

**EXPLORING UNINVOLVED
COMMUNITY MEMBERS'
PERCEPTIONS OF HIV/AIDS CARE
AND SUPPORT IN KWANGCOLOSI,
KWAZULU-NATAL, SOUTH AFRICA**

BY

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Submitted in partial fulfilment of the requirements of a
degree of Masters in Social Sciences (Health Promotions), in
the graduate Programme of Psychology, University of
KwaZulu-Natal;
South Africa

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November 2009

DECLARATION

I hereby declare that this dissertation is my own original work. All other resources have been duly acknowledged. This research has not previously been submitted to any other institution for degree or examination purposes.

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ABSTRACT

This study explores the perceptions of care and support for those with HIV/AIDS by community members within the KwaNgcolosi community who are currently not involved in such care and support, and have no current perceived obligation to do so. The Social Capital framework was used to understand the current community perceptions and dynamics related to current care and support for those who are ill with HIV/AIDS. This was followed with suggestions for how this could be improved, current obstacles to this, and possible personal contributions towards improving the current situation.

Data was collected by means of six semi-structured, in-depth focus groups, which were conducted in IsiZulu with the assistance of a translator. These were then transcribed and thematically analysed. Overlapping quantitative data specifically for the themes of social cohesion and trust exists in the form of two social assessment surveys, and so frequency counts were done with applicable survey questions, and compared with data collected from focus group interviews.

Focus group discussions revealed a marked difference between perceived ideals of how care and support should be, and what is currently happening within the community. Mistrust and stigma surrounding HIV/AIDS appear to still be prevalent within the community, which hampers community social networks and involvement, and acts as a barrier for those who wish to provide care and support for those who are ill. Triangulation with Social Assessment surveys, revealed a discrepancy between social cohesion as related to HIV/AIDS, and general social cohesion within the KwaNgcolosi community. This social cohesion is not currently leading to collective action, which points to a deficit both in information sharing regarding how to do so, as well as a deficit in Social Bridging.

Family members and individuals who are ill may, for various reasons, also prevent community members who wish to become involved, from providing care and support to those who are ill. Reciprocity also affects the social credibility of community initiatives, which are not taken seriously if nothing can be expected in return. Additionally, expectations of economic reciprocity regarding contributions to household expenses negatively affects providing care for family members, who are blamed once they become ill, if they did not contribute to the household while still working. Social norms regarding gendered social and economic expectations also hinder and restrict desires to assist in care and support for those who are ill with HIV/AIDS.

The obstacles highlighted by the themes of trust, reciprocity and social norms have resulted in potential barriers to mobilization of social networks, and resources that may be available through these networks. There is a need to provide education to community members according to their perceived contributions, in providing care and support for those with HIV/AIDS, and in keeping with current gendered norms which point towards women undertaking much of the physical aspects of care and support, with men engaging in social and emotional support. However, care should be taken that current destructive gender stereotypes, in which women are expected to undertake primary caregiving roles, are not encouraged and perpetuated.

Additionally, education surrounding perceived contributions to HIV/AIDS care and support will increase perceived personal abilities and competence, and act as an enabling factor towards more individuals becoming involved in care and support. Gateways to identified sources for information, such as the Home Based Caregivers and the KwaNgcolosi Clinic should also be tapped, and a flow of information encouraged.

However, the current situation is a complex combination of stigma, discrimination and blame towards those who are ill, as well as mistrust from the ill person and their family members, who isolate themselves and block any attempts of care and support from community members. This has resulted in many possibilities and untapped resources within the community. Future initiatives must therefore, from a programme perspective, shift from a focus on current obstacles, to encouraging and developing community members' potential contributions towards care and support for those with HIV/AIDS.

ACKNOWLEDGEMENTS

First and foremost, I wish to acknowledge and thank my family, who taught me the value of education. Without you I wouldn't be where I am today.

Thank you to my supervisor Prof. Yvonne Sliep for your support and guidance, for your patience and understanding, and for always being available when needed.

Thanks also to Dr Wenche Dageid, for your support and guidance in helping to shape this dissertation into what it is, and for your willingness to give up your time.

Thanks goes to all those who assisted in the logistics of this study, especially to Casper Mbatha, Mthokozisi Hlengwa, Yandiswa Kweyama, Patricia Mthethwa, and Thobeka Ndlela.

Finally, to my classmates and all those who supported me in this process – I greatly appreciate you all.

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CHAPTER ONE

INTRODUCTION

1.1 Overview

The main focus of this study is to explore the perceptions surrounding care for someone with HIV/AIDS, by community members currently not involved in care in the area of KwaNgcolosi, KwaZulu-Natal, South Africa. These community members additionally have no current perceived obligation to assist in care and support (for example, if one is a family member of one who has HIV/AIDS).

This dissertation is divided into seven chapters:

Chapter one introduces the study. It provides relevant background information, outlines the research problem, states the purpose and objectives of the research, and finally summarises the significance of the study.

Chapter two introduces the theoretical framework used to inform this study, namely Social Capital. This chapter provides a discussion of the various significant authors and their contributions to the definition of Social Capital. It then presents the levels, functions, and elements of Social Capital used to ascertain and measure its presence in a community. It also reviews negative aspects of this theory, presented as destructive Social Capital. The operationalization of Social Capital and its application to a South African, HIV/AIDS context is then discussed, and followed by critical discussion of the limitations of the Social Capital theory.

Chapter three reviews relevant literature to this study, presented according to the following themes: Defining “care”, with reference to a South African context; care for someone who has HIV/AIDS in South Africa; experiences and perceptions of those requiring care; experiences and perceptions of caregivers;

community and care for someone with HIV/AIDS; potential for change regarding the current situation; and care, HIV/AIDS, and Social Capital.

Chapter four outlines the study methodology. Qualitative techniques, in the form of six focus group discussions were used as a means of data collection. The study area, sample considerations and criteria, and ethical considerations are presented.

Chapter five presents, reviews, and summarizes the focus group discussions.

Chapter six presents an analysis and findings of the focus group discussions according to the Social Capital theoretical framework.

Chapter seven reviews and concludes this study, discussing limitations, considerations, and recommendations for future endeavours in this area of research.

1.2 Background to the Study

HIV/AIDS statistics have rapidly increased in the past decade to a point where it is now estimated that by 2007, between 30 and 36 million people were living with HIV globally (WHO/UNAIDS, 2008). In 2007, Sub-Saharan Africa was burdened with almost one third (32%) of new HIV infections worldwide and where adult HIV/AIDS prevalence is now estimated to be 15% and where 72% of all AIDS deaths occurred in 2007 (UNAIDS, 2008). Within South Africa, between 4.9 and 6.1 million people are living with HIV/AIDS, making this the country with the largest HIV infections in the world, as well as the country with the most rapid infection rate (UNAIDS, 2008). Here, between 2000 and 2010, it is expected that anywhere between 5 million and 7 million people will die of AIDS (Dorrington, Bowen, Distiller, Lake, & Besesar, 2008). In addition to a high burden of individuals living with HIV/AIDS requiring care, in 2002, 48.5% of the population was living in poverty according to the national poverty line of R354 per adult equivalent per month (Frye, 2006). According to WHO estimates,

there is a shortage of more than 800 000 health care workers in Sub-Saharan Africa, with the burden felt more in rural areas, particularly those that have been severely affected by the HIV/AIDS epidemic (Lewis, 2008). In South Africa alone, in June 2008 the shortage of nurses was approaching 40 000 (Naidoo, 2008). Implicit in this is inadequate access to health care facilities, resources, and necessary supplies needed to care for those who are ill. A further consideration is the fact that the need for care and support will continue to increase, taxing an already insufficient health care system, as people currently infected with HIV develop AIDS related symptoms.

1.3 Problem Statement

As a result of the above-mentioned deficits, the onus currently falls mainly on the shoulders of community members and caregivers who are given the responsibility of caring for HIV/AIDS patients, whether voluntarily or because they are obliged to, to secure and provide adequate care for those for whom they are responsible. Research appears to point to caring for such a person as being the responsibility of primarily one person, often without assistance, either external or from other community members, leading to great burden – emotional, physical, and financial – being placed on the caregiver (Akintola, 2006; Kipp, Nkosi, Laing & Jhangri, 2006; Swaans, Broerse, Van Diepen, Salomon, Gibson & Bunders, 2008; Wight, Beals, Miller-Martinez, Murphy & Aneshensel, 2007). Community members may exacerbate this situation through shunning the person who is sick, for various reasons, and by association, the caregiver as well (Dilger, 2006; Ndinda, Chimbwete, McGrath, & Pool, 2007).

A deeper understanding of the dynamics contributing to the current situation with regards to care for those who have HIV/AIDS necessitates an exploration of the motivation and perceived possibilities around the provision of care. There is substantial evidence to suggest that social support helps individuals to maintain their health (Hudson, Miramontes, & Portillo, 2001), as well as positively influencing the efficacy and effectiveness of those currently in the role of

caregiver for people with HIV/AIDS (Gregson, Terceira, Mushati, Nyamukapa & Campbell, 2003; Maslanka, 1996). In the South African context, where social support forms an essential level of care that HIV/AIDS patients receive, mobilizing social support and community collective action should be regarded as highly important, and receive due attention and encouragement.

1.4 Purpose of this Research

In order to gain an understanding of how care and support for people with HIV/AIDS is understood and talked about, this study begins by exploring the attitudes and perceptions of individuals in a geographical community towards those who have HIV/AIDS. Following this, the expectations regarding who will care for those who are sick, and why, as well as what roles they fill/needs that are provided for are discussed, as well as perceived potential and requirements for change.

Through this, perceived community solidarity is explored, by means of participants' perceptions of those for whom they might be expected to care should they become ill, as well as whether or not they feel they can rely on other members of the community, should they require any form of assistance. The boundaries of these expectations and care is also examined, by discussing when participants feel they would not be expected to care for, or to assist with care for someone who is ill, and reasons informing this. During focus group discussions, through some initial prompting from the researcher and translator but also largely through ideas of focus group participants themselves, understandings of care were extended to include psychosocial care and exploring different ways in which care like this could be provided outside of the formal health sector.

The primary questions that this research therefore explores is:

- How do members of the KwaNgcolosi community perceive “care and support”, specifically for those who have HIV/AIDS?

- How could the identified areas of care and support best be met according to members of KwaNgcolosi community?
- What would enable or inhibit more active participation in care and support according to the community of KwaNgcolosi and what would the identified care and support activities look like?

1.5 Objectives of the Study

It is widely recognized that providing care for someone who is ill is associated with great burden, financially, physically, and psychologically (Claxton, Catalán & Burgess, 1998; Demmer, 2006; Kipp *et al*, 2006; Wight *et al*, 2007). This is exacerbated when considering that care for someone who has HIV/AIDS makes relevant the social stigma, as well as many other complex social and psychological issues associated with the disease (Claxton *et al*, 1998; Demmer, 2006; Kipp *et al*, 2006; Wight *et al*, 2007). Providing care, therefore, is undertaken with tremendous pressure and burden, motivated by extrinsic as well as intrinsic factors (England, 2005). Understanding the dynamics, forms and motivations of care, becomes even more relevant when bearing in mind that government assistance for such individuals is minimal in South Africa, where poverty is rife and housing, medical and financial shortages are common (Frye, 2006; Lewis, 2008), making the primary responsibility for securing and providing necessary resources that of the primary caregiver's.

From the above, it becomes apparent that the main source of effective assistance for care of those who have HIV/AIDS will be the local community in which such individuals live. Currently, the literature indicates that caregiving is usually the responsibility of a single individual, often a relative of the person who is ill with HIV/AIDS (Demmer, 2006; Kipp *et al*, 2006; Miller, Bishop, Herman & Stein, 2007). Social mobilization and collective action will provide those who care for people with HIV/AIDS with greater levels of efficacy and effectiveness, as well as improved quality of care for those who are ill (Hudson *et al*, 2001; Maslanka, 1996).

The purposes of this research are therefore:

1. To explore the perceptions of a cross sector of community groups regarding care and support of those who have HIV/AIDS .
2. To explore and understand perceived community resources with regards to care for those who have HIV/AIDS.
3. To explore perceived barriers and enabling factors to increase more active care and support for those with HIV/AIDS.

1.6 Significance of Study

As part of a larger body of research, namely “The role of social capital in promoting community based care and support for people living with HIV/AIDS in KwaZulu-Natal, South Africa”, this study explores care and support for people who are living with HIV/AIDS in the KwaNgcolosi area, KwaZulu-Natal, South Africa. Within the overall study, the current aspects and providers of care are covered. This thesis is the only part of the overall study that explores the gaps and untapped resources within the community that may not be visible yet, as a possibility to assist with care and support, particularly with a shift away from physical support only, to include psychosocial care and support. The aim of this is to mobilize these currently untapped resources, with a focus on what focus group participants feel that they can offer, rather than meeting what has been expressed as perceived needs by a particular project.

The Social Capital perspective is used to form a framework through which to understand the experiences, perceptions and attitudes of community members not currently involved in caring for someone who has HIV/AIDS, their current perceived access to Social Capital as a means of motivation to assist in providing and accessing needed support to those who are ill and their current caregivers, and its influence on the quality and quantity of care given to those who have HIV/AIDS. This particular part of the study focuses on Social Bonding and

Social Cohesion, and how these can be understood as possible means of strengthening increased access for HIV/AIDS patients, especially in terms of psychosocial resources and support within the community.

CHAPTER TWO

THEORETICAL FRAMEWORK

2.1 Introduction

The concept of Social Capital has been in existence for a fair amount of time, although the term has only fairly recently been formalized and begun to gain popularity (Labonte, 1999; Portes, 1998). The nature of the theory lends itself to application in many different contexts, interpretations and uses, and has come to be seen as “something of a cure-all for the maladies affecting society both at home and abroad” (Portes, 1998: 2). The underlying thesis of Social Capital, according to Field (2003), is that “relationships matter”, and social networks function as a valuable asset, in terms of providing access to beneficial resources. This is because they provide members that can be called upon in a crisis; can be enjoyed simply for their own sake, or can be used as a means of accessing some form of benefit or gain (Woolcock, 2001). For the purposes of this chapter the uses and definitions of Social Capital will be discussed with regards to applicability in the social sciences, and a working definition used for this study, arising from a discussion of relevant literature, will then be presented. Within the social sciences, Social Capital refers to intangible assets such as trust, networks and social norms, as well as connections between and interactions within social groups and networks (Hseih, 2008). Furthermore, it may be seen as a set of social and material resources that are accessed through these interactions (Putnam, 1994). There is also substantial evidence to suggest that social support helps individuals to maintain their health (Hudson *et al*, 2001). Although social capital is a neutral concept, its utilization may take many forms: It can be used positively - as people interact and have their social needs satisfied, this may produce "social potentiality sufficient to the substantial improvement of living conditions in the whole community" (Putnam, 2000) as well as negatively, to "produce or reproduce inequality, demonstrating how people gain access to powerful positions through the direct and indirect employment of social connections." (Foley & Edwards, 1997).

2.2 Definitions of Social Capital

There are several theorists who have proposed definitions of Social Capital, however for practicality purposes, five authors shall be mentioned in this study. The first concrete analysis and definition of Social Capital was produced by Bourdieu (1985), who defined Social Capital as “the aggregate of actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition” (Bourdieu, 1985). From this it becomes apparent that there are two elements to Social Capital: Firstly, the social relationship itself, which allows access by individuals to the resources of their acquaintances, and secondly, the amount and quality of such resources (Portes, 1998), and thirdly, as the potential or untapped resources. It would appear, however, that although Bourdieu recognizes the many different forms of capital (economic, cultural and social), recognizing the relatively unique characteristics and dynamics of each, he places great emphasis on how all of these can ultimately lead to, and be reduced to, economic capital and resources – such as subsidized loans and protected markets (Bourdieu, 1985). Additionally, there appears to be an emphasis on conflicts and power dynamics, with Social Capital becoming a resource which can be used in the symbolic struggles in society, as well as influencing power relations and the way in which they increase or decrease an individual’s ability to advance his/her interests (Siisiäinen, 2000). However, a discussion regarding how economics is linked to Social Capital is a complex discussion which is beyond the scope of this study, as this research focuses primarily on the relationships between homogenous individuals within one community.

A second significant author is Glen Loury (1977), who utilized the concept of Social Capital in his critique of theories of racial income inequality and resultant policy implications (Portes, 1998). He felt that traditional economic theories were too individualistic, focusing simply on the acquisition of marketable skills in order to produce competent individuals who were on competitive par with their

counterparts, and legal frameworks prohibiting racial discrimination. Such an approach, however, would not solve any problems or reduce discrepancies, for two reasons: Firstly, poverty was inherited from parents, resulting in relatively low opportunities and access to material resources, and secondly, individuals coming from such backgrounds would have relatively little information about work opportunities, as well as low connection to the labour market. Individual success therefore is not a result merely of competence – this is strongly influenced by the conditioning individuals receive as a result of the context and environment in which they grow up (Loury, 1997; Portes, 1998). This is evident within the site of this study, where households of different generations appear to reflect similar socioeconomic statuses, as well as similar income brackets and sources of income.

