can do that, that is what I would like them to do, give support.

INTERVIEWER: Tell me about the support that you get from her?

RESPONDENT: she comes and asks us how we feel, that is what she is doing sit with us laughing, talking.

INTERVIEWER: Ok how does that help you?

RESPONDENT: its very nice, sometimes it is very nice meeting someone who is not a member of your family, coming to your family and sympathise, sitting and talking about things and not about your ills sometimes, but general knowledge, its open.

INTERVIEWER: And what does that do for your life and how does it help you care for your mother?

RESPONDENT: if someone is coming to my place and talking generally, it helps me not to stress, to think about one thing.

INTERVIEWER: Would you say that it kind of takes your mind off your problems that you are facing?

RESPONDENT: yes.

INTERVIEWER: Is there anyone else in your community who is available to help, we have spoken about friends, family, home based carer, is there anyone else, any person, any organisation, an NGO for example or maybe a church that can provide any kind of support or is providing any kind of support.

RESPONDENT: there is no one.

Who do you think should be giving you that kind of support?

RESPONDENT: I think everyone must support, just everyone, 'cause you never know what the future has in store for you/everyone needs to come as we are all the people, if someone is sick give her a call and if you know where they stay, their situation, how do they suffer and you do have money or something you must come and give a hand.

INTERVIEWER: What do you think is stopping people from helping?

RESPONDENT: people have their own things and stuff to do, I think and some they just don't care, like there is nothing…like it doesn't touch their hearts.

INTERVIEWER: Ok just to answer the question, is there anyone, I'm not talking about friends and families, maybe a church or an NGO maybe through the school that can provide any kind of help?

RESPONDENT: nothing.

INTERVIEWER: What kind of help or I should ask who do you think-in terms of organisations-should be helping you?

RESPONDENT: I think NGO must help us.

INTERVIEWER: What kind of help would you like to receive from them?

RESPONDENT: first NGO's is receiving funds from the government and NGO are required to help the needy people, so they need to do that/we do have NGO in this community.

INTERVIEWER: Ok so can you tell me about that NGO?

RESPONDENT: I once go there I think its Sethani, I was willing to study, so I went there looking for help, but they refused they said they do not give help, the do not give that help that is what they told me, they only give help to those children from secondary and primary.

INTERVIEWER: Ok so Sethani did not help you?

RESPONDENT: yes.

INTERVIEWER: What kind of help do you think you could get that they are offering, in terms of the help that you might need to help your mother?

RESPONDENT: they do give food parcels to others.

INTERVIEWER: Ok but you haven't received any parcels?

RESPONDENT: no.

INTERVIEWER: Why do you think you haven't been receiving food parcels?

RESPONDENT: I guess information was not sent to all people, I think people…they did not register; I think there was a register.

INTERVIEWER: Ok so you didn't register?

RESPONDENT: we didn't register, because they didn't tell us, we would register if they had told us, but they didn't tell us.

INTERVIEWER: Is it possible to register now?

RESPONDENT: I think it is full in the list.

INTERVIEWER: What would you like to see change in your life that might make it easier to care for your mother?

RESPONDENT: the thing that I…the only thing that I need is to study and then after the study I can get work, if I could find a job, that is something I need.

INTERVIEWER: Ok so you say that you would like to study and that it is important that you have work, which will then make it easier for you to care for your mother?

RESPONDENT: yes, it's unlike sitting at home thinking…

INTERVIEWER: What about your community, is there anything that you would like to see change that would make it easier?

RESPONDENT: I don't know…most of the people don't work, they don't…yes they don't work so sometimes people would like to help, but they don't have money/so maybe if they can open those opportunities so that people can get a job…

INTERVIEWER: And then people can help financially as well.

RESPONDENT: yes.

INTERVIEWER: Ok apart from job creation, what else would you like to see change in your community, you mentioned things about not being able to tell people about her status, would you like to see something change on that?

RESPONDENT: yes, if she feels that way she feels that way I cannot change that feeling and maybe it can make her feel worse, if she don't feel like it, she don't feel like it, if she don't feel like it then I also don't feel like it.

INTERVIEWER: Is there anything that you would like to add to what has been said?

RESPONDENT: no.

INTERVIEWER: Ok so there is one other bit that I missed out, what about people in communities that are away from your…that are different from your community, do you receive any help from them

RESPONDENT: in other communities?

INTERVIEWER: People in other communities yes, who are facing similar difficulties, they also have people they need to look after?

RESPONDENT: as you can see this place, this place is different from other places, what I can say is the other communities are better than this kwaNgcolosi, so their lives are easier than here/even on transport, some people just move from their house to the stop just about 4 seconds it easier, in the rural area you need to walk, it's a long way to a bus stop.

