

**EXPLORING HOW CARE AND SUPPORT  
AROUND HIV/AIDS IS PERCEIVED BY  
VOLUNTEER COMMUNITY WORKERS AT  
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. All citations, references and borrowed ideas have been duly acknowledged. This research has not previously been submitted to any other institution for any degree or examination purposes.

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## **DEDICATION**

This study is dedicated to two special people in my life. One is my Husband Dr. Emmanuel Kasimbazi who supported me with everything he had and endured my two year absence even when it seemed unbearable. The other is my three year old daughter Ola Kunda who missed me a great deal and constantly explained to people that ‘her mom was away in Kwazulu Natal learning the Zulu Dance’.

## **ABSTRACT**

The study focuses on how care and support around HIV/AIDS is perceived by volunteer community workers in Kwangcolosi, Kwazulu Natal. Using the social capital framework, the dissertation seeks to understand and illuminate the existing care and support efforts from the community from the perspective of volunteer caregivers. It emanates from the realization that government efforts in the area of care and support for those infected and affected by HIV/AIDS in most rural or peri-urban areas are usually insufficient. Community or family members usually have to step in to fill this gap but their efforts are seldom documented, let alone recognized. These community initiatives have been defined in the wider concept of social capital.

The study sought to explore the perceptions of volunteer community workers on care and support provided to people living with HIV/AIDS (PLWHAs). The social capital framework and specifically the levels of bonding and bridging and the elements of trust, norms, reciprocity and social networks that act as resources for collective action was used to inform the understanding of these collective community efforts.

The study findings revealed that denial, mistrust, stigma and discrimination were some of the hindering factors of social trust which in effect weakened social bonding and bridging. Social norms were also perceived to be on the wane and social networks amongst community members were reported to be existent though feeble. Reciprocity though paltry existed amongst a few community members who borrowed from one another and this played an important role in care and support of those affected by HIV/AIDS.

The study concluded that factors such as rural urban migration, urbanization, globalization, poverty and unemployment have diminished social networks and cohesion and this has negatively impacted on care and support provision by community members. The general perception about volunteerism among

volunteer community workers was that there is need to financially facilitate volunteers to motivate them to meet expenses that are associated with volunteering such as transport and feeding.

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# CHAPTER ONE

## INTRODUCTION

The purpose of this chapter is to give a general introduction to the study. The chapter provides the overview of the whole dissertation, background of the study, the statement of the research problem, significance of the study, as well as the research questions addressed in the study. The chapter also presents the conceptual and key definitions of the terms used in the dissertation.

### 1.1 Overview

Communities with high levels of social capital may be more effectively able to implement health interventions like care and support for those infected and affected by HIV/AIDS. This is possible with increased information channels, community interaction, mutual support and care that are facilitated by social capital. This interaction enables people to build communities, to commit themselves to each other, and to knit the social fabric. Care and support for those infected and affected in the communities is provided by different categories of people however its continuity depends on their perceptions.

The main focus of this dissertation is to explore the perceptions of volunteer community workers on care and Support around HIV/AIDS in Kwangcolosi, Kwazulu Natal. The dissertation is divided into seven chapters. The first chapter provides a general introduction to the study. It provides the background of the study, the statement of the research problem, significance of the study, as well as the research questions addressed in the study. The chapter also presents the conceptual and key definitions of the terms used in the dissertation.

The second chapter presents the theoretical framework that underpins the study. The social capital theory is analyzed under the four elements of social capital which include norms, trust, reciprocity and networks. These elements are further discussed under the following levels; bonding and bridging leaving out linking as these two levels locate social capital at the community and civil society levels.

The third chapter reviews the related literature to the study. The review is based on the following themes; contextualization of Ubuntu as a backdrop for care and support, elements of social capital and how they relate to care and support, informal care and support and volunteerism in the care and support context.

Chapter four describes the qualitative method of research which was the only research method used to collect data. The chapter also describes the study area, study sample, participant selection criteria and the ethical considerations in qualitative research.

Chapter five presents the summary of the interviews and focus group discussions with the participants.

Chapter six analyses the findings of the study. The findings are analysed according to the four elements of social capital as indicated in the above chapter. The chapter also provides the summary of the findings. The final chapter presents the conclusion, recommendations and considerations for further research.

## **1.2 Background to the Study**

Recent statistics (UNAIDS, 2006) estimated that about 39.5 million people worldwide are living with HIV/AIDS. The report also approximated that more than three quarters of all AIDS deaths globally in 2007 occurred in sub-Saharan Africa. With an estimated 5.5 million (4.9 million–6.1 million) people living with HIV/AIDS, South Africa is the country with the largest number of infections in the world. In 2007, it was also estimated by South African Department of Health that 18.3% of adults of 15–49 years were living with HIV in 2006 (Department of Health South Africa, 2007). More than half (55%) of all South Africans infected with HIV reside in the KwaZulu-Natal and Gauteng provinces (Dorrington, Bradshaw, Johnson & Budlender, 2004; UNAIDS, 2006).

By 2006, it was estimated that 5.5 of 44 million South Africans were HIV positive (UNAIDS, 2006). The Province of Kwazulu Natal had the highest overall HIV/AIDS

prevalence rate of 16.5%. The prevalence of HIV among antenatal attendees in the province soars at 39.1% (Department of Health, 2006). The HIV prevalence rate for adults aged between 15 and 49 years was 18.8%. With almost 1,000 people dying from AIDS every day in South Africa, it has been suggested that by 2012 around 1.5 million people will still die from AIDS-related illnesses if the treatment scale-up continues at the current rate (Walensky et al., 2008). Yet, it is not only the infection rate that is alarming but also the inadequate care and support that is increasingly becoming a matter of concern (Gilson, 2003). In addition, there is disturbing lack of government leadership and support for people infected and affected by HIV/AIDS in South Africa (Lewis, 2006).

### **1.3 Care and Support in the Context of HIV/AIDS**

Care literally means to address physical needs, help or comfort. In this context, care denotes addressing of physical needs, moral support, spiritual support, help or comfort to those infected and affected by HIV/AIDS. These are usually acts through which people demonstrate their sentiments of care and love. These acts may also extend well beyond daily nursing tasks to include any activity that contributes towards the welfare of others. Examples include sharing money and food, providing labor and time, attending funerals, and visiting others; all of which are acts of care through which people mobilize sentiment in order to strengthen or heal relationships (Klairs, 2002; Livingston, 2003).

Care is also often described in the constructs of 'linked' or 'unlinked' care. Linked care on one hand entails care provided in the home by trained professionals or volunteers for patients and their families (Ogden, Esim & Grown, 2004). Unlinked Care on the other hand refers to the care provided in the home by unpaid and untrained family members usually female friends and neighbors of those living with HIV/AIDS, which is not linked up with any formal care and support service (Uys, 2003).

Concepts like home-based care, homecare and community home-based care are usually used interchangeably to denote care that takes place in a home. They refer to both clinical and non-clinical care that is provided by lay, volunteer or professional providers who are linked to programs and care (non-clinical) that is provided by family members who are not linked to programs (Ogden, et al., 2004). On the whole, the three terms may include the day-to-day support which a chronically ill person receives within the community, either from family members, neighbors, volunteers or agencies from outside the community (Uys, 2003).

Volunteers provide spiritual support by praying with the patients. They also provide moral support by showing them love and compassion, and by talking and listening to them. In addition, volunteer caregivers provide basic nursing care, including mouth care, cleaning pressure sores, skin care, turning bedridden patients, support for adequate nutrition, and monitoring drug adherence, among other things (Ogden et al., 2004). The caregivers also assist patients with daily activities such as feeding, bathing, dressing, walking, and going to the toilet. They also assist with household chores, shopping, cooking, transportation, and making telephone calls. Social support provided by volunteer community workers also involves connecting those infected and affected by HIV/AIDS to wider community resources and information. These may include, support groups, church groups, welfare services, and material assistance. However, social support is normally weakened in communities with widespread denial, stigma and discrimination (Population Council and Health Systems Trust, 2006; Akintola, 2006). The terms care and support are usually used interchangeably, signifying clinical and non-clinical care, treatment-focused activities, emotional and spiritual support, counseling, and activities that are more broadly health or well-being-oriented such as income-generating projects.

Support on the other hand means to give aid and courage. It may take the form of social or material provision of support whereas care means to have regard or consideration for another. As opposed to care, support for those infected and affected by HIV/AIDS is normally provided by non-medics, often in the home, embracing

psychosocial, spiritual, and other non-medical forms of care (Ogden et al., 2004; Akintola, 2004).

Social support is the main thrust of this study. It involves the physical, emotional, spiritual and moral comfort given to those infected and affected by HIV/AIDS by the volunteer community workers and the rest of community members. Social support is very vital for those affected and infected by HIV/AIDS to give them hope and courage to face effects of the HIV/AIDS pandemic.

Material support on the other hand involves the provision of food, clothing and on rare occasions financial support to those infected and affected by HIV/AIDS. In terms of material support, volunteers assist with soliciting financial and material assistance from neighbours, religious organisations or dealing with doctors or other medical personnel. Volunteers also link those infected and affected by HIV/AIDS to the civil society and government to access the necessary material resources (Birdsall & Kelly, 2005). However, social support and material support are normally weakened in communities with widespread denial, stigma and discrimination (Population Council and Health Systems Trust, 2006, Akintola, 2006).

#### **1.4 Problem Statement**

In Africa, where two-thirds of the world's HIV-positive people live, health care systems were already weak and under-financed before the advent of AIDS (UNAIDS, 2001). These systems are now crumbling under the added strain of millions of new patients. In many places, facilities for diagnosis are inadequate and drug supplies erratic, even for HIV-related conditions that are easy to diagnose and inexpensive to treat. Access will remain uneven and compromised until countries are able to afford AIDS-related drugs and diagnostic equipment and equip their health systems with the necessary infrastructure and adequately trained staff (WHO, 2008). Many developing countries, struggle to allocate sufficient portions of their national budgets to the health and education sector because most of the budget goes to service foreign debts. In addition, the number of people and families living with HIV/AIDS who need care

and support services is continuously increasing (WHO, 2008). This poses remarkable challenges to the health care and community systems which are trying to cope with and respond to the pandemic (Bernard, Charafeddine, Frohlich, Daniel, Kestens and Potvin, 2007).

Recent studies suggest that social approaches to the organization and delivery of public health may have considerable potential for health improvement specifically for those who are infected and affected by HIV/AIDS particularly those who require care and support in their communities (WHO, 2008). Social support and care in the community are provided by a number of caregivers including family members, neighbours, community health workers, volunteer community workers are the interest group for this study.

This is because volunteer community workers are able to provide both physical support such as cleaning, cooking, fetching water, bathing the sick and washing their linen and psychosocial support such counseling, spiritual, and praying with the sick and giving them hope hence the need to understand what they perceive. Care and support especially at the community level is still inadequate yet the demand for it is ever increasing owing to the growing number of those infected and affected by HIV/AIDS (Buve, Kalibala and McIntyre, 2003).

The role of communities and community organizations specifically those that involve volunteers is especially important. Their work promotes social solidarity with HIV-infected individuals and their families provide them with emotional support, and helps protect them against discrimination and violations of their rights. Often their activism helps prompt governments to devote more resources to the AIDS response and spurs companies to lower drug prices. The availability of HIV/AIDS care and support is a source of hope and can be a powerful incentive for people to go for voluntary counselling and testing (VCT). Care providers who look after HIV-positive people demonstrate to others that there is no need to fear being infected through

everyday contact and thus help dispel misguided beliefs about HIV transmission (UNAIDS 2001).

When HIV/AIDS strikes a household the stress associated with illness, death, and uncertainty about the future can be devastating. Household resources erode quickly, as adults become caregivers for sick family members, whilst some of them may be sick themselves, and they may have to take in the orphaned children of relatives, neighbours, and friends. The transition from relative comfort to destitution can be swift and scary. Poor families that may be already struggling to make ends meet are even more vulnerable to the consequences of HIV/AIDS (World Bank, 2003).

A household's ability to offset the impact of HIV/AIDS depends on many factors which include access to the resources of extended family members, and the ability of community members to provide temporary relief. Seeking relief from family, friends, and neighbours is an important coping mechanism for households affected by HIV/AIDS. Provision of short-term relief and assistance by individuals and organizations within the community to those in need is a long-standing community safety net that has been used as a common response to an array of disasters, natural and man-made (SAT, 2001).

The existing care and support provided at an informal level by the volunteer community workers though paltry is also undermined by limited support and recognition from government and other stakeholders (Orner, 2006). Besides, a number of those that are involved in the provision of care and support are themselves infected with HIV/AIDS. The problem of insufficient care and support is exacerbated by the fact that it is mainly the elderly members of the community that are involved in the provision of care and support while the youths continue to display lack of interest in the provision of care and support (Akintola, 2005).

Even though the death rate due to HIV/AIDS is reducing due to the availability of treatment and care and support, HIV/AIDS care and support efforts are not as

adequate as required. Such a state of affairs is an indicator that in the future; there will be a bigger number of those in need of care and support while the number of care and support providers will have dwindled. There is a need therefore to understand what volunteer community workers perceive as the available care and support in the community and to investigate the impeding challenges to implementing care and support.

### **1.5 Study Objectives**

The main objective of this study is to explore how care and support around HIV/AIDS is perceived by volunteer community workers in Kwangcolosi, Kwazulu Natal.

The specific objectives of the study are:

- i. To explore and analyse how volunteer community workers perceive care and support around HIV/AIDS provided by them to the community;
- ii. To describe and analyse how volunteer community workers perceive care and support as provided by community members to those infected and affected by HIV/AIDS;
- iii. To investigate perceived challenges of implementing care and support for those infected and affected by HIV/AIDS;
- iv. To make recommendations on how to improve care and support provided by the volunteers for those infected and affected by HIV/AIDS.

### **1.6 Significance of the Study**

The role of community based volunteer caregivers is increasingly becoming an important integral part of the global response to HIV/AIDS (WHO, 2002). The Care they provide ranges from positive healing sentiment of love and concern, and moral social norms. These are usually acts through which people demonstrate care and love. These acts may also extend well beyond daily nursing tasks to include any activity that contributes towards the welfare of others (Ogden et al., 2004). It is at this level that awareness is spread or ignorance reinforced. It is through people's daily interactions with one another that a climate of compassion and solidarity or of fear

and neglect is created (Parker and Birdsall, 2005). Many households in South Africa barely survive, through casual work, subsistence gardening or trading, old age pensions or mutual borrowing and assistance (AIDS Foundation South Africa, 2005). The impact of AIDS has stretched these survival strategies to breaking point in many cases. The burn out has come up as a result of some of those infected and affected by HIV/AIDS having to queue all day at a clinic with a sick relative, having to bury numerous loved ones, neighbours having to attend or help pay for very many funerals and grandmothers having to take care of so many orphaned grandchildren. To this extent, volunteer community workers play an important role in sharing the burden with those infected and affected by HIV/AIDS (WHO, 2002).

The support and services invested in community responses to HIV/AIDS, and the acknowledgement of those responses, will determine for how long and how effectively they can continue. This study contributes to the on-going debate about the importance of care and support in local communities in relation to HIV/AIDS. Care and support is a big topic and is better understood through a theoretical framework that lends itself to the described problem and the social capital framework fits this description. There is growing enthusiasm around the idea that levels of health might be better in communities characterized by high levels of social capital (Putnam, 1993; Campbell, 2001). This framework with all its advantages will fully be discussed in Chapter Two.

Care and support for those infected and affected in the communities is provided by many people but for the purpose of this study, only the perceptions of volunteer community workers will be explored. The research results could benefit policy makers especially the departments of Welfare, and Health and the recommendations could aid those organisations involved in the provision of care and support both at formal and informal levels.

## CHAPTER TWO

### THEORETICAL FRAMEWORK

*"The new currency won't be intellectual capital. It will be social capital-the collective value of whom we know and what we'll do for each other. When social connections are strong and numerous, there is more trust, reciprocity, information flow, collective action, happiness, and, by the way, greater wealth."*

James Kouzes, 2000

#### **2.1 Introduction**

The purpose of this chapter is to present the theoretical basis of the study. This study is guided by the theory of social capital. This theory is illustrated by the levels of social bonding, social bridging and social linking as well as the elements of social Capital. The theory of social capital is presented in three sections. The first section describes the social capital theory in general terms. The section proceeds to elaborate on the elements and levels of social capital and how they relate to care and support for those infected and affected by HIV/ADS. The chapter ends with the analysis of how the social capital theory is operationalised under the elements and levels of social capital theory.

#### **2.2 The Social Capital Theory**

The theory of Social Capital refers to the features of social relationships such as interpersonal trust, norms of reciprocity, and membership of civic organizations which act as resources for individuals and facilitate collective action for mutual benefit (Putnam, 1993). The Social capital theory is complex and intricate for researchers as well as practitioners. Its complexity emanates from the concept being analyzed from different disciplines and backgrounds for various purposes. This leads to significant diversity, controversy and disagreement regarding the theory (Evans, 1996). However, the potential for social capital to make a positive contribution to outcomes in diverse areas of social concern such as health, community safety and

education has captured the interest of policy makers, social analysts and researchers (Australia Bureau of Statistics, 2002). This interest has led to a demand for statistics that measure the concept of social capital, and that can be applied to informing policy development and further research (World Bank, 2003). International organisations such as the OECD and the World Bank have done considerable work on social capital, and a number of national statistical agencies such as Statistics Canada and Office of National Statistics in the United Kingdom are currently progressing work on the measurement of social capital.

Social capital is an old concept but the term has only been coined fairly recently (Bankston and Zhou, 2002; Labonte, 1999; Portes and Sensenbrenner, 1993; Putnam, 1995). The modern development of the concept came from three key authors, Bourdieu, Coleman and Putnam with many other authors contributing to the current multidisciplinary theory. According to Bourdieu, social capital is equated to membership in a group that provides each of its members with the backing of the collectivity-owned capital, a credential which entitles them to credit (Bourdieu, 1985).

Coleman draws together insights from both sociology and economics to define social capital a variety of different entities having two characteristics in common consisting of some aspect of social structures, and they facilitate certain actions of actors whether persons or corporate actors within the structure (Coleman, 1988).

Putnam on his part defines social capital as 'features of social organization such as networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit' (Putnam, 1995).

Whilst the three authors provide different definitions of social capital, they all agree that it deals with certain aspects of social structure that enable social action (Adam and Roncevic, 2003). In the current study, social capital is understood as the value of

social networks, bonding similar people and bridging between diverse people, with norms of reciprocity (Ulsaner, 2001).

Social capital is a broad framework that has been applied in a variety of contexts to explain the ability of communities to solve the problems of collective action, ranging from the provision of public education, to the maintenance of effective and smooth-functioning government institutions, as well as the exercise of informal control over criminal behavior (Falk, Golding, and Balatti, 2000). The concept of social capital has been recently extended to the health field to explain geographic variations in mortality and morbidity as well as to illustrate improvement in health where larger stocks of social capital exist. This has led to calls for a radical rethinking of health planning and to the need to understand how social capital may translate into better health outcomes and health equity (Wilkinson & Marmot, 2003).

### **2.2.1 Elements of Social Capital**

This study is based on four elements of social capital. The first one is social trust. Social trust is the extent to which individuals believe that others mean what they say and will follow through on their commitments. Social trust is essential to understanding social capital which denotes a relationship of reliance. In social psychology, social trust is integral to the idea of social influence: it is easier to influence or persuade someone who is trusting. The notion of trust is increasingly adopted to predict acceptance of behaviours by others, for example individuals, community members, civic society and government agencies (Leach, Neil, Pelkey and Sabatier, 2002). One of the major components that sustain social capital is trust between and among people and groups facilitating cooperation and coordination for mutual benefit (Putnam, 1995:67). In communities where people are affected by HIV/AIDS, trust diminishes stigma and discrimination and encourages those infected to disclose their HIV+ status which in turn helps them to access resources for care and support for their benefit.

The second element is reciprocity which is the type of social capital that is embedded within personal relations where one gives to someone else expecting fair and tangible returns at some undefined future date. The expectation that the giver will be repaid is based on social consequences. (Dickhaut and McCabe, 1995). The ethic of reciprocity or the Golden Rule is a fundamental moral principle which simply means "treat others as you would like to be treated." (Reinikainen, 2005). Reciprocity is a key intervening variable through which shared social rules are enabled to yield social stability. It is based on a mutual or cooperative exchange of favours or privileges. It is exemplified by the American expression "You scratch my back, and I'll scratch yours" and the Latin expression "Quid pro quo" which means "something for something" (Wattles, 1996). High levels of social capital are argued to give rise to a higher level of reciprocal relationships hence lead to more cooperative and well functioning communities. In terms of care and support, reciprocity may include a household HIV/AIDS patient caregiver approaching a neighbour to take care of the patient while he/she goes to the market to buy food (Wattles, 1996).

The third is social norms. These are customary rules of behaviour that coordinate our interactions with others. Once a particular way of doing things becomes established as a rule, it continues in force because it is desirable to conform to the rule given the expectation that others are going to conform (Posner, 2000). Social norms are further conceptualized as the rules that a community uses for appropriate and inappropriate values, beliefs, attitudes and behaviours. These rules may be explicit or implicit. Norms are often transmitted by non-verbal behaviour, for example with 'dirty looks' when people act outside the norms. They may also be transmitted through stories, rituals and role-model behaviour (Posner, 2000). There are different mechanisms by which norms are held in place. These mechanisms are held in place by shared expectations about the appropriate solution to a given problem. They may be sustained by the threat of social disapproval or punishment for norm violations (Coleman, 1990) for example among the Zulu people in South Africa which is area of this study, when someone is ill and bedridden; there is a norm of ukubona which literally means (going to see the sick person). If a community member is ill and

neighbours and friends do not go to “see” the ill person, those neighbours and friends’ gestures are met with disapproval while they will also not feel comfortable.