Another significant theorist that will be discussed here is Coleman (1988), who built on the work done by Loury, focusing on how Social Capital contributed to the production of Human Capital. Coleman refined Loury's definition, describing Social Capital as "a variety of entities with two elements in common: They all consist of some aspect of social structures, and they facilitate certain action of actors – whether persons or corporate actors – within the structure", and the actors involved as rational beings with certain interests in resources and events, and the availability of such to the actors (Coleman 1988:S98). Coleman clarified and named some of the mechanisms that generated Social Capital (reciprocity, expectations and norms), the consequences of its possession (privileged access to information), and the social organizations that provide the context for such to occur (Coleman, 1988; Portes, 1998). Resources therefore have the attributes of a gift for those who are the recipients of the consequences of Social Capital – a distinction should then be made between the gifts, or resources, themselves, and the ability to access them through environmental conditions, contexts, memberships in relevant groups and such (Portes, 1998). However, the motivation of both donors and recipients in such transactions must be noted. The motivation and desire of recipients to have access to resources provided through

Social Capital is understandable. The motivation of donors are more complex – such individuals are expected to provide needed resources without the expectation of any short-term, immediate obvious benefits. Although often melded together by Coleman, the following three elements therefore need to be distinguished in order to fully understand the essence and nature of Social Capital: Those requiring resources (the possessors); those agreeing to demands (the sources), and the resources themselves. Social Capital therefore describes the nature of relations between individuals, and is largely intangible, but is significant in that it is able to facilitate productive activity (O'Brien & Ó Fathaigh, 2005). As such, when considering care and support for those with HIV/AIDS, it is important to note the relationships between the provider and recipient, as well as other significant people such as family members who influence such relationships.

It is interesting to note at this point that although the above authors seem to consider networks and membership in groups as being important prerequisites for the production of Social Capital, Burt (1992) in fact theorises the opposite. “Structural holes”, or the relative absence of social ties, result in social mobility, advantageous because instead of being tied to networks which he claims often convey redundant information, social mobility allows for access to and acquisition of new data and resources (Portes, 1998). According to this, in a community such as KwaNgcolosi, those who experience a lack of social ties and networks should be the same individuals who are more socially mobile than their more connected counterparts, thus being richer resources of new information.

The last prominent author that will be mentioned is Putnam (1994). His work focuses largely on Social Capital and its applicability in a well-functioning democracy, where he refers to Social Capital as “networks and norms of civic engagement” (Putnam, 1994:3). He theorises that Social Capital has three components: Norms and moral obligations; social values such as trust and reciprocity; and social networks (Putnam, 1994; Siisiäinen, 2000). By illustrating his work using examples drawn from both medieval and modern-day Italy, and by

comparison of two neighbourhoods in San José, Costa Rica, he proposes that horizontal engagement in communal clubs and societies, as well as social interest and investment in the community helps to build Social Capital, resulting in a community that is well-bonded, unified and can work together collaboratively for the good of their society as a whole (Putnam, 1994). According to this then, if the economic system is functioning well, it is demonstrative of that area's high levels of Social Capital (Siisiäinen, 2000). Putnam (1994) therefore claims there is a direct link between the levels of engagement in community activities, and the same community's ability to engage with social and economic problems (O'Brien & Ó Fathaigh, 2005). According to this, it may be ascertained that in an area such as KwaNgcolosi, the degree of engagement with economic and social issues directly and indirectly arising from HIV/AIDS observed may be indicative of the amount of Social Capital present within this community.

2.3 Forms of Social Capital

As seen above, precise definitions of Social Capital may vary. Similarly, several authors have proposed various forms that Social Capital may take. For the purposes of this study, divisions of Social Capital into Social Bonding, Bridging and Linking, and Structural and Cognitive Social Capital are discussed below.

2.3.1 Levels of Social Capital

Although as discussed above, there are many overlapping definitions of Social Capital, theorists also argue that there are several distinct levels of Social Capital (Baum & Zierch, 2003). These may be defined as Social Bonding, Social Bridging, and Social Linking. These definitions reflect the notion of vertical and horizontal constructs of Social Capital, where vertical Social Capital exists in relationships between different levels of society (such as government and community), and horizontal Social Capital is found in relationships between individuals or groups of similar background and context (Harper *et al*, 2002).

Social Bonding

This refers to horizontal ties and social cohesion between individuals, groups and neighbours sharing similar characteristics within a community group structure (Harper *et al*, 2002). This form of Social Capital increases the likelihood that individuals will move beyond their own diverse self-interests, towards social action that will benefit all involved (Larsen, Harlan, Bolin, Hackett, Hope, Kirby, Nelson, Rex & Wolf, 2004). Social Bonding operates to provide resources for poorer, homogenous communities, and is restricted to simply enabling people to “get by”, or in other words, providing only those resources necessary for daily living, while allowing richer communities to consolidate their economic advantages relative to less advantaged communities (Edwards, Franklin & Holland, 2003). This form of Social Capital can, however be exclusionary, as discussed under *Destructive Social Capital* (2.6). Social Bonding will not necessarily result in any civic action, but is a necessary predecessor of the formation of Social Bridging, which is more likely to result in action (Putnam, 1994; Larsen *et al*, 2004).

Social Bonding is an important aspect of Social Capital within KwaNgcolosi. Since this is a community akin to that described by Edwards *et al* (2003), Social Bonding provides and accounts for the sharing of resources within this community between friends and neighbours.

Social Bridging

The second level is Social Bridging – this refers to horizontal trust and reciprocal connections between different communities/groups/individuals, who do not share common identity traits/ideals (Harper *et al*, 2002). This level is more valuable than Bonding Social Capital as it’s purpose is more for the benefit of the public as a whole (Edwards *et al*, 2003). According to Putnam (2000), Social Bridging is more inclusive than Social Bonding, and may incorporate individuals across various social divides, generating broader social identities and reciprocity. This level of Social Capital is produced when members of one group connect with

members of another group, seeking access, support, or information. Larsen *et al* (2004) define Social Bridging as local residents' efforts to extend contact beyond members of their own neighbourhood. The social and economic context of such individuals and their relationships significantly impacts the type of Social Capital that will be produced: While Social Bonding may be present in most neighbourhoods, regardless of socioeconomic status, those falling in lower income brackets were much less likely to extend beyond Social Bonding, to form relationships that would produce Bridging Social Capital (Edwards *et al*, 2003; Larsen *et al*, 2004). The community of KwaNgcolosi falls into such a category, being characterised by low income and socioeconomic resources. As such, although Social Bonding may be present within this community, Social Bridging is largely lacking, although there are external HIV/AIDS organizations functioning within the area. However, the perceived importance of such organizations to community members as a resource is questionable. Such a discussion is beyond the scope of this thesis and so it will suffice to say that such organizations are present, they are largely not noted by participants of this study. As such, it may be inferred that they are not seen as valuable resources to community members, therefore indicating a significant lack of Social Bridging within this community.

Social Linking

Although much literature only distinguishes between Social Bonding and Social Bridging, Szretzer & Woolcock (2004) conceptualized a third category - Social Linking. Although similar to Social Bridging in that it spans across different communities and individuals, it differs in that it refers to vertical relationships, with power differentials – such as between communities and governments or municipalities (Baum & Zierch, 2003). Additionally, Social Linking may lead to an increase in health inequalities (Szreter, 2002). This is particularly important to note, since significant disparities are currently noted with regards to health inequalities within South Africa. At present, communities such as KwaNgcolosi

experience very limited access to formal health care as a result of poor socioeconomic resources within the community.

2.3.2 Cognitive and Structural Social Capital

In addition to Social Capital occurring at different levels, Bain & Hicks (1998), in Subramanian, Lochner, & Kawachi (2002), distinguish individuals' perceptions and experiences of Social Capital into Cognitive Social Capital, and Structural Social Capital.

Cognitive Social Capital

Cognitive Social Capital (CSC) refers to individuals' perceptions of support (Harper *et al*, 2002). These include the elements of Social Capital related to trust, reciprocity, and sharing (Subramanian *et al*, 2002). A useful definition is given by Pronkyk, Harphan, Morison, Hargreaves, Kim, Phetla, Watts & Porter (2008), where Cognitive Social Capital is defined as perceived levels of reciprocity and community support; perceived solidarity in response to a crisis event; and participation in collective action. Franke (2005) refers to CSC as the "micro" approach as it focuses on the propensity of actors to work collaboratively, and the value of collaborative action. As such, CSC within KwaNgcolosi may be seen as accounting for and resulting from the perceptions of trust, reciprocity, support and solidarity within the community, manifested in the way in which crises are handled, such as caring for someone with HIV/AIDS where there are insufficient resources available.

Structural Social Capital

While Cognitive Social Capital deals with how people "feel", Structural Social Capital (SSC) refers to what individuals "do" with regard to social relations (Harper *et al*, 2002). This includes group membership, and the extent and intensity of their associational links (Pronkyk *et al*, 2008; Subramanian *et al*, 2002). Structural Social Capital may also be referred to as the "meso" approach, in that it is concerned with structures within a community that enable co-

operation. SSC emphasizes environmental, social, and political structures within a community, which create conditions for the communication of social norms and values that encourage social engagement and action (Franke, 2005). Within KwaNgcolosi, the structures noted as important for the caring of HIV/AIDS are the KwaNgcolosi Clinic, and the Home Based Caregivers. Although other organizations function within the community, they are not mentioned by participants of discussions for this thesis, or are mentioned disparagingly.

2.4 Functions of Social Capital

Empirical literature appears to point towards three basic functions of Social Capital: Firstly, as a source of control; secondly, as a source of family support; and thirdly, as a source of benefits through networks (Portes, 1998). The first – control – is generally manifested as rule enforcement, evident in relationships between authoritarian parents, teachers and students, and law enforcement agencies and the general public. The second – family support – is generally sourced from parents or other kin, and is evident more in homes where one parent has the primary responsibility of raising the children. In such a case, the children are the recipients and the parents the possessors. The third form of Social Capital – benefits through networks – appears to be the most common. This refers to benefits accrued through membership in social groups and networks outside of the immediate family. This is evident in a study done by Gregson *et al* (2003), who found that young women who actively participated in local community groups exhibited behaviour associated with avoidance of HIV, and increased psychosocial determinants associated with protective behaviour – however this does seem to be dependent upon characteristics of the group, such as group purpose, functionality, and the education level of the participant.

Additionally, according to Spellerberg (2001), Social Capital provides more than simply the acquisition of knowledge and resources through relationships and participation in communities and groups – it provides for the dialogue surrounding information gained, and subsequent assimilation and accommodation

of such information. People utilize this Social Capital in three distinct ways: Firstly, processing information. More than simply accessing information, individuals need to be able to discuss information with others in order to gain understanding. Secondly, Social Capital allows individuals to assess risks and opportunities, through allowing for the assessment – through discussion with others about the reputation and perceived reliability of a person or agency, before pursuing any course of action. Thirdly, access to Social Capital and the discussions with others allows for “checking out” situations, individuals and agencies – namely, knowledge about the available political, social and economic choices.

2.5 Social Capital and Health

Public Health has long known about the link between social networks, social support, and health (Harper *et al*, 2002), and in recent years Social Capital has become a popular topic in Public Health research (Poortinga, 2006) for its ability to assist in better understand the mechanisms within the community that assist with health (Chiu, Grobbelaar, Sikkema, Vandormoel, Bomela, & Kershaw, 2008). Contextual trust, specifically, has been shown to have significant correlation to health (Subramanian *et al*, 2002).

There is also substantial evidence to suggest that social support helps individuals to maintain their health (Hudson *et al*, 2001). The possibility of the applicability of this in relation to HIV/AIDS is also explored in this study. Since in South Africa the majority of responsibility for care falls to community members and informal caregivers, it is considered important to understand their associated feelings, attitudes, perceptions, social norms, and perceived levels of community support and solidarity. According to Maslanka (1996), support appears to be the strongest variable that positively influences the efficacy and effective performance of HIV/AIDS caregivers.

2.6 Elements of Social Capital Used in This Study

For the purposes of this study, the above key indicators have been refined, and four elements have been chosen as representative of the relative presence or absence of Social Capital within the community: Trust, Reciprocity, Social Norms, and Social Networks.

2.6.1 Trust

Although potentially oversimplified, simply put, “Nothing happens if you don’t trust people” (Prusak, 2001). According to Putnam (1994), trust takes different forms: “Thin trust” is generalizable, and concerns all people that one is not necessarily acquainted with. Trusting and trustworthiness increase with social connection (Glaeser, Laibson, Scheinkman & Soutter, 2000). The willingness of community members and neighbours to intervene in situations when necessary, for the common good, is dependent largely on mutual trust and solidarity (Lindström, Merlo & Östegren, 2003). Trust sustains Social Capital by promoting facilitated and coordinated action that is mutually beneficial (Putnam, 1995). Distrust in the government and health care system is also seen as a barrier to care, and is related to poorer health (Whetten, Leserman, Whetten, Ostermann, Thielman, Swatz & Stangl, 2006).

Effective care and support for someone with HIV/AIDS is largely dependent on trust. According to Putnam (1994), trust is part of that which enables community members to act together more efficiently in the pursuit of shared goals. Gossip is therefore seen as a barrier to trust (Campbell & MacPhail, 2002).

Additionally, trust, or the amount of trust that individuals have in one another is not seen as common to all members of a community. Individual characteristics predict trust as well as trustworthiness (Glaeser *et al*, 2000). Individuals who have higher status are trusted more by others, and as such have more Social Capital available to them (Glaeser *et al*, 2000).

2.6.2 Reciprocity

According to Bourdieu (1985:52), “The reproduction of Social Capital presupposes an unceasing effort of sociability, a continuous series of exchanges in which recognition is endlessly affirmed and reaffirmed”. Reciprocity may be seen in societies where “people are always doing things for each other” (Coleman, 1988: S102). If one person provides resources, in any form and not necessarily materially for another, the expectation of reciprocity is that that person who received the resources will reciprocate, either in the new or distant future, with resources of equivalent value (Baum & Zierch, 2003).

Within the South African context, in the case of old people it is now generally expected that their children will care for them when they are ailing. The quality of care will depend on how they treated their children when they were younger: If they treated them well; their children will treat them well in return; but if they treated them badly, they can expect the same in return. However, if the person’s children are not living nearby, the responsibility may fall to others who the ailing person took care of when he/she was younger (van der Geest, 2000).

Reciprocity may also be a motivation for providing care, as caregivers who care for family members who are ill feel that they receive as much as they give, in terms of affection and care, to those who are ill (Linsk & Pointdexter, 2000). However, the pension fund has also changed the dynamics of such relationships, as was noted in this study: Family members may take care of one who is ill simply to be able to collect their pension money.

However, it must be noted that Thomas (2007) found that in Namibia, perceptions around reciprocity to be changing: Although in the past there was a social norm for neighbours to help one another as needed, as economic growth has occurred and employment opportunities increased, whether or not one was likely to receive what was requested depended on perceived socioeconomic status, or perceived likelihood of being in an economic position to reciprocate in the future.

2.6.3 Social Norms

According to Lyon (2000:666), norms may be seen as “part of social structure or a habit that shapes intuitive actions and allows agents to assume away risk” (i.e. Generalized trust). Additionally, norms are not generated at will – they are historically and culturally rooted, and are sustained through continued articulation over time. They are learned through socialization, particularly in childhood, from structures such as families, schools, religious institutions, and from civil society, should they take action against one who breaks such norms (Lyon, 2000). Coleman (1988) refers to norms as guiding principles that allow individuals to act in mutually cooperative ways. Research has also indicated a link between the level of Social Capital in a community and the formation of normative beliefs, health behaviours, and resource availability (Chiu *et al*, 2008).

Currently, there are many social perceptions regarding HIV/AIDS care, which have been discussed above. These may directly influence the nature and forms of care that community members are prepared to provide and assist with. For example, when considering assistance by providing food - according to van der Geest (2000), it is a social norm for community members within a rural community of Ghana, which is similar to that of NwaNgcolosi, to provide food for a neighbour who they see is without. There is often no set time, amount or type of food that is given. People who live nearby may therefore improvise – if they see that a person is without food, they will bring some for him/her, but won't when they see that others have brought. However, there does appear to be some evidence to suggest that the social issues and negative perceptions surrounding HIV/AIDS may override any obligations to provide help and care for others - in Uganda it is not uncommon for neighbours to refuse help when requested by the caregiver of someone who they know is sick with AIDS (Kipp *et al*, 2006).