INTERVIEWER: Its quite important having to be able to move about, what do you think people from other communities could offer you, I am not talking about government, I'm just talking about people like you, like the home based carers or maybe a kind of a support group in other communities/do you receive any help or do you have any knowledge of any group like that?

RESPONDENT: yes like the other group in Botha's Hill, but then they don't help us, but when someone is sick they give them help, all the people in the area, well almost.

INTERVIEWER: But it's just that people in Botha's Hill don't help people in kwaNgcolosi?

RESPONDENT: yes.

INTERVIEWER: Would you like to see some kind of help coming in from other communities?

RESPONDENT: yes and some other NGO's like the Village Trust.

INTERVIEWER: The Village Trust, what is the Village Trust?

RESPONDENT: its an NGO, they help, they really do help they even sponsor other NGO's.

INTERVIEWER: Are they not working in kwaNgcolosi?

RESPONDENT: no they don't work here.

INTERVIEWER: Ok why do you think they are not working here?

RESPONDENT: I don't know I never did that research.

INTERVIEWER: Is there anything that you would like to ask me?

RESPONDENT: I need to know why you are doing this…oh you did stay that you are doing it, because you are in university and you are studying, but then I need to know what exactly you are studying?

Psychology.

RESPONDENT: oh so you deal with the mind?

INTERVIEWER: Yes.

RESPONDENT: so how can this help me?

INTERVIEWER: In your mind?

RESPONDENT: yes.

INTERVIEWER: Well the purpose of this interview really is to understand your

experiences, so really its just about getting information and what I would do is…this will form part of my research which will hopefully be accessible to other people/other people who would understand what's its like to care for someone who is sick, because not a lot of people do understand and there isn't a lot of research being done on the carers/there is a lot of work being done on people who are HIV positive and right now there are people who come through kwaNgcolosi to find out the experiences of a home based carers/but not a lot of people who come to find out about what it is like to care for someone who is close to you and is sick/so I would really like to create more information so that people would know about what is happening..

RESPONDENT: how will it help?

INTERVIEWER: Well talking helps too, sometimes talking helps me so…and it might help you too in that way.

RESPONDENT: is Psychology helping financially or just in the mind, 'cause in my knowledge it's the mind?

INTERVIEWER: It's just with the mind, yes.

RESPONDENT: you know sometimes you get mentally disturbed through stress, how do you help…I mean since you have studied, how do you avoid stress?

INTERVIEWER: You know mentally disturbed could mean a lot of things.

RESPONDENT: if you get it by stress?

INTERVIEWER: It can mean stress, it can be depression, it can be sometimes there is…some of the way that your brain works, you actually have to be Psychologist to be able to understand what is wrong there exactly/it is not just one kind of mental illness, there is a lot of different things that could be wrong with a person.

RESPONDENT: so what do you do then, do you advise them?

INTERVIEWER: Sometimes people just need to talk things out and work it out in their heads, sometimes they give people medication for the pressure, sometimes really it is stuff that is in your brain chemicals that are not working well/so the medication helps to make those chemicals work a bit better, but it very difficult to say there's one kind of treatment or one kind of mental illness, because there isn't one kind of mental illness/about stress the best way that I can answer it now is try to find things that will help you release your stress, so if talking to a friend helps then you should make an effort to

do that and with different people its different things you need to understand yourself.

RESPONDENT: but sometimes you do talk to people and you feel better, but when you are alone it comes back, so how do you deal with that as Psychologist, I can go to my friend talk to my friend or whoever, but when I am with them I feel better and when I go to my place again stress again/it come to my mind that I must see a Psychologist, maybe I come to talk to you like I am talking to my friend and then I'm home again and I am stressed?

INTERVIEWER: A Psychologist might do something different, in the sense that they…psychology is not just listening, but a big part of it there are listening aspects to understand your problem to be able to help/but then they kind of work out what you need to do to distress, I mean it is not the same with everybody, but its not like the Psychologist will tell you what to do its kind of like you have to do that by yourself, it is different from what a Doctor would do/if you go to a doctor with a problem, you tell the Doctor you got a headache and my head is paining and then the Doctor tells you what is wrong with you and then he tells you what you need to do, you take that medication and this medication/with psychology a lot of problems we have are problems we have in our lives that we are not dealing with anymore, a good Psychologist won't tell you what to do, but will help you understand your problem so you can understand what you need to do to fix the problem.

RESPONDENT: so do you do that?

INTERVIEWER: I'm actually a student Psychologist.

RESPONDENT: so you are good then?

INTERVIEWER: I'm trying, I'm not good, but I'm trying.

INTERVIEWER: Is there anything else?

RESPONDENT: no, that's it.

INTERVIEWER: Are you sure?

RESPONDENT: yes.

INTERVIEWER: Well my number is on the form, I don't know if you took it down.

RESPONDENT: I did.