The final element is social networks which refers to the ties between individuals or groups (Cohen and Prusak, 2001). Under the social capital theory, social networks can be formal or informal. Whilst formal networks include those developed through formal organizations such as voluntary organizations and associations (Pollack, 2004), informal networks include friendships, family, neighbour and work related ties. Both formal and informal social networks have been useful in consolidating social support and material resources to help those infected and affected by HIV/AIDS.

Social support encompasses an extensive range of initiatives, including support of orphans and vulnerable children, counselling and spiritual and pastoral care, household assistance, nutrition support, and palliative/home-based care for the terminally ill by relatives, friends and neighbours or the civil society.

### **2.2.2 Levels of Social Capital**

The theory of social capital can further analysed under three levels. The levels are bonding, bridging and linking. These levels reflect the different types of social capital that they promote.

The first level which is social bonding refers to the strong ties that are shared amongst dense, inward looking social networks, such as among family members, close friends, church groups, or ethnic fraternal organizations (Warschauer, 2003:7-8). These bonds are typically inwardly-focused and serve as social protection mechanisms when a community member is facing a crisis. Bonds within the community encourage reciprocity and reinforces trust which important factors in social capital generation. The foregoing analysis demonstrates that bonding social capital can be essential for the diffusion of information, establishing health norms, controlling deviancy,

generating mutual care and support for the vulnerable especially those infected and affected by HIV/AIDS (Patulny, 2003).

The second level is bridging social capital that describes linkages that reach beyond the confines of the close community and intersect with other homogeneous groupings (Warschauer, 2003:7-8). Social bridging integrates the levels and nature of contact and engagement between different social groups or communities. It brings people in contact with resources and benefits that are accrued from having a wide and varied range of social contacts. It is even more useful in dislocated communities where there is limited existing trust and supporting networks amongst different groups, and these would need to be linked to networks of influence outside of their geographical location (Islam, Merlo, Kawachi, Lindstrom and Gerdtham, 2006). This level of social capital is crucial to the success of civil society (such as NGOs, CBOs and FBOs) because it provides opportunities for participation, increased networks for exchange, and channels to voice concern to those who may be locked out of more formal avenues to affect change (World Bank, 2003). These civic networks foster norms of reciprocity which reinforce sentiments of trust within a society. They also serve to improve the effectiveness of communication and social organization that is essential in the provision of care and support for those infected and affected by HIV/AIDS (Putnam, 1993). In addition, these links may help improve collective action for example providing care and support for orphans and vulnerable children and for those infected and affected by HIV/AIDS in the community (Pridmore, 2007).

The third level is linking social capital which describes connections with people in positions of power. It is characterized by relations between those within a hierarchy where there are differing levels of power and is vital for accessing support from formal institutions (Grootaert, 1998). It is different from bonding and bridging levels because it is concerned with relations between people who are not on an equal footing. For example, it is linking social capital when an NGO connects home based carers to the department of social welfare to obtain grants for those infected with HIV/AIDS in their communities (Ogden et al., 2004). Social linking is concerned

with vertical linkages that allow essential responses to health crises such as the provision of care and support for those infected and affected by HIV/AIDS.

### **2.3 Operationalisation of the Social Capital Theory**

Social capital is useful as a theory to understand the perceptions of volunteer community workers towards provision of care and support to those infected and affected by HIV/AIDS. This understanding is hinged on the elements and levels of social capital. The key elements that operationalise social capital in the current study include norms, reciprocity, trust and social networks which serve as mechanisms for mitigating effects of HIV/AIDS. These elements incorporate the strength of social ties, social trust and relationships within a community, the sense of collective responsibility and common outlook, which influence a community's willingness and ability to organize care and support for those infected and affected by HIV/AIDS in the community.

Social bonding is a very important level of social capital which facilitates transfer within the community, so that if one family faces a negative shock, their neighbors in the community will help support them (Carter and Maluccio, 2003). Bonding social capital is also assumed to improve information flow within the community, allowing community members to better monitor each other's wellbeing which improves the provision of care and support for those infected and affected by HIV/AIDS. Like bonding social capital, bridging social capital on one hand is assumed to improve information flow, but in this case, it improves information flow between communities. Bridging social capital on the other hand enables members to reach for outside sources of information, support and resources, without necessarily relying on stringent norms (Putnam, 2000; Narayan, 1999).

## **CHAPTER THREE**

### **LITERATURE REVIEW**

#### **3.1 Introduction**

This chapter presents a review of the literature on the perceptions of care and support around HIV/AIDS by volunteer community workers. The purpose of the chapter is to review the literature on how care and support is related to the concepts and theories of social capital. The review of the Literature is based on three main themes. The first one is social capital. Under this theme, the elements and levels of social capital are reviewed related to care and support. The second one is care and support both at the household and community level. The review contextualises Ubuntu as a backdrop to care and support under the social capital framework. Under the third, the review proceeds to analyse the concept of volunteerism and how it enhances the existing care and support under home base care for those infected and affected by HIV/AIDS. The bridging component of volunteerism which is civil society is also reviewed. The final review is the challenges of volunteerism in care and support for those infected and affected by HIV/AIDS.

#### **3.2 Social Capital and HIV/AIDS**

Social capital has been applied in various disciplines and more recently to understand the impact of HIV/AIDS (Pronyk, 2002; Perry, Williams, Wallerstein, and Waitzkin, 2008). Several authors have linked the HIV/AIDS pandemic to social capital usually pointing out how factors related to the disease such as stigma, discrimination and the costs posed by care for the sick as well as orphans erode and put pressure on social capital (Campbell, Williams and Gilgen, 2002; Foster, 2004). For example, Campbell et al. (2002) carried out an exploratory study investigating links between sexual health and social capital in a South African mining community. However, their study has highlighted that the interface between HIV infection and social capital is complex and defies easy generalization.

Whilst social capital brings potentially positive contributions towards care and support, the application may have some negative consequences. Portes (1998) identifies four possible negative consequences: firstly, the exclusion of outsiders, secondly, excessive claims on group members, thirdly, restrictions on freedoms of individuals, and lastly, downward levelling of norms. It is important to note however that the utility of the concept of social capital lies in its flexibility and its consequent capacity to explain the negative spill-overs of certain social relationships. In effect, not all social networks are equally useful in progressing the interests of individuals or, indeed, the group (Bond, 2002). One can conclude that HIV/AIDS is likely to have an impact on social capital through stigma and discrimination, the burden it poses on traditional social networks that mitigate risks and increased poverty.

### **3.2.1 Levels of Social Capital**

Social capital has also been located at three levels which have been distinguished as bonding, bridging or linking, reflecting the different types of social capital that they promote.

#### *Social Bonding*

Bonding social capital refers to the strong ties that are shared among dense, inward looking social networks, such as among family members, close friends, church groups, or ethnic fraternal organizations (Warschauer, 2003:7-8). At the family level, the strong ties that connect family members whether nuclear or extended neighbours, and close friends and colleagues also known as “bonding” social relations, which exist among people who share common characteristics. These relations are typically inwardly-focused and serve as social protection mechanisms when the family is facing a crisis. Bonding relationships act as the primary vehicles for the transmission of behavioural norms younger members of the community. The family’s ability to meet children’s physical and emotional needs strongly influences their perceptions of the trustworthiness of others outside the family. Family dynamics also encourage reciprocity and exchange, two other important factors in social capital generation. The material and emotional support shared freely between family members generates

an implicit willingness to return such support in reciprocity. Bonding social capital can be important for the diffusion of information, establishing health norms, controlling deviancy, generating mutual aid, and protecting the vulnerable (Patulny, 2003).

Bonding social capital at the community level refers to intra-community networks which link individuals together along horizontal lines that bring integration and cohesion through trust, reciprocal support and a positive identity. Its effects include facilitation of collective problem solving or collective identity (Lomas, 1998). Bonding social capital plays a dual role: it brings the strength of social solidarity, but sometimes at the cost of antagonism with, or distance from, other groups (Warschauer, 2003:7-8). Bonding social capital comprises tight-knit, homogeneous groups of people that provide important safety nets for one another in times of crisis. Such groups may also provide meaningful psychological support (Chavez, Kemp & Harris, 2004). Forms of bonding social capital may include close family, provincial religious groups and community groupings (Woolcock & Narayan, 2000).

### *Social Bridging*

Bridging social capital describes linkages that reach beyond the confines of the close community and intersect with other homogeneous groupings. They are ties that are formed with those from other social circles (Warschauer, 2003:7-8). It integrates the levels and nature of contact and engagement between different social groups or communities. By this, diverse groups with varying levels of access to material and symbolic power are linked. It brings people in contact with resources and benefits that are accrued from having a wide and varied range of social contacts. In dislocated communities, there is generally little evidence of existing trusting and supporting networks amongst different groups, and these would need to be actively facilitated (Islam et al., 2006). Small groups can also be linked to networks of influence outside of their geographical location.

This type of social capital is crucial to the success of civil society because it provides opportunities for participation, increased networks for exchange, and channels to voice concern to those who may be locked out of more formal avenues to affect change. Civil society in the context of this study refers to the range of informal and formal networks and organisations unrelated to government or private sector that play a role in HIV/AIDS management (Campbell, Nair, Maimane and Sibiyi, 2008). NGO responses have often been perceived to complement households and communities efforts to mitigate the impact HIV/AIDS. These civic networks, or linkages, foster norms of reciprocity which reinforce sentiments of trust within a society and also serve to improve the effectiveness of communication and social organization (Putnam, 1993). In terms of relevance to health, bridging social capital can be important to the diffusion of information, service delivery and implementation, the control of deviancy, and reinforcing extant health norms. In addition, these links may help improve collective action for example providing care and support for orphans and vulnerable children and for those infected and affected by HIV/AIDS in the community (Pridmore, 2007).

It has been argued that the cohesiveness of a society is actually dependent on the existence of 'bridging capital' (or 'cross-cutting ties') as it is these relatively infrequent, but very important ties that connect disparate groups and form the criss-crossing web of interrelations between groups which underpins society as a whole (Narayan, 1999). According to this argument, it is the relatively weak linkages that exist between tightly-knit groupings or clusters of individuals that prevent society from fragmenting; they allow for information and new ideas to spread across various subgroups and for collective action to emerge among them (Birdsall and Kelly, 2005). The same further state that NGOs have come together in coalitions to promote a more coherent response where directories of AIDS service organizations have been developed and information on funding for HIV/AIDS work has been concretised (Birdsall and Kelly, 2005).

A number of reasons have been advanced for the success of NGOs in terms of provision of care and support to those infected and affected by HIV/AIDS. Firstly, NGO's have different operational structures from governments and this puts them in a better position to respond quickly though on a smaller scale to care and support needs in a given community. Their response is largely enabled by their closeness to community members and understanding of power relations and influences at local level (Nel, Binns and Motteux, 2001; Liebowitz, 2002). Secondly, NGOs are in a better position than government to provide care and support to stigmatised groups as they can easily reach marginalized groups (DeJong, 2003). Most NGOs that operate in communities are preoccupied with providing education around behaviour change, care and support and treatment (DeJong, 2003; Birdsall and Kelly, 2005; Campbell et al., 2008).

#### *Social Linking*

Linking social capital describes connections with people in positions of power and is characterized by relations between those within a hierarchy where there are differing levels of power. Linking social capital is vital for accessing support from formal institutions (National Statistics online, 2008). It is different from bonding and bridging because it is concerned with relations between people who are not on an equal footing. Relations between government and communities are encompassed within linking social capital. The public sector (i.e., the state and its institutions) is central to the functioning and welfare of society and government laws and regulations dictate the amount of space available for civil society, and either allow it to become diverse and flourish or wither away. At the level of state capacity and function, and its relations with civil society, various aspects become relevant to health status (Winter, 2000).

The South African government supports home-based care for people living with Aids and HIV, partly because hospitals cannot cope with the number of people needing care and partly because this form of care where the terminally ill are looked after by their families is considered more appropriate in that it offers the sick a loving,

familiar environment (UNAIDS, 2000b). Despite government's commitment to starting an ARV treatment program, there have been a number of implementation challenges for example the slow pace at which drugs are made available (WHO, 2008). Perhaps one of the biggest challenges to the government in the provision of care and support to people infected and affected by HIV/AIDS is the lack of a definite policy with respect to the provision of care and support to persons infected and affected by HIV/AIDS (Swidler, 2006). The government's policy comprises the use of traditional remedies as well as ARVs and this breeds uncertainty. Such uncertainty has hindered the provision of care and support to persons infected and affected by HIV/AIDS as those involved in the provision of care and support are not sure as to which of the two approaches is effective. Critics of South Africa's department of Health lay the blame on the fact that South Africa also delayed the rollout of antiretroviral drugs for HIV positive adults, despite having one of the highest number HIV positive people in the world (Swidler, 2006).

In addition, government response to HIV/AIDS in South Africa has been affected by structural barriers to establishing an effective HIV/AIDS response (SACN, 2003). Most responses to the legacy of apartheid's unequal distribution of services led to many government structures undergoing amalgamation and restructuring hence the need for capacity. Delays in appointments, key posts remaining vacant, and insufficiently capacitated staff being tasked with a great workload have not only led to inefficiency, but also poor government response to care and support for those infected and affected by HIV/AIDS. The second is the lack of strategic planning around the impact of HIV/AIDS and its long-term consequences, both for communities and local authorities. This, coupled with financial and technical constraints, has severely hampered the ability of municipalities and government to adopt a proactive approach to the epidemic

### **3.2.2 Elements of Social Capital**

Different studies on social capital have described various elements of social capital (Putnam, Leonardi et al., 1993). This study uses the core elements of social capital as

described by Putnam which include social norms, trust, social networks and reciprocity. These elements are discussed in the section below.

### *Social Norms*

Norms are defined as a set of behavioural models and rules that are assimilated within a society. Social norms consist of rules of conduct and models of behaviour prescribed by a society. They are rooted in the customs, traditions and value systems that gradually develop in this society (Elster, 1989). Norms have been described as standards of behaviour set from within the community itself (Putnam, Leonardi et al., 1993). The community may levy sanctions on those who do not behave according to the prescribed standards. In addition, social norms are shared understandings, informal rules and conventions that prescribe, proscribe and modulate certain behaviours in various circumstances (Productivity Commission, 2003).

Social norms generally include principles such as, honesty, law abidingness, the work ethic, respect for elders, tolerance and acceptance of diversity, and helping people in need (Productivity Commission, 2003). Norms are often unwritten but can be expressed or reinforced through tribal or religious beliefs and folktales, social sayings, music dance and drama. Lenaka (1995); Harpham, Grant and Thomas (2002) assert that, social norms can also be embodied in laws and regulations. According to Bowles and Gintis (2000), compliance with social norms may be encouraged through internal psychological sanctions, such as guilt, or external sanctions such as shame and ostracism.

In terms of HIV/AIDS in South Africa, social norms determine the level of participation in voluntary support and care giving. Voluntary care giving is left mainly to the females because, cultural belief that it is the duty of women to take care of the sick. The few male volunteer care givers are regarded by their peers as deviants doing unmanly duties (Akintola, 2006). Such perceptions influenced by social norms have inevitably undermined the magnitude of care and support due to the disproportionate number of volunteers providing care and support for people infected and affected by HIV/AIDS who are in dire need of such care and support.

### *Reciprocity*

In social psychology, reciprocity refers to responding to a positive action with another positive action, and responding to a negative action with another negative one (Fehr and Simon, 2000). Reciprocal actions are important to social psychology as they can help explain the maintenance of social norms.

Reciprocity may be specific or generalized: that is, whether the favourable act will be reciprocated, when, by and to whom. This may or may not be known before the person commits to doing that act. According to Kawachi and Berkman (2000) direct exchange of favours can be seen as a form of transaction that requires no more motivation than narrow self-interest. Taylor (1982) explains that each individual acting in a system of reciprocity is usually characterised by a combination of short-term selflessness and long-term self-interest: One provides help with the hope of being helped in the future, but reciprocity also exists in the general context among communities, groups and societies.

Different societies have different social norms of reciprocity. Some of the norms of reciprocity prevalent in western societies differ distinctly from those in developing countries (Lenaka, 1995). In most African countries, norms regulate the process of social capital, for example, those who do not contribute for funeral expenses may not get any contribution in terms of money and labour when they lose a member of their household to HIV/AIDS or any other causes. Mutangadura, G., Mukurazita, D., & Jackson, (1999) assert that for individuals infected and affected by HIV/AIDS, norms have been used as coping mechanisms to cushion the difficulties associated with this scourge through assistance from other households' members. In a study done by Mutangadura, et.al (1999) assert that 80% to 90% of bereaved households were likely to receive assistance in cash or kind from members of other households.

Putnam (1993) argues that while some social norms operate at the broad societal level, different groups within a particular society can also have their own. For example, in sub-saharan Africa, it has been reported by UNAIDS (1999) that members of such groups support each other in everyday life activities such as helping

with the provision of food to the sick and money which might be used to buy medicines and to cover transport costs to the healthcare facilities. Another example is that contributions may also help to cater for funeral expenses in case of death of a PLWA (Mutangadura et al., 1999). In certain communities, social support groups are formed for specific activities, for example, burial societies, grain-saving schemes and labour-sharing schemes (UNAIDS 1999). All the above examples indicate how reciprocity applies to care and support in cases of sickness and death from HIV/AIDS.

### *Trust*

Trust refers to the level of confidence that others will act as they say or are expected to act, or that what they say is reliable (Putnam, 1993). Trust is essentially a psychological state. In common understanding, to trust someone else is a voluntary action based on expectations of how others will behave in relation to oneself in the future. These expectations may be disappointed and if so, will generate negative outcomes (Brockner & Siegel, 1996; Luhmann, 2000). Trust, therefore, involves an element of risk derived from one individual's uncertainty regarding the motives, intentions and future actions of another on whom they depend (Coulson, 1998; Lewicki & Bunker, 1996; Kramer, 1999). The types of expected behaviours that generally underlie trust include technical competence, openness, concern, and reliability (Coulson, 1998).

Generally, people may trust others because trust is a strategic behaviour rooted in risk and expectations about how another person will behave. Strategic trust can vary between a state of complete trust and complete distrust, depending on the level of uncertainty calculated to surround the relationship (Gambetta, 2000). In this form, to trust means “that you are prepared to make yourself vulnerable, to run a risk that the other partner will exploit you, and to build up credit by doing more than the minimum necessary in the hope that, if you have problems yourself, your partner will help you in return” (Coulson, 1998, p. 4). The value of trust is, therefore, largely instrumental in relation to care and support for those infected and affected by HIV/AIDS. This is

largely because people can only go for VCT to institutions and people they trust, after which they can only disclose their status to those they trust and in terms of care and support, those infected and affected by HIV/AIDS can only let only those volunteers and neighbors they trust to take care of them.

Trust is a moralistic or altruistic behaviour rooted in expectations about how people should behave (Mansbridge, 1999; Ulsaner, 2001). Based on a belief in the goodwill of others, in this form of trust one trusts the other more than is warranted, as a gift, for the good of both the other and the community (Mansbridge, 1999). The value of this form of trust is, moreover, both intrinsic and instrumental as altruistic trust expresses respect for others, catalyses cooperation, enhances volunteerism and creates even more altruistic trust through modelling behaviour to others (Mansbridge, 1999). For example, when volunteers carry out care and support work in the communities on sheer altruistic grounds, it is a gift to the community and their behaviour sets an example for other community members to follow. This form of trust strengthens social bonding. Although people can 'invest' trust in others, a person's level of trust in another depends largely on the person's perception of the other's trustworthiness. In the case of volunteer community workers, they have to prove that they will not exacerbate stigma in order to earn the trust of the community members (Gilson, 2003).

Fukuyama (1995) confirms the above argument of trust at the community level by defining trust as the expectation that arises within a community of regular, honest and cooperative behaviour, based on commonly shared norms, on the part of other members of the community. Levels of trust are likely to vary both between different groups within a society, as well as between different societies (Putnam 2001). While trust based on personal experience and ongoing relationships may be more robust than trust based on community norms, Putnam (2001) argues that trust based on community norms is more valuable as it extends the radius of trust to a wider circle of people. His argument allows a much larger range of networks with their associated benefits to all people most especially those living with HIV/AIDS.

Stigma and discrimination are largely attributable to fear, therefore they undermine trust. Fear is exacerbated by the fright of contagion (Campbell et al, 2002). Fear of the possibility of contagion is so strong that people do not want to get close to the infected person. So they place this fear on those who remind them of the HIV/AIDS pandemic. The hatred that a person feels for the disease becomes a hatred for the person who has the disease. People infected with HIV/AIDS usually decline to disclose information concerning their HIV status because of the stigma associated with HIV/AIDS. Those that are infected with HIV/AIDS are considered prostitutes (Chesney and Smith, 1999). Therefore, not only are they reluctant to disclose their HIV-status to the volunteers, but also they are not willing to go for voluntary HIV-testing and counselling for fear that those to whom they will give information concerning their status will disclose it to the community. This makes the work of the volunteers difficult. Such stigma can largely be attributed to wide spread lack of awareness about HIV/AIDS.

### *Networks*

A network is an interconnected group of people who usually have an attribute in common (Productivity Commission, 2003). An individual may be a part of separate networks of relationships based on his or her neighbourhood and could also be apart of several networks simultaneously. Being part of a network provides individuals with benefits such as a greater pool of social support when needed, access to information and a wider range of opportunities (Gitell & Vidal, 1998; Jamil & Muriisa, 2004).

Networks arise from recreational preferences, vocation, gender, sero status, politics, religion, race or national grouping (Harpham et al., 2002). Each of these groupings may come with different norms and levels of mutual obligation or expectation, and may generate different levels of 'generalized trust' towards others within or outside the grouping (Putnam, 1993).

Networks may play an important role in the provision of other aspects of social capital. The emphasis on social norms, networks and participation in the social capital approach makes its use even more appropriate (Putnam, 1993). The concepts in the social capital framework such as trust, shared values and norms, social cohesion and participation in civic groups and networks, reciprocal support and positive identity (Bourdieu, 1985; Coleman, 1990; Putnam, 1993) help to improve lives of those living with HIV/AIDS in African communities. To illustrate this, Foster (2004), following a study done in Zimbabwe, concludes that social insurance for most people is provided through kinship ties (networks) that enable household members to access economic, social, psychological and emotional support from their relatives in times of need. Community members, including neighbours, friends and community voluntary associations, contribute to household support systems.