Social norms may additionally undercut any efforts at community involvement in caregiving. Social norms regarding gendered divisions of labour and caregiving

mean that care work is considered an “unmanly” task (Akintola, 2006). This means that the majority of the burden of caregiving, whether formal or informal, is shouldered by women, while a vast potential for assistance in caregiving remains untapped.

2.6.4 Social Networks

According to Bourdieu (1985), social networks are not solid, everlasting structures produced by a single act of institution, but rather require ongoing effort and investment. These networks differ in both structure (type – informal or formal, size/capacity, spatial existence – household or global, structure – open or closed, dense or sparse homogenous or heterogeneous, and relational – horizontal or vertical) and in quality (norms of trust and norms of reciprocity). Networks can be either formal or informal. Formal networks include associations/groups, civic relations, work-based, and institutional relations. Informal social networks are made up of immediate and extended family relations, friends/intimates, and neighbours (Stone, 2002). Participation in networks as a mechanism of Social Capital, whether obligatory or voluntary, allows for access to social resources and thus produce Social Capital (Herrerros, 2004). Social networks in the form of local associations may function act as an adaptive mechanism to effectively respond to changes in their external environment (Thomas, 1988).

Knowlton (2003) states that access to informal caregiving, which is conceptualized as a resource, is affected by social network characteristics, as well as sociocultural factors and resource exchange. This implies that informal care is contextual, and is affected by the nature, number, and type of social networks within that context.

Social network resources and caregiving may take several forms. For example, households who have lost their primary source of income as a result of the breadwinner or caregiver stopping work due to the illness may draw on social networks as a means of economic survival. Relatives and friends may contribute

money where possible (Naidu & Harris, 2006). Since the beginning of the HIV/AIDS epidemic there has been a significant increase in family and community support (Akintola, 2008). However, connections to such networks and social support may be restricted as a result of stigma (Akintola, 2008). Caregiving in itself may reduce or even completely prevent the ability of caregivers to attend or participate in social activities (Akintola, 2008); places where social networking is done.

Social networks also provide for an alternative place to send children who can no longer be looked after by those who they currently reside with because of HIV/AIDS (Steinberg, Johnson, Schierhout & Ndegwa, 2002). However, in areas where economic heterogeneity is increasing, social networks may become strained as issues such as jealousy arise from perceived socioeconomic inequality (Thomas, 2007).

2.7 Destructive Social Capital

Although Social Capital is usually associated with positive outcomes for participants, it is important to note that this is not always the case; there are also potential negative outcomes from social networks and group membership. According to Portes (1998), these can be classified into four groups: Exclusion of outsiders; excess claims on group members, restrictions on individual freedom; and downward leveling norms.

Additionally, as mentioned above by Burt (1992), membership in social groups may be problematic in that it supplies individuals with redundant information, while reducing social mobility and thus cutting them off from new sources of knowledge, resources and opportunities. According to Stack (1974), survival in poor urban communities often depends on close interactions with friends and relatives in similar situations. However, these ties are often limited to the proximity of the environment in which these individuals live and move every day, thus denying them new information about other opportunities and how to achieve

them (Portes, 1998). Furthermore, in resource poor and socially disadvantaged settings, individuals are dependent on Social Capital to meet material as well as emotional needs. Interruptions in the resources available to individuals – through time-space dislocation – and instability of social networks, result in an inability to provide needed resources for urgent as well as ongoing needs. These lead to searches for new sources of Social Capital, which are limited to settings where stigma does not negatively affect access to such (Takahashi & Magalong, 2008).

In light of the above, when considering the community of KwaNgcolosi it becomes apparent that the information currently available regarding HIV/AIDS is redundant, common to members within this community, and that Social Capital is required for both emotional and material needs of people living with HIV/AIDS in this community. Additionally, Destructive Social Capital is significant in that it results in the perpetuation of negative, or downward levelling norms regarding care and support for those with HIV/AIDS, as well as facilitating the exclusion of those infected and affected by the disease from potentially advantageous group membership, thus restricting the availability of emotional and material resources needed to assist and care and support for those who are ill with the disease.

2.8 Operationalization and Application of Social Capital to a South African, HIV/AIDS Context

Research appears to point towards a positive link between social support, social networks, and health (Harper *et al*, 2002). Within the context of HIV, Social Capital becomes a relevant factor in determining the nature and norms of interactions between community members involved in care for those with HIV/AIDS. Social Capital can be used positively to increase awareness and self-efficacy of individuals and communities, such as providing knowledge and therefore increasing confidence regarding how to meet the needs of one with HIV/AIDS; however it can be used detrimentally, as in the fostering of negative or detrimental social norms and views, such as the perpetuation of beliefs encouraging blame and stigma regarding those with HIV/AIDS.

In addition to the above, it must be noted that Social Capital is not equally available to all. This is significant when considering how Social Capital may affect the self-efficacy of an individual, and his/her coping ability when faced with a life-threatening disease such as HIV. Access to Social Capital may be limited by geographic and social isolation, as well as socio-economic position, which may also affect the value of Social Capital. This is seen most clearly in a study which examined the psychological and psychosocial differences between African women, and European women (who generally live in more enabling environments both economically and socially) who are HIV-positive. According to a study done by Orr *et al* (1994) cited in Bungener, Marchand-Gonod, & Jouvent (2000), African women are nine times more likely to die of AIDS than white women. A psychiatric diagnosis revealed a significant difference between the two groups, with the African women appearing to be more susceptible to mental illnesses and disorders (77% as opposed to 52%). There also appeared to be a significant difference in the decision to disclose between the two groups, with 73% of European women chose to tell their sisters, and 60% their mothers, while of the African women, only 40% disclosed to their mothers and 16% shared their status with their sisters. In addition, given the widely accepted stigma associated with being HIV-positive observed in South Africa, it is not surprising that 70% of the European women chose to disclose their status to their friends, whereas 38% of the African women made the same decision.

Social Capital, although promoting the formation of groups of individuals who share a common trait or interest (“bonding”), may also lead to the exclusion of others. In the context of HIV, this may lead to group formation consisting of those who promote stigma surrounding HIV, and the exclusion of those who are known to be HIV-positive. This in turn will result in a decrease of social capital for such individuals, who will find themselves more susceptible to mental and emotional illness as well as reduced chance of all individual members of a

community working together to increase and promote living standards and a sense of wellbeing for the community as a whole.

2.9 Limitations of Social Capital

Social Capital has attracted the attention of policy-makers, as it provides a theoretical framework for seeking less costly, non-economic solutions to social problems (Portes, 1998). While this is advantageous in that power and responsibility – ultimately empowerment – is given to the community, it is also disadvantageous as this may be used as justification for absolving policy makers, government officials and such, of responsibility for bringing about needed change. Furthermore, there is a tendency to naïvely treat Social Capital as a “good thing”, largely ignoring Bourdieu’s exploration of how Social Capital may allow some individuals to access resources and power, but exclude others (Bourdieu, 1985; Smith, 2007).

Additionally, while Social Capital focuses largely on expanding trust, reciprocity and empowerment, these alone are not enough to overcome social inequalities, health disparities and poor access to resources (Takahashi & Magalong, 2008). Social Capital also fails to address gender differences, and the way in which women negotiate social interactions, form social networks, and manage care for those who are ill (Smith, 2007). This is particularly important when considering the context of HIV/AIDS within KwaNgcolosi, where the majority of care is provided by women.

The name of this theory – Social Capital – lends itself to the danger of capitalization discourse, and viewing of social phenomena from an economic paradigm (Smith, 2007). However, according to Woolcock (2001:75), this is not necessarily a bad thing, as the name then rises above what he calls “imperialism wars”, to provide a common, interdisciplinary discourse that bridges current divides.

2.10 Definition of Social Capital used for this Research

With regard to the above discussion of Social Capital, for the purposes of this study, Social Capital will be understood to refer to the degree of connectedness, specifically considering social relations, between those within KwaNgcolosi, and the effects of and resources provided by such relationships to those within that set population, specifically regarding issues related to care for one with HIV/AIDS.

Additionally, community perceptions of care and support, which is the focus of this study, fall primarily under Bonding Social Capital. This research will therefore make reference to the levels of Social Capital where relevant, but findings in this study will be explored in relation to the elements of trust, reciprocity, social norms, and social networks.

2.11 Conclusion

From the above, it therefore becomes apparent that all human interactions are producers of social capital, which is a significant determining factor of the nature of these relationships, as well as the dynamics that occur in such. Social capital may be used to foster feelings of trust and obligations of reciprocity, particularly if one partner in the relationship is seen to be in a position of higher authority. This may place individuals at increased risk of contracting HIV, but may also be a protective mechanism, and be used to enhance feelings of well-being and increase mental health when faced with a potentially fatal illness, as well as potentially motivate individuals to the significant improvement of living conditions of the whole community.

CHAPTER THREE

LITERATURE REVIEW

3.1 Introduction

This literature review will begin by contextualising the issue, and creating a backdrop in order to understand the current situation regarding community dynamics regarding HIV/AIDS. Following this, the concept of “care” will first be introduced and discussed, with reference to its application in a traditional African setting. A discussion of the experiences and perceptions of those who find themselves ill with HIV/AIDS, and the resultant experiences of those who care for them, and their expected and perceived roles will then contextualize this.

3.2 Contextualising the Issue: HIV/AIDS and the Community

Any exploration seeking to understand the dynamics of care and support regarding HIV/AIDS necessitates an understanding of the social dynamics present in the relevant community context.

3.2.1 The South African Rural Community

Poverty and unemployment levels are extremely high in South Africa (Frye, 2006). In fact, since democracy was achieved in 1994, jobs have been shed in order to allow the South African economy to compete globally, and since then insufficient jobs have been created in order to provide for new job market entrants – resulting in more than two thirds of the country’s population aged 18-35 being unemployed (Møller, 2006). Therefore, when crisis strikes in such communities, the most common strategies are to sell assets, reduce food intake, and to remove children from school so as to save on school fees (Frye, 2006).

3.2.2 Economic Impact of HIV

Owing to the above-mentioned current situation in South Africa, HIV/AIDS often has significant impact on the economic situations of many households. It must be noted here that although the Western notion of family and consequently

household consists of a nucleated, conjugal family, the African concept comprises a household of “patriarchal command in patrilineally extended households” (Naidu & Harris, 2006:417). This implies a wide range of possibilities regarding who may physically reside in that household, who will be expected to provide income for the household, as well as who will be permitted to have access to those financial resources.

In areas where there are very few economic activities, it is widely accepted for able community members to migrate to urban areas to work, and then send money home to relatives (Dilger, 2006; van der Geest, 2000). There are, however, tensions associated with this practice – most notably in complaints of family members left at home that those engaging in migrant labour do not demonstrate any gratefulness nor willingness to contribute to those left at home. Migrant labourers themselves complain of excessive demands made by their rural relatives (Dilger, 2006). Such perceptions are also common to members of the KwaNgcolosi community, regarding family members who have left the area and found work elsewhere.

In light of the above, it becomes apparent that the impact of HIV/AIDS is far-reaching when considering that HIV/AIDS infection and mortality is highest amongst those who find themselves at a point where they are most economically active and thus in the often in the role of being providers for their families (Gregson, Mushati & Nyamukapa, 2007). Illness or death resulting from HIV/AIDS thus also often results in loss of the household’s primary breadwinner (Demmer, 2006). The ill person then may try to work for as long as possible in order to provide income for as long as possible. In areas where unemployment is high, it is very unlikely that any working household members will be able to secure a second job in order to supplement income (or have the time to, since work and travel may take up over 10 hours of each day) (Naidu & Harris, 2006).

In addition to one who is ill with HIV/AIDS losing his/her job, the disease may also result in the primary caregiver losing his/her job, in order to take care of the one who is ill (Gregson *et al*, 2007). This financial burden may then also be added to as costs must be outlaid for health expenses, and funeral expenses (Akintola, 2006; Gregson *et al*, 2007). Income then appears to be erratic, and apart from regular earnings may be sourced from selling assets, social grants, irregular transfers from other migrant worker relatives, social grants (generally either for child maintenance or for those who are elderly), and in a lump sum once the person who is ill has passed away (Barrett, Reardon & Webb, 2001; Naidu & Harris, 2006). In situations where the one who becomes the primary caregiver is very young, she may also drop out of school, further exacerbating the economic situation and cycle of the household as she is then unable to secure anything but basic-skilled work in the future (Steinberg *et al*, 2002).

In some cases, it would appear that once the primary breadwinner has died from HIV/AIDS, the household may dissolve, with members migrating out (Gregson *et al*, 2007). In particular, children may be sent to be taken care of by other relatives (Naidu & Harris, 2006). The formation of “non-traditional homes”, also appear to be increasing – these being homes that are headed by a single parent, orphans, or the elderly (Akintola, 2008).

3.2.3 Social Perceptions

The situation in rural South Africa regarding HIV/AIDS is often exacerbated by social perceptions held by community members about the sickness. The social perceptions of HIV/AIDS in any community become relevant for the effect that it has on the cohesiveness within the community, conceptualized in this study as Cognitive Social Capital. Any form of blame, stigma, jealousy, and denial detrimentally affects and erodes the bondedness of the community, affecting the relationships of community members and tendency to rely on one another in times of need.

According to Kleinman, Eisenberg & Good (2006), there is a discrepancy between disease and illness. Disease encompasses the biomedical and biophysiological malfunction of system/s, whereas illness represents more than simply biomedical, biological and physiological processes; it includes the personal, interpersonal and cultural reactions to such, including the cultural and social issues that affect and shape perceptions, explanations, labels, and value placed on discomfort experienced as a result of the disease. Given this understanding, it then becomes apparent that biopsychosocial considerations of illness are extremely important in understanding the nature of any disease.

Much literature seems to point towards blame of individuals who contract the disease. Stadler (2003) found that the rise in HIV/AIDS infection rates was believed to be caused by a perceived negative shift in thinking and decline in value systems. Social discourses around sexuality therefore attribute the spread of HIV/AIDS to a decline in morality, and those who have contracted the disease are assumed to have been living an “immoral lifestyle” (Dilger, 2006). Such descriptions are often associated more with women than men, particularly in communities where gender inequality is still prevalent. Women are also more likely to be blamed for infecting their husbands, and consequently being disowned by the family upon his death than vice versa (Ndinda *et al*, 2007).

Denial of HIV/AIDS appears to still be significant, although not overwhelmingly prevalent, in admitting to having, or caring for one with HIV/AIDS. In situations where individuals do not admit to the one who is ill having HIV/AIDS, symptomatic explanations of flu or TB are usually given. When admitting to being HIV positive, hostility from family members is rare, but is quite common from community members (Steinberg *et al*, 2002).

Denial may also be seen in employment of alternative explanations of illness, such as Witchcraft, which also allows for the allocation of blame (Stadler, 2003). Witchcraft may also be used as an alternative, socially acceptable explanation for

those who do not wish to acknowledge the existence of HIV/AIDS (Thomas, 2007) - this prevents a frightening notion for some, as while HIV/AIDS is seen as something that may be controlled, witchcraft is seen as something which cannot (Bond, Chase & Aggleton, 2002). Witchcraft may also be used as a means to prevent stigma and rejection, and allowing for blame to be externalized rather than internalized (Thomas, 2007).

It therefore becomes apparent that stigma is still a prevailing issue with regards to one who has HIV/AIDS (Bond *et al*, 2002; Brown, Trujillo & Macintyre, 2001; Ogden & Nyblade, 2005; Plattner & Meiring, 2006; Skinner & Mfecane, 2004). Literature points to stigma both in terms of the self-perceptions of the person themselves who has HIV/AIDS and their close family members and associates, and in terms of stigma as a manifestation of perceptions by others towards those with HIV/AIDS and their associates. With regards to the first category, Ogden & Nyblade (2005) divide this into primary and secondary stigma, where primary stigma occurs when one who has HIV/AIDS imposes stigma upon him/herself. Such individuals internalize the socio-cultural beliefs and norms of the community of which they form a part (Rohleder & Gibson, 2006), and may perhaps believe that they are being punished for something (Plattner & Meiring, 2006). Secondary stigma occurs by association, where family members and associates of one who has HIV/AIDS may also find themselves bearing the same social stigma (Ogden & Nyblade, 2005). Stigma as a manifestation of perceptions by community members and such towards those who are ill, may range from simple, subtle actions, to extreme and overt abandonment, rejection, and degradation (Bond *et al*, 2002).

3.3 Care and HIV/AIDS

According to WHO estimates, there is a shortage of more than 800 000 health care workers in Sub-Saharan Africa, with the burden felt more in rural areas, particularly those that have been severely affected by the HIV/AIDS epidemic (Lewis, 2008). In South Africa alone, in June 2008 the shortage of nurses was

approaching 40 000 (Naidoo, 2008). Implicit in this is inadequate access to health care facilities, resources, and necessary supplies needed to care for those who are ill. A further consideration is the fact that the need for care and support will continue to increase, taxing an already insufficient health care system, as people currently infected with HIV develop AIDS related symptoms. There is therefore a current tendency to favour care that is based within relevant communities for the disease, rather than looking to the formal health care system. This is the case in KwaNcgolosi, with care appearing to be sourced either from community members, home based caregivers, or formal health care workers, seen in the KwaNcgolosi community as both those affiliated with the clinic, and those who visit homes, known in this community as *uNompilo*.

There is a large amount of literature that focuses on community caregivers of those with HIV/AIDS (see below), which will be discussed briefly in this chapter, primarily in order to assist in the contextualization of the disease. This section will therefore begin with a discussion of care and how it is understood within the African context, and then will move on to explore the expectations and roles related to care for one who is ill with HIV/AIDS.

3.3.1 Understanding Care

In any society, if one is ill, it is expected that other, more able members of that society will provide appropriate care. Tronto (1993) offers an explanation for this, stating that in order for a person to be seen as “morally good”, he/she must endeavour to meet care needs that are required of him/her, regardless of the manner of such requirements. Furthermore, a moral society is one that provides adequately and meets the needs of its members.

This is particularly relevant in a South African context, where the notion of *Ubuntu* underlies much of the traditional African way of life. *Ubuntu* places emphasis on community and collective unity and solidarity, where life is communal and consists of integrated networks of mutual relations (De Villiers,

2005). The concept of *Ubuntu* stretches beyond simply referring to a group of people; it encompasses the idea of unity and interdependence of individuals, both conceptually and practically, in which relationships based on empathy, sharing and cooperation are seen as fundamental to existence as a social being (Murithi, 2006). It may be regarded as that which encompasses the traditional African outlook of, among other things, unity, friendship, love and generosity (Bell, 2002, in Bamford, 2007). *Ubuntu*, then, in its most fundamental form, may be seen as that which underlies the motivation for all care and reciprocal acts, both to close family members, as well as within the community as a whole.

3.3.2 Providing Care

The definition of “caregiver” is still disputed among academics, as well as among community members. While those who are formal caregivers appear to easily identify themselves as “caregivers”, this title appears to be more ambiguous among informal caregivers. When questioned, one who performs all the duties common to being a caregiver, may reply “But I’m a daughter, not a carer.” Additionally, within a marriage relationship, spouses do not view what they are doing as “care”, as marriage implicitly places expectations that they will be “carers” throughout the period of their marriage. Community members therefore have difficulty in identifying themselves as carers as well as family members. (Ungerson, 1993: 166).

Considering this, it becomes apparent that the role of caregiver is a fluid one, intertwined with many other perceived roles – both voluntary and obligatory. As such, for the purposes of this research, a caregiver may be seen as any person who fulfils a care need of any person who is ill with HIV/AIDS. This does not necessarily mean that such a person is the primary caregiver, nor that they strive to meet all apparent caregiving needs – simply that they identify and strive to meet any perceived need of one who is ill with HIV/AIDS.

3.3.3 Social and Community Expectations and Roles

Recent changes in society at large, and in this case particularly management of the family and family affairs, have resulted in uncertainty over who provides care for an ailing relative. Traditionally, those who were working were expected to provide support where they could, financial and otherwise, for all relatives (van der Geest, 2000). However, these days middle-class, urbanised African families tend to try and keep their non-nuclear relatives at bay, in order to avoid social claims on their income and possessions. However, younger relatives may strengthen ties when they consider it to be useful to themselves. As a result, family relations may fluctuate according to what is at stake.

This situation is further exacerbated by migration of those who are able to work and earn an income - and only return home for short periods, if at all. Those who are sick may therefore find themselves in a situation where they have few or no relatives in the vicinity to care for them.

Perceived obligation appears to be a powerful and often primary motivation for providing care. This may be out of a sense of duty, or may be because of fear of what would become of the person who is ill, should the concerned person not provide care (Linsk & Pointdexter, 2000). There also appears to be a socially accepted and expected gender role difference in terms of care: If one requires physical assistance of any form, it will be provided by the closest family members (both in terms of proximity as well as genetically); and usually women - partners, mothers, or other relatives (Campbell, Nair, Maimane, & Sibiya, 2008; Demmer, 2006; Kipp *et al*, 2006; van der Geest, 2000). Women will provide the primary, hands-on, physical care, and may cover a wide range of activities and responsibilities. Men's duties are usually those that cover finances, and that which requires physical strength, but can be accomplished in a short time period – however such arrangements are dependant on household structure and living arrangements (Akintola, 2008). If the males in the home are not working, for any reason, they will usually leave the women to provide primary care while they seek

alternate activities outside the home (Akintola, 2006). Altruism may also be cited as a reason for providing care, particularly when concerning a family member, as those who assume the role of caregivers are concerned for the well-being of the one who is ill (Linsk & Pointdexter, 2000). Younger caregivers seem to perceive themselves as contributors towards ongoing care, rather than being the primary providers of care themselves (Linsk & Pointdexter, 2000).

However, much research has been done into the personal cost of providing care to the caregiver. These may include grief related to loss and potential loss of the one who is ill; stress caused by lack of resources to provide adequate care, as well as already feeling unable to provide adequately for other dependants; feeling emotionally, physically and psychologically ill-equipped to deal with associated issues; having to deal with social issues such as stigma; and having no emotional outlet (Demmer, 2006; Knowlton, 2003; Kipp *et al*, 2006; Linsk & Pointdexter, 2000). Additionally, adopting the role of caregiver may lead to little or no consideration given to the physical or emotional needs of the caregivers themselves, and may also result in isolation from other community resources (Linsk & Pointdexter, 2000).

3.3.4 Caregivers

Care for one with HIV/AIDS, in addition to falling to family members or close significant others (usually termed Informal Care), may also be provided through organizations created almost solely for the purpose of providing HIV/AIDS care. Such caregivers are trained, and may or may not receive remuneration for their efforts.

Home Based Care

Home Based Caregivers are unpaid, volunteer care workers who assist by assuming some of the caregiving roles, assisting in decreasing the burden felt by the informal primary caregivers (Akintola, 2008). These caregivers may be members of the ill person's family, or other relevant community members, or they

may belong to a variety of organizations – community based, faith-based, non-governmental, and non-profit organizations. Such caregivers are also usually members of the community in which they work (Akintola, 2008). Volunteers Home Based Care workers spend an inordinate amount of time providing care, and thus miss out on opportunities for increasing human capital with capacity building through development programmes (Akintola, 2008). However, there is evidence to suggest that Home Based Care organizations are not growing at a rate sufficient to meet the growing demands for care (Nsutebu, Walley, Mataka, & Simon, 2001).

3.4 Conclusion

Within South Africa, the rural community is characterised by poor infrastructure, high rates of poverty and unemployment, and poor access to resources. The impact of the HIV/AIDS epidemic is therefore exacerbated, as it is often the breadwinner of such households who becomes ill with the disease. Stigma and secrecy are still prevalent perceptions associated with the disease, and negatively impact care and support for those with HIV/AIDS, where blame, secrecy, suspicion and denial are common. Resources within the formal health care sector are inadequate to cope with current demands, and care by community members and family are hampered by the negative perceptions of the disease. Those who are primary caregivers to those with HIV/AIDS are therefore faced with an increased burden. Other resources for care are available in the form of Home Based Caregivers, however these are insufficient to meet current demands.

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CHAPTER FOUR

RESEARCH METHODS

4.1 Introduction

This chapter outlines the methodology used in this study. It begins by describing the study design, sampling, and data collection procedure, by means of qualitative focus groups. This chapter discusses the practical issues and dynamics associated with conducting focus groups, particularly those experienced in cross-cultural research and when a translator is used. The method of data analysis is then explained, including triangulation that was also used where deemed necessary, with a social assessment survey that was done for the larger Social Capital project, and ethical issues related to this study.

4.2 Study Design

The method deemed appropriate for this research is qualitative interpretivist, as this study explores the experiences, perceptions and understandings around providing assistance and care for those who are afflicted with HIV/AIDS and the perceived motivation behind doing so, by those who are not currently involved in providing care. Interpretations will be triangulated with data from the overall project Social Assessment surveys. The qualitative approach places emphasis on the social context and how social processes and the creation of social meanings occur within specific contexts, including what occurred before, and what is happening at the time of the study. The three key focuses of qualitative interpretivist research are subjective perceptions and understandings, which come from experience; objective actions or behaviours, and the context in which all this occurs (Ulin, Robinson, Tolley, & McNeill, 2002). Unlike quantitative approaches, which only gather surface information, the qualitative approach allows for capturing the full richness of human experience; the “*life-world* as it is lived, felt, undergone, made sense of, and accomplished by human beings” (Polkinghorne, 2005: 137). Rather than attempting to identify, isolate and control variables, the qualitative approach focuses on exploring what is real for

participants and how they make sense of their world, using language to understand, collect and analyse information (Terre Blanche *et al*, 2006). Furthermore, it allows for flexibility in content, focus, and question (Neuman, 2006). This is particularly useful in this study, as it allowed the research to remain open to whatever ideas, perceptions, opinions or feelings that participants expressed, as well as allowing for differences between participant groups.

Interpretive research emphasizes understanding phenomena in context, as well as positioning the researcher as the primary “instrument” in collecting and analyzing data (Terre Blanche *et al*, 2006). This means that all texts that are analysed must be understood in relation to the context in which they were produced. Additionally, the researcher as the primary instrument must be able to listen to participants, as well as accurately and appropriately describe and interpret his/her own presence in the process and overall study. Subjectivity is therefore seen as the means to empathically understand personal and social realities.

When using any data gathering technique, it is always useful to be aware of the strengths, as well as the limitations. Qualitative methods, as with any techniques, have their own set of limitations. As this type of data is not directly observable, it depends on participants’ ability to reflect upon, discuss, and effectively communicate aspects of their experiences (this is true of both qualitative and quantitative techniques). Furthermore, reflection on an experience (such as anxiety) may serve to change that experience (distance the person from and lessen anxiety) (Polkinghorne, 2005). Additionally, as this is an interpretivist study, it relies largely on the ideas and interpretation of the researcher. This means that the researcher needs to be aware and critically reflexive of her own role and influence in the process, as well as her own constructed understandings.

4.3 Study Area

Research and data collection occurred in the KwaNgcolosi area, which is found within the Valley of a 1000 Hills, approximately 40km outside of Durban,

KwaZulu-Natal, South Africa. There are approximately 20 000 people living in this area (Statistics South Africa, 2001, in City Population South Africa: eThekweni, 2009). The area is characterized by poor infrastructure, lack of resources including significant lack of access to electricity and running water, high unemployment rates and high levels of poverty.

4.4 Study Sample

Qualitative research focuses on exploring, describing, and understanding human experience through collection of intense, full accounts of the issues being researched. Participants of qualitative research studies are therefore chosen, not because they meet statistical requirements, but rather in terms of their ability to add to and enrich the structure and character of that which is being studied (Polkinghorne, 2005). Therefore, those individuals who can provide the most insight into an experience are generally those who have had experience relevant to the study, and who can provide rich information.

Participants of this study are homogenous in terms of language, ethnicity, culture and socio-economic background. They are Zulu-speaking and have a minimum age of 18. This age was decided, since it is adults that are usually expected to adopt caregiving roles, and this thesis was aimed at those who would be in a position to provide care, but currently are not, and have no perceived obligation to do so. Since this research forms part of a larger body of research, as mentioned in the introduction, orientation to the context by other members of the research team occurred prior to the outset of this study.

Members of the community were identified who are not currently providing care, and who have no current perceived obligations, social, familial or otherwise, to be doing so. Participants were chosen from those who had already participated in the initial questionnaire survey for the overall research project.

Initially approximately 13 participants were identified and recruited for each focus group, however between 4 and 8 participants arrived for each focus group discussion. Grouping was done according to age and gender, which is discussed below.

4.4.1 Screening

Participants for this study were randomly chosen from respondents of the overall Social Capital survey. Unfortunately, there was no question in this survey related to respondents' current or past roles regarding care for one with HIV/AIDS, and so no screening was done. This did result in one focus group including two participants who are currently Home Based Caregivers. This was only discovered at a later date, and steps were then taken to rectify and repeat that focus group with different community members. However, this has added richness to the study and has produced some interesting additional information for discussion on focus group dynamics. This will be discussed later.

4.5 Data Collection Procedure

After participants were identified, they were invited to participate in focus groups. These were conducted in a small, private room in a community centre that was conveniently located for participants. Focus group discussions occurred with the assistance of a Zulu translator, who is also member of the research team and therefore familiar with the area as well as the community. Discussions were audio recorded by means of a voice recorder, transcribed and then translated into English. Prior to each focus group, consent forms were given to participants, confidentiality explained to them, and the process and reasons for the study. Ethical issues were also covered, both verbally and in the consent form.

Six focus groups were held, with divisions made according to gender and age. Groups consisted of community members currently not providing care, and were comprised of individuals aged 18-25, 26-45, and 45 and older. For each age group both males and females were interviewed. The reasons for these divisions were

informed by the literature review, which pointed to differing culturally and socially accepted norms, priorities, and roles. Homogenous groups are also more effective in generating information (McLafferty, 2004). These age group and gender divisions were selected because each age group is at a different developmental stage and could have different views regarding the topic. Different priorities are set according to the life situation, and focus group discussions aimed at exploring HIV/AIDS perception in relation to care and support. In addition in hierarchical societies age and gender tend to influence who is given the privilege to speak and it was important to incorporate all the possible voices in the research topic. Each focus group discussion lasted for approximately 1 hour. The discussions were largely unstructured, but were guided by a number of preset questions informed by the research questions (see Appendix 1).

Focus groups were chosen as data collection method because it provided the possibility to give a wide scope of the population a voice regarding perceptions of care and support around HIV/AIDS. Additionally, focus groups provide formal examples of everyday speech within the community (Denzin & Lincoln, 2005), as well as providing direct access to intersubjective experience, reflecting the social realities of a particular cultural group, and understanding attitudes and opinions regarding various social issues (McLafferty, 2004). Although focus groups may not easily provide access for the researcher into individual biographies, they allow observation of how knowledge and ideas both develop and operate within a cultural context (Kitzinger, 1994). This allows understanding of shared experience, as well as exploring differences between people who may be initially perceived as homogenous (Terre Blanche *et al*, 2006). Additionally, focus groups are advantageous as they widen the range of responses, assist other participants in remembering forgotten details, and release inhibitions that may discourage participant disclosure of information (Catterall & Maclaran, 1997; Kitzinger, 1994). In a focus group, discussion is based on a particular topic, and group discussion assists in generating information. All groups, no matter how temporary, are subject to group processes (Catterall & Maclaran, 1997). This is

particularly important to note, as in this study focus groups ranged from 4 to 8 participants who were recruited from various areas of KwaNgcolosi and so were not necessarily acquainted with one another. Focus groups were therefore used in this study to provide insight into how the concept of HIV/AIDS is understood and discussed between community members, and its associated emotions, as well as to explore perceptions surrounding psychosocial support.

However, there are some limitations to using focus groups as a means of data collection. Although they may promote discussion amongst participants, they may also threaten the possibility of open discussion by all participants, and prevent any deviation from the accepted focus of the group (Kitzinger, 1994). There is the possibility of what Janis (1982) referred to as the “groupthink” phenomenon – where it becomes difficult to extract individual perceptions and opinions from that of the group, and individual responses may be contaminated by the group. The exception to this is when group dynamics are sought specifically for the use of an intervention (Basch, 1987). Additionally, focus groups are neither as useful as participant observation in providing access to and understanding of phenomena in context, nor do they allow for the rich, in-depth understanding gained through individual interviews. However, focus groups do combine both goals better than either method would do alone (McLafferty, 2004).

Another criticism of focus groups is given by Kitzinger (1994), who states that focus groups are sometimes simply used as a cost-effective method of interviewing several people at once. Group interactions are largely ignored, and in reading such transcripts it is often difficult to believe that there was more than one person in the room at the same time. Although focus groups were deemed the most appropriate data collection method for this study because, as mentioned above, this thesis focuses on grass-roots perceptions and participation in HIV/AIDS care, a lack of participant interaction with one another was also observed in this particular study. This may be attributed to the fact that when explaining the focus group procedure to participants, they were not explicitly

encouraged to interact with one another – rather, each participant was given a number (R1 – R8, to make transcription easier) and they were told that once a question was asked, if they felt they would like to respond they could do so by stating “R1 - I think....” and so forth. Additionally, this lack of group interaction may be attributed to culture, language and gender differences, which will be discussed below.

Although focus group discussions may have some limitations, it was still advantageous in this study in that it allowed the researcher to explore the consensus in the ideas and opinions expressed by the groups, who, although not necessarily speaking and interacting with one another, did build on and follow on from one another's ideas when responding to questions.