Voluntary associations influence social interaction and co-operation between actors in several ways (Putnam, 1993). Firstly, associations increase the potential costs to a defector in any individual transaction. Secondly, associations foster robust norms of reciprocity. Thirdly, associations facilitate communication and improve the free flow of information about the trustworthiness of individuals which allows reputations to be transmitted and refined. Finally, associations embody past success at collaboration, which can serve as a culturally defined template for future collaboration. Studies indicate a changing face of social networks. It has been said that women living alone, particularly widows, consciously develop supportive social networks to offset isolation (Gitell & Vidal, 1998). While the initial period following the death of a partner can be difficult, older women may forge a positive new phase, characterized by entrenched social networks.

Foster (2004) asserts that governments have been slow to respond to the orphan crisis in sub-Saharan Africa that is intimately linked to the epidemic causing families and communities to take up most of the care and support costs. This strain on social networks could lead to adverse impact on social capital or even to the disintegration

of the existing mechanism to address care and support needs of those infected and affected by HIV/AIDS.

### **3.3 Care and Support**

#### **3.3.1 Care and Support in Households Affected by HIV/AIDS**

According to a UNAIDS report, a household is a group of persons who live in the same dwelling and eat meals together (UNAIDS, 1999). Throughout history the family, or in economic parlance the household, has formed the crucial social and economic unit on which most human societies have been based (Poortinga, 2006). The extended family safety net has been the most effective community response to the AIDS crisis (Mukoyogo and Williams, 1991). Relatives and friends may provide both moral and material support to the sick on the assumption of future reciprocation and sometimes out of sheer lack of alternative. Preparation of food, work on land or overseeing livestock will be done by another family member or neighbour in addition to their own tasks (UNAIDS, 1999).

HIV/AIDS affects families in a number of ways, from additional financial strain and increased care demands and to bereavement and orphan-hood. Care and support activities extend well beyond the needs of the HIV-positive person and often include complex dynamics involving the larger family. Family members sometimes demonstrate negative attitudes, refuse to provide care and support to a family member with AIDS, or refuse to disclose a family member's status despite the clear need for care and support. In some instances food parcels distributed to AIDS patients are exchanged for liquor or other goods, rather than consumed (Barnett & Whiteside, 2006). It is important to note that AIDS affects the entire family unit, not only the person who is HIV-positive, and that it can be very difficult for the volunteers to provide care and support to a household affected by HIV/AIDS.

Household carers face many challenges when taking care of patients in the home. The first major challenge is lack of training (Akintola, 2004). Household carers lack

information about the disease they are managing or what to expect over time. In some instances, many do not know that the loved one in their care has AIDS. The second challenge is the lack of facilities like gloves or medication. This exposes the household carers to infection and insufficient provision of services (Orner, 2006). The third one is HIV/AIDS related stigma. The household carers may be closed off at the time they need it most (Ogden, Esim and Grown, 2006). When the carer starts to feel that his patient has been neglected, she/he may experience frustration and burn-out (Akintola, 2004; Ogden et al., 2004). The fourth challenge is the crumbling traditional safety nets mainly because of dynamism inherent in household structures especially in areas highly affected by HIV/AIDS. These safety nets are affected by the new trend of nuclear families which tend to concentrate on their affairs ignoring the affairs of the extended family.

Care is even more compounded by HIV/AIDS which is a long illness and patients require more attention such that productive time is spent looking after them and sometimes household items are sold to generate income which in turn leads to impoverishment (Ogden et al., 2006). This goes to show that over time the ability of families and social networks to absorb these care and support demands will decrease as more adults die young as a result of HIV/AIDS (Ogden et al., 2006).

### **3.3.2 Care and Support at a Community Level**

Care and support at the community-level is an immediate, direct, and flexible response to the existing care and support needs in the community. These responses emerge from local conditions, are driven by community members, are responsive to local needs, reflect local forms of organising and acting, and draw upon available resources (Gitell & Vidal, 1998; Campbell et al, 2008). According to Foster (2004), spontaneous and informal actions that are undertaken to care and support those infected with HIV/AIDS and orphans and vulnerable children are some of the community responses to HIV/AIDS. He notes that community initiatives are usually started by small groups of motivated individuals who are driven by a sense of obligation to care and support those infected and affected by HIV/AIDS where there

is limited or non-existent government services. Foster (2004), further notes that these initiatives generally share the same fundamental principles of social cohesion, namely; reciprocity and community solidarity fueled by social trust; consensus-based decision-making, self-reliance through local mobilization of resources, local leadership; volunteerism (altruism emanating from sense of community ownership); innovation and problem-solving; and association with faith-based organisations.

However, community initiatives for improving care and support should not be seen as an alternative to the government provided service delivery. Community initiatives of care and support work well when complemented by government support (OSAA, 2003). It also important to note though community initiatives are important pillars in care and support for those infected and affected with HIV/AIDS, there are constraints associated with them. These may include resource constraints, operational inefficiencies, limited outreach (both in terms of geography and number of beneficiaries), inadequate consultation and engagement with community members, competition with other groups over resources, and dependency on external funding for sustainability (Jamil & Muriisa, 2004). Birdsall and Kelly (2005), note however, that the most successful and sustainable initiatives are those that had established partnerships and referral relationships with other local programmes, and that operated in communities with high levels of social cohesion.

### **3.3.3 Contextualizing Ubuntu as a Backdrop for Care and Support within the Social Capital Framework**

Ubuntu (a Zulu word) serves as the spiritual foundation of African societies. It is a unifying vision or world view enshrined in the Zulu maxim *umuntu ngumuntu ngabantu*, literally meaning “a person is a person through other persons” (Shutte, 1993). *Ubuntu* describes a human being as being-with-others and prescribes what being-with-others should be all about. In effect, the values articulated in *Ubuntu* are coherent with the elements of social capital, which makes this evaluation of social capital nothing but an endorsement of the African *Ubuntu*.

Ubuntu is also described as the principle of caring for each other's well-being and a spirit of mutual support each individual's humanity is ideally expressed through his or her relationship with others and theirs in turn through recognition of the individual's humanity (Shutte, 1993; Masina, 2000). Ubuntu also acknowledges both the rights and the responsibilities of every citizen in promoting individual and societal well-being.

The Ubuntu notion suggests that our own well-being will be harmed when our neighbours, friends and people in the broader society are not enjoying well-being. This echoes the spirit of social capital in a way that the existence of high levels of social capital contributes to a better chance of harmonious living which has a good implication for care and support when it is needed (Khoza, 1994). Social capital is based on trust and shared values that enable exchange of goods and services in a reciprocal relationship. It encourages individuals, groups and communities to access the existing networks to be able to manage better challenging situations (Mbigi, 1995).

### **3.4 Home Based Care**

Home Based Care (HBC) can be defined as the provision of basic nursing care needs by formal or informal caregivers to people in their own homes (Elsevier, 2009; Uys, 2002). This service is provided to people who have mental, physical, emotional and social needs including those living with HIV/AIDS. The care given is meant to restore and maintain the individual's maximum level of comfort, function and health, including care towards a dignified death (Homan et al., 2005).

HBC services in the South Africa are provided by non-profit organisations (NPOs) which are tendered for and subsidized by the provincial governments. Patients who need ongoing care at home upon discharge from hospital are referred to a health facility at primary health care level in the area in which they live who also refer them to a to the NPO partner responsible for HBC services in the area (Akintola, 2004).

The NPO co-coordinator assesses the needs of the individual in their home and develops a care plan for them. The sister then assigns a caregiver to the individual.

Caregivers from the various organisations have to complete a home-based care course facilitated by the Department of Health. Continuous, in-service training is provided by the Department to ensure competence. Home based carers are expected to help patients and their family members to live and cope independently (Ogden, et al., 2004). Volunteers are also recruited to complement the services given by Home based care workers. They make themselves available as companions, fetch medication, and do shopping errands.

HBC is not a 24-hour service and does not replace the family as the primary caregiver. It is only meant to be a complementary and supportive service to prevent "burn-out" for caregivers who are forced to care for sick relatives (Akintola, 2004).

Home and community-based care for people living with HIV/AIDS therefore remains integral to the global AIDS response (Ogden et al., 2004). The Community in this case refers to informal support groups of relatives, neighbours, church members, and friends who improvise to provide care and support for those infected and affected by HIV/AIDS (Birdsall and Kelly, 2005). The Care they provide ranges from positive healing sentiment to love. These are usually acts through which people demonstrate care and love.

Home-based care programmes for people living with HIV/AIDS or integrated with other health needs are rapidly expanding in sub-Saharan Africa as a response to HIV/AIDS (Berman, 2002). This is because of the inability of hospitals and other formal health institutions to cope with the increased demand at the same time as their real budgets are in decline because of economic structural adjustment measures. At its worst, home care equates to home neglect, but at its best, it helps patients live through their illness and die in some dignity and comfort in familiar surroundings with their family around them (Drimie & Gandure, 2005).

Home based care may not necessarily be the definitive answer to care for the HIV/AIDS patients or any other chronic illnesses. This is mainly because of limited resources, and lack of training which is also compounded by the burden that comes with care giving and the fear of infection. Hence most of the patients are left unattended to and are provided inadequate health services. Moreover, in the areas where the home based care workers operate, their number is not proportionate to the ever increasing demands of the patient care and support needs though their efforts are supplemented by the input of the family caregivers and community volunteers (WHO, 2002; Uys, 2003).

### **3.5 Volunteerism**

Volunteerism is the willingness of people to work on behalf of others without the expectation of pay or other tangible gain. A volunteer is defined as someone who gives time, effort and talent to a need or cause without profiting monetarily. The White paper for social welfare in South Africa (1997:98) defines a volunteer as “a professional or non-professional person who provides a service to welfare of development organization usually without re-imburement”. The face of volunteers differs from context to context. Volunteers in the western world differ from those in sub-Saharan context which is endemic with HIV/AIDS. Moreover, material and psychological demands placed on volunteers in the in the context of the HIV/AIDS epidemic is different from what may be required under normal, or pre-epidemic, circumstances (Mutangadura, Mukurazita and Jackson, 1999; Uys, 2002).

Volunteers are recruited from the communities and trained in basic nursing care. They visit homes of sick people to offer basic nursing services, counselling, health education, nutrition monitoring and also psychosocial support (Uys, 2002). Basic nursing activities carried out include the cleaning of wounds, treating pressure sores, mouth care, turning the patient, assisting with toileting, and assistance with visiting health facilities and the procurement of medication from the health facilities. They also teach the families basic skills on how to grow farm vegetable gardens for

subsistence. Volunteers also train family members to become the primary caregivers (Akintola, 2004).

In addition, volunteers also provide moral and spiritual support to the sick. They also provide directly observed treatment (DOTS) for those who are on TB medication. The volunteers do not prescribe or administer any drugs, but refer serious cases to the health facilities. Many of these home care programmes have had to include the care of patients with other chronic diseases in the programmes in order to avoid being stigmatized by community members (Fox, Fawcett, Kelly and Ntlabati, 2002; Akintola, 2004; Ogden et al., 2004).

There are two types of volunteering: managed and unmanaged. Managed volunteering takes place through organisations in the non-profit public and private sectors and tends to be more organized (Dingle, 2001). An example of this is home based care programmes. Unmanaged volunteerism on the other hand, is unstructured and unsystematic where helping takes place between friends, relatives and neighbours. An example may include a neighbour taking care of an elderly woman next door.

According to Dingle (2001) volunteerism provides two important benefits in home based care. The first one is that it helps to create a stable and cohesive society by bringing people together to act for the good of the community; voluntary action creates bonds of trust and encourages cooperation and in that sense enhances social capital. It also empowers individuals without substantive contribution to get involved in care and support for the affected household. For example unemployed people who undertake to do household chores for those infected and affected by HIV/AIDS.

The second is that it adds value to the services that governments provide. Many tasks that volunteers undertake voluntarily such as caring for the sick are valuable supplements to the services that governments offer. For example, home based carers offer complementary services in the care and support of the HIV/AIDS patients

especially when hospitals and other health care institutions cannot cope with the increasing number of patients either because of limited personnel, funds or infrastructure (Fox et al., 2002).

In addition, voluntary organizations are a guarantee for social welfare especially in the care and support of those infected and affected by HIV/AIDS, the elderly, orphans and vulnerable children and the disabled in the communities (Carter and Maluccio, 2003). In essence, the volunteer is not simply a one-way act with one giver and one receiver, but has multiple benefits for those people involved and for society at large. Voluntary organizations emerge from the desire of people to demonstrate their concerns for the well-being of others by taking action. As individuals, they may become involved within their community, or with groups whose goals, hopes or values they share. Indeed volunteer contributions are central to communities because they provide assistance to the needy.

Volunteering provides crucial learning opportunities and leadership development for those who volunteer. It is a means by which marginalised people such as those who are HIV/AIDS positive, the elderly, orphans and vulnerable children can assert their own value and power. The act of volunteering itself is a form of civic participation that creates a learning ground for a wider range of civic engagements. This is important to care and support for those infected and affected by HIV/AIDS as it provides a forum through which those infected and affected by HIV/AIDS can assert their needs.

Volunteering is a partnership that involves an exchange for mutual benefit, and it demands respect for all the parties involved. Through volunteering people give expression to their shared humanity and sense of community (Carter and Maluccio, 2003). For example in Pietermaritzburg, the City-Wide Home-Based Care Network mobilises caregivers who provide unquantifiable support to the many people infected or affected by HIV/AIDS and in the surrounding areas and organisation called the

Valley of a Thousand Hills in Kwazulu-Natal that works with about two hundred voluntary home-base carers.

Finally, volunteering offers the chance for young people to learn vital, job-related and organisational skills which can then open up formal education or job opportunities. It also offers the chance to take ownership of community problems and responsibilities and become active citizens (Foster, 2002). Such community responsibilities may include provision of care and support to those infected and affected by HIV/AIDS. The literature on Volunteerism highlighted important issues of utilizing volunteerism in care and support for people infected and affected by HIV/AIDS. Whilst volunteerism is lauded for creating a stable, cohesive society and adding value to the services that governments provide, it is riddled with challenges (Campbell, Nair, Maimane and Sibiyi, 2007).

### **3.5.1 Challenges to Volunteering in Care and Support around HIV/AIDS**

The challenges that volunteers face include the secrecy that many families maintain about the status of the family member they are caring for, which leads to their alienation from potential care and support from volunteer community workers (Campbell et al., 2008)

At the emotional level, patients and volunteer community workers feel isolated in a community where stigma makes people reluctant to disclose their HIV status, often even to their carers. This means that both patients and carers often battle on with no emotional support. Fear of disclosure also limits peoples' access to what little care or support might be available (Campbell et al., 2007). Most PWA do not want their families to know that they are HIV positive. For fear that their family members will be afraid to look after them (Uys, 2003). This undermines home-based care and support from the families of those infected with HIV/AIDS.

Few volunteer health workers have basic literacy, some volunteer community workers don't have any kind of HIV/AIDS knowledge or training, and they work

without any kind of payment or even stipend to cover their expenses. Their work involves walking long distances on foot, often up steep hills, and often in conditions of searing heat, to households which might be several kilometres apart (Campbell et al., 2007).

Studies indicate that due to the increased interest in caring for patients in their homes, the community health workers who are salaried government workers are beginning to look at volunteers as potential healthcare workers who are poised to take their jobs and are therefore not cooperating with them (Campbell et al., 2007; Campbell et al., 2008; Uys, 2003). Unfortunately, this competition affects the performance of either of the providers leaving the patients' needs of care and support unmet. Volunteer caregivers are subjected to constant worry about the pain and suffering of their patients which causes them to have sleepless nights and nightmares. Their inability to provide a cure for their illness causes them guilty feelings, which is exacerbated by the eventual death of the patient (Campbell and Foulis, 2004; Akintola, 2006). The effect of this has been to discourage reciprocity by volunteers. This explains why there is apathy among the community members towards volunteering to give care and support to people infected and affected by HIV/AIDS. There is a high and unmet demand for caregivers and a need for more staff and volunteers (Birdsall and Kelly, 2005).

Fear and distress about the state of patients also confronts the volunteers caring for the terminally ill patients, bathing them, cleaning their sores and changing their nappies produces intense emotional distress because it highlights the deteriorating state and imminent demise of the patient. Patients may cry and express pain and agony when being bathed which results in constant emotional trauma to the volunteers (Akintola, 2006; Bachmann & Booyesen, 2004).

### **3.6 Conclusion**

Whilst social capital impacts positively on care and support through its core elements of social norms, trust, social networks and reciprocity, it is not devoid of negative consequences which include the exclusion of outsiders, restrictions on freedom of individuals and downward levelling of norms. Community-level responses are seen as immediate, direct, and flexible; they emerge from local conditions, are driven by community members, are responsive to local needs, reflect local forms of organising and acting, and draw upon available resources. Community efforts fill the gaps in care and support but are operating with limited resources and little external support. Key challenges include recruiting and managing volunteers and accessing resources. However, the most successful and sustainable initiatives were those that had established partnerships and referral relationships with other local programmes, and that operated in communities with high levels of social cohesion. The Ubuntu notion is consistent with the values and ideas promoted by the social capital elements. It is based on trust, encourages reciprocity and supports social norms all of which promote care and support. Volunteers are at the forefront of the provision of informal care and support to households affected by HIV/AIDS. Their activities include visiting homes of sick people to offer basic nursing services, counseling, health education, nutrition monitoring and also psychosocial support. However notwithstanding the enormous contribution of volunteers to the provision of care and support, they face a lot of challenges ranging from lack of facilitation to discrimination.

## **CHAPTER FOUR**

### **RESEARCH METHODS**

#### **4.1 Introduction**

The purpose of this chapter is to present the methodology used in this study. The presentation in this chapter is done in eight sections: study design, study area, study sample, Data collection procedures (semi structured interviews and focus group discussions) data analysis, the role of a translator, ethical considerations and validity and reliability.

#### **4.2 Study Design**

In this study, the topic greatly influenced the choice of a qualitative approach. The research focus for this study was on perceptions of volunteer community workers on care and support around HIV/AIDS. Further, qualitative research helps to gain insights, perceptions and understanding of phenomena of this nature since it requires drawing out participants' experiences and stories. In qualitative research, the data generated consists mostly of descriptions of what is being done, how it is done, the implications this has on the community and how the community responds to the relevant actions. These could not be adequately captured by statistical procedures of quantitative research methods but is more compatible with qualitative methods which are designed to capture the complexity of human experiences as perceived and described by of the actors in their own (Creswell, 1998).

In-depth interviews and focus group discussions were employed as the method of data collection. An interview guide to facilitate this process was developed (See appendix). The key informants for this study were purposefully selected based on their unique characteristics as active voluntary community workers. In-depth interviews were conducted with the participants followed by a focus groups interview to verify data obtained. The participants were selected based on their recognition as volunteer community workers and the willingness to be interviewed. The most experienced 13 participants were selected from the 40 volunteer community workers

in Kwangcolosi, Kwazulu Natal. The one on one interview with each of the 13 selected Volunteer community workers took 3 weeks plus another week of focus group discussions.

### **4.3 Study Area**

Kwangcolosi is a peri-urban area of Kwazulu-Natal. Ngcolosi is a tribal area in the Valley of a Thousand Hills. The people have been displaced due to the building of a dam. The area is characterized by high unemployment and poverty. The area has poor infrastructure, high unemployment and lacks educational resources. The majority of the community lives in huts, some with access to electricity and water. The community in Kwangcolosi, Kwazulu-Natal, is greatly affected by HIV/AIDS, TB and associated illnesses. Many children have been orphaned and are living with extended family who are willing to care for them but unable to provide financially due to unemployment and sickness.

### **4.4 Study Sample**

The main research participants for this study were purposefully selected based on their unique characteristics as active voluntary community workers. A group of 13 community health workers and were selected out of the 40 active volunteer community members. The study focused on perceptions of care and support around HIV/AIDS by volunteer community workers of Uthando Lo Mama, a local NPO that comprises all the volunteer community workers at Kwangcolosi, Kwazulu Natal. “Uthando Lo Mama” which means “The Love of a mother” started in 2002 by Ms. Thandi Langa with other women because there were sick people in the community who needed care and support that was not easily provided by family members. When the idea of Uthando Lo Mama was conceived, Ms Langa wanted to involve older women who were willing to volunteer and unemployed youth like those who had finished matric and were doing nothing. In order to do this work successfully, the volunteer community workers were trained in daily care and counseling in Durban by a family health trainer who is responsible for home based care at the district in workshops. Though still challenged by lack of resources, Uthando Lo Mama is now

registered as a Non Profit Organization and it's now comprised of about 40 members though only 21 receive a monthly stipend of R500 each.

#### **4.5 Data Collection Procedures**

All the interviews were conducted privately at a small volunteer office in Kwangcolosi. Interviews were recorded with the permission of those interviewed and notes were taken in case of recording problems. The duration of interviews ranged from 50 minutes to one hour and 20 minutes. Interview highlights in Chapter Five are chosen according to the content of the quote and its relevance to the research questions. When quoted, edits are shown using '...' General impressions of the interview process were that the majority of respondents had a well-informed and holistic understanding of the needs of care and support around HIV/AIDS affected and infected community members. Secondly, there was a high level of agreement concerning what happens in the community around care and support for those infected by HIV/AIDS and how current efforts can be strengthened amongst the comments and opinions of respondents.

Open-ended questions were asked so the respondents used their own words, followed their own thoughts, and arrived at their own conclusions (Posavac and Carey, 1989; Patton, 2001). These questions required the interpretations, opinions, and feelings of the respondents. Such interpretative questions are thought to be relatively easy to answer because they follow the respondents' own descriptions of the activities or issues in question (Patton, 1987). If necessary, the topic of each question was explained briefly to ensure that the respondents understood the questions. Care was taken to avoid divulging the opinions of either the interviewer or the translator.