4.5.1 Focus Group Dynamics

Qualitative data, in its oral form, is a product of the interactions between participants and researcher (Polkinghorne, 2005). Additionally, it must be noted that any experience is made sense of through frameworks involving language, gender, social class, race and ethnicity. Participants are rarely able to give complete accounts of motivations and actions; qualitative data therefore involves accounts or stories of their experiences (Denzin & Lincoln, 1998, in Polkinghorne, 2005).

Much research describes rich interactions between participants; how they question and interact with one another during focus groups (Kitzinger, 1994), however such interactions were largely lacking during this study. The following explores the dynamics and experiences of these focus groups from the perception of the researcher, and discusses possible attributable reasons for the focus group dynamics observed in this research.

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Settings

Focus group discussions occurred in a private room in a community center. The researcher sat behind a table, used for the audio voice recorder and for note taking. The translator sat next to the researcher. Benches and chairs, as available, were placed around the table, where participants sat, according to their choosing.

The Role of Facilitator and Translator

According to Basch (1987:415), the role of the facilitator (alternatively termed ‘moderator’) is to “create non-threatening supportive climate that encourages all participants to share views; facilitating interaction among members; interjecting probing comments, transitional questions and summaries without interfering too brusquely with the dialogue; covering important topics and questions while relying on judgements to abandon aspects of the outline, noting non-verbal responses”. Millward (1995) argues that although the primary researcher may not be very experienced, and therefore not have highly polished facilitation skills, he/she should still be directly involved in facilitation, as he/she will be sensitive to relevant issues, and to understand the need for methodological rigour.

Similar to findings by McLafferty (2004), but in contrast to other research mentioned by the same author, in this study using participants that were not familiar with each other, or the facilitator, appeared to impact negatively on group dynamics: Participants appear to discuss issues through the facilitator/translator rather than with one another, requiring the facilitator to assume a more interventionist role, requiring probing and guiding of the focus group by the facilitator.

Language and Culture

In any cross-language research, the researcher must always bear in mind that language is tied to social reality: Language is an integral part of conceptualization and understanding of inherited values and beliefs (Temple & Edwards, 2002). The production of qualitative data during focus groups involves

the transfer of recalled experience from memory into language discourse. These accounts are then produced in ordinary spoken language, or in prose form (Polkinghorne, 2005).

Qualitative interpretivist research holds that there is more than one correct way to describe the world. This means that although researcher and participants (and, logically translators as well) may understand one another's viewpoints through dialogue, each is a producer of unique, individual accounts, understandings, and viewpoints (Temple & Edwards, 2002).

When such accounts are then translated into another language, it is important to be aware that communication across languages involves more than simply the transfer of information (Temple & Edwards, 2002). It must be noted that translation of data from one language to another may distort meaning, thus changing how someone or something is perceived (Polkinghorne, 2005; Temple, 2006). Literature suggests that there is no "one" correct translation; no match-for-match wording. Rather, there is an array of word combinations that can be used to convey meaning (Temple & Edwards, 2002). In addition to translating from one language to another, translators, rather than providing word-for-word translations, may then of necessity convey concepts and ideas between the researcher and participants. How knowledgeable the researcher is about the participants' culture also plays a significant role in research findings Tsai, Chloe, Lim, Acorda, Chan, Taylor, & Tu (2004). Overing (1987) argues that this should not cause over-anxiety; however researchers involved in cross-cultural and translation research should be wary of the capacity that may open up for participants (and/or the researcher) to use terms that are not understood cross-culturally. The researcher – and translator – is therefore pivotal in conclusions drawn, and must ensure that all concepts used during data collection and analysis are appropriately understood. Additionally, there has been some concern with whether the sociodemographic characteristics of researcher and participants may

influence responses given during discussions, increasing the likelihood of socially desirable answers being given (Babbie & Mouton, 2001).

In this study, during focus group discussions, verbal accounts and discussions were translated verbally for the researcher into English, and again later both English and IsiZulu were transcribed from the voice recorder. The IsiZulu transcription sections were then translated into English, enabling the researcher to compare what was said in IsiZulu and in English during focus groups, ensuring maximum consistency and therefore accuracy in data analysis, as well as checking with other IsiZulu speakers to ensure accuracy of translations. The transcribers of the focus groups for this study are African peers of the researcher that are members of the same academic institution, and familiar with both traditional African and Western concepts and understandings, as well as trained and experienced in the process of data transcription and translation. In qualitative research use often has to be made of translators working in different contexts. Although this is not ideal the transcription of both English and IsiZulu allowed for double-checking of translation accuracy with other peers, and so ensured validity of data. In view of these considerations, it may therefore be assumed that the consistency of data generated for this study has been maintained through translation.

4.6 Data Analysis

Analysis was interpretive, by means of thematic analytic methods, which was used to understand patterns of shared understanding amongst participants, and any variability in those patterns. Since this is an interpretivist study, it is assumed that meanings and perceptions of our participants are derived from experiences around them, and that reality is subjective rather than objective, which also means that perceptions of experiences of the participants may differ from those of the interviewer. This has important implications for research analysis: thematic content analysis will therefore be used. Although the steps outlined by theorists largely overlap, the five steps outlined by Terre Blanche *et al*, (2006) were

primarily used for analysis in this study, with some reference to other authors where applicable, and with NVIVO 8 computer software.

When analyzing the transcripts of focus groups, the social context was considered, and whether findings here are transferable to other geographic areas. Thematic analysis focuses on searching within transcripts for the emergence of patterns of shared understanding and themes. Qualitative research assumes that opinions held by individuals are transferable to all individuals of that target group, and therefore it is assumed that views expressed by our participants are reflective of all individuals of their cultural, racial and gender group within this area. Additionally, since this is an interpretivist study, it is assumed that reality is subjective rather than objective, and that meanings and perceptions of participants are derived from experiences (Ulin *et al*, 2002).

The first step of this process was reading and developing an intimate relationship with the data. This involves becoming familiar and immersing oneself in the content to be analysed. This step began long before textual analysis was undertaken; it commenced right from when interviews/focus groups were planned and participants identified. This means that by the time data analysis began, the researcher already had a preliminary understanding about the phenomena being explored (Terre Blanche *et al*, 2006). Then, immersion again occurred in reading and rereading texts or transcripts of interviews and looking for emerging themes and developing tentative explanations. This step also involved noting the quality of the transcripts, including the portrayed neutrality in asking questions and responding to participants' answers, and the richness in detail of the field notes (Ulin *et al*, 2002). In this step, identification of patterns and recurring themes across focus groups also began.

Secondly, themes were identified. This was done using the same words, style, or terms used by participants themselves. These were then used to establish connections and infer general rules or classes from specific occurrences – thus a

bottom-up, rather than a top-down approach: Themes emerged from the text, rather than the researcher beginning with predetermined themes and fitting text to these themes. The identification of themes was more than simply summarizing content; it occurs with consideration given to processes, functions, tensions, and contradictions (Terre Blanche *et al*, 2006). Subsequently, the information relevant to this theme was displayed in detail, and then reduced to its essential points. Next, each theme was then examined in an attempt to discover the underlying core meanings and feelings of the participants, and then finally an overall evaluation and interpretation was done, assessing the emergent themes and how they relate to each other (Ulin *et al*, 2002). The data was then understood from a Social Capital Framework with particular attention to social bonding and social bridging.

The third step in data analysis according to Terre Blanche *et al* (2006) was coding. Data was marked at relevant instances as pertaining to one or more themes – these can be phrases, lines, sentences, or even whole paragraphs. NVIVO 8 was useful for this as data can be efficiently stored, coded, and grouped. These were then easily retrieved as needed.

Fourth, elaboration occurred – as data was broken down into themes and coded, events and discussions no longer appeared linearly. Common topics, some of which were expressed in several ways, were grouped together under a single theme. Elaboration then occurred as each theme was studied and considered in more detail. This allowed for the more subtle nuances to be seen. (Terre Blanche *et al*, 2006).

The final step in data analysis according to Terre Blanche *et al* (2006) was putting together the interpretation of the data, and checking it. This is the written account, seen in subsequent chapters of this thesis, and is presented under the themes used for analysis. This interpretation has been reviewed, and identified

weaknesses have been attended to. The researcher's personal role in the entire process has also once again been reviewed and considered.

4.7 Triangulation

According to Babbie & Mouton (2001), triangulation is advantageous in social research in that it eliminates biases resulting from single-method studies. Triangulation was done in this study by means of comparison of findings from focus group discussions, to relevant questions within the two Social Assessment Surveys undertaken for the purposes of the larger overall study, namely "The role of social capital in promoting community based care and support for people living with HIV/AIDS in KwaZulu-Natal, South Africa". The first Social Assessment survey dealt with Social Capital in general within the KwaNgcolosi community, and was undertaken by 1024 respondents. The second Social Assessment survey asked specifically about Social Capital as it relates to HIV/AIDS within this community, and was undertaken by 989 respondents. The content of these surveys overlaps on the themes of trust and social cohesion, and so frequency counts of responses of relevant questions were done, and compared to findings from focus group discussions.

4.8 Ethical Considerations

It is widely acknowledged that HIV/AIDS is a sensitive topic in discussion, particularly since there is still a significant amount of stigma attached to the illness. As such, steps were taken to protect all participants and to provide psychological support should it be required.

4.8.1 Informed consent

The aims of this study were explained to participants when they were initially approached, and they were invited to participate on a voluntary basis. Participants who chose to participate were asked to sign an informed consent form, and were told that should they feel the need, they were able to withdraw at any time.

4.8.2 Confidentiality

All participants were assured of confidentiality. This was achieved through storage of audio recordings so that only the researcher has access to them, and other members of the larger research team, should they so require. Names and identifying characteristics of participants have been changed in order to protect their identity, and only altered names and characteristics were used in any written reports. Furthermore, participants were requested during the focus group to respect the confidentiality of other members of the focus group, and not divulge any information shared to others.

4.8.3 Nonmaleficence and Beneficence

Since issues surrounding HIV/AIDS may be deemed as sensitive, the following steps were taken to ensure that the participants do not experience any harmful negative consequences: Participants were informed that participation is voluntary, and that they could withdraw at any time, should they have felt the need to do so. Individuals were invited to contact the researcher at any time following interviews and the focus group, should they have felt the need to discuss any sensitive issues further, or require psychological debriefing, in which case they would have been directed to an identified professional who is qualified to do so.

As mentioned above caring for one who is ill with HIV/AIDS is a potentially stressful occupation, usually associated with high levels of burden. This research may inform an intervention aimed at community mobilization, endeavouring to create a situation where the various needs of patients are met by many individuals within the community, where the burden of care is made more manageable by sharing it between many people instead of simply being shouldered by one individual.

4.9 Trustworthiness of this study

The trustworthiness of a study is vitally important, as it determines whether or not the findings of that study are noteworthy, and should be taken account of (Terre Blanche *et al*, 2006). Consideration has been given to the trustworthiness of this study as follows:

4.9.1 Credibility

According to Ulin *et al* (2002), credibility refers to the extent to which the findings in the focus groups are considered to be accurate, sufficiently rich, grounded in and supported by narrative data, and show a logical relationship to each other. Inferences and conclusions drawn from qualitative research should as far as possible accurately reflect the views of the participants (Terre Blanche *et al*, 2006). In this study, this was determined by comparison between focus groups to establish similarities and differences between groups, through discussion and debriefing with other members of the research team, and in keeping with suggestions by Tsai *et al* (2004), through using translators and transcribers who were familiar with both the English and IsiZulu language and culture, and finally, through triangulation with data from questionnaires administered for the overall project.

4.9.2 Dependability

Whether or not the findings of qualitative studies are dependable depends on the consistency of the research process, and whether it is done with careful consideration of and adherence to consistency in qualitative research rules and conventions (Ulin *et al*, 2002). Research questions in this study are considered to be clear and logically connected to research design and purpose. In terms of data collection protocol, there was only one researcher which minimizes the issue of dependability with regards to data collection protocol, although two different translators were used. However, this is not considered as an area which negatively affected the consistency and dependability of findings in this study, as although each translator's style varied as described above, the researcher had

already established good rapport with both translators, and in both situations it was still the researcher who primarily facilitated and guided the focus group discussion. Additionally, there are some parallel findings across groups.

4.9.3 Confirmability

Confirmability refers to whether or not findings and conclusions of this study are true to the research objectives, rather than values and biases of the researcher (Terre Blanche *et al*, 2006). This means that although the researcher recognizes and documents his/her own role in the research process, the distinction is maintained between personal values and those of the research participants (Ulin *et al*, 2002). In this study, this was achieved through documentation and reviewing of field notes, process notes, and reviewing the proposal, notes, and personal expectations of the study,

4.9.4 Transferability

This refers to whether the findings of this research are transferrable to other contexts (Terre Blanche *et al*, 2006). According to Ulin *et al* (2002), qualitative research should aim to produce findings that are conceptually, rather than statistically, representative of specific groups or populations within a given context. Since the participants for this research were purposively sampled from different areas within KwaNgcolosi, it may be concluded that the findings of this research accurately represent the current situation regarding community perceptions of care and support for one who has HIV/AIDS. The transferability of this study may also be determined through comparison with available literature on the findings of similar studies (see literature review). Contextual factors should however still be considered if wishing to transfer findings from this study to other studies.

4.10 Conclusion

This study makes use of the qualitative research methodology, which allows for in-depth exploration and understanding of community members' perceptions and

understandings of care and support regarding care for those with HIV/AIDS by those who are not currently providing care. Semi-structured focus group discussions are utilized as they allow for the discussion and exploration of group norms, as well as the generation of new ideas.

CHAPTER FIVE

PRESENTATION AND DISCUSSION OF RESULTS

5.1 Introduction

This chapter simultaneously presents and discusses the data collected for this study with community members who are currently not involved in providing care and support for those with HIV/AIDS in the KwaNgcolosi community, according to focus group discussions. Analysis using the Social Capital framework is done in Chapter 6. This chapter begins by exploring the current community perceptions of HIV/AIDS care and support within the community, and then moves on to perceptions of how people with HIV/AIDS should ideally be treated, supported and cared for, according to these community members. Following this is an exploration of both the perceived enabling and hindering factors affecting the transition from the perceived current to ideal situation within the KwaNgcolosi community, as well as what the community members themselves feel that they are able to contribute in order to create a better situation regarding care and support for those living with HIV/AIDS.

5.2 HIV/AIDS Care and Support in KwaNgcolosi

Based on what was discussed in focus groups, the current HIV/AIDS care situation in KwaNgcolosi is rooted in the social perceptions of the disease. This in turn seems to affect the way that those who are ill with HIV/AIDS are treated, both by family members and friends, as well as how they themselves perceive and expect others' opinions of them to be.

5.2.1 “They Have Behaved Badly”: Social Perceptions of HIV/AIDS Within the KwaNgcolosi Community

“AIDS was introduced in the beginning as a disease that you get because you behave badly. It stayed in people’s minds that that is how you get it. It was said you get it through sex, especially – because you have slept with a person like this.

*It stayed like that. But now it is becoming clear that you can get it even if you did not f**k anybody. So no it takes a long time to be erased because it was said you get it through sex, they will say that I got it because I f**ked and did not carry myself well.”*

Respondent 2

Focus Group 6, Men 46 and older

The above quotation accurately captures the perceptions of the majority of people in KwaNgcolosi, according to focus group participants. Although not all focus groups articulated the roots of the social perceptions, all focus groups discussions that did attempt to offer explanations for the current situation, gave explanations similar to one another. No alternative reasons nor perceptions were offered. All described HIV/AIDS as still perceived as something contracted because one acted “badly”. Understandings of what it means to behave ‘badly’ are evident in participants’ use of words such as “dirty” and “f**k” to refer to sex. Other focus group participants also spoke about offspring becoming HIV positive because they disobeyed their parents and snuck out of the house, ignoring household duties, such as leaving pots to burn on the fire. In particular, those family members who had jobs and moved out of the community but did not send money back home to assist their family, only returning home once they are too ill to work are considered to have behaved “badly”, not considering their family. Bond *et al* (2002) noted that those who are HIV positive often have assumptions made about their past sexual history, and it is generally believed that they have been promiscuous. This was also reflected by focus group participants, who spoke about those “disobedient” children returning home pregnant. Such perceptions within the KwaNgcolosi community have lead to prevailing shame, denial and secrecy around the disease, which in turn affects the perceptions of the ill people themselves, as well as those of family members, friends and neighbours, and the community at large. The individual, as well as his/her family, may fear gossip, discrimination, and stigma from community members, and therefore may isolate him/herself from others.

According to Bond *et al* (2002), stigma acts as a significant barrier to sufficient care and support for those who are ill with HIV/AIDS. This is problematic, as such perceptions are still widely documented in other literature (Campbell, Foulis, Maimane, & Sibiyi, 2005; Dilger, 2006; , Kipp *et al*, 2006; Ogden, Esim, & Grown, 2006). Although Ndinda *et al* (2007) found that attitudes towards those with HIV/AIDS appears to vary according to context, and appears to be changing as awareness around the disease increases, it appears that in this context of the KwaNgcolosi community, stigma is still prevalent.

5.2.2 The Link Between Community Perceptions and Care

All focus groups spoke about a discrepancy between what they felt care and support *should* look like in their community, and what was actually happening. All focus groups stated that the root of all reasons for the discrepancy was that the prevailing social perceptions of HIV/AIDS within the KwaNgcolosi community significantly impacts community members' reactions to individuals once they are aware that such people have HIV/AIDS. This in turn affects the way that they interact with the person who is ill, as well as affecting any potential for providing care and support for such a person.

"...maybe the person was your friend or maybe a relative, and it might happen that before they fell sick you use to sit with them in the streets and take high fives from him. Now that he sick you don't want to do all of that, which affects him in a very negative way, that last week you were doing this and now you're no long doing it, but you are doing something else."

Respondent 6

Focus Group 1, Men 18-25 years.

Other reactions observed by participants in the focus group of women aged 26-45 were HIV/AIDS being a taboo subject in the home and therefore blocking any attempts at care for the one who is ill. Focus groups of men and women aged 26-

45 and 46 and older said that even for those who do wish to care for and support those who have HIV/AIDS, they are often met with resistance either by the family members, or by the ill people themselves, as the social perceptions of HIV/AIDS have lead to mistrust of both other community members, and of other care providers within the community, both by the individual who is sick themselves, as well as their family members. Many focus group participants across groups expressed a desire to assist in some form of care and support for the one who is sick, but feeling unable to, either because of family members, or because of the person themselves who is sick.

“I’ll go to a person here who is sick and somebody like their mother will say to you “What? Where did you hear that he was sick? He’s not sick.” But you as a person know for a fact that he is sick until you hear that now there is a funeral for this person who was supposedly not sick.”

Respondent 5

Focus Group 4, Men 26-45 years

There is much secrecy surrounding HIV/AIDS, especially when it comes to disclosure to other community members. This can be understood through the stigma and denial that surrounds the disease (Campbell *et al*, 2005). According to focus group participants, this is because apart from denial of the disease, they wish to protect him/her from the stigma, blame and gossip that is prevalent in the community.

However, it was noted in the focus groups of women aged 18-25 that in some cases, community members do assist in care and support. One respondent in particular, described her mother:

“What I know about my mother and her friends and most of them were sick, she gave them a lot of support it was physical support but also she did everything that

they used to do before like going out, sit with them and have a talk. In her group, which is a large group of friends, she was like the motivational speaker of her group. She's that kind of a woman. They continued doing all the activities they used to do. That's what I saw my mother doing."

Respondent 1

Focus Group 2, Women 18-25 years

It therefore appears that although it is not seen as a norm within the community, there are some individuals who are successfully providing care and support for their friends (and family members).

5.2.3 Family Attitudes

Families handle having a family member who is sick with HIV/AIDS and requiring care in different ways. Although focus group participants noted that it appears to be the family who is the primary source of care for one who is ill with HIV/AIDS, apart from persisting denial of the disease in some families, in extreme circumstances the family will blatantly neglect the person who is ill, blaming them for contracting the disease. Such blame is a central cause of stigma, in many different contexts (Ogden & Nyblade, 2005). Bond *et al* (2002) also noted that stigma and similar perceptions regarding HIV/AIDS are expressed in various forms, ranging from subtle acts to blatant rejection of those who are ill. Similar stories emerged from focus group participants in this study, where in some cases parents will demonstrate neglect of the child, rejecting them because they blame them for contracting the disease, and/or because they did not assist by contributing financially after moving out of their parents' home.

"It has happened, maybe you find that they had deserted their parents, they had moved out of their home and rented their own place, working and spending their own money. Then they get sick and their family says; "oh no, we don't want

him/her,” but when they die the family does bury them, but at first tell them to go away.”

Respondent 4

Focus Group 1, Men 18-25 years

In some cases, the rejection is blatant and family members will do nothing to assist the sick person at all.

“The parent will go with big guts to show you the conditions of the sick person, and would say come and see your person what she/he is doing in the house. What he/she has done, what he/she has done here in the house. You find, the dishes that are, that are not supposed to be there during the day at 1. They are there, sitting in the house, the person is telling you that you must come and see your person.”

Respondent 1

Focus Group 5, Women 46 and older

However, all focus groups except men aged 46 and older also noted that attitudes of family members towards those who are ill are not universal. Although the men aged 46 and older spoke only about seeing discrimination and stigma within families, all other focus groups said that from what they had seen, some families express understanding, but some still demonstrate blatant stigma and blame.

“I wouldn’t say with everybody, but there are some cases like families who do not fully understand, like if I had a fight with my sister and my status is out there everybody knows, then whenever we have a fight that’s going to be like her trump card, that you are like this, so it’s going to be used as a way of swearing at me. But it’s not all families, some families are more understanding, but I would say that some still need more education around that.”

Respondent 10

Focus Group 3, Women 26-45 years

In some cases, care is attempted by family members, although lack of physical resources such as food, money, transport when necessary, also act as obstacles to care.

5.2.4 Individual's Own Perceptions of HIV/AIDS

HIV/AIDS is largely seen as a “blame-the-victim” disease (Fife & Wright, 2000). According to Rohleder & Gibson (2006), individuals who have HIV/AIDS often internalise social perceptions of the illness, coming to view the disease and associated perceptions as part of themselves and their identity. This results in what Bond *et al* (2002) refer to as “self-stigma”, and may lead to self-deprecation, particularly as such internalized perceptions are communicated to them repeatedly by other family and community members that they interact with. In KwaNgcolosi, such identity negotiations coupled with an awareness of prevailing social perceptions within the community may explain why individuals seem to display a lack of trust of others, and appear unwilling to accept any potential care and support from other community members, preferring to rather isolate themselves.

“It is not easy to help because this thing that this person is suffering from is a ‘feel-it-alone’ – only they can feel it. They tell themselves that it’s their business, it’s their problem alone. So how are you going to help them? As you help them, what have you heard them say [by way of needing help]?”

Respondent 3

Focus Group 6, Men 46 and older

According to focus group participants then, the current situation regarding HIV/AIDS care may therefore also be exacerbated as the ill person does not seek any form of care or assistance.

5.2.5 Symbols of Stigma

A final interesting observation by community members was the symbolism attached to certain physical and material resources and actions associated with caring for one with HIV/AIDS, and how this influences perceptions surrounding the disease. Although the focus groups of men aged 18-25 and 26-45, and of women 46 and older recognised the practical necessity of wearing gloves, in order to protect against infection from the sick person, two focus groups mentioned concern about what the repercussions of using gloves may be. The first group was the men aged 18-25, who spoke about the effect it may have on the ill person:

“What I say is maybe the thing that makes people with HIV isolate themselves from their families is that; every time they come to him/her they wear gloves. So it makes him/her think that maybe now they are different from everyone else. Then he/she thinks they will die from this thing they have...”

Respondent 4

Focus Group 1, Men 18-25 years

The second group who mentioned this was the women aged 26-45. They discussed its repercussions on the family rather than the person who is ill, specifically in homes where HIV/AIDS is not accepted.

“Another thing is that like we were saying some people don’t disclose, or sometimes they will disclose to the mother but not to the father, but then when you come to help, you’re going to put on gloves, that’s the first thing you do, but then you leave the house, it might be that you’re never going to come back because you put on gloves in front of the father and then there was a fight after you left or something but that means that might be something that stands in the way.”

Respondent 6

Focus Group 3, Women 26-45 years

It would appear therefore that not necessarily the gloves themselves, as both groups acknowledged that gloves were necessary for providing care for one ill with HIV/AIDS, but what the gloves represented, as a cascade of associations, were seen as an obstacle to providing care for those who are ill. The men aged 26-45 felt that since gloves were a practical necessity in some cases, they should only be worn in cases where it was considered essential, such as when a person is bleeding.

The second negative symbol associated with HIV/AIDS care and support was mentioned, also by the women aged 26-45 years, and concerned the architecture of the local clinic. It appeared that the way the clinic had been structured, was to provide one door at the front where all chronic medication would be obtained, and a separate door at the back of the clinic where the Voluntary Counselling and Testing (VCT) room was situated. This was perhaps done in order to provide some privacy to those who were going for VCT, however it seems to have been a counterproductive endeavour.

“... like when you get to the clinic you find that there’s the door where you get your medication for chronic illnesses right at the front, and right at the back there’s that door to the ARV clinic; the counselling room or whatever. But then when you are sick and you need to go to that door over there, you have to stand and wait until all these people for the chronic illness, for the chronic medication are gone, because you are too ashamed to just walk straight on. So then why is it not that all the doors are in the same place and there’s no door that is branded, you know “That is THAT door,” anyone who walks through there is sick with that, and so it makes it easier for people to get on with it.”

Respondent 6

Focus Group 3, Women 26-45 years

5.2.6 Thoughts on Organizational Care and Assistance for Those Living with HIV/AIDS

There are several other sources of care for those with HIV/AIDS within the KwaNgcolosi community. With regards to organizational assistance, the participants reported that the three prominent organizations within the community: the Home-Based Care workers, Formal Healthworkers (or *uNompilo*), and the assistance received at the KwaNgcolosi clinic. Additionally, although not associated with any organization, informal caregivers also assist in caring for those who are ill.

Home Based Caregivers

Out of the three above mentioned organizations, the perceptions of the focus group participants is that the only one that seems to function as it is supposed to is that of the Home Based Care workers. These volunteers assist families in physical care work of those who are sick. Based on anecdotes, descriptions and discussions during focus groups, they appear to be trusted by the community, although they may be met with suspicion when visiting a home for the first time, as individuals in that home may be wary, fearing gossip from community members and wanting to know who said there was an ill person in their home. The proportion of caring shouldered by the carers appears to be based on how willing or unwilling the family is to contribute to care themselves.

“I would say the family, because whatever happens they are the ones who see first, you see, they are the closest who can help. Even if they do call someone from the outside, but they are the ones who helped him/her first. An outside person would be, health workers.”

Respondent 6

Focus Group 1, Men 18-25 years

Campbell *et al* (2008) also found that the majority of care for those with HIV/AIDS was provided by family, neighbours and Home Based Caregivers.

However, according to participants, the Home Based Caregivers appear to be more prominent in some areas of KwaNgcolosi than in other areas. Additionally, it seems the Home Based Caregivers are the first ones to assist in care, and care for the sick person within the home. They are seen as more knowledgeable and possessing the skills necessary for care that the family may not necessarily have. It appears that the Formal Health Care workers are then summoned if needed.

Formal Health Workers (uNompilo)

All focus group participants who mentioned them expressed very little trust in the Formal Health Workers within the community, whom they refer to as *uNompilo*. The community members are unsure of the Health Workers' precise role in the community, and some distrust them outright.

“The community...the people in the community do not understand well, the role of health workers in the community; they are more familiar with the home based, because they are the ones who do more visible work in people’s homes. Most of the time health workers just gather and have meetings we barely ever see them doing anything else. They use to do it before though before the home based came about, now they don’t do it anymore.”

Respondent 6

Focus Group 1, Men 18-25 years

The current situation regarding Formal Health Workers is consistent with what was predicted by Hermann, Van Damme, Pariyo, Schouten, Assefa, Cirera, & Massavon (2009), who foresaw that insufficient supervision and a lack of continual training would result in a decrease of service delivery over time, resulting in the situation described by one respondent below:

“There is this woman who used to live by my house who has passed away she used to say “the only thing I want is my money at the end of the month and the free food that they give us” but that food is not supposed to be for them, they are

supposed to be taking it to the people but they take it home with them and give it to the family, their children and whoever else they favour and that will be it. The health workers barely ever do their work.

Respondent 1

Focus Group 2, Women 18-25 years

Focus group members also stated that they felt these health workers did not help people, but rather they were extremely judgemental, gossiping about those who were sick and openly talking about how they did not want to visit certain ill individuals. The participants in the focus group of men aged 26-45 went so far as to say that the Formal Health Workers should be removed from the community completely because they are not doing anything; rather, the number of Home Based Caregivers should be increased. However, as the Home Based Caregivers are part of an organization which also does not receive supervision nor additional ongoing training, speculation may occur as to whether or not the perceived attitudes of Formal Health Care Workers may come to be expressed by Home Based Caregivers over time as well. Considering this, an important distinction between the Formal Health Workers and the Home Based Caregivers: The former are paid a salary, while the latter are volunteers. As the above quote indicates, motivation may therefore be primarily financial gain, rather than obtaining satisfaction from the work.

Furthermore, in the Commodification of Emotion Framework outlined by England (2005), care comes to be seen as a commodity which can be bought, thus alienating caregivers from their true feelings and results in a capitalist approach to caregiving. This may explain what has occurred with the Formal Health Workers within KwaNgcolosi, particularly since focus group participants noted that in the beginning, Formal Health Workers were very helpful to community members.

“The thing is, I’ve seen them but I’m not sure if they’re still alive because I hardly see them anymore she’s the one who used to help us with our uncle ... [she]

helped us a lot. I really saw her helping us because she would come and care for our uncle.”

Respondent [unknown]

Focus Group 2, Females 18-25 years

The KwaNgcolosi Clinic

Although only one focus group spoke about the clinic, they seemed to have a very negative view of it, and feel that the stigma and negative social perceptions of HIV/AIDS are also reflected by the clinic staff. Additionally, the necessity of use of a different door through the architectural structure of the clinic may encourage differential treatment towards those visiting the clinic for reasons associated with HIV/AIDS.

“In my experience they get treated differently, like if you get to the clinic, I don’t know because people maybe people with chronic illnesses are older people, they get treated with respect but then you go to the other side, to the ARV clinic, and you can see that the nurses do not have patience with these people, and they treat them however. It’s kind of you can actually get a sense ... like “It’s their fault that they are sick and the way that they are,” whereas with the chronically ill people like the old ladies who are queuing for their medication, for their treatment, it’s like there is a justification for that ... They do get treated differently.”

Respondent 2

Focus Group 3, Women 26-45 years

Stigma and discrimination has also been noted by other research done amongst health care professionals (Reis, Heisler, Amowitz, Moreland, Mafeni, Anyamele, & Iacopino, 2005). In such cases it is acted out through differing attitudes towards sick patients, and through differing quality of care. Deetlefs, Greeff, & Koen (2003:26,28) noted that health professionals’ attitudes towards HIV-positive individuals influences behaviour towards them. Such attitudes arise from fear of

contracting the disease, from anger about denial surrounding the disease, and as a reaction to painful or stressful events associated with those who are ill, and because of a belief that “the disease is spread because of ignorance and disbelief about the existence of the disease” and that HIV was contracted by “irresponsible action.”

Informal Caregivers

A final source of assistance for care within the community appears to be informal caregivers. Although these are not recognised as being affiliated with any organization, they adopt the role as primary caregiver for the one who is ill with HIV/AIDS, and may be a family member or other community member. The informal caregiver is usually then the only one who cares for the ill person, although they may be assisted sometimes by other organizational care workers, generally the home based caregivers. Such a person usually does not have a formal job, and cares full-time for the person with HIV/AIDS, having no additional material resources to assist them in this. This role was noted by those in the focus groups both of men and women aged 18-25, as well as in the focus group of women aged 26-45, but was not common to other focus group discussions.

“It does happen sometimes [that nobody in the family is willing to provide care], but then someone from the family would decide that there should be one person at least that is going to help the home based. That could be the person who will care for the sick person, and they will have a person to talk with about the virus. Not that there will be no person to help out, there is always at least one person compassionate enough to want to care for them.”

Respondent 1

Focus Group 2, Women 18-25 years

Ogden *et al* (2006) term such caregivers who are not affiliated with an organization ‘unlinked care workers’. These individuals receive no formal

training, no organizational support, and no material resources such as gloves. They therefore lack information about HIV/AIDS, and may not even be aware that the one they are caring for is ill with HIV/AIDS.

From the information gathered, it appears that within the KwaNgcolosi community that the current situation regarding HIV/AIDS care and support is less than satisfactory. Focus group discussions then moved on to explore what informants felt an ideal situation *would* look like, and perceived mechanisms and obstacles for achieving this.

5.3 “It’s About Giving Love and Hope”: What Should Be Happening

All focus groups noted a discrepancy between what is currently happening in their community around care and support for those who are ill with HIV/AIDS, and focus group participants’ perceived ideal situation. Similar findings are discussed in Ndinda *et al* (2007), who also noted there seems to be challenges in treating individuals who are ill as it is perceived they should be treated. The possibility of such responses being attributed to social desirability was also mentioned, and it is acknowledged that this may also be a possibility in this study.