##### **4.5.1 Semi-Structured Interviews**

Qualitative data was derived from 13 individual interviews with volunteer community Workers in Kwangcolosi, Kwazulu Natal. A semi-structured interview was designed where predetermined questions were consistently and systematically asked to all

interviewees and other areas of interest were followed up with probes as they became apparently important (Berg, 1989).

The semi-structured interview method was an effective way of discussing issues around the main research questions whilst allowing the opportunity of exploring related issues or individual cases. All the questions relied on personal opinions, perceptions and experiences of the volunteer community workers hence needed probing to develop a more complete narrative (Berg, 1989) and this could only have been done through this method of interviewing. Probing also meant that any confusion that may have arisen between the interviewer, translator and respondent could be addressed.

Interviews focused on volunteer community Workers in Kwangcolosi, because these people have been working with the community of Kwangcolosi for the past five years around care and support and have an in depth and broad understanding of the needs and the care available to HIV/AIDS affected and infected community members.

All the interviews were conducted privately at a small volunteer office in Kwangcolosi. Interviews were recorded with the permission of those interviewed and notes were taken in case of recording problems. The duration of interviews ranged from 50 minutes to one hour and 20 minutes. Observations about each interview (such as emotional responses and attitudes) were recorded during the interview.

#### **4.5.2 Focus Group Discussions**

Focus groups are a form of group interview that capitalises on communication between research participants using group interaction as part of the method to generate data. In the present study, the focus group discussions were done immediately after one on one interviews. Two Focus group discussions were conducted privately at Uthando Lo Mama office in Kwangcolosi. One focus group comprised of seven members while the other comprised of six. The focus groups discussions were recorded with the permission of participants and notes were taken to

back up the recording. The duration of interviews ranged from 50 minutes to one hour and 20 minutes. The participants who took part in the one on one interviews were the only ones who participated in the focus group discussions. The idea behind the focus group method was that group processes could help people to explore and clarify the views that were expressed in a one on one interview. The focus group discussion helped participants to explore the issues of importance to them, in their own vocabulary, generating their own questions and pursuing their own priorities. The method was useful for exploring participants' perceptions on care and support around HIV/AIDS. I also engaged in conversations with the focus group discussion participants before the focus group discussions began which also helped me to tap into the many different forms of communication that people use in day to day interaction, including jokes, anecdotes, teasing, and arguing. Gaining access to such variety of communication was useful because the participants' knowledge and attitudes are not entirely encapsulated in reasoned responses to direct questions.

#### **4.5.3 The Role of a Translator**

Translators enable the cross-cultural communication which is necessary in research by converting one language into another. The translator accompanied me on all occasions and was very useful especially for the occasions when interviewees could not, or preferred not to speak English. I asked questions through the interpreter, who would then interpret the response from the participant to me. This method was adopted because it enabled me to follow the entire interview and to ask further questions, as required. The interpreter carried out most of the interview with the aim of improving the flow of interviews and making the interviews less burdensome. This allowed for the interviews to flow like a guided conversation with a purpose rather than a structured question and answer situation. The interviews were semi- structured and the interpreter had quickly become familiar with the aims of the interview guide. With the participants' permission, all of the interviews were audio-taped and transcribed so that the full interview transcript was available to me in the end. I preferred someone who relatively understands my area of inquiry in order to accurately convert information from Isizulu, to English. Being Zulu speaking herself,

I trusted that she would be sensitive to the Zulu culture, associated with the participants. The translator was fluent in both Isizulu and English.

I also understood that translating involves more than replacing a word with its equivalent in another language hence my choice of this particular translator. The translator was also mindful of various cultural references that needed to be explained to me such as colloquialisms, slang, and other expressions that do not translate literally.

#### **4.6 Data Analysis**

The primary objective for data collection was to represent the subjective views of volunteer community workers who shared their experiences and perceptions of care and support for those infected and affected by HIV/AIDS in KwaNgqolosi, Kwazulu Natal in interviews and focus group discussions. Data was analysed based on the theory driven thematic analysis; specifically exploring themes according social capital framework elements which include trust, reciprocity, norms and social networks under the levels (bonding and bridging leaving out linking). Transcripts were read and re-read so that I could familiarize myself with the content. Data was then classified according to emerging themes and patterns whilst keeping within the framework of social capital which helped make the data manageable.

The theory led thematic analysis interprets various aspects of the research data to match the already constituted theoretical categories (Boyatzis, 1998; Hayes, 1997). Under the theory led thematic analysis, it is important that the theoretical framework and methods match what the researcher wants to know, and that they acknowledge these decisions, and recognize them as decisions (Braun and Clarke, 2006).

During coding, many important questions came especially ‘what counted as a theme and what ‘size’ a theme needed to be?’ Boyatzis defined a theme as “a pattern in the information that at minimum describes and organises the possible observations and at maximum interprets aspects of the phenomenon” (Boyatzis 1998:161). A theme in

this present study constituted that what captured something important about the theory in relation to the perceptions of care and support by volunteer community workers around HIV/AIDS in the Kwangcolosi community. Marshall & Rossman (1998) state that data collection and data analysis in qualitative research should be a simultaneous process. The data collection and analysis stages in this study therefore were undertaken concurrently, and data was reread before undertaking further analysis to ensure that the developing themes were grounded in the original data.

Boyatzis (1998) identified seven phases of the theory led thematic analysis that have guided the analysis in this study. Firstly, the researcher has to familiarize him/herself with the collected data. Secondly, data is transcribed, read and re-read while noting down the initial ideas. Thirdly, Interesting features of the data that match the theoretical categories are coded in a thematic fashion across the entire data set, allotting data relevant to each theoretical category. Fourthly, potential themes are thought out and relevant data is put under each potential theme. Fifthly, themes are reviewed checking to be sure that the themes match the theoretical categories and also to be sure that the coded extracts match the themes generating a thematic 'map' of the analysis. The sixth step is an ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme. Finally, a report is produced that presents a final opportunity for analysis. The final product is done through selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature. These seven stages were strictly adhered to in the present study.

#### **4.7 Ethical Considerations**

This study touches on some ethical issues and recognizes that HIV/AIDS is a sensitive topic given the stigma attached to the disease. It is respected that many people living with HIV/AIDS may not be willing to come out and discuss their situation openly. The concern is that the study involves discussions and interviews on care of people living with HIV/AIDS without offering any immediate help for relief of symptoms. The discussions with the community home-based care providers are yet

another concern in that they may reveal areas where the care-givers need support and this is not immediately available or guaranteed from the study.

In view of these concerns the researcher ensured that participation was voluntary and only with informed consent of the individual participants. The benefits of the study to the individual participants may be not be immediate but it is hoped that the recommendations made to organizations providing training and supervision of community home care providers, to the Department of Health and the Kwazulu Natal Health Services in particular should be of benefit to the volunteer community workers and eventually the people living with HIV/AIDS.

Confidentiality for participants was ensured through the use of numbers and fictitious names for identification as well as through adherence to venues of each participant's choice for discussion and interviews.

#### **4.8 Validity and Reliability**

Validity in qualitative research refers to the authenticity of the study. Neuman (2004) argues that in order to uphold validity in a qualitative study, the researcher has to give a truthful, undistorted account of the informants' opinions, experiences and understanding. Validity in this study espoused use of the thematic analysis while closely relating to the texts. Reliability refers to how dependable and consistent a research study is. In the case of this study, I closely referred to the transcriptions.

#### **4.9 Conclusion**

Qualitative research method was the main method in this study given that the research objective required understanding the perceptions of volunteer community workers on care and support around HIV/AIDS in Kwangcolosi, Kwazulu Natal. This method was especially helpful in obtaining culturally specific information about the values, opinions, behaviors, and social contexts relating to care and support around HIV/AIDS. The method also helped to provide information on the inner feelings or the often contradictory behaviors, beliefs, opinions, emotions, and relationships of individuals on care and support around HIV/AIDS in the Kwangcolosi Community

The sample study was based on purposive sampling. The research specifically adopted semi-structured interviews which were optimal for collecting data on individuals' personal histories, perceptions and experiences since this research involved exploring care and support around HIV/AIDS which is a sensitive topic. Focus group discussions was another qualitative method use that was effective in eliciting data on the cultural norms of a group and in generating broad perceptions on issues of concern on care and support around HIV/AIDS within the Kwangcolosi community.

# CHAPTER FIVE

## PRESENTATION OF DATA AND ANALYSIS

### 5.1 Introduction

The purpose of this chapter is to provide the analysis of the data that was collected from the interviews and focus group discussions with volunteer community workers regarding their perceptions on care and support for those affected and /or infected with HIV/AIDS in Kwangcolosi area, Kwazulu Natal. The chapter provides its findings on how volunteer community workers perceive care and support provided by them to the community and how they perceive care and support provided by volunteering community members including relatives, neighbours and friends for those affected and infected by HIV/AIDS in the community. Data was elicited from 13 women volunteers who were purposefully selected from forty volunteers based on the longest volunteering experience in the group. Social capital has been used as a theoretical framework for this study. The analysis of data is based on the four elements of social capital namely: trust, reciprocity, networks, and social norms which fall under the levels of bonding and bridging social capital. The responses from the participants are presented in italics.

### 5.2 Trust

Trust refers to the level of confidence that others will act as they say or are expected to act, or the belief that what they say is reliable (Organisation for Economic Co-operation and Development, 2001). Trust among the members of a community facilitates information and knowledge sharing, cooperation and other forms of collective action within and outside the community (Berg, Dickhaut, and McCabe, 1995). Trust that is more robust is created and nurtured by repeated interactions between community members and is based on the community's view of the other person's norms and values (Ulsaner, (2001). Trust facilitates volunteerism in care and support for persons infected and affected by HIV/AIDS and the lack thereof leads to other negative consequences which have undermined social bonding (Ogden et al., 2004). This section analyses participants' perceptions of trust in relation to care and

support for those infected and affected by HIV/AIDS in Kwangcolosi community. The element of trust is further divided into sub-themes that were selected based on the how volunteer community workers perceive care and support. This next section presents the sub-themes of trust in relation to HIV/AIDS and care below:

### **5.2.1 Perceptions of HIV/AIDS in Kwangcolosi Community**

Perception in this context refers to people's understanding of HIV/AIDS in terms of its transmission, treatment, care and support. According to Mutangadura, Mukurazita, and Jackson (1999) perceptions of HIV/AIDS in a community are imperative precursors for behavioral responses to the disease. It is also argued that while surveys in quantitative research are useful towards tracking general level key areas, it is crucial that a deeper understanding of basic knowledge generated in quantitative research is necessary to reach at a sufficient response to address HIV/AIDS care and support (Akintola, 2006). Therefore an understanding of perceptions of HIV/AIDS in the Kwangcolosi community is very important to the extent that it will help map out the magnitude of care and support provided by community members to those infected and affected by HIV/AIDS. Perception of HIV/AIDS in Kwangcolosi is illustrated in the following sub-themes that emerged during the analysis:

#### *Mistrust and Shame*

Mistrust implies lack of trust or confidence arising from suspicion (Organisation for Economic Co-operation and Development, 2001). Lack of trust is usually generated by internal stigma and feelings of guilt on the side of the sick person and the family and may also be perpetuated by the new practices that depict fear, denial, stigma and discrimination which have flourished in the communities with the advent of HIV/AIDS (Taylor, Seeley and Kajura, 1993). These authors further argue that the most destructive stressor is that of feeling isolated which may be caused by the loss of support by lovers, family, and friends. These same feelings of isolation may be played out by family members who prefer to "hide" the sick person because they think that's what he/she would prefer or even to protect their family name from the impending rumours. According to the perceptions of volunteer community workers, some of the

families of HIV positive patients do not trust some neighbours enough to let them into their homes to visit the sick. This is illustrated in the response below:

*The family members of the sick might be scared because the neighbour might come and see how sick their person is and they might see that the person is HIV positive and run around gossiping about them that this person is sick like this and they are looking like that which the family doesn't like. So it is really up to the sick person because some of them choose whom they want to be seen by (Participant 5).*

The HIV positive patients and their family members do not trust neighbours because when patients are already bedridden and thin to the bone, they are ashamed of themselves because HIV/AIDS is associated with promiscuity. Birdsall and Kelly (2005) argue that people with HIV/AIDS may be suspected by others as “contagious” and that makes them to feel rejected and undesirable which may cause infected people to withdraw and isolate themselves from others. Inevitably this may lead to an emotional breakdown because their feelings continue to be suppressed. These feelings of mistrust and shame affect the quality of care and support given to those infected and affected by HIV/AIDS from the community members. Mistrust has also hindered the work of community volunteer workers because those infected with HIV/AIDS believe that the volunteers will gossip about them notwithstanding the fact that the volunteers uphold the principle of confidentiality. This view is shared by Mosoetsa (2004) who observes that lack of trust of the community members by those infected and their families has resulted in alienation of community members which has led to the break down of social cohesion in most communities.

### *Stigma and Discrimination*

Stigma involves the social expression of negative attitudes and beliefs that contribute to processes of rejection, isolation, marginalization and harm of others (Skinner & Mfecane, 2004). Stigma and discrimination are some of the challenges to HIV/AIDS in most communities (Akintola, 2005). Whereas stigma is largely related to ideas about others, discrimination involves some form of direct enactment of stigma which

may be verbal or physical, and which is likely to be hurtful and/or harmful to the person to whom it is addressed (Parker & Birdsall, 2005).

In Kwangcolosi community, it emerged from the study findings that stigma and discrimination can arise from community-level responses to HIV and AIDS. People with, or suspected of having, HIV may be turned away from health care services, denied housing and employment, shunned by their friends and colleagues, turned down for insurance coverage or refused entry into foreign countries. In some cases, they may be evicted from home by their families, divorced by their spouses, and suffer physical violence or even murder. According to the interview with one of the volunteers in Kwangcolosi community, some Volunteer community workers experienced cases of HIV/AIDS Stigma, denial and discrimination where for instance some community members plotted the murder of two girls who were believed to have been infected. One volunteer community worker narrated:

*I remember in 1994, it was discovered that 2 girls in this community had this disease. The community got together and agreed that the girls should be shot. People found cops who were going to do the shooting but the girls ran away. They would have been shot because they were going to spread the disease in this area. (Participant 8)*

Such acts create fear among those that are infected with HIV/AIDS and culminate in refusal to disclose. This makes it difficult for the volunteer community workers to provide the necessary care and support. The above account further portrays fear and rejection by the community of the people known to suffer from HIV/AIDS.

Stigma and discrimination are some of the major obstacles to effective HIV/AIDS prevention, treatment, care and support (Bond, 2002). According to Campbell et al. (2005) stigma is found in the thoughts of people and communities when they believe that a particular illness or something a person has done or feels is shameful and brings disgrace on themselves, their family or their community. Stigma occurs at different levels including the individual level where one is influenced by social processes related to assumptions, stereotypes, and generalizations and labelling of people as

falling into a particular category (Parker & Birdsall, 2005). According to some of the study participants, fear of discrimination prevents people from seeking treatment for AIDS or from acknowledging their HIV status publicly. This fear is characteristic of responses such as:

*They say “you have come here to see how I am sick to go around talking about me to everyone, go away, I don’t need you” and so that keeps most neighbours away (Participant 5).*

Internal stigma is enacted or caused by external stigma and often results in the refusal or reluctance to disclose HIV status or the denial of HIV/AIDS and unwillingness to seek help by those living with HIV/AIDS. As a result, the sick person is guilty of having brought the disease upon oneself. Some of them feel they deserve to be punished and in their self-judgment hence chase away well intentioned neighbours and friends who would provide care and support as a Volunteer community worker reported:

*...even the sick people do not want to be seen. They say you have come here to see how am sick to go around talking about me to everyone, go away, I don’t need you and so that keeps most neighbours away. (Participant 3)*

Most community members are not only reluctant to join voluntary care organizations because of fear of infection but also the fear that they may not be welcomed to some households with those infected by HIV/AIDS. As one of the respondents stated:

*... the family might be scared to tell people what is going on and the other people might be scared to go where they are not invited. (Participant 5)*

Stigma and discrimination were also cited as one of the reasons why those infected with HIV/AIDS do not trust their relatives, friends and neighbours enough to disclose their HIV status so as to receive counselling and the necessary care and support:

*‘They are not honest because they think people will laugh at them and say that they were promiscuous but we tell them that it is not only through behaving badly that one can get it but also maybe accidentally through accidents (sic). (Participant 8)*

According to this response, guilt and blame appears as one of the major hindrances to providing care and support to those infected by HIV/AIDS by the volunteers. This drives the epidemic underground and perpetuates its silent nature, thus undermining supportive strategies and affecting health-seeking behaviour (Campbell, 2003). Relatives, friends and neighbours do not only place blame on those infected by HIV/AIDS but also shun them. This is mainly due to lack of awareness about HIV/AIDS and its modes of transmission and the fear of contagion. One of the respondents noted:

*'People do not want to be associated with people who had HIV/AIDS because they heard that it was a contagious thing like we would get there and see people standing by and not helping and we had to educate them that it is not high risk to touch a sick person so long as you protect yourself correctly. People look at HIV/AIDS as a deadly disease that is here to wipe them out. (Participant 9)*

The foregoing response reveals that lack of knowledge on HIV/AIDS has adverse effects on care and support as it discourages members of the community from becoming volunteers. This further illustrates disproportionate numbers of volunteers compared to those in need of care and support. This attitude displayed by some of these community members is consistent with Ogden & Nyblade (2005) argument that HIV/AIDS is associated with stigma, repression and discrimination, as individuals affected (or believed to be affected) by HIV have been rejected by their families, their loved ones and their communities.

Stigma and discrimination may also stem from the community and family members' belief that people suffering from HIV/AIDS got what they deserved. This attitude is often born out of anger and a sense of betrayal that the sick person violated the norms of his/her community and therefore deserves punishment as noted by one of the respondents:

*'Some don't want anything to do with the sick person because they feel they can get it from you and every life threatening illness is now labelled HIV/AIDS. Sick people are shunned and blamed like this saying that "He/She got what they were looking for in*

*promiscuity” especially if the sick people did not conform to how society expected them to.*

*(Participant 2)*

Findings from the interviews conducted in this study revealed that stigma and discrimination are some of the serious barriers to care and support for those infected and affected by HIV/AIDS. Responses from various volunteer community workers point to the fact that even trained volunteers who are willing to assist the ill may find it hard to access them because they are hidden by relatives or do not want to be seen by other people. Those who have had the courage to go for Voluntary Counselling and Testing (VCT) will not disclose their status to get help because of internal stigma and the fear that they will be discriminated once they disclose. Ogden et al. (2004) also agree that stigma and discrimination have weakened the traditional safety nets of care and support by households and the wider community. Fear of stigma amongst PLHA, or people who believe they are HIV positive, has been found to be a barrier to accessing Voluntary Counselling and Testing (VCT) and other HIV/AIDS-related support services (Ogden & Nyblade, 2005). This may include fears of disclosure, fears of judgmental attitudes of health workers, and fears of confidentiality. It should also be noted that fear of stigma intersects with other psychological processes to do with HIV infection, including guilt at potentially having infected others, fear of illness and death, feelings of inadequacy, and denial.

### **5.3 Social Norms**

Social norms are shared understandings, informal rules and conventions that prescribe, proscribe and modulate certain behaviours in various circumstances in different societies (Productivity Commission, 2003). Robust social norms have positive implications for strong community bonds for care and support. Mutangadura, et. al., (1999) assert that for individuals infected and affected by HIV/AIDS, societal norms have been used as coping mechanisms to cushion the difficulties associated with HIV/AIDS care and support through assistance from households and other community members. This section analyses participants’ perceptions of social norms in relation to care and support for those infected and affected by HIV/AIDS in

Kwangcolosi community. The element of social norms is further divided into 2 sub-themes namely; Ubuntu and Altruism. Whilst Ubuntu and altruism both embody being humane and catering to the needs of others in the community, Ubuntu brings in the unique African perception of togetherness, sympathy, care and sensitivity for the needs of others at the community level (Khoza, 1994). Altruism depends on personal judgment to extend a helping hand to those in need whereas Ubuntu is a community responsibility (Batson, 1991). In the present study, both altruism and Ubuntu are described as practices that bring people together.

### **5.3.1 Standards and Practices that Encourage Togetherness**

#### *Ubuntu*

The concept of Ubuntu is a cultural world-view that tries to capture the essence of what it means to be human (Murithi, 2004). Ubuntu cultural attitudes and values therefore provide the foundation for the social norms by which people live. Through internalizing and sharing these cultural attitudes and values with their fellow community members, and by handing them down to future generations, societies can and do re-construct themselves on the basis of a particular cultural image (Murithi, 2004). As asserted by Masina & Nomonde (2000) Ubuntu is historically as a world view that has kept African people cohesive and may still be an important thread that holds African communities together in all adversities including provision of care and support for persons infected and affected by HIV/AIDS. Ubuntu is found in diverse forms in many societies throughout Africa specifically among the Bantu languages of East, Central and Southern Africa (Murithi, 1999). In the Bantu cultural literature, a person who manifests Ubuntu is one who is kind, helpful, not quarrelsome, slow to anger, generous, helpful to others, cooperative, and courageous (Mbigi, 1995). The actions of people such as these can create a network through sharing wealth and resources in ways that help people cope with and absorb risks that would otherwise be overwhelming to the individual (Murithi, 2004).

In the Kwangcolosi community, there are some practices that encourage togetherness. These practices are built on the notions of Ubuntu and altruism. Ubuntu in this community is seen as progress and every activity that brings community members together is perceived to be done in the spirit of Ubuntu. These activities include contribution to families that need community support, like bereaved families. In this sense, Ubuntu is therefore a foundation of care and support systems. From the perspective of volunteer community workers who participated in this study, Ubuntu is understood in various ways such as, a way of moving forward, building love and togetherness and getting together for a good cause as reflected in some of the volunteers responses thus:

*'Ubuntu is a way of moving forward, it's about building love and togetherness and no discrimination' (FGD)*

*'Getting together for a good cause like collecting money and buying blankets, a teamwork kind of thing, it's not a new thing because long ago when somebody had died, you would see all the neighbours coming together with baskets on their heads carrying potatoes, flour and other foodstuffs bringing it to the bereaved family and then feed the gravediggers and that was Ubuntu' (FGD)*

According to the participants, the concept of Ubuntu promotes love and discourages discrimination. Ubuntu is perceived to encourage unity in the community which in turn promotes care and support for those infected and affected by HIV/AIDS. Another volunteer community worker reckons that even their getting together to do voluntary work is Ubuntu. She also gives an example of being shaken out of her comfort at night to go and help call an ambulance to take a sick person to the hospital as a form of Ubuntu.

*'Even our getting together as Volunteer community workers is Ubuntu, because we get here talk and come up with the same word which we take back to our communities coz I know that what I am saying, other Volunteer community workers are saying in their respective sections. Even being woken up in the middle of the night in an*

*emergency and I call an ambulance and it comes in time to help is also a form of Ubuntu.'*  
(FGD)

There are however those who argue that the concept of Ubuntu has changed from what originally it was conceived to be (Khoza, 1994). Some participants were in agreement with the fact that with time, Ubuntu has weakened and the factors given for its decline include lack of commitment, loss of love, and poor upbringing. Others argued that the concept is on the wane while others assert that it has disappeared altogether; as one volunteer community worker stated:

*'Ubuntu is not the same anymore. People have changed. The love that people of long ago had is not there anymore. People are not as committed as those people were. It is the loss of that love because the people who brought us up helped us to act that way but the children of these days have lost that love. Even I notice with the young generation, whenever you tell them to act this way and the other way, they tell you that that was those times and today is today.'*(FGD, 3)

This response indicates that lack of love, lack of commitment and poor upbringing are some of the factors that have eroded the Ubuntu philosophy. The volunteer community worker also alludes to a paradigm shift in the way of thinking which heightened the differences in thinking and diluted the Ubuntu values.

Just like many changes that have swept over the world, the concept of Ubuntu is no exception. Factors like globalization, rural-urban migration, advancement in technology and many others have affected the African way of living generally and Ubuntu specifically (Mbigi, 1995). Putting Ubuntu in context in Kwangcolosi, one volunteer community worker recounted:

*In those days, women stayed at home and there was food because it came from the fields and food was in abundance because it came from the land. They had a lot of time to stay at home and do things and get together with other people and in that way, they had more time to help. Even when the men went to Joburg to work, their hearts*

*were at rest because they knew that their wives were at home bringing up their children in a good way and even when there was a problem, their neighbours were there to check and see what was wrong and would come to help them. But now, the changes came with the developments that came with electricity women had to also go and find work and this time they were not working in the fields and not with their hands anymore but in the factories with machines. Women leave home in the morning and come back late in the evening, tired. There is no time to meet anymore. Another thing is that a neighbour may lose someone and a relative also dies at the same time. It will be hard for one to choose where to go. It may be hard for one to divide oneself to choose where to go and nowadays people are dying a lot so it is hard to find time to go to any of the funerals. Another thing is that people have taken status seriously. So the rich people will stick with rich people and the poor people are not part of that so that there is that separation as well.*

*(Participant 6)*

This volunteer community worker has elucidated on the other factors that have led to the decline of social bonding, such as advancement in technology where women have to work in factories instead of staying home and bonding with neighbours. This means that there is no time to meet and bond and strengthen the values of Ubuntu. Equally important is the factor of too many HIV/AIDS related deaths where there is no time for one to go to all the funerals. What also emerged as important was the ever-widening gap between the rich and the poor such that people bonded more with those of their social standing which turned out as negative social capital (Baum and Ziersch, 2003). The decline of the notion of Ubuntu has had a negative impact on care and support in Kwangcolosi community. The new trend now is that members of the community are less willing to provide care and support to persons infected and affected by HIV/AIDS because Ubuntu is perceived as a notion that has its place in the past.

### *Altruism*

Altruism is selfless concern for the welfare of others. It implies that when one does something for someone, he/she expects nothing in return (Fehr and Fischbacher,

2003). Altruism can be distinguished from a feeling of loyalty and duty. Altruism focuses on a motivation to help others or a want to do good without reward, while duty focuses on a moral obligation towards a specific individual (for example, a king), a specific organization (for example, a government), or an abstract concept (for example, Ubuntu). Some individuals may feel both altruism and duty, while others may not. Pure altruism is giving without regard to reward or the benefits of recognition (Akintola, 2004, 2005). Some have argued that altruism is demeaning to the individual and that no moral obligation to help others actually exists (Batson, 1991).

Altruism is predicated on the assumption that others are more important than one's self and such a position is degrading and demeaning. Advocates of altruism as an ethical doctrine maintain that one ought to act, or refrain from acting, so that a benefit or good is bestowed on other people, if necessary to the exclusion of one's own interests. If one performs an act beneficial to others with a view to gaining some personal benefit, then it isn't an altruistically motivated act (UNAIDS, 2001). It is a traditional virtue in many cultures, and central to many religious traditions. Most people who perform altruistic acts usually derive satisfaction from the feeling that they have contributed to the welfare of others. In the present study responses from some of the volunteers confirmed altruism in the community as one volunteer observed:

*'We (volunteers) expect that the sick people get better, healthy, nothing much more. I am a volunteer. If the person is lying in bed powerless, I continue to give care and medicine and one time when I meet them walking the streets, I am happy that I helped someone get well, contributed and they are grateful and usually say, "Thank you, you helped me get back on my feet" and that makes me happy.'*(Participant 11)

The desire to work for the good of others was commonly expressed as a reason for volunteering for the HIV/AIDS care and support. Many respondents acknowledged that they knew the scale of HIV/AIDS and that much care and support for those

infected and affected was needed in their community; hence the spirit of altruism. One respondent stated:

*'I don't expect much from helping people. I think I was created like that and I get satisfaction when people say thank you. In fact, I always say if I got a bag of money, I could call neighbours and we share. I am just like that. (Participant 12)*

This response is consistent with the argument by Akintola (2006) that some people are motivated to volunteer out of their innate personality characteristics of helping others. These authors further suggest that some people feel a sense of duty and obligation to volunteer while others are driven by a desire to satisfy their own interests and seize the chance of volunteering to keep productive by using their existing skills and develop new ones. The reasons given for altruism range from personality, compassion and love to expectation of a stipend as illustrated below:

*It depends on what kind of person one is. Like from long ago, I have been a kind of person who likes to help other people who were sick, like I wanted sick people to get better and wanted to give something to people who were poor though I did not have much myself. I have tried going to some churches and asked church members to help and at least give some food parcels but that did not yield much, I actually got nothing from the church. So I think it depends on what kind of person you are. Sometimes I go to people who are sick and I tell them to take their medicine but they have no food and even I wonder how they can take their medicine on an empty stomach and that makes it hard for them to get better. (Participant 1)*

Personality and compassion were the main reasons identified by most participants for altruism. A number of volunteers provide care and support out of kindness and love for those infected and affected by HIV/AIDS at whatever cost. However, the volunteerism shown by some of the respondents was not entirely for altruistic purposes. Many respondents felt that in the absence of anything better to do, offering to help in the HIV/AIDS care and support programme was a more attractive option than simply sitting at home. Furthermore, some harboured hopes of eventually

securing employment in the formal health sector when job openings became available. Those who had this view took volunteerism as displaying an interest in nursing which might improve their chances of attaining further education within the formal health sector. Though not directly expressed, one volunteer community worker brought this need to the fore:

*'We do not expect to get anything from it, we only expect that our community is alright, people are helped and we are happy. (Hesitates...looks up...) For us as volunteer community workers we are motivated by learning about what problems there are in the community...(pauses) and who knows maybe one day a hospital may be built and we will be the people to; look after the sick people there. I am expecting that people get better and get cured and be like everybody else. I do it out of a good heart. I felt for the sick and the elderly. I believe that for one to help a person one has to have that love for people, you just have to have that calling. As you can see not everybody is running out of their houses to go and help, I have spoken to some people who say that they would never do something like that but that is fine with me because they do not feel that way. It's the same as being a nurse; one has to have that loving heart first and love helping heart because they will not give you anything in return and it is a big sacrifice but you have to love doing it but of course, nurses get some pay.*

*(Participant 10)*

Most of the participants shared this sentiment but some did not openly express it. Whilst volunteers and are not expected to be paid, some volunteer community workers anticipated payment in the future for their care and support services though this was not openly expressed:

*As we do what we do, we also hope that one day at some point we...we will get.. get to make...uuuhhh get a salary or..Something... (Seriously), Government he can pay us for the work.*

*(Participant 4)*

It is evident from the above interviews that motivation for volunteering is based on different reasons. Some volunteers believe that volunteering has to be done out of

purely altruistic motives while others believe that they should be remunerated. Whatever the reasons for volunteering maybe, altruism has played an important role in the provision of care and support for those infected and affected by HIV/AIDS.

Whilst many volunteer community workers did their work out of pure altruism and expected no rewards, for some others, there were often undertones of hope and future expectations. Some expected to be trained and work in healthcare whereas others expected to be salaried workers in future but it also looked like it was “politically correct” to mention that they were doing volunteerism out of a good heart and sheer altruism. It is also evident from the foregoing response that some people believe that altruism and the spirit of volunteerism are inherent and not attained through training or practice.

#### **5.4 Reciprocity**

Reciprocity refers to responding to a positive action with another positive action, and responding to a negative action with another negative one (Fehr and Simon, 2000). Reciprocity applies to care and support in that some members of the community provide care and support expecting that the favour will be returned in cases of sickness and death from HIV/AIDS. The nature of reciprocity determines the effectiveness of social bonding which affect the scale of care and support (Berg, Dickhaut and McCabe, 1995). Positive reciprocal actions differ from altruistic actions as they only flow from other positive actions and they differ from social gift giving in that they are not actions taken with the hope or expectation of future positive responses (Fehr and Fischbacher, 2003). The nature of reciprocity determines the effectiveness of social bonds which affect the scale of care and support (Berg et. al, 1995). Reciprocity is further divided into sub themes which are reviewed below:

##### *Reciprocal support*

Positive reciprocal actions differ from altruistic actions as they only flow from other positive actions and they differ from social gift giving in that they are not actions taken with the hope or expectation of future positive responses

*It might be just feeling for the neighbour and also thinking that I might also get sick one day and someone will help me so I go in and help with that spirit and help my neighbour. (Participant3)*

The above respondent brings to light the fact that people may help each other knowing that when their turn comes and they need help, someone they helped will return the favour. In the Kwangcolosi community, reciprocity was also demonstrated by community members borrowing from one another as illustrated in the response below:

*People borrow money from each other because nobody can afford to give free money. Some people even give food some neighbours who sit around lazily and cannot work in a garden to show them that “you too can have this if you work hard”. (Participant 9)*

Apart from the reciprocity in the community, members of Kwangcolosi seemed to expect reciprocity from Government. Most of these people join the volunteers expecting that government will return the favour and pay them as one respondent expressed:

*Most of the time, many people who are unemployed and stay home, they tend to want to volunteer when you promise them that maybe one day government will look out for you and give you a stipend then they get involved. (Participant 8)*

Reciprocal actions are important to care and support as they can help explain the maintenance of social norms (Campbell et al., 2002). If a sufficient proportion of the population interprets the breaking of a social norm by another as a hostile action and if these people are willing to take (potentially costly) action to punish the rule-breaker then this can maintain the norm in the absence of formal sanctions. The punishing action may range from negative words to complete social ostracism.

### *Family Obligations*

According to most of the studies that were reviewed, family caregivers provide care and support for different reasons. For most, it is out of lack of alternative, while for

others is because they have no job (Homan et al., 2005). But in the present study, most respondents reported that their support is based on the love and emotional attachment for their sick relatives which sometimes culminates in long term motivation to care and support them throughout the sickness. This was emphasised by one of the respondents who stated that:

*The love of my sister and brother who passed away has made me pursue to choose to be a volunteer... Now whenever I go to homes I do counselling for the sick person and call some family members and counsel them too. I tell them that I don't look after the sick person because I am a fool, I am here to help you to take care of your sick person but you must help too because she/he is you blood and you must not run away from them. I also encourage them not to blame the sick people.* (Participant 6)

Family caregivers do not expect anything out of providing care and support for the sick relative. Most of them do not expect much in return like any acts of reciprocity except the wellbeing of their sick relative as these volunteer community workers stated:

*The family members do not expect anything except that the sick people get better and regain their health.* (Participant 9)

*The family members are motivated by the love of the sick person and they don't care what it is they are sick with because they want them to live* (participant 3).

Studies that have been carried out on informal care giving indicate that most of the informal caregivers were women, that is, mothers, sisters, sisters in law, aunts mothers-in-law and even grandmothers of the ill (WHO, 2002; Akintola, 2004, 2005, 2006). This current study has confirmed that there is always a problem with care if there is no female in the household where there is a bed-ridden patient as one volunteer stated:

*It's usually the family of that person that take care of him/her especially the mother and if the mother is not there that is the problem. The father will start by counting all*

*the problems the sick person has put the family through whereas the mother will welcome the sick person with open arms.* (Participant 9)

The above responses confirm that family relations play a very important role in care and support for the long term sickness such as HIV/AIDS. It is important to note that care and support is usually given by females rather than males.

Reciprocity generally plays an important role in the provision of care and support as it motivates volunteers to provide the needed care and support in anticipation that those they have helped will return the favour. Volunteers also expect government's reciprocity in form of pay or stipend. The above respondent brings to light the fact that people may help each other knowing that when their turn comes and they need help, someone they helped will return the favour. Reciprocity encourages care and support for the ill in the community.

### **5.5 Social Networks**

A network is an interconnected group of people who usually have an attribute in common (Productivity Commission, 2003). Community-based care has been promoted as the best option since it would be impracticable to give proper care for hundreds of thousands of people dying from AIDS in public hospitals. The burden of care and support is then shifted to impoverished rural communities, where sick family members return when they can no longer work or care for themselves. Extended families and kinship networks are generally regarded as the main source of care and support for those infected with HIV/AIDS. In these circumstances, social networks serve to alleviate the burden associated with providing care and support for those affected and infected by HIV/AIDS. However support from these networks is often impeded by various factors including poverty, stigma and discrimination, rural urban migration among others. Volunteer community workers however continue to solicit contributions from individuals in their communities. In-kind contributions may include food, clothing, space, and supplies.

### *Community Solidarity*

In most African communities, there are spontaneous, informal and ordinary actions that are undertaken to support the ill, orphans and vulnerable children who may be slipping through the traditional safety net of the extended family as the effects HIV/AIDS increase (Foster, 2002). The same author notes that community initiatives are usually started by small groups of motivated individuals who are driven by a sense of obligation to care for those in need, against a backdrop of limited or non-existent public services. This was echoed in the following response:

*Neighbours really get along and do some things together and there is that garden project going on and some neighbours can borrow and lend each other like transport and if you run out of Millie mill for the children and I have some I can lend you some but it does not happen with all the neighbours. (Participant 7)*

In some instances, informal groups of volunteers may expand in size or beyond the scope of their activities and become more formalized. Signs of this include the establishment of committees, collection of membership contributions or donations, introduction of income-generating activities, approval of internal management rules, opening a bank account, and offering training activities (Foster, 2002). This was highlighted by respondents who concurred with Foster by giving a brief background of how their program started:

*Thandaza Group started with women coming together as volunteers in 2004 because there were sick people in the community who needed our help. We were initially not trained in basic care but in 2006 we got training in home based care, counselling and DOTS after which we applied for the status of Non-Profit Organisation (NPO).*

The community solidarity is at times exhibited through the generous contributions of community members in terms of food and discounts as expressed by a volunteer;

*Some people have vegetable gardens and they come to us with dishes full of spinach, carrot and say, give to your sick people and for some we take little money we go to*

*their gardens, they give us so much for so little money because they know that we shall take to the sick people.* (Participant 7)

The responses above articulate the solidarity in the community as a means of supporting each other in the case of crises such as HIV/AIDS. Community-level responses are seen as immediate, direct, and flexible; they emerge from local conditions, are driven by community members, are responsive to local needs, reflect local forms of organizing and acting, and draw upon available resources (Birdsall and Kelly, 2005; Goudge, Gilson & Msimango, 2003).

According to the perception of volunteer community workers in Kwangcolosi community, solidarity is understood as collective efforts, borrowing money and food from one another as illustrated in the following response:

*Neighbours get along and do some things together and there is that garden project going on and some neighbours can borrow and lend each other like transport and if you run out of Millie mill for the children and I have some I can lend you some but it does not happen with all the neighbours.* (Participant 12).

Community solidarity is at times exhibited through the generous contributions of community members in terms of food and discounts as expressed by a volunteer:

*Some people have vegetable gardens and they come to us with dishes full of spinach, carrot and say, give to your sick people and for some we take little money we go to their gardens, they give us so much for so little money because they know that we shall take to the sick people.* (Participant 8)

However, social networks have been greatly undermined by many factors which include the refusal by volunteer community groups to cooperate with other groups that are doing the same work of care and support for those affected by HIV/AIDS. For example, this study found out that relations between volunteer community workers and community health workers were strained as one participant put it

**Researcher:** *What is your relationship with community health workers?*

*FGD :( A prolonged Aaaaaaarhhhhhhggghhhhhh) ...(they all burst out laughing, look at each other briefly and one of them speaks). Our relationship is very strained because this volunteer work we started is relatively new so when they got to know that we had started it; to them it was as if we were going to replace them. It was so bad that they really really hate us. Even the people in CHW who were my friends do not speak to me anymore. At one point our supervisor and the valley Trust representative who was their supervisor came together to try and reconcile us and explain that our duties are independent of each others' duties but it was not possible that day for them to understand. For some them are beginning to see that we do different things from us but up to now some of them still hate us.*

The strained relationship seems to stem from competition. According to this participant, the community health workers feared that the volunteers who were relatively new were poised to take their jobs.

#### *Contribution and Moral support*

Volunteer community workers alone cannot tackle or take responsibility for all the care and support of HIV/AIDS infected and affected persons. Their services cannot cope with the demand for imminent care and support services needs in the community. It is essential that community members get involved and materially or contribute to complement the activities of volunteer community workers in any other way. Volunteer community workers may solicit contributions from individuals in their communities. In-kind contributions may include food, clothing, space, and supplies. In the course of the study, it was found that some community members make material contributions to care and support activities. These contributions from the community though meagre encourage care and support for those infected and affected by HIV/AIDS and even motivate volunteer community workers. The respondents thus stated:

*Some people have vegetable gardens and they come to us with dishes full of spinach, carrot and say, give to your sick people and for some we take little money we go to*

*their gardens, they give us so much for so little money because they know that we shall take to the sick people.* (Participant 10)

In some rare instances, some community members make contributions towards the welfare of those infected and affected by HIV/AIDS; this was clearly articulated in the response of one volunteer;

*HEH...Sometimes people from their own resources a community member might contribute some rice here, some Millie mill, some bit of potatoes there and take it to those who really need it but this is rare.* (Participant 10)

Cooperation also depends on the relationship that the affected household have with the rest of the community members;

*When a person is really sick, some neighbours who have been cooperating with this sick people will bring food, give the sick people a bath, cook for the sick...some neighbours do that.* (Participant 8)

The respondents indicate that neighbours cooperate on a small scale so as to assist each other. However this cooperation is undermined by poverty whereby people may have the spirit to contribute but have nothing. It is important to note that contribution may not only be material in a crisis. People may contribute labour.

## **5.6 Challenges to Participation in Care and Support for those Infected by HIV/AIDS**

The volunteer community workers identified a number of challenges to the provision of care and support. These challenges are discussed under the following sub-themes namely, the mystery of the new disease; fear and denial; general lack of resources; growing apathy; challenges of volunteering in a cash economy; self centeredness and limited awareness.

### *The mystery of the new disease*

HIV/AIDS is different from many other health problems because its infection is life-long and eventually leads to death. Transmission is related to sexual behavior, which

is usually a domain of privacy and secrecy in most societies. Initial reactions of society to HIV/AIDS are often characterized by fear, stigma and discrimination, leading to social rejection of those infected and affected by HIV/AIDS. According to some of the respondents, the advent HIV/AIDS has brought changes in the way the ill and dead are handled in the community. The mystery of HIV/AIDS has led to mistrust especially of the sick person by the community or household members and has further led to the weakening of community safety nets. Many stories and myths are made about the disease and this increases fear. Some respondents expressed their concern over the mystery of HIV/AIDS and how it has hindered care and support services. One respondent stated:

*When neighbours come, they just stand in a safe distance and greet but will not want to get their hands dirty. Even in the home, relatives do not look after their sick, when you get there, they say, well, your person is behind there and the sick is locked in a small room, hungry and have perhaps soiled themselves and just lie there without help and you as volunteer community worker have to deal with that.*  
(Participant 10)

Provision of care and support is further undermined by internal stigma by the ill themselves who in frustration shun people who would otherwise provide them with care and support. This was apparent in the response of one volunteer;

*We are about 3 volunteers from my area but neighbours won't help and even the sick people do not want to be seen. They say you have come here to see how am sick to go around talking about me to everyone, go away, I don't need you and so that keeps most neighbours away.*  
(Participant 3)

The fear of getting infection with HIV/AIDS is yet another challenge that has negative implications for care and support of persons infected with HIV/AIDS (Campbell et al., 2008). Family members are reluctant to help their sick persons because of fear of contracting the disease through such means. Others fear to join the volunteer community workers because they fear being exposed to the risks of

contracting HIV/AIDS through such modes of transmission. As one volunteer worker stated:

*'Sometimes it's about safety. Its not that people are not sympathetic, but they fear to catch the disease. Sometimes you get to the sick and they have soiled themselves and maybe the mother is even present and when you ask them why they did not help, the mother will say, well, I love my son, but I did not have gloves to put on their hands to help him. And sometimes you find some who tie bread plastics on their hands wanting to help and wash and clean the sick person so the issue of safety is big also.'*  
(Participant 10)

These responses confirm that HIV/AIDS being a new disease, is still confusing people because the symptoms and the process of sickness is not well understood by most people in the community. This is compounded by the failure to determine the cause of death in most cases.