5.3.1 Social Perceptions of Ideal Care and Support

All participants expressed opinions that care and support for HIV/AIDS should ideally being the same as for any other disease, with care and support being about unconditional love; that the person who is ill required love, acceptance and patience. This, more than anything else, appears to be a priority. However, it is interesting to note that this came out as the first response in all focus groups except with the men aged 46 and older, who spoke about understanding care and support as being primarily about physical, care, and then went on later to speak about the sick person requiring love and support as well. Additionally, all groups mentioned that those who are ill should be given everything that they require to assist them in becoming well again.

“...people in the homes [who are sick with HIV/AIDS] firstly need to be given love. They should be loved and be treated like ordinary people and mustn't be separated from other people with the idea that there could spread their diseases to other people if they are kept with other people. They should be treated the same like other people, so that they could believe that if they are being treated they are going to feel better. And understand that even if they go to hospital and when they come back home, at home they, They love me like before I got sick.”

Respondent 4

Focus Group 5, Women 46 and older

5.3.2 Organizational Care

Both male and female participants aged 18-25 also articulated specifically that those family members who provide care for one who is ill with HIV/AIDS should do so because they have a desire to, rather than simply seeing it as an obligatory role. In the case of the latter group, this applied to both those family and community members who assist, but also Home Based Carers and Formal Health Workers.

Additionally, female focus groups aged 26-45 said that Home Based Caregivers should work in collaboration with families, that they should be organized and formulate a plan together, and rely on each other in order to provide care and support for the one who is ill.

“The way that I see it, I think that like say if a caregiver hears that there is a sick person in that household, before they even start helping there should be a session where a form is filled, an agreement form is filled where it says ‘this is what I am going to do’ where the family also signs saying ‘this is how we’re going to help’ like if the caregiver is off, it’s their off day, then the family should be able to do this and that would help a lot.”

Respondent 6

Focus Group 3, Women 26-45 years

The reasons for the women aged 26-45 years mentioning that they would like care to be collaborative may be understood when considering that it is primarily women of this age group, who assume the roles of providing care for those who are ill (Ungerson, 1993). As such, these women are most at risk of stress and burnout (Akintola, 2006; Kipp *et al*, 2006). In the case of community members who are not providing care, this group of women are more likely than other focus groups, to then be aware of the stress and burden of their contemporaries who are providing care, and therefore may be aware more than other groups for need of assistance in the caregiving role.

5.3.3 Structural Assistance for Care and Support

In order to achieve a better situation of care and support for those ill with HIV/AIDS, community members felt that additional structural resources would be beneficial.

A Place Specifically for Care

Almost all focus groups expressed a desire for a structure such as a hospice within the community, where people ill with HIV/AIDS could be taken and where family and community members could feel reassured that while there, those who are ill with HIV/AIDS will receive proper, continuous care. It is interesting to note that the young men aged 18-25 spoke of a place where ill *youth* specifically, whose families did not understand their situation, could live. The only exception to this was the women aged 26-45, who spoke about further development of the clinic that is already within the community, which could empower community members to assist in care and support for those who have HIV/AIDS.

Youth Club

Both the male and female focus groups aged 18-25 also spoke about having a youth club, where those who wanted to could meet. However the function that

such a club would serve appears to differ between these two groups. For the men, it would be a place where those youth who were ill and were receiving insufficient care could stay and other youth could visit them there.

“I think if maybe they could build a place where the youth with AIDS could live, where the youth could understand how the sick people feel at that time. ... Maybe the community youth could come up with solutions and help him with his problem; they could take him to another place where he could stay, because his family doesn’t understand his situation at that particular time [and he is experiencing stigma and discrimination at home].”

Respondent 1

Focus Group 1, Men 18-25 years

For the women, the club would serve as a place where the youth could meet and bond together, as well as being a place where they could organize and coordinate a collaborative care effort and provide care and support for those who are ill.

“Personally I think we should form a youth club, we should have specific times and dates on when we should meet, then we should have a programme stating exactly what we will be doing... the youth like music, so we can have something like that...then from there we can take it further on and eventually get to the main idea which is care. Then from there each person will say whether they are willing to do that or not. From there we can then form a group of people who are willing to give support.”

Respondent 2

Focus Group 2, Women 18-25 years

5.4 Identified Obstacles to Achieving an Ideal Situation

The perceived discrepancy between the current and ideal situation regarding care and support within the KwaNgcolosi community was attributed to several reasons.

5.4.1 Stigma, Shame and Silence

Respondents noted that the discrimination and silence around HIV/AIDS still functioned as a significant barrier to HIV/AIDS care and support, as not knowing one was ill with the disease prevented one from being able to do anything about it.

“People don’t want to come out or to divulge their status. They would come with stories like “no, I am like this, and this, and I have TB, or no it is a traditional thing, they would come up with preparing to be a Sangoma, [traditional healer working with ancestral spirits] and tell you this and that. I think [that they think] it is a shameful disease because it came the wrong way, since this disease came by sex, whereas it can come in different ways.”

Respondent 1

Focus Group 5, Women 46 and older

Many participants demonstrated knowing that HIV/AIDS can come “different ways”, although they described the current social norms and perceptions within the community as still being that HIV/AIDS is shameful. There therefore appears to be a cognitive recognition that HIV/AIDS *shouldn’t* be shameful, although it seems that this is still the prevailing normative perception within the community. In cases where neighbours do not have a good, close relationship, this appears also to lead to the questioning of motives and a lack of trust of community members who wish to assist in care.

“I would say that the neighbours, sometimes it looks like the neighbours are not helping but that could also be about the relationship that they have with the household where there is a sick person. If they don’t get along very well then they’re not going to come along when somebody’s sick because then it’s gonna look like they’re just coming here to make fun of the sick person, I mean it could

be something that is about the parents or even the children, but if the relationship is not so good then the neighbour is not going to come.”

Respondent 8

Focus Group 3, Women 26-45 years

5.4.2 Community (Un)Willingness for Involvement

Focus groups spoke about an unwillingness for community members to become involved in care and support for those with HIV/AIDS, and unwilling to participate in any endeavours seeking to promote such.

“The thing is the youth from here is not into things like that, if you are doing that sort of thing you become a laughing stock.”

Respondent 2

Focus Group 1, Men 18-25 years

This attitude appeared to particularly apply to endeavours around HIV/AIDS. Furthermore, the social norm of alcohol indulgence was also a perceived obstacle for any endeavours.

“It is not easy to get together, because today’s youth drink too much, you find that you have invited to a sports day or dance and they arrive drunk and they start causing chaos and being rude and he destroys whatever it was that we were trying to form. Now we can’t do it as we had planned, because now they are stabbing each other and fighting. That is what I usually see.”

Respondent 4

Focus Group 2, Women 18-25 years

In addition to the active resistance mentioned by the youth of the community as mentioned above, the men in both focus groups aged 26-45 and 46 and older described a more passive resistance, where men of these ages simply were uninterested, preferring rather to drink and smoke.

“It is supposed to be difficult [to get them to participate]. They are drunks, they smoke, they are rude, they crush dagga, they cannot listen to another person speaking. Why? Because it’s the dagga that roars in their heads. That is why you will not get them.”

Respondent 4

Focus Group 6, Men 46 and older

Based on the fact that it was only male that mentioned alcohol and dagga as a barrier, it seems that this is an obstacle for men rather than women in this community. According to Wolff, Busza, Bufumbo, & Whitworth (2006), drinking is a culturally- and socially-embedded activity, with many important local meanings attached, with gender norms pointing towards women traditionally being expected to stay at home and see to household duties, while men are expected to consume alcohol as a display of masculinity (Brown, Sorrell, & Rafaelli, 2005, Wolff *et al*, 2006).

5.4.3 Socioeconomic Resources

A lack of physical, monetary resources was also perceived as a barrier to assisting in care by men aged 46 and older. However, this point was interesting in that it was followed by a perceived need to then seek for alternative ways in which people are, in fact, able to help.

“What beats us is because we are some of the people who feel pain when there is a person suffering from any disease. It becomes painful for us. Sometimes we are beaten by the fact that we have nothing in the hand. No money; I say that because right now I am not working, you do not even have the littlest amount of money to get up and face them. How you can help them is to sit down with them and talk about this thing.”

Respondent 2

Focus Group 6, Men 46 and older.

Socioeconomic resources as a perceived barrier may be understood when considering that traditionally, it is the men who are expected to be the primary breadwinners and provide for their household (Seeley, Grellier & Barnett, 2004).

5.5 Proposed Solutions to Perceived Obstacles

Although focus group participants were aware of many obstacles to improving the current situation around care and support for those with HIV/AIDS, they also suggested solutions in the forms of community members requiring more education, both in terms of how to provide care and how to relate and talk to someone who is ill, making HIV/AIDS a socially acceptable topic, through this removing the stigma and silence around the disease, and making care for HIV/AIDS patients a collaborative effort. Participants also spoke about their own potential roles and contributions to care.

5.5.1 Education

All focus groups expressed a desire for more education around the disease. Although there have been many media campaigns aimed at reducing stigma and discrimination towards those who have the disease, there appears to have been a lack of education on how to manage with the disease, on a practical level. This appears to be a potentially effective suggestion, as Brown *et al* (2001) found that stigma can be reduced through a variety of intervention strategies such as information, counselling, coping, and contact skills.

“I think that the government should call together the community and conduct workshops, maybe on Saturday’s, they could call a meeting and teach everybody about caring for an HIV person. There has to be people to do that kind of work.”

Respondent 4

Focus Group 1, Men 18-25 years

However, Omoto & Snyder (1995:672) noted that in order for one to be a successful volunteer caregiver, among other things, one should possess predisposing personality traits, such as a “helpful disposition”. Community members also expressed a need for those only who have a desire to provide care, and who can be trusted, to be trained. This was expressed by both the men and women aged 18-25.

“... you don't just take anyone form the community; you have to ask for the people who actually love to help people. If you just take anyone then you get people who will take their skills and use them selfishly to the people they like in the community. They have to work with the community and hear from the community as to who will be more suitable. So if those people have to do such a job, they will be people who will not go around gossiping. They have to be trained to respect patient-carer confidentiality, you know what I mean.”

Respondent 2

Focus Group 1, Men 18-25 years

There was also a recognition that education alone is insufficient for effective care. Again, the solution was proposed to train people who have a desire to care for those who are ill, in order to produce an effective organizational caring system.

“Personally I think we should find those people who are willing to do the work, because now we have been educated about HIV/AIDS, and that use a condom yet a lot of people don't do it. Everyday on TV we are told to condomise and be wise, but even today you will find that there are people who are going to test and 50 people would be tested positive, we are being educated it is just that people are being ignorant. So that is why we need to find people who are willing to do this, who will say they love doing it and it comes from the bottom of their hearts.”

Respondent 1

Focus Group 2, Women 18-25 years

Additionally, women aged 26-45 expressed a desire to know how to talk to one who has HIV/AIDS. Since there is so much stigma, discrimination and silence around the disease, they were unsure of how to talk to one who is ill, or what to say.

“[I would like] To know more about like how do you approach a sick person, how do you speak to a sick person, what sorts of conversations do you have when you come to see a sick person, do you talk about your sickness that is the reason for your being there in the first place, or do you talk about other things, soccer or whatever? So just to know more about it.”

Respondent 6

Focus Group 3, Women 26-45 years

The male focus group aged 46 and older expressed a similar need to learn how to talk. However, it appeared that they felt comfortable broaching the subject – this was common to the other two male focus groups as well - and talking about it with those who were ill, and saw its value, but the men aged 46 and older felt that it was necessary to broach it gently.

“How you can help them is to sit down with them and talk about this thing. And learning to approach them, to learn in your mouth to approach them so that you can talk about this thing. You cannot just get there and say, “you are suffering from Aids?” you just talk about other things, and you slowly introduce this thing, and you go away. You come back another day, you talk about other things, and throw in a little bit of this thing. In the end, they will see and they will not be scared of you. Then you can broach the subject of how they can be helped. You learn to approach them because if you just crash on them, you will fight.”

Respondent 2

Focus Group 6, Men 46 and older

The above differences between male and female groups may be seen as a result of socially acceptable norms regarding sexual matters. Men are expected to be confident and in control, and are expected to be decision-makers in sexual matters, while women are expected to be coy, never initiating nor permitted to discuss anything related to sexual matters (Varga, 2003). As a result of such socialization, women would then feel less comfortable than men discussing issues related to sexual matters. However, such an explanation then points to the persistent cognitive association of HIV/AIDS with bad or deviant sexual matters. Such a continued association contradicts the statement made by focus groups that although HIV/AIDS was initially introduced as a disease contracted through “bad” behaviour, participants now know that it is contracted in “other ways”.

5.5.2 Changing Social Norms

In addition to a needed change in one-on-one social interactions between one who is ill with HIV/AIDS and other individuals, focus group participants also felt that a shift in collective community perceptions and outreach would be beneficial. Male participants aged 26-45, and 46 and older felt that HIV/AIDS should become a socially acceptable conversation topic; one that they could discuss during normal everyday activities. They felt that being able to talk about the disease would help to address the current silence, fear and discrimination currently associated with it.

“It is something that we should talk about, sitting, eating tea, in buses – we should just talk about it. It should be familiar that a person is just sick like anybody else. It is just talking, that we contribute by talking.”

Respondent 2

Focus Group 6, Men 46 and Older

The men in all focus groups expressed a desire to learn how to and be able to visit those who are ill and show their support through talking to and encouraging them.

“I would like to be trained to talk to them, have a conversation with them and tell them there is nothing difference between you and I. Give them some wise words and tell them that life goes on as it has been.”

Respondent 1

Focus Group 1, Men 18-25 years

However, there was a difference between the age groups of men in that the focus groups of men aged both 18-25 and 26-45 said they would like to be trained on how to speak to someone with HIV/AIDS, whereas the men aged 46 and older seemed to feel able to talk to those who were ill. The only perceived obstacle for this group would be the ill person themselves.

“How you can help them is to sit down with them and talk about this thing... It is just learning to approach them so that they do not get angry about the way you are going to speak.”

Respondent 2

Focus Group 6, Men 46 and Older

5.5.3 Collaboration

The men aged 18-25 discussed adopting different, collaborative roles regarding care and support for those who are ill, recognising that those requiring care had many needs. They felt that each person should be trained in their area of interest – this was not necessarily limited to the currently accepted activities of caregiving.

“You can’t just train people who themselves don’t know their area of interest. If I want to help the community I have to know exactly what I want to do for them and then acquire those skills. For instance there must be a fitness trainer, a

nutritionist, a counselor, and each one knows that they have their own area of speciality. Not that the same person will come with the same kind of help that doesn't cover much, no! A person who is sick needs different kinds of care and help."

Respondent 6

Focus Group 1, Men 18-25 years

The men in this focus group also spoke about physically exercising with the person who is ill, to keep them fit and healthy – through activities such as lifting weights (dumbbells), or walking. The women aged 26-45 mentioned the same idea.

The women aged 18-25 were similar to the men of the same age group in that they spoke about adopting different roles so that care and support became a collaborative effort. Similar findings were noted by Linsk & Pointdexter (2000), who stated that younger people seem to prefer to see themselves as ongoing contributors towards care, thus making it a collaborative effort, rather than adopting roles of primary caregivers. The women aged 18-25, however, differed from the men of the same age group, in that they spoke about getting together and forming an organization, through which they could work together to provide care and support. This idea was repeated in the focus group of women aged 26-45, however the latter spoke about adopting different roles within organizations as applied to dividing into teams and organizing resources to assist in care. These women however spoke more about aspects currently associated with caregiving such as cleaning, administering medication, talking and motivating. Such care would be organized and done with consideration to what other women were doing.

"I think umm...okay because we will be in groups, right? There should be people in subgroups, there should be those who will change nappies, administer pills and motivational speakers because not all of us are the same some can change

nappies and others can clean and stuff. So it's better that we are grouped, because I can't go and change someone's nappies and we are not all the same emotionally, because even seeing a sick person is just too much for me, so I'd rather be a supervisor."

Respondent 5

Focus Group 2, Women 18-25 years

However, the women aged 18-25 spoke more about becoming involved with the ill person themselves, whereas the women aged 26-45, although mentioning care and support, focussed more on the logistics and arranging sources and such.

"I think that it works much better, like say for example we're a group and there's ten of us, we could have a group, like subdivide, have a group of three, a group of three, a group of four, some group goes to the school, some group goes to ask for donations from Shoprite or wherever and maybe have something that we can be identified with, like sort of a, like something that makes us uniform, but that we do different tasks so that we can accomplish more."

Respondent 6

Focus Group 3, Women 26-45 years

It is interesting to note that although the women in the above-mentioned two focus groups had earlier in discussions spoken about care and support being about unconditional love, and visiting and speaking to the person who is ill to show him/her that s/he is still accepted, when questioned about their own contributions to care and support they almost exclusively talked about doing something tangible or concrete. Although all groups spoke about showing love through activities such as visiting and talking, bathing, helping, cooking, the women appeared to focus more than the men on physical aspects of care.