#### *Fear and Denial*

HIV denial refers to the hypothesis that AIDS is not caused by HIV, but by some other factor, or combinations of factors (Duesberg, 1988). Denial can broadly be defined as the psychological process by which human beings protect themselves from things which threaten them by blocking knowledge of those things from their awareness (Ogden & Nyblade, 2005). It is a defense which distorts reality by keeping people from feeling the pain and uncomfortable truth about things people do not want to face. In terms of HIV/AIDS, denial manifests in refusal by to go for voluntary counselling and testing denying that they have the HIV/AIDS or could ever catch it.

Most participants revealed that HIV/AIDS in Kwangcolosi community is not openly talked about and some who have it can only say they have TB or some other ailment. This can be attributed to lack of awareness on how HIV/AIDS is transmitted and how it can be prevented. As a result of denial, HIV/AIDS patients prefer to go to traditional healers and carry out ceremonies instead of going to health care workers to care and support provided by volunteers.

*There is not much understanding. Many people are still in denial and so many people waste their parents' money by going to traditional healers and doing a whole lot of other ceremonies when they very well know that they are hiv+(Participant 1).*

*People see it as something that they cannot talk about, even if they get it they have it they just say they have T.B but we go on and tell them to go and test and get help from the hospital (Participant 4).*

The fear of rejection is yet another factor that has led to denial in Kwangcolosi. This seems to be the reason for refusal to test for HIV/AIDS and even after testing, this fear leads to non-disclosure of one's sero status as this participant narrated:

*People still do not want to disclose their status on HIV/AIDS like one day a woman I know called me to her house and told me she was HIV+ and even showed me her results that she had carefully put away. She was very depressed and had lost so much weight. She told me that I should never tell anyone in her household that she was positive. I promised her I was not going to tell anyone but I advised that if she shared with them it would be better but I would keep my word. I counseled her and told her to go back to the clinic and check for her CD4 count and to eat well, have safer sex and her CD4 was low but now she is on medication and is looking better. (Participant 9)*

Because of the fear of being judged harshly and being shunned by close friends, people refuse to go for VCT and deny within themselves that they were not prostitutes therefore could never catch HIV/AIDS. As a result, the infant mortality rate has increased because mothers refuse to test for HIV/AIDS when they are pregnant. In this community, people who have HIV/AIDS are looked at as promiscuous and careless. This feeling is reflected in some of the respondents' views below:

*...Even young children are dying just because their parents refuse to test when they are pregnant. And then they all deny that they are going to get it. Whenever we try to tell them that HIV/AIDS is here and it will kill many people if we don't care they say*

*I won't die from AIDS because it's for people who have many boyfriends and they don't know that all unprotected sex is potentially risky. (Participant 5)*

Denial may lead to adverse effects such as premature death. This may be evidenced by the fact that community members who have followed this belief and totally rejected treatment with ARVs have died prematurely. Some of their care givers have had a bad experience as another community worker in Kwangcolosi lamented:

*...My heart aches for my neighbour who died – she only ate the beetroots and garlic – I keep telling myself that she would still be alive had she taken the ARV's. (Participant 8)*

In a one interview, one of the volunteer community workers made reference to the Minister's suggestion of dietary aversion in a way that portrayed that she still believes that beetroot and garlic concoction works to keep HIV/AIDS at bay as she stated:

*I remembered when the Minister of Health, Mrs. Manto Tshabalala-Msimang, said we don't want these ARV's which are dangerous. We must eat vegetables. I advise people to look after themselves, stay away from sex, eat boiled food with vegetables, be free emotionally, exercise, and get enough rest; and not to lose hope because they will live longer. (Participant 2)*

Being judgemental and apportioning blame has further exacerbated denial and disintegrated the community, weakening trust and social bonding. This notion is double edged in that it keeps away the 'would be' care givers and discourages community support and the mistrust based on suspicion breaks down social bonding. On the other hand, denial may be exacerbated by stigma and discrimination arising from community-level responses to HIV and AIDS. The harassing of individuals suspected of being infected has been widely reported (Campbell, Foulis, Maimane, and Sibiyi, 2005). It is often motivated by the need to blame and punish and in extreme circumstances can extend to acts of violence and murder. Such extreme cases may be exemplified by the stoning and beating to death in December 1998, of one Gugu Dhlamini by neighbours in KwaMashu Township near Durban, South Africa,

after speaking out openly on her HIV positive status (UNESCO, 2004). This indicates that denial undermines trust and consequently weakens social bonding. It can also be inferred from the foregoing accounts that lack of knowledge impairs care and support for those infected with HIV. Participants' views suggested that people affected and/or infected with HIV/AIDS had lost trust in their neighbours and as a result there was mistrust and shame, stigma and discrimination, and denial on the part of people living with HIV/AIDS.

#### *General lack of resources*

In South Africa, the state is the main provider of basic necessities especially to the unemployed people in rural and peri-urban areas (Barnett and Whiteside, 2002). Therefore when government cannot provide basic necessities especially those needed in care and support for those infected by HIV/AIDS in communities, community members generally lack resources to manage an expensive illness like HIV/AIDS. Whilst the South African Government provides some grants to help poor families care for their children, many families struggle to access these grants either because they don't know about them, they lack the necessary documents, or they have no transport to get to the welfare offices. In KwaZulu-Natal South Africa, there are limited resources to support volunteer services. This affects the morale and de-motivates the volunteers. Most of the volunteers who work in the community reported limited and lack of resources to use in care for the bedridden patients. Volunteers reported lack of basic care like bandages and antiseptics and the lack of these basics affects their morale and de-motivates them. The need for government support was echoed by volunteers in the following excerpts:

*Government can contribute resources to those who are already volunteering like provide enough cleaning agents bigger kits of gloves, Diapers, antiseptics and over the counter medicines. People say to us I have a headache and we have to get from our own money to buy painkillers. (Participant 2)*

In addition to lack of the physical resources to take care of the sick, the volunteers propose that government should take them on as salaried workers to do the work as was put by one volunteer:

*If government paid people like us to do the work (Giggles!!) But if government gave us more resources to do the work like you go the sick person and have sprained an ankle and we have no bandages or even the simple over-the counter medicines like cough syrups, zambuk etc and some even have sores and you would need savlon to clean the sores but it is not available, provision of such would ease our work (Participant 1)*

The perception that Government should pay volunteers a salary to carry on and manage care and support needs in the community came up a number of times from the interviews. Another critical aspect that came up on how government can better encourage care and support was that it could build a hospice in this community where all the sick people could be cared for in one place. This according to this participant could cut down on the time wasted walking long distances from house to house to take care of the sick and this was reflected in this response:

*Government can contribute better by building a hospice where we can find all the sick people are in one place and we go and work on them at once. It gets very tiring to move long distances from house to house working on the sick person. This also wastes time because most of the time is spent walking. Government can also pay us so that we are working for a salary, we would do our work better. Households are affected if they can get help from government can fence off some land where fruits and vegetables are grown so that they are safe (Participant 9).*

On how government can better encourage care and support in the community, issues like poverty alleviation, provision of food, and salaries for volunteers came up as areas that government could address as was pointed out by this participant:

*I would like Government to help especially the PLWAs. You are confronted with this horrible poverty. You get there and the sick people are hungry, the structure is a mud*

*hut that is falling apart and not even plastered and you wonder how people moreover sick people can live like that. But now Government is beginning to get involved by giving us that that stipend which for me is to buy shoes coz we walk a lot and people are also getting involved because now they are forcing us hard not asking nicely to come and look after these people who are very sick but government can improve our working conditions at least give us a salary and transport so that we can help better.(Participant11)*

The above responses express the lack of resources and the difficult conditions under which volunteers have to provide the required care and support for those affected by HIV/AIDS in the community. They describe the sick people living in poor conditions where in some instances they lack basics like food. They also emphasise that government ought to pay them a salary.

The above responses express the lack of resources and the difficult conditions under which volunteers have to provide the required care and support for those affected by HIV/AIDS in the community. They describe the sick people living in poor conditions where in some instances they lack basics like food. The volunteers implore government to provide necessities such as cleaning agents, bigger kits of gloves, Diapers, antiseptics and over the counter medicines to ease their work in the community. The volunteers also requested government to help improve their working conditions by providing them a salary and transport to and from the homes of those who are bed-ridden. They suggested that a hospice be built where the entire bed-ridden can be cared for and monitored in the same place. They felt that this would ease the problem of long distances in a rough terrain.

#### *Burden that comes with care*

Care-giving is usually carried out by family members who serve as primary caregivers, and by community members who are recruited and trained to provide service as volunteer care-givers. Care-giving activities include provision of physical and emotional support to patients, and work such as carrying, lifting and bathing of

patients, staying awake at night to attend to patients who are in the terminal stages of their illness, and cleaning those with frequent bouts of diarrhoea.

Volunteer caregivers' work involves transferring knowledge by training family members on how to care for the sick, visiting several homes a day, working for long hours and walking in heat of day to assist. Many volunteer care-givers become the primary care-givers of the sick person. Most of them reported being affected by the situation in which they find the sick person. Logistics like lack of hospital cards transport costs and bad temper on the side of the patients One volunteer community worker stated:

*'It is a long way to visit the homes of the patients. We walk long distances, whether it rains or shines. The footpaths are bad. You get there and they have not left any food for the patient. There is no fire and no wood; s/he is locked in the house even when it's hot outside. Some patients are bad tempered; they don't want any visitors – especially the first visit. They do not have clinic cards. Transport to the clinic is scarce because there is no money to pay. The community is scared, so it is difficult to start a support group – it becomes a challenge to counsel the patient. Once I tried to give my father-in-law a bath but he refused and said he could not be helped by a makoti. I had to ask the neighbour's son to help him. (participant 4).*

The responses above demonstrate that care-giving is very demanding for the family and volunteer caregivers. The work leads to physical, emotional and psychological, social and economic stress. Care-givers experience physical stress and related symptoms such as headaches, backaches, and general body weakness and fatigue. Some of the family members also face the risk of infection with TB because of frequent close contact with patients and also risk HIV infection because they do not use protective devices when caring for the sick. Emotional and psychological stress manifests in sleeplessness, nightmares, feelings of guilt, helplessness and hopelessness about the imminent and frequent deaths of patients, and tearfulness' as one of the respondents intimated:

*'It does affect our social lives. Like when they dish up at home, I tell them to dish up some more food and a glass of juice to take to the sick person who has no food and*

*sometimes it is that we work with the elderly and we meet really sad situations. Like I went to see this old mother with grandchildren and food had been brought from her relatives and she asked me to warm it for her and when the child asked for some, the woman said she wouldn't give any of her food from her relatives. I have a heart condition and situations like that make my pressure go up, and that night, I did not sleep. (Participant 1)*

Caregivers experience social stress as a result of alienation from friends and other social activities and also strains in caregiver-care recipient relationship. The economic burden of caring for the sick sometimes falls on the caregivers who often have to grapple with increased cost of living, decreased income from loss of jobs/job opportunities, transport to health facilities and transport of dead/funeral costs. One volunteer community worker pointed out:

*'Most times we run out of supplies like disposable nappies, porridge, gloves etc. Sometimes you get to the sick person and you want to warm water but they won't let you use their stove and say you will use up the electricity, so as a volunteer community worker you go out, look for wood and make a fire and they won't even come out and help you at least to show that they are appreciative for the help you give to the sick person. You do all this and walk away sore and sad wondering whether this person is loved and you wish for a hospice or at least a place where you could take that sick person and look after them knowing that they are not safe with their own family. And the saddest thing is when you hear people talking about you in the community that you are not helping in their houses when you know very well that you have been walking around helping as much as you could. (Participant 8)*

Another aspect that was raised by the volunteer community workers in the course of the study was that they were being ridiculed for doing what they do. Some people in the community looked down on those who had decided to work for free. This denigration was felt by some of the volunteer community workers:

*Now that we are doing this work, people meet us and ask us, "How much do you make doing this work?" so we say, we don't make any money, we are just*

*volunteering and so they say, C'mon, I wouldn't be caught alive doing all that, walking all these long distances, looking after the elderly and doing all that dirty work for no pay?'. This is so discouraging to us to have community members say that. (Participant 8)*

This study shows that many individuals are not in a position to volunteer in home-based care without undermining the wellbeing of their households. The ever increasing needs of the affected households are enormous and intricate. Substantial investment is in the care for people living with HIV/AIDS and their families are therefore crucial. AIDS being a long illness makes a long-standing impact in terms of the work that has to be done. Those in their prime, economically-active years are most likely to acquire HIV infection, and this has a profound impact on the ability of households to maintain viability. The impact of the disease on a household's functioning may build incrementally, and the burden of household work will increase accordingly. Usually, additional dependents are also taken into the home including older relatives, related children orphaned by the epidemic who will also require care and attention. All of this work is layered on top of the existing care that continues to be undertaken to maintain the health and well-being of other household members and with a decreasing amount of household income as previously productive adults fall sick and eventually die. In most cases, these extra burdens of care and support are borne by women, and the implications for their own health and well-being can be enormous.

### *Growing Apathy*

Apathy is a state of indifference where an individual has an absence of interest or concern to certain aspects of emotional, social, or physical life (American Psychological Association, 2008). It is a common feeling of complete discontent for one's emotional behaviour. Apathy can be object-specific, toward a person, activity or environment. It is a common reaction to stress where it manifests as 'learned helplessness' and is commonly associated with depression. It can also reflect a non-pathological lack of interest in things one does not consider important. One of the

volunteer community workers acknowledged the growing indifference amongst community members and explained that the diminishing community spirit has resulted from other factors such as poverty and the onset of new diseases;

*Long ago people used to care for each other but now they do not. It's also about the fact that there is poverty; people are not doing very well economically and... (hesitates) there is no love anymore. Diseases that have come up causing many deaths nowadays.., I think that is why people are just looking and not helping.*  
(Participant 5)

There is growing apathy in South Africa as far as community care and support is concerned. Russel and Schneider (2000) point out that the concept of “community” in South Africa needs to be seen in the light of the country’s political and economic history.

While reminiscing on what used to happen when people lived harmoniously some volunteer community workers commented on how individualism is fast overtaking the community spirit;

*People of generations before ours were more empathetic. They would go to the sick person and help in every way they can, not like today where you have to wear gloves before you can attempt to clean.*  
(Participant 2)

History notwithstanding, South Africa like any other country in the region has been disrupted by issues of migration, urbanization and globalization which mostly increase income inequalities and leave most people in the community poor, unemployed and hence apathetic. One volunteer community worker talks about community support in frustration;

*They don't want to help. They don't even want to join organisations like Uthando Lo Mama our organization because they don't want to help if somebody is sick; they say it's their problem (inkingha yakhe). Many people are selfish.* (Participant 6)

### *Challenges of Volunteerism in Cash Economy*

There is a growing recognition of the importance of social capital in maintaining communities, and volunteering is viewed as one of the major components of social capital (Onyx and Leonard 2002). In some circumstances, assumptions about the role of social capital in communities have resulted in an over-reliance on volunteerism and volunteers to care for and support those infected and affected by HIV/AIDS. The importance of care and support responsibility and its costs for those who undertake it are not recognised in national and international HIV/AIDS policy and programming.

Recent studies have indicated that volunteerism cannot be taken for granted, and that there is a need to provide incentives, material help and skills for this approach to work effectively (UNAIDS, 2000). This is the case because the people who are volunteering in community home-based programs are often the “breadwinners” their own homes. The responsibility of volunteering imposes financial burdens in caregiving as it requires expenditure on meals, medicines, transport costs, as well as diverting their time from other productive chores. Most volunteers with sick family members face the opposing pressures to work fewer hours so as to spend more time caring, or to work more hours to earn more money to pay for increased expenditures. Furthermore, volunteers have to manage competing demands for their household needs such as farming, time with their family, especially children who need guidance with their school-assigned homework, and their own businesses. All these challenges limit provision care and support through voluntary services. In the present study, this was affirmed by one respondent a volunteer community worker in Kwangcolosi who stated that:

*It's about the money, people want to do things that they get rewards for, so it's only a few people that are going to help for nothing. Even there where I went for that service, I realized that there were many people because they were food parcels and blankets so these people were here to get some of these things and that's why they came in big numbers.*

(Participant 1)

*If money was given to those who volunteer that would encourage people to help but the lack of material benefits discourages volunteerism.* (Participant 2)

The above responses confirm that economic conditions are creating a significant departure from the original thinking of volunteerism. Hence people expect remuneration or some sort of compensation such as transport to do volunteer work. A volunteer community worker explained the need for financial facilitation:

*The government could give us money because the people do not want to work for nothing and the government could also give us food parcels to give to those who are sick. Government must pay a little bit to boost us it can give us something for transport at least. And since we are community volunteers, government should help us to have a place of our own which looks like a place of health where people can contact us* (Participant 7)

Most of the responses from the volunteer community workers advocated government involvement in spheres of life including provision of care and support. Due to hunger and poverty that is rife in the community, the volunteers face the challenge of being asked to provide food for the sick in addition to their caring roles. The volunteers also face the challenge of walking long distances on a rough terrain to provide their services which is a big discouragement to them. Volunteers express their concern for the need for government to provide a hospice where all the sick could be cared for in one place- the place which the above volunteer refers to as ‘a place of health. The most critical coping strategy for any household affected by HIV/AIDS is access to community resources as short-term relief for households in desperate need. If too many families slip into destitution, the community safety net can rapidly be overwhelmed, with fewer people within the community such as volunteers able to share their resources just when demand for such resources increases. Little success in developing community-created safety nets is often reported when the majority of people are living in abject poverty.

### *Self-Centeredness*

Self-centeredness refers to a person who is only concerned with himself or herself.

A respondent in Kwangcolosi describing self-centred persons stated that:

*I think that those who don't want to help are hard hearted people, very bad hearted people and community knows them and looks at them in the same way. You see some of them in church uniforms going to church and in my view they would much rather sit at home and not go to church if they are pretenders and when they have a sick person, they also run to me to help. I cannot do much I have to help even though they do not want to help other people. (Participant 1)*

Self-centeredness refers to a person who is only concerned with himself or herself. It may also refer to selfish attitudes towards oneself. In a community like Kwangcolosi, self-centeredness affects the role a person can play to get involved in activities that concern the community as a whole. These persons are easily identified and understood by community members as one volunteer community worker noted;

*Some of the people in the community look at them as bad people but some do not care. (Pause), it's none of their business. (Participant 2)*

Negligence or blatant refusal to help community members in need of care and support is a violation of Social norms where community members are expected to assist one another in times of crisis as one respondent noted;

*That is seen as bad neighborliness. If a neighbour is sick you should go and visit them, when you wake up in the morning, you should greet your neighbour and ask them how they slept, if you don't greet people how will you know what is wrong with them/ Neighbours should help each other, hold each other's hand but for the bad neighbours who don't help, we don't try to punish them (laughs), by doing wrong to those who do wrong to us. (Participant 2)*

Community members who are miserly and stingy are well known to other community members and suffer no penalty but they are held in contempt by other community members as one respondent stated;

*We don't do anything with such kind of people. Some have big gardens but they cannot give for even the sick people for free otherwise you must buy from them. (Participant 7)*

People in the community who display pride and aloofness when they are expected to join in and help those who are infected and affected by HIV/AIDS have sown seeds of discord which has weakened social bonding. A volunteer described the attitude held by the community towards such people;

*They look at them like people who are proud with inflated egos, like people who put themselves above the rest. (Participant 5)*

The above responses depict self-centred people in the community who only approach volunteers when they have a problem but do not help others in need. The community looks at them as pretenders who go to religious organizations like churches and do not embrace the values taught in the churches. The community further looks at these uncooperative self centred individuals as proud people who elevate themselves above others and lack the necessary community spirit.

#### *Limited Awareness*

HIV/AIDS is a new disease that people do not understand as a result, they do not know what to do and how to do it in case a loved one is suffering from the disease. In the Kwangcolosi community, there seemed to be a gap of knowledge on volunteerism, care and support to those who are infected and affected by HIV/AIDS. From the study, it was apparent that even those want to help do not know what to do as one respondent pointed out:

*Like this Organization of volunteers I am involved in should go around and bring the community together teach them that if your loved one is sick, you don't have to run away from them its good to take care of them and respect them... I have personally lost a brother and sister to HIV/AIDS. I was young at the time they died. My mom was working so that we can go to school but whenever I was left with any of the sick people, I had no idea what to do for them, maybe I would only bring what they asked for but did not know that I was supposed to supervise them to take their medication but I loved them. Now whenever I go to homes I do counselling for the sick person and call some family members and counsel them too. I tell them that I don't look after the sick person because I am a fool, I say to them, "I am here to help you to take care of your sick person but you must help too because she/he is your blood and you must not run away from them". I think people can help well if they are well informed on how to mix with the sick, what to do for them; because some don't help because they don't know what to do. (Participant 8)*

The statement of the respondent confirms that lack of awareness can affect the provision of care and support because the would-be volunteers are not sensitized about the right techniques of handling people with HIV/AIDS. The need to educate the public was confirmed by the respondent who stated:

*I think that the community has to be educated about HIV/AIDS. They think that if you go on and help, you might get the disease yourself. They need to know about the things you can do to protect yourself. (Participant 4)*

Some respondents were of the view that people who are already volunteering are best suited to raise awareness around care and support. This was confirmed by respondent who stated that:

*I think the people who are helping already should speak to the community members who do not want to help and make them understand how important it is to help and how neighbours ought to get along and do things together, that there should not be*

*the uplifting of some community members while others get left behind but that as a community we move together and that if something happens to someone, others should be able to reach out and help. (Participant 3)*

Another volunteer community worker who was in agreement with the above respondent suggested group meetings as the best approach through which awareness could be raised;

*If there were more volunteers like us it would help and also if awareness was raised around the helping sick people and being more compassionate, that would help. That could be done by bringing people together in a group and be told what to do. (Participant 2)*

In order to overcome fear that is caused by inadequate knowledge about HIV/AIDS, one respondent suggested educating community members;

*I think that the community has to be educated about HIV/AIDS. They think that if you go on and help, you might get the disease yourself they need to know about the things you can do to protect yourself. (Participant 2)*

The first two set of interviews indicate that lack of awareness is fundamental in the development of care and support systems. The last five sets of interviews indicate that awareness can be made by people who know and have experienced the matters of volunteering.

It is evident from the above responses that while government is already involved in the provision of care and support, the respondents were of the view that government's contribution to care and support can be enhanced by provision of resources such as bandages, over the counter medicines like Zambuk, bigger kits with gloves, diapers, antiseptics. Provision of a stipend to the volunteers so that they can meet expenses associated with volunteering such as transport and daily expenditure is also crucial.

The government's contribution would further be augmented by building hospices, poverty alleviation and caring for orphans.

### **5.7 Volunteer Perceptions of Ways in which Community Members would improve Care and Support**

In the light of the challenges that impede care provision in the community, Volunteer community workers suggested ways in which community members can be involved in care and support for those infected and affected by HIV/AIDS in the following excerpts: It is at community level that people living with HIV/AIDS find care, comfort and support, or suffer rejection and discrimination (Bond, 2002). It is at this level that awareness is spread or ignorance reinforced. It is through people's daily interactions with one another that a climate of compassion and solidarity or of fear and neglect is created (Skinner and Mfecane, 2004). However, it is not guaranteed that all communities that have members with HIV/AIDS are ardent to get involved in care and support of those affected (UNAIDS, 2001). In light of this, the volunteer community workers came up with suggestions they perceive to enable community participation in care and support for those infected and affected by HIV/AIDS as below:

One of the participants suggested raising awareness on the importance of volunteerism in care and support and stated that:

*If people were educated more around HIV/AIDS they would help well. If community members should be more empathetic to go and visit the sick more, it would be good.*  
(Participant 2)

Echoing the importance of raising awareness in the community, another participant stated that:

*I think the people who are helping already should speak to the community members who do not want to help and make them understand how important it is to help and how neighbours to get along and do things together that there should not be the uplifting of some community members while others get left behind but that as a*

*community we move together and that if something happens to someone, others should be able to reach out and help. (Participant 3)*

Material contribution and goodwill from community members were also sighted as another way of strengthening care and support amongst community members as a participant stated:

*The community members like those who have gardens could contribute some vegetables like there are some elderly women who live in isolation such that they have to wait at the end of the month to get pension but if community members contributed spinach here, a cabbage there that would help the sick and elderly to stretch up till the end of the month . Neighbours can bring some meallie meall to the sick people to make porridge at least so that the sick can take their medication when they are not hungry. (Participant 4)*

Another participant suggested formation of clubs as a way of mobilising the community members to get together and marshal efforts for care and support

*If they formed clubs or groups where they share knowledge and do things together then that would help. (Participant 5)*

One of the participants who was in agreement with marshalling efforts also added that when people finally get together, there will be accountability which will result in HIV/AIDS prevention. She stated:

*People could be brought together and taught more about ARVs and how to be responsible for each other as a community. Alcohol is helping the spread of HIV/AIDS because young girls are not answerable to anybody so they stay in Taverns 24 hours and do not even know which man they slept with and hence contract HIV/AIDS and pass it on easily so the community can talk to those girls so that they change their ways. (Participant 10)*

The perceptions of the respondents on how the community can respond better to care and support are broad and varied. They include encouraging community meetings, sensitisation and awareness campaign on HIV/AIDS. Some respondents also deemed

it important that those who are already involved in the provision of care and support should encourage other members of the community to get involved in the provision of care and support. There was almost a general consensus that scarcity of food is a big setback to the volunteers. Therefore, community members can contribute by providing food to those who are infected and affected by HIV/AIDS. Forming clubs or groups and community peer education were also perceived to be important in improving on how the community can contribute to care and support. The responses below demonstrate how important community involvement is in the provision of care and support to those infected and affected by HIV/AIDS. There is however wide spread ignorance both among the volunteers and members of the community on how HIV/AIDS is caused and spread and on the best prevention measures for HIV/AIDS. Poverty also features prominently among the key hindrances to the provision of care and support by members of the community.

### **5.7 Volunteer Perceptions of Continuity of Volunteering**

Continuity of care and support is crucial since there is limited government support of people suffering from HIV/AIDS. However, there is an increasing decline of this support due to new demands of life.

On whether people will be willing to volunteer in 10 years time on in caring and supporting those infected and Affected by HIV/AIDS, the volunteer community workers had divergent views as some of them noted:

*I think the voluntary spirit is dying out because the young generation doesn't have a heart like ours of caring. Besides, I think HIV/AIDS will die out because we are busy teaching people what they must do not to get the disease. (Participant 7)*

*I don't know if people will be willing to help in the future because people are reluctant to help even now. They think that voluntary work is for people who are seated at home doing nothing, so...And the youth who would continue don't look interested, so...I don't know. (Participant 6)*

It is apparent from the above responses that the future of volunteerism is rather uncertain. There is a general feeling among members of the community that volunteerism will die away because the spread of HIV/AIDS would have been controlled and that the rate of HIV/AIDS would have gone down as a result of the current effort by volunteers in the area of sensitization. Also, a section of the members of the community believe that volunteerism will eventually be eroded because of the perception that members have of volunteers. A large number of the community perceives volunteerism as work for those who lack what to do. Other volunteer community workers held dissenting views to the foregoing, as illustrated in the responses below:

*Seeing the way people are getting sick all the time, I cannot predict whether people will still be willing to volunteer in the next 10 years.* (Participant 12)

*Yes as long as there are sick people, as long as there are people who still need help, people will still volunteer even in 10 years, it might also help if us the volunteers talk to the people to help and tell them about the rewards of making people feel better.* (Participant 4)

Some of the volunteer community workers were non-committal as to the future of volunteerism. The high rate at which people are getting infected has been cited as a demoralizing factor to the volunteers. The number of volunteers is not proportionate to the number of those who are infected and affected by HIV/AIDS. Lack of facilitation to the volunteers does not help the situation either. On the other hand however, some volunteer workers noted that as long as there are sick people in the community, volunteers will be motivated to volunteer. Another volunteer community worker expressed optimism about the future of volunteerism:

*People might be thinking about helping in 10 years time. Many people are beginning to get interested and are inquiring about how they can join HBCs and we tell them to go to people and start helping.* (Participant 4)

*I think so because I think that by that time, people will be educated around issues of HIV/AIDS.*  
(Participant 2)

The above responses indicate that there is mixed reaction on whether people will be willing to volunteer in the future. Most respondents on one hand were not certain about volunteering in the future and some cited lack of enthusiasm in voluntary activities by the youth, and many would-be volunteers getting infected. On the other hand, other respondents were hopeful that there will be volunteering in future emanating from their awareness raising activities in the community in addition to the growing interest in the community about volunteering.

## **5.8 Conclusion and Summary of Findings**

This chapter analysed the findings based on the elements of social capital and in addition challenges and perceived facilitating factors were highlighted.

### *Conclusion*

The chapter focused on the analysis of data on how care and support around HIV/AIDS is perceived by volunteer community workers in Kwangcolosi, Kwazulu Natal. In analyzing the data, the chapter demonstrated how volunteer community workers perceive care and support around HIV/AIDS provided by them and by the community members to those infected and affected by HIV/AIDS. The chapter further illustrated perceived challenges of implementing care and support and facilitating factors to care and support were also highlighted.

The study concludes that stigma and discrimination are some of the serious barriers to care and support for those infected and affected by HIV/AIDS. According to the volunteer community workers, stigma and discrimination have weakened the traditional safety nets of care and support by households and the wider community. The fear of stigma intersects with other psychological processes to do with HIV infection, including guilt at potentially having infected others, fear of illness and

death, feelings of inadequacy, and denial to aggravate the already worsening situation of limited care and support. Reciprocity and cooperation which are important for facilitating care and support are undermined by poverty whereby people may have the spirit to contribute but have nothing. Volunteerism is also diminished by expecting government's reciprocity in form of pay or stipend. Volunteers who have been instrumental in providing care and support lack the essential resources and this coupled with difficult conditions under which they work have impeded provision of their services for those affected by HIV/AIDS in the community. Altruism which was considered a major driving force in the provision of care and support by volunteers is impaired by many expectations of volunteers who hope to be trained as nurses.

Community solidarity which is fundamental in bringing people together to boost existing care and support is on the wane. It has been greatly undermined by rural urban migration, poverty, unemployment and effects of HIV/AIDS. With the increasing prevalence rates of HIV/AIDS in Kwangcolosi, the community may find it difficult to continue to take care and support those infected and affected by HIV/AIDS. In the current study, many of the participants revealed that there are numerous socio-economic difficulties in the area such that kinship support was found to be hardly available. Migration and the splitting-up of families have led to weakened family ties. Beyond the immediate and extended family, households in crisis who have been assumed to turn to friends and neighbours for assistance have been deterred by poverty which limits the support one can get from relatives. The current study also found that support from friends and neighbours tends to be short-term and unreliable, usually limited to prayers and emotional support. Suspicion and accusations arising from fear create an atmosphere of dwindling interpersonal trust which impedes access to care and support that might be provided by community members.

### *Summary of Findings*

In terms of trust: denial, mistrust and stigma and discrimination were drawn out as some of the hindering factors of social trust which in effect weakened social bonding

and bridging. Weak social relationships both at the household, community level and civic society level affect the provision of care and support to those infected and affected by HIV/AIDS.

Social norms were estimated to be on the wane. Going through the historical trail, some respondents noted that the African togetherness that people leaned on in crisis times in rural and peri-urban areas such as Ubuntu was seen to be diminishing because of factors such as rural urban migration, urbanization, globalization, poverty and unemployment.

Regarding social networks, horizontal networks amongst community members existed though feeble. Factors advanced for the weakness in the networks included lack of time to get together, the divisions fuelled by religious beliefs and cultural beliefs, limited awareness about volunteering and HIV/AIDS and inadequate government support for volunteers. The networks amongst groups that operate in the Kwangcolosi area were undermined by competition and uncoordinated groups which all provide care and support.

Reciprocity existed where community members borrowed from one another and that family relations played an important role in care and support of those affected by HIV/AIDS. Community members also made some contributions especially to those they cooperated with but their contributions were often affected by factors like poverty (lack of material things to contribute), self-centeredness in addition to the fact that HIV/AIDS was a new and mysterious disease. The fear of contagion in this case weakened social cohesion and hindered effective care and support from community members.

Poverty has been compounded by the prevalence of a high number of orphans which has also culminated in child-headed families. This in effect has escalated the spread of HIV/AIDS because young girls resort to commercial sex so as to be able to support their families. The meagre pension earned by the few individuals is not sufficient to

sustain a family. Therefore persons infected and affected by HIV/AIDS look to volunteers for the provision of and financial support which volunteers cannot afford.

The effect of myths and traditional/cultural beliefs cannot escape mention here, it is apparent from the various responses obtained in the course of this study that some people who are infected with HIV/AIDS are reluctant to take ARVs under the honest but mistaken belief that ARVs are dangerous and poisonous they therefore prefer traditional healers. This explains why in some instances volunteers are shunned for fear that they are going to encourage them to take ARVs.

Stigma and ignorance are some of the biggest hindrances to care and support by volunteer. In certain instances those that are infected with HIV/AIDS deliberately decline to disclose their HIV-status for fear of being discriminated against and being isolated in the community since owing to ignorance, it is believed in some sections of the community that HIV/AIDS is contagious. Therefore not only are those suspected to be infected with HIV/AIDS isolated but also eliminated by killing. Therefore a person infected with HIV/AIDS would rather live in denial than expose him/herself to violence. Hence it is increasingly becoming difficult for the volunteers to disseminate information to those infected with HIV/AIDS until they reach such a stage when the symptoms and signs are so clear that one cannot hide any more in which case it may be too late for ARVs.

While volunteers have played an important role in providing care and support to those infected and affected by HIV/AIDS, there is an urgent need to sensitize members of the community about the following: ways, in which HIV/AIDS is spread, the importance of ARVs, stigma and discrimination, measures to reduce poverty in this community should be devised. There is need to financially facilitate volunteers to motivate them to make it possible for them to meet expenses that are associated with volunteering such as transport and subsistence.

## **CHAPTER SIX**

### **CONCLUSION AND RECOMMENDATIONS**

#### **6.1 Conclusion**

This study related the elements of social capital to care and support around HIV/AIDS using Kwangcolosi, Kwazulu Natal as the study area. Social Capital which is the attitude, spirit and willingness of people to engage in collective action is very crucial in maintaining communities and sustaining social infrastructure. It acts as a social springboard for community members' survival and welfare where volunteering is viewed as one of its major components, particularly in resource limited settings. Social capital is applied to a variety of contexts to explain the ability of communities to solve the problems that require collective action. It is applied to problems ranging from the provision of public education, maintenance of effective and smooth-functioning government institutions, as well as the exercise of informal control over criminal behaviour. Social capital however, cannot be totally delinked from economic and human capital although it provides additional insight into the obstacles of care and support.

In terms of measuring of social capital, the study adopted four of the elements of social capital which include trust, reciprocity, social networks and norms and these were analysed under the bonding and bridging levels of social capital from the volunteer community workers' perceptions of care and support in their community. It was established in the course of the study that whilst social capital impacts positively on care and support through its core elements of social norms, trust, social networks and reciprocity, it is not devoid of negative consequences which include the exclusion of outsiders, restrictions on freedom of individuals and downward levelling of norms.

The volunteer community workers in Kwangcolosi were of the view that the burden of care and support has often fallen heavily on the shoulders of impoverished rural communities where family members infected with HIV/AIDS return when they can

no longer work or care for themselves. In light of the burgeoning number of persons who need care and support, community-based care or home based care has been promoted as the best option since it would be impossible to care properly for hundreds of thousands of people dying from AIDS in public hospitals. However, it is dangerous to assume that communities have limitless resilience and capacity to care for dying people and provide for those they leave behind. There is a critical need for social protection and interventions to support the most vulnerable communities and households affected by this epidemic. Preserving extended family and community ties is also an insurance mechanism because such ties allow families to share risk and gain access to additional resources. There is therefore an urgent need to promote community solidarity, moral and reciprocal support. The study came up with a number of findings.

Many households in South Africa barely survive, through casual work, subsistence gardening or trading, old age pensions or mutual borrowing and assistance. The impact of AIDS has stretched these survival strategies to breaking point in many cases. The burn out has come up as a result of some of those infected and affected by HIV/AIDS having to queue all day at a clinic with a sick relative, having to bury numerous loved ones, neighbours having to attend or help pay for very many funerals and grandmothers having to take care of so many orphaned grandchildren. To this extent, volunteer community workers play an important role in sharing the burden with those infected and affected by HIV/AIDS

It was established in the course of the study that the perceptions of HIV/AIDS in Kwangcolosi community is characterized by denial, stigma and discrimination. These have caused mistrust and shame among community members which have undermined the provision of care and support. Stigma stems from fear of contagion and fear of disclosing one's HIV status. As regards to community cohesion, the general finding was that people and neighbours get along by way of sharing food, visiting each other and sharing communal gardens. However, religion and politics have been divisive factors that have undermined social bonding. Togetherness in the Kwangcolosi

community was attributed to altruism and Ubuntu. Ubuntu in this context was seen as a cultural world-view that captures the essence of what it means to be human, hence a foundation of care and support systems in the community. The volunteer community workers drew a clear distinction between the concept of Ubuntu today and in the past.

While in the past Ubuntu among other things, took the form of women's groups getting together as a community to provide both social support and material support such as food to the needy members of the community. Men went out to look for work as they were the sole bread winners. But today, women who were mainly involved in helping one another in the past have taken up paid employments. The existence of volunteer community workers today is evidence that Ubuntu still thrives. However it is no longer embraced by the entire community as the case was in the past. This explains why the level of participation in volunteering to provide care and support to those infected and affected by HIV/AIDS is low.

The ideal of Ubuntu was however deemed to be on the decline in the community, also highly undermined by many factors such as poverty, high rates of unemployment, rural urban migration, and the advent of HIV/AIDS, hence these factors led to apathy that was suffocating the community spirit. The Kwangcolosi community follows practices that have encouraged togetherness. These practices include: cultural ceremonies, art and craft groups, stokvels, communal gardens, sewing clubs and poultry.

The volunteers made a distinction between the perception of care and support in the past and today. They noted that care and support in the past was in form of people visiting each other and provision of food to the sick. In addition, there were not many hospitals; therefore, recourse was sought through traditional healers (inyangas and sangomas). Today, the dawn of HIV/AIDS has given a different depiction to care and support. The support that was normally given to the families with the sick has started diminishing due to many factors that include stigma and discrimination and fear of contagion among others. Whilst a few neighbours and friends are still willing to volunteer and help those infected and affected by HIV/AIDS, community

togetherness is perceived as ebbing if this volunteerism is not recognized and strengthened.

Provision of care and support by community members of Kwangcolosi has been largely by women most of whom are elderly. The volunteer community were workers observed that the low community participation in the provision of care and support especially by the youth to those who are infected with HIV/AIDS is due to fear of contagion and general lack of interest. Contribution by the community members towards care and support in terms of time and resources is hindered by poverty, limited awareness on HIV/AIDS, and the growing apathy especially from the youth who come across as individualistic and shunning community spirit. Nonetheless, there is some small scale contribution in terms of funeral expenses, food, prayers, fetching water and cooking especially for the elderly. The main set back to contribution in terms of resources and time is that the patients usually turn away members of the community who would be willing to help for fear of disclosure, guilt and shame.

Community members have been motivated to participate in the provision of care and support to those infected and affected by HIV/AIDS by the improved knowledge about HIV/AIDS, compassion. Others are motivated by their own family experience of losing loved ones. A number of factors were cited as hindering volunteerism which also included lack of facilitation. There is general mistrust between family care takers and volunteering neighbours for fear that the neighbours will disclose the HIV status of the sick person to the community. Some volunteers also get a rude reception from the relatives of those infected with HIV/AIDS for fear of disclosure. Some volunteers are discouraged by the ingratitude of the members of the community who perceive them to be salary earners and hence heap all the care work on them. Volunteering is becoming increasingly difficult for people to undertake activities in which they donate their time and effort because most of them are the bread winners in their own households such that paid jobs take precedence over volunteering. Even those already

involved in voluntary work need a small stipend to be able to meet expenses that come with volunteering such as transport.

Trust has facilitated volunteerism in the care and support for people infected and affected by HIV/AIDS and the lack thereof has led to negative consequences which have undermined social bonding. Volunteers' views suggested that people affected and/or infected with HIV/AIDS had lost trust in their neighbours and as a result there was mistrust and shame, stigma and discrimination, and denial on the part of people living with HIV/AIDS. According to the volunteer community workers, lack of trust is usually generated by internal stigma and feelings of guilt on the side of the sick person and the family and may also be perpetuated by the new norms of fear, denial, stigma and discrimination that are associated with HIV/AIDS. This lack of trust of the community members by those infected with HIV/AIDS and their families has led to the break down of social cohesion in most communities. In effect, those infected and affected by HIV/AIDS do not get the much needed care and support from the community members.

The social norm of altruism was demonstrated by the desire by the volunteer community workers to work for the good of others. This was cited by the volunteer community workers as the main reason for volunteering to provide care and support to those infected and affected by HIV/AIDS. Many volunteer community workers acknowledged that they knew the scale of HIV/AIDS and that much care and support for those infected and affected was needed in their community hence the spirit of altruism.

Reciprocity applies to care and support in that some members of the community provide care and support expecting that the favour will be returned in cases of sickness and death from HIV/AIDS. Family caregivers may provide care and support for lack of choice. Their support is based on the love and emotional attachment for their sick relatives which sometimes culminates in long term motivation to care and support them throughout the sickness.

The role of Social Networks and Bridging in the provision of care and support to those infected and affected by HIV/AIDS cannot be overemphasised owing to the fact that volunteer community workers alone cannot tackle or take responsibility for all the care and support of HIV/AIDS infected and affected persons: In the course of the study, it was found that some community members make material contributions such as food to facilitate care and support activities. These contributions encourage care and support for those infected and affected with HIV/AIDS and even motivate volunteer community workers

In a few isolated cases however, family members leave their patients with a few trusted neighbours. The expectations of family care givers from caring for those that are infected and affected by HIV/AIDS ranges from desire to see patients recover, sense of duty to love for the sick. On the other hand volunteer community workers give the service out of sheer altruism while others derive satisfaction from seeing that the patient is healed, they also expect to attain community solidarity through provision of care and support; others expect that they will one time be paid a stipend. The reasons for volunteering in the provision of care and support range from ones personality, compassion, reciprocity to expectation of a stipend.

While government is already involved in the provision of care and support, the respondents were of the view that government's contribution could be made better through facilitation ranging from provision of stipend and resources such as bandages, over the counter medicines, cleaning agents, provision of bigger kits of gloves, diapers, and antiseptics. Government's contribution could also take the form of motivating community members to provide care and support, provision of food parcels for the sick, making available teaching facilities to the volunteers and making provision to the orphans and vulnerable children.

Most respondents noted that there was a need to raise awareness on HIV/AIDS care and support in the community. HIV/AIDS as a new disease that comes with distressing symptoms and long illness is baffling to community members. They

revealed that most HIV/AIDS programmes in the media concentrated on prevention while care and support was not given the attention it deserved. As a result, denial, stigma and discrimination were still rife in the community and even those who loved their patients and wanted to care for them did not know how to go about it. The volunteer community members were of the view that community members' response to care and support would be improved through community meetings, sensitization about HIV/AIDS. They also stated that community contribution would also take the form of providing food to the sick and forming knowledge sharing groups. Community members that do not participate in the provision of care and support are considered hard hearted, bad people, bad neighbours, proud with an inflated ego. They are sometimes subjected to retribution in their own time of need.

In terms of continuity of care and support in the next ten or so years, the responses were broad and diverse. Some respondents were of the view that people in the community will emulate the good work started by the present volunteer community workers and opt to carry on with it. Other respondents were of the view that volunteerism will continue due to improved awareness of HIV/AIDS. Some respondents expressed optimism that as long as there are sick people, there will always be volunteers. Others were non-committal and uncertain of the future of volunteering.

Despite the optimism, there is a need for government and other stakeholders to recognise and acknowledge community responses of care and support services and the acknowledgement of those responses will determine for how long and how effectively these responses can continue. Individuals concerned for their friends, neighbours, and extended family members often organize to provide moral support and material relief to households affected by HIV/AIDS. They create a safety net for the people in their community whose immediate survival is threatened. When HIV/AIDS overburdens extended family support mechanisms, the community's role becomes critical. Such community efforts reinforce families' ability to cope with their burdens. The impact of AIDS is stretching these survival strategies to breaking point

in many cases in the communities. As the number the sick and helpless in the community grows, and the burials become an everyday chore, and grandmothers assume the parenting role, the challenges to care and support need to be addressed so that the necessary interventions sought to step up efforts to meet the ever increasing demand of care and support.

## **6.2 Limitations of the Study**

All my respondents were volunteer community workers who sometimes misinterpreted my position as a student researcher and responded as if I was compiling a report to government to articulate their 'cause'. Whilst there was clearly truth in most answers, some responses may have been biased towards the need of further financial support and funding partly through (unfortunately false) perceptions of my being from Government. I was given the impression that some people saw this as an opportunity to try to secure further funding. However my familiarity with those I had met previously may also have been an advantage: people may have felt more comfortable with me than a complete stranger and I could elicit more open and honest answers.

I tried to constantly explain my position and used different methods of data collection like use of narratives, focus group discussions, and one on one interviews to balance this out but I doubt I overcame this barrier entirely.

Being a black woman could have helped me to get through to the respondents as I observed that they were relatively relaxed until they knew that I was from another country (Uganda) and moreover did not speak their language (IsiZulu). Being from the University also gave me a higher status than the respondents such that the first interviews, the respondents kept asking me whether they had answered the questions well and I had to always re-assure them at the beginning of the interview that there was no wrong or right answer. I also noticed that most of them would thank me afterwards for 'teaching them a lot' which might have been related to the fact that I was from the University. I had to explain that I was here to learn from them instead.

The use of a translator would have inevitably led to some of her own interpretation being added to responses, however, this was balanced by two benefits: firstly, the translator being a Zulu girl herself was more approachable for the respondents and, secondly, my interpreter's local knowledge and insight of the Zulu culture, enabled me to see the rather subtle way that people express the issues and concerns which could otherwise have been lost. The sensitivity of this topic and the short time-span of my visit meant that my methods of inquiry were restricted. The volunteer community workers asked me to help them with some paperwork for their organization and I observed this helped to build the trusting relationship required for these issues.

### **6.3 Recommendations**

This research identified that the main gaps in achieving adequate care and support around HIV/AIDS in KwaZulu Natal include: growing apathy, self centeredness limited awareness, limited social cohesion, the mystery of the new disease; fear and denial of HIV/AIDS infection; general lack of resources for care and support services and challenges of abject poverty and volunteering. Based on the above gaps, the following recommendations are proposed:

#### **6.3.1 Promotion of social cohesion**

There is an urgent need to revive the philosophy of Ubuntu, community solidarity and moral and reciprocal support. Volunteers should be encouraged to promote these three important notions, institutions such as schools and religious organisations should also get involved in the exercise of promoting Ubuntu, community solidarity and moral and reciprocal support. Revival of those notions will lessen the volunteers' work load since community members will be in a position to render a helping hand to those who are in dire need of support and care as a result of HIV/AIDS. This in effect promotes self-sustenance in these communities. Competition between organizations was also mentioned as a stumbling block in terms of record keeping and reporting. Competition for clients, overlapping services, and clients using multiple services were all raised as issues affecting data collection and reporting. It was recommended that

HBC programs, in conjunction with government and donors, develop a standardized reporting system that responds to the needs of all parties.

### **6.3.2 Raising awareness on care and support**

The volunteers in Kwangcolosi lack training in community-based HIV prevention, treatment, care and support. As a result, the quality of care and support given to those infected and affected by HIV/AIDS is inadequate. Volunteers and other community members at large need to be trained to ensure that barriers to care and support such as denial are diminished among those that are infected and affected by HIV/AIDS. This can be done by using local mass media and theatre (drama, music, and dance) as an intervention to alleviate stigma and discrimination, self centeredness, and demystify the notion of the “mystery of the new disease” thereby promoting care and support.

### **6.3.3 Funding**

Grassroots initiatives such as volunteering for care and support must be funded to scale up and maximize care and support at the community level and to enable grassroots practitioners to claim respect and recognition from professional health and development workers. Networks of grassroots volunteers must be resourced to promote the exchange of effective responses and to facilitate their participation in the bottom up design of policy and programs related to the pandemic care and support initiatives. In recognition of community contributions, donors, governments, and development agencies should commit a percentage, at the minimum percentage of all HIV-Aids funding, to community based programming and organizations especially those that are currently undertaking care and support single-handedly.

There is also need for a concerted effort from governments, NGOs and grassroots communities to work in partnership to establish a code of ethics that guides resource mobilization and allocation rooted in the principle that those most affected should have the greatest say. Standards of accountability that protect HIV AIDS funds from corrupt use and that dismantle elite and bureaucratic systems that widely hinder the proper use of resources must be put in place. Such funds could be used to remunerate

volunteer community workers, provision of equipment to be used by the volunteers in the course of their duties, meet the volunteers' transport costs and construction of hospice.

#### **6.3.4 Capacity building**

South Africa should adopt the WHO/IFRC training package so that the quality of information and the skills of volunteers and informal care givers can be improved. Care and support initiatives must become job creation programs in this community to enable grassroots women and communities to sustain the work they have been doing informally over the years. Poor communities should be trained and funded to conduct their own needs assessment and to evaluate and monitor existing HIV/AIDS related care and support service programs. The government should set aside training and capacity building funds which must be redistributed away from professional support to underwrite peer learning and community- to-community exchange of expertise and methods and equalize training opportunities.

#### **6.3.5 Long term funding is needed for HBC programs.**

Programs need long term funding if they are to provide good care for their communities. Clients will expect programs to deliver care for as long as they need it and there needs to be continuity in service provision especially due to the fact that many more people are getting infected with HIV/AIDS. Longer term funding will allow HBC programs to plan for the future and strengthen their programs. Studies quantifying the contributions of HBC programs to the quality of life of clients may be useful in securing donor and other funding.

#### **6.3.6 Need for initiatives to provide economic and emotional support to volunteer caregivers**

Volunteer caregivers are often as poor as the households they are serving and need stipends if they are to deliver services. In addition, volunteers need assistance with emotional support and may have medical needs of their own, including access to

treatment. Policymakers and donors need to consider these needs when drawing up policy and funding priorities.

#### **6.3.7 Clarity is needed on training and payment for home-based caregivers.**

There is little clarity from the government on training and payment for volunteers. The Department of Health does not currently recognize training programs run by other organizations, and it is difficult to register training programs with the local skills training body. Stipends also need to be standardized with donors and with the relevant government departments.

#### **6.4 Areas for Further Research**

- Care and support to persons with disabilities resulting from HIV/AIDS should research about.
- Further studies are needed to investigate the extent to which families can provide care for people living with HIV or AIDS.
- There is need for research that seeks to explain the underlying socio-cultural factors that compel elderly women and not their male counterparts to provide care and support to those infected and affected by HIV/AIDS.

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## APPENDICES

### APPENDIX 1 (a)

**UNIVERSITY OF KWAZULU-NATAL**  
**MA HEALTH PROMOTION IN PSYCHOLOGY**  
**FOCUS GROUP AND INTERVIEW CONSENT FORM**

I, Annette Kezaabu Kasimbazi (Student number: 206516829), am currently working on a Masters in Health Promotion project, the topic of which is *Exploring how care and Support around HIV/AIDS is perceived by volunteer community workers in KwaNgcolosi, Kwa-Zulu Natal*. The project necessitates focus groups discussions and semi-structured interviews with volunteer Community workers. Participation in these focus groups, and interviews is voluntary, with the understanding that:

- Strict confidentiality in respect of each individual will be maintained
- Anonymity will be respected and if desired, no names will be used in the finished project
- Any person who wishes to withdraw from the research may do so without fear of judgment or repercussions
- A professional conduct will be adopted with respect to the feelings and information shared between researchers and the participants.

It is the requirement of the University that a consent form is signed by all respondents so as to maintain a professional code of ethics on the part of the researcher.

If any further information is required from participants, they may contact the project supervisor Professor Yvonne Sliep on 031 260 7982 (work).

I, \_\_\_\_\_ acknowledge that I have read the reasons and conditions presented for the MA project being undertaken by Annette Kezaabu Kasimbazi and that I voluntary participate in said research.

\_\_\_\_\_  
Name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**APPENDIX 1 (b) Consent Form in Isizulu**  
**Imvume yokubuza iqoqo labantu imibuzo**

Mina, Annette Kezaabu Kasimbazi (Student number: 206516829), owenza izifundo zeMasters kwezokuthuthukiswa kweZempilo, osihloko sithi *Exploring how care and support around HIV/AIDS is perceived by Volunteer community workers in KwaNgqolosi, KwaZulu-Natal*.

Lezifundo zidinga ukuthi iqoqo labasebenzi beZempilo baphendule imibuzo, bese ngamunye ngamunye anginike ulwazi olujulile ngahlangabezana nako emsebenzini wokunakekela izimo ze HIV ne AIDS emphakathini asebenza kuwona. Ulwazi oluningi luzotholakala emdlalweni weshashalazi ozokwenziwa ngabasebenzi beZempilo.

Ukuphendula lemibuzo nokudlala umdlalo weshashalazi akuphoqeletwe, futhi abazobandakanyeka bayazi ukuthi:

Lonke ulwazi olunikeziwe angeke lwaziwe omunye ngomunye.  
Ukuzibandakanya kwabo kuzohlala kuyimfihlo, angeke amagama angempela asetshenziswe embhalweni ophelele ozogcinwa.  
Noma umuphi umuntu ofuna ukuyeka ukubandakanyeka nokuphendulwa kwemibuzo angayeka noma nini ngaphandle kokusaba ukuhlukunyezwa.  
Ababuza imibuzo bazoziphatha ngendlela enenhlonipho emphakathini.

Kuwumgomo weUniversity ukuthi lesisivumelwano sisayinwe ngabo bonke ababandakanyekayo kulezifundo ukuze kubonakale ukuthi lona obuza imibuzo uyilandeleli imigomo ebekiwe.

Uma kunolwazi oludingekayo, ungathintana nomphathi wabafundi (supervisor) uProfesa Yvonne Sliep ku 031-260 7982 (ofisi).

Mina, \_\_\_\_\_ngiyavuma ukuthi ngiyifundile imibandela nemigomo ebekiwe ukwenziwa kwalwezifundo zeMasters ngu Annette Kezaabu Kasimbazi nokuthi angipheqeletwe ukuzibandakanya kulezifundo.

\_\_\_\_\_  
Igama

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## APPENDIX 2

### **Interview guide for semi structured Interviews**

1. How is HIV/AIDS perceived in your community?
2. How well do people of KwaNgcolosi community get along?
3. Are there any practices supportive of doing things collectively?
4. In your tradition, how do you handle situations of sickness in relation to the sick people and their care takers? And now in relation to HIV/AIDS, how are the sick handled?
5. What would encourage community members to participate in taking care of those sick with HIV/AIDS?
6. Do community members who have sick people welcome other community members who come to visit the sick person? Or
  - Do the patients' care takers feel free to leave the sick in the hands of volunteering neighbours?
7. What are your expectations as a volunteer community worker, when you care and support those infected and affected by HIV/AIDS?
8. What would happen to people who do not want to volunteer to care and support people with HIV/AIDS?
9. What do people contribute to each other?
10. If somebody in your community is sick with HIV/AIDS, who is the first to take care?
11. When does government come in?
12. Would people in your community or yourself be willing to volunteer in 10 years time?
13. How do you think community members would respond better?
14. What are some of the challenges to volunteering?
15. How do you think Government would contribute to the voluntary spirit in the community?

## APPENDIX 3

### **Sample Interview: Participant 6**

#### **How is HIV/AIDS perceived in your community?**

AIDS is a big disease in this community. Even young children are dying just because their parents refuse to test when they are pregnant. And then they all deny that they are going to get it. Whenever we try to tell them that HIV/AIDS is here and it will kill many people if we don't care they say 'I won't die from AIDS because it's for people who have many boyfriends and they don't know that all unprotected sex is potentially risky whether with your husband or one boyfriend.

#### **How well do people of KwaNgcolosi community get along?**

They don't want to do that. They don't even want to join organisations like Uthando Lo Mama our organization because they don't want to help if somebody is sick; they say it's their problem (inkingha yakhe). Many people are selfish.

#### **Are there any practices supportive of doing things collectively?**

There are some stokvels and some women are doing gardens and some are baking but young people don't want to join these groups and I think it's more of an age thing. The youth can only learn well if there are facilities to learn and if maybe if some people came from other provinces to teach them. Like when I visit home I take knowledge to the young people and they are willing to learn but lack facilitation.

Things have also changed these days that young people also lack respect. In the old days, men were head of the family but now the contribution is 50-50. And even young children don't respect their elders because of this rights thing. They say I have got my own rights and I cannot do anything other people tell me to because I have got my own rights and I can only do what I want to do not what my parents tell me to do. Rights have gone to the heads of young people to make them act differently.

#### **In your tradition, how do you handle situations of sickness in relation to the sick people and their care takers? And now in relation to HIV/AIDS, how are the sick handled?**

In the olden days, HIV/AIDS was not known and there were not many diseases. The only diseases were like those one got from drinking dirty water because some of them drunk water

from the wells where also cows drank and got water borne disease but even then, if someone died, they dug a hole and buried their person respectfully but now if you just dug a hole as a community and buried that person you get arrested. This is because when someone dies you have to take them to the mortuary and postmortem is done and other tests before they are buried.

Also in the olden days people visited each other and brought food for the sick person and even those who are caring for her/him because they knew the carer had no time to prepare food. But nowadays, people don't bring food, or even anything, if someone is sick they say it's her/his problem. Even some relatives of the sick, when we go to see the person, they tell us, "there is your person" and you realize that family doesn't want to have anything to do with the sick person. Even some of the mothers..Eish..(Hesitates)..They don't want to help their children they say .."I wasn't there when she/he got it". But some mothers still do care.

### **What would encourage community members to participate in taking care of those sick with HIV/AIDS?**

Like this Organization I am in Uthando Lo Mama should go around and bring the community together teach them that if your loved one is sick, you don't have to run away from them its good to take care of them and respect them because it is your blood coz I have personally lost a brother and sister to HIV/AIDS. I was young at the time they died. My mom was working so that we can go to school but whenever I was left with any of the sick people, I had no idea what to do for them, maybe I would only bring what they asked for but did not know that I was supposed to supervise them to take their medication but I loved them. That Love has made me pursue to be a home based carer. Now whenever I go to homes I do counseling for the sick person and call some family members and counsel them too. I tell them that I don't look after the sick person because I am a fool, I am here to help you to take care of your sick person but you must help too because she/he is you blood and you must not run away from them. I also encourage them not to blame the sick people.

### **Do people who have sick people welcome people who come to visit the sick person?**

No, they don't. I might tell some one of our peers that one of us is sick and when the friend goes either of the family members of the sick says "what do you want here?" If the friend

insists they were told that there was a sick person, the family member says to them, “the person you are looking for is not here, go away”. Sometimes it is difficult to get into these families because they don’t want their homes to be associated with HIV/AIDS. Even the community members really ...Eish.(pauses, disturbed) stigma is a big thing here my friend. When one has HIV/AIDS, it’s as if there is a big label on their forehead saying “INGCULAZI” as they walk which also means “HIV/AIDS positive” and people give them names like there goes “INGCULAZA”

Even if you had friends before you got HIV when people know you have it, you lose those friends and so many people who are infected are undergoing a lot of stress that when we meet them they are suicidal but then we are trained to counsel them.

**Do the patients’ care takers feel free to leave the sick in the hands of volunteering neighbours?**

Some people do trust some neighbours but those who do call us to take care of their sick person. You can only leave the sick person with a few trusted friends because there is also the problem of TSOTSIS.

**What are your expectations as volunteer community workers when you care and support those infected and affected by HIV/AIDS?**

We expect that the sick people get better, healthy, nothing much more. I am a volunteer. If the person is lying in bed powerless, I continue to give care and medicine and one time when I meet them walking the streets, I am happy that I helped someone get well, and contributed that way and they are grateful and usually say, “Thank you, you helped me get back on my feet” and that makes me happy.

**Are there any NGOs operating in this area?**

No, it’s only Uthando Lo MAMA only that I know.

**What would happen to people who do not want to volunteer to care and support people with HIV/AIDS?**

Some community members would like to punish them and me too, I think they should pay for being selfish. For example when my sister was sick I was going to school and my younger sister also was going to school, we asked my neighbour to help my sick sister but she refused, my sister later passed away but now her daughter also got sick and she came to ask for our help that my sister and I help her. We also said “no” because she had refused to help us with ours. We later realized that we were wrong to refuse and pay wrong with wrong and we went and helped. She was ashamed and came and apologized that she had not helped us in the first place.

### **What do people contribute to each other?**

For some very very poor families when their sick person dies, the councilor can go to the mortuary and help with the arrangements while some community members contribute some little money to cover the small funeral so that that person can be buried in peace.

And in sickness some people help and contribute some little food from home and if “my person” is going to the hospital has no transport, I might take from my pocket and donate it so that they can go to the clinic.

### **If somebody in your community is sick with HIV/AIDS, who is the first to take care?**

It is usually the ONOMPILO (community health workers) because they are the ones who walk the villages and establish cleanliness and hygiene and when they hear or see that there is a sick person in this or that village and me as a home based carer, I have to go bath her, change her linens and help the person to take her medication very early in the morning so that whoever comes to see the person will find them clean and bathed. The Onompilos know first because they are well known in the villages and they came earlier than home base carer so many people know Onompilos than the home based carers the Onompilos introduced the home based carers.

### **When does government come in?**

Government donate nappies, Vaseline, ARVS etc but that only happens if the sick person has gone to the clinic, tested HIV positive and had their CD4 count tested.

**Would people in your community or yourselves be willing to volunteer in 10 years time?**

I don't know because people are reluctant to help even now. They think that voluntary work is for people who are seated at home doing nothing, so...And the youth who would continue don't look interested, so...I don't know.

**How do you think community members would respond better?**

I think people can help well if they are well informed on how to mix with the sick, what to do for them; because some don't help because they don't know what to do.

**How can the youth be helped to make their contribution?**

If we can have sports and games in the community and have a talk about HIV/AIDS before the game, the youth can listen better if there are many activities and you get audience with the youth in that way.

**How do you think Government would contribute to the voluntary spirit in the community?**

Maybe if the government can provide facilities to teach people about HIV/AIDS. The government should also think about the safety of the orphans and vulnerable children from hunger and rape.

**APPENDIX 4 (a)**  
**Focus Group discussion cues**

1. How well do people of KwaNgcolosi community get along?
2. How helpful are people of KwaNgcolosi to each other during the time of HIV/AIDS sickness?
3. How willing are neighbours to volunteer in taking care of the sick in this community?
4. Do the patients' care takers feel free to leave the sick in the hands of volunteering neighbours?
5. What are your expectations as volunteer community workers?
6. What sanctions are imposed on neighbours who don't volunteer to help those infected and affected by HIV/AIDS?
7. Is there Fair contribution in the KwaNgcolosi community in terms of time and resources? If so, what is commonly contributed?
8. In your view, what motivates individuals or groups to engage with HIV/AIDS-related issues in a public or collective way?
9. Are there certain conditions (norms) under which community responses emerge and are sustained in the KwaNgcolosi community?
10. In what ways, in your view would government, CBOs, FBOs, NGOs or donor policies better support and encourage such activity in the community?

## APPENDIX 4 (b)

### **Focus Group discussion cues in Isizulu**

#### **Imibuzo yabantu abayiqoqo**

1. Abantu bakwaNgcolosi bazwana kangakanani?
2. Abantu bakwaNgcolosi basizana kangakanani uma omunye wabo ephethwe yingciwane lengculazi?
3. Omakhelwane bazimisele kangakanani ukuxhasa ekunakekelweni komuntu ophethwe isifo sengculazi?
4. Ngabe onompilo abaqeqeshiwe ukunakekela abagulayo bayakhululeka yini ukushiya iziguli zabo ezandleni zalabo abafuna ukusiza?
5. Yini enikulindele nina njengabantu abasizana nonompilo?
6. Yini isijeziso esinikwa labomakhelwane abangabasizi labo abaphethwe yigciwane lengculazi?
7. Lapha kwaNgcolosi, kungabe kukhona umnikelo onjengesikhathi noma imali nokunye okhishwayo ukusiza? Uma ukhona uvame ukuba yini?
8. Ngokwakho, yini ekhuthaza abantu ukuthi bazibandakanye emphakathini nalabo abaphethwe ingculazi?
9. Kungabe kukhona yini izinto ezenziwa lapha kwaNgcolosi ezingenambuyiselo kodwa ezibonakalisa ubumbano emphakathini?
10. Yiziphi izindlela, ngokwakho uhulumeni , amasonto, izinhlangano zomphakathi ezingasiza ngayo ukuthuthukisa nokukhuthaza ukubambisana nokusizana nabantu abaphethwe yingculazi nemindeneni yabo?