All women in all focus groups spoke about being prepared to assist in physical care; cleaning and bathing the ill person, and in cleaning the home and cooking if necessary.

“Yes, you clean the person, you bath, you give person food, if the person couldn’t stand maybe you cook the porridge. Maybe you change the person her night dress, change her sheets and wash them, maybe sometimes if you get there and find out that indeed this person does not have anybody, you need to do the washing. If you can even the blankets must be washed and take the person outside for fresh air and also the floors. Wipe the floors.”

Respondent [unknown]

Focus Group 5, Women 46 and older

The men aged 46 and older also expressed being willing to bathe and clean a person who is ill, although they felt that women who were ill may not be comfortable with them, as men, in that regard.

5.6 Summary of Results

The community members of KwaNgcolosi feel that the current situation regarding care and support for those who are ill with HIV/AIDS is less than an ideal situation. Most notably, care and support should be about unconditional love, whereas it appears that currently many people who are ill are not being sufficiently taken care of, mostly owing to negative perceptions of family members, both of the disease and of the person who has contracted it. Although community members recognise that there are obstacles preventing the ideal situation from occurring, they have also conceptualized and suggested solutions to these difficulties, namely education, and changing social norms and perceptions. Each focus group also discussed ways in which they would be able to assist in care and support. The women aged 18-25 and 26-45 expressed a desire to form an organization and work together. All women spoke about taking care of the physical aspects of taking care of and cleaning a person and their immediate

environment, whereas the men were more concerned with providing support through visiting and talking. However the younger men also were similar to the women in that they spoke about collaborative care, although they did not speak about organizations. All focus groups also made reference to structural support they would like to receive, in the form of a hospice, clinic, or youth centre.

Therefore the members of the KwaNgcolosi community see care and support as multi-faceted. Each community member has different interests, and the form which care and support takes should be according to these interests. There does appear to be an optimism that the ideal situation can be achieved, although community members are looking to outside sources for training and development.

CHAPTER SIX

ANALYSIS OF RESULTS USING THE SOCIAL CAPITAL FRAMEWORK

6.1 Introduction

This chapter discusses and analyses the focus group discussions according to the Social Capital framework. It begins with a discussion of the link between Social Capital and health, and focus group participants' perceptions of the link between support, stress, and health. Following this is an exploration of the current dynamics within the KwaNgcolosi community with regards to the elements of trust, reciprocity, social norms and social networks, and how these function on the levels of Social Bonding, Social Bridging, and Social Linking, to produce the situation currently perceived by focus group participants within this community. Triangulation using the social assessment surveys – both on Social Capital in general (1024 respondents), and on Social Capital and HIV/AIDS (989 respondents) - undertaken for the overall project mentioned in Chapter 1 was done with some responses, specifically those regarding trust and community solidarity. Although an in-depth triangulation is beyond the scope of the study, frequency counts of responses were done where applicable.

6.2 Social Cohesion within KwaNgcolosi

From focus group discussions it may be deduced that there is low social cohesion within the KwaNgcolosi community with regards to issues related to HIV/AIDS, which is conceptualised according to Hsieh (2008:152) as “the abundance of moral support, which, instead of leaving individuals to rely on their own resources, leads them to share in the collective energy and supports them when their individual resources are exhausted.” According to focus group participants, such sharing and support is currently not occurring – those who are ill are largely isolated from other community members, and in extreme cases by family members as well. Reasons for this vary, but appear largely to stem from fear and

lack of trust. Community members who do wish to provide care and support also often find themselves prevented from doing so by these same reasons – however focus group participants also spoke of many other community members who were not interested in caring for or supporting those ill with HIV/AIDS, attributing this to reasons such as destructive social norms. Additionally, focus group participants felt that any initiatives to increase social cohesion within the community may not be taken seriously, or might be met with a general lack of interest.

Considering the social assessment survey responses, in terms of both overall general social cohesion and social cohesion related to HIV/AIDS, and given focus groups' perceptions of low levels of social cohesion related to HIV/AIDS, it appears that social cohesion when concerned with HIV/AIDS is lower than for other community issues. When asked about the feeling of togetherness within the community, 5.8% of survey respondents felt that people were very distant, 12.4% felt that they were somewhat distant, 16.8% felt that people were neither distant nor close. The majority (62.4%) felt that community members were close, with 38.1% saying somewhat close, and 24.3% responding very close. Additionally, when asked how many close friends they have, or people that they felt at ease with discussing private matters, 20.3% of respondents said none, 31% of respondents felt that they had one close friend, and 22.2% said two close friends. 15.1% felt that they had between 3 and 6 close friends, and less than 2% felt that they had between 6 and 10 close friends. There was one response each (0.1%) for 12, 14, 18, 22, and 30 close friends.

In terms of reliance on others for resources, 45.2% of survey respondents felt that they could not rely on anybody beyond their immediate family to borrow money, 8.3% were unsure, and 45.3% felt that they were able to. When considering whether or not community members could rely on others to take care of their child while they were away, 21.8% felt that they could not, 9% were undecided, and 68.1% felt that they could. Additionally, if help was needed, 31.2% of

respondents felt that most people in the community would not be willing to help, 17.4% were undecided, and 50.8% felt that others would assist them. However, the translation of this perceived social cohesion into collective action is very low: When asked how often within the last 12 months community members had gotten together to jointly request something from leaders that would benefit the community, 37.6% said never, 36.8% said once, 19.4% said a few times (3 or less) 3.6% said many times (6 or less), and 0.9% said very often. It would therefore appear that although there is perceived general trust and social cohesion within this community, this is not leading to collective action. A tentative explanation for this, however, may be a lack of knowledge about how to take action, or how to speak to leaders, which points to a deficit in information sharing through networking, as well as a deficit in Social Bridging.

When considering social cohesion in relation to HIV/AIDS, it is important to note that in terms of the notion of *Ubuntu* as a motivating factor in joining in volunteer activities for one with HIV/AIDS, 21% of survey respondents felt that it was not important, 26.3% were unsure, and 52.4% felt that it is an influential factor. When asked if they would join a group or organization providing HIV/AIDS services within the community, 22.8% said that they would not, 6.3% were unsure, and 70.8% said that they would join. This is consistent with the observed, current untapped potential within this community with regards to care and support for those with HIV/AIDS. It therefore appears that although there may be a willingness to participate in care and support for those with HIV/AIDS, there is currently no space in which to do so. However, it is interesting to note that focus group participants felt that there would be a lack of interest from community members regarding HIV/AIDS initiatives, whereas the social assessment survey indicates that this would not be the case. Two tentative explanations may be offered for this discrepancy: Firstly, the lack of social discussion and informal conveying of information regarding HIV/AIDS within this community, may have resulted in community members feeling that others are still holding persisting negative beliefs about the disease, even if they do not have the same beliefs

themselves. Therefore, although there is a current lack of social cohesion regarding HIV/AIDS within the KwaNgcolosi community, this may not be because of a lack of willingness, but is rather attributed to the current lack of trust, reciprocity, and social norms surrounding the disease, and an “othering” of perceptions, attitudes and norms surrounding HIV/AIDS. The second potential explanation is the possibility of social desirability in the survey responses. Social desirability is explained by Mick (1996) as the tendency of respondents to portray themselves in a positive light, in accordance with current social and cultural norms. As such, respondents of this survey giving socially desirable answers would then portray themselves as being willing to assist and engage in community activities.

6.2.1 Social Capital, Social Cohesion and Health

McKenzie, Whitley & Weich (2002), and Helliwell & Putnam (2004) note that the social context significantly affects individual’s mental and physical health. It therefore becomes apparent that social cohesion within the community plays an important role in the health of an individual. As such, the emotions and perceptions of an individual who is ill with HIV/AIDS may be seen as an indicator of the perceived attitudes and situation within the community. Focus group participants noted that for those who were ill with HIV/AIDS, stress was extremely common, and in fact was perceived by many as the primary reason of death. This confirms the current lack of social cohesion noted within the KwaNgcolosi community in relation to HIV/AIDS.

The perceptions of stress as it related to HIV/AIDS were noted by the focus group of men aged 18-25, and two of the female focus groups, aged 26-45 and 46 and older. Such findings are noted by Poortinga (2006), who concluded that personal levels of social support are consistent with higher levels of self-reported health status. As such, higher levels of Bonding Social Capital result in better health, in addition to greater access to social networks, and social support.

The stress of such individuals may be attributed to two causes. Firstly, in a context where HIV/AIDS is viewed as a shameful disease and therefore linked to stigma and a lack of support – reduced levels of Social Capital - those who have the disease are likely to become stressed (Chiu *et al*, 2008), thus negatively affecting their health status.

Secondly, the focus group of men aged 18-25 and 26-45 spoke about the person who is ill with HIV/AIDS thinking that they are going to die, which participants also felt was a cause of stress for such people. South Africa has an extremely high HIV/AIDS burden (WHO/UNAIDS, 2008), and insufficient health resources to meet the needs created by this burden, particularly in rural areas (Lewis, 2008), such as the community of KwaNgcolosi. A perceived lack of access to formal health care and resources may also be a cause of stress. Stafford, De Silva, Stansfield & Marmot (2007) and Poortinga (2006) also noted that lower socio-economic status seems to be associated with lower health status. This is applicable to the KwaNgcolosi community, as the majority of individuals residing here would fall into this category.

6.3 Understandings of Care and Support for Those with HIV/AIDS

When asked about their understandings of care and support for those with HIV/AIDS, all focus groups immediately mentioned it was about showing love and acceptance. The only exception to this was the focus group of men aged 46 and older, however they mentioned the importance of acceptance later in the discussion. Additionally, all then mentioned needing to visit and take care of the person who is ill, and the need to assist to physical needs. However, it was also noted that this is not currently happening. With reference to the Social Capital Framework, the reasons for this may be understood by considerations of trust, reciprocity, social norms, and social networks, and how these influence care and support for those who are ill.

6.3.1 How Trust Influences Care and Support

Taylor, Williams, Dal Grande, & Herriott (2006) found that lower levels of trust, community involvement, and social activities, were seen in poorer communities. Given that KwaNgolosi is an area characterised by poor socioeconomic status and resources, it may therefore be expected that this community exhibits trust, social activities and involvement consistent with what was observed in other poor communities. Trust (or mistrust) is evident in the social interactions between those who are ill, family members and other community members; Home Based Caregivers, and other Health Care workers. According to the social assessment survey,

According to Stone (2002), when norms of trust are present, family members trust one another to provide care for each other. However, trust sustains Social Capital (Putnam, 1995), and when trust is not present, community networks are lower. As such, access to resources for care and support is limited, since these networks are only created when individuals spend time with one another, investing in and creating such networks (Glaeser *et al*, 2000). As such, isolation through mistrust acts as a destructive force for social networks. This appears to be the case in KwaNgolosi, where focus group participants noted that people with HIV/AIDS are largely isolated from the rest of the community.

6.3.2 Expectations of Reciprocity Influencing Care and Support

There is a significant link between trust and reciprocity (Carter & Castillo, 2002). As such, when trust exists in a relationship, reciprocity will likely be present. Trust and reciprocity are also underlying principles of *Ubuntu*, where it is understood that all existence is communal, with a network of mutual support (De Villiers, 2005). Sharing and co-operation are seen as fundamental to social living (Murithi, 2006).

Within South Africa, it is common practice that family members will leave home to secure jobs and live in other areas. However, in such situations there is an

expectation that the person who is working will send money home to the family (Dilger, 2006). As such, according to focus group participants, individuals who function according to the principles of *Ubuntu* before becoming ill may expect reciprocal acts of care and support once they are sick. There is also a perception that those who are not treated well once they require care and support, are perceived as deserving by family members. In such cases, care is therefore provided out of duty, or because there is a perceived benefit, such as a social grant.

However, it is important to note that trust and reciprocity are different to altruism (Carter & Castillo, 2002). Focus group respondents noted that in cases where the family will neglect the ill person, there will be one individual who will provide care for him/her, adopting the role of informal primary caregiver. This may be seen to be done out of intrinsically motivating factors, such as compassion for the one who is ill, as there is no perceived future benefit for caring for one who has HIV/AIDS.

6.4 Ways of Best Meeting the Identified Care and Support Needs, According to Focus Group Participants

According to focus group participants, care and support should primarily be about providing love and acceptance. There was a division according to age, and also according to gender, regarding how these needs should be met, and what focus group participants felt they could do in order to assist in meeting identified care and support needs.

6.4.1 Encouraging and Fostering Social Networks

Social networking as a means to meet the needs of those with HIV/AIDS took two forms in focus group discussions: Forming care organizations, and having a youth centre within KwaNgcolosi that would function either as a meeting place for such young organizations, or as a place of support where those who had HIV/AIDS could reside and receive needed care and support. These can be

understood by considering current social norms regarding caregiving roles. Such initiatives may be successful, as 70.8% of survey respondents said that they would be prepared to participate in an organization providing HIV/AIDS services within the community.

6.4.2 Gendered Social Norms and Roles

It appears that social norms surrounding care and support for those with HIV/AIDS are largely influenced by current prevailing gender norms, which influence dynamics in the community regarding caregiving. Research points towards caregiving being primarily undertaken by women (Campbell *et al*, 2008; Wight *et al*, 2007). The majority of Home Based Caregivers are also women (Akintola, 2006). This may have resulted in a social norm in which women involved in caregiving efforts do so as part of an organization. Such a norm was reflected in the suggestions of women aged 18-25 and 26-45 – the age of most Home Based Caregivers – to form organizations in order to assist in care. The women aged 26-45 even suggested that they have a uniform to identify themselves as being part of a group.

Additionally, traditionally it is still expected that women will take care of domestic chores within the home (Kipp *et al*, 2006). All of the female focus groups also mentioned caring through bathing, cleaning the home and such. Although these suggestions will cater for the physical aspects of HIV/AIDS, there are also psychosocial aspects of care and support for those with HIV/AIDS.

Men are traditionally expected to provide income for the household (Kipp *et al*, 2006; Seeley *et al*, 2004), as well as to frequent local shebeens where drinking, but also a great amount of socialisation is done (Wolff *et al*, 2006). As such, men in all focus groups felt that care and support needs could be met by visiting the ill person and talking to him/her, and through this showing support and acceptance, thus meeting psychosocial needs of those who are ill.

6.5 Perceived Obstacles to Meeting Identified Care and Support Needs

However, although the desire to do so exists, focus group participants also noted that there are several obstacles to becoming involved in care and support for those with HIV/AIDS.

6.5.1 Trust, Mistrust, Cynicism and Suspicion

The greatest obstacle to becoming involved in care and support for those with HIV/AIDS, according to focus group participants, is a lack of trust. This acts as a significant barrier to any attempted efforts.

Trust and Stigma

According to Skinner & Mfecane (2004), stigma counteracts trust. Therefore, those who experience stigma, or are aware of stigma in the community, are less likely to trust others. A lack of trust others is also evident in the unwillingness to disclose an HIV-positive status, even when one is ill – this unwillingness appears to be limited exclusively to being ill with HIV/AIDS. It therefore becomes apparent that stigma and mistrust is a major obstacle to providing care for those with HIV/AIDS, particularly since according to focus group participants. Although there has been much research done into stigma surrounding HIV/AIDS, it appears that the current situation is still the same as that observed years ago (for example, Caldwell, Caldwell & Quiggin, 1989, and Chiu *et al*, 2008). As such, it appears that those who are ill still fear the gossip which may be attributed to the stigma associated with the disease. The silence that exists as a result of stigma is demonstrated both by the individual who is ill, as well as their family members being unwilling to disclose their status. Additionally, participants felt that the family members of those who are ill also exhibit mistrust and an unwillingness to disclose to other community members.

In the social assessment survey, when considering general trust, 37.5% of respondents felt that in general people could not be trusted, 13% were unsure, and 47.5% felt that people could be trusted. However, when asked whether

respondents felt that they had to be alert or others would try to take advantage of them, 11% felt that this was not the case, 10.5% were neutral, and 77.9% of individuals agreed with this.

When concerning HIV/AIDS, 5.5% felt that family, neighbours and friends could only be trusted to a very small extent, 7.7% felt that they could be trusted to a small extent, 21.1% felt average, 29.3% said to a greater extent, and 36.1% felt that they could be trusted to a very great extent. Again, this may point to a discrepancy between what is felt by community members and what is occurring around care and support for those with HIV/AIDS, where stigma and a lack of trust are commonplace, according to focus group participants. However, it should be noted that this question was ambivalent, in that the question asked how much respondents felt that friends, family and community members could be trusted either to do a good job, or provide services. As such, this question may then be perceived as how much individuals felt that friends, family and other community members could be relied on, in comparison to other sources of care.

Trust and Caregiving

Mistrust acts as a significant barrier to providing care and support. This is demonstrated in perceptions of the Formal Health Workers (also known in the KwaNgcolosi community as *uNompilo*), perceptions of the stigma surrounding HIV/AIDS, and perceptions of health care workers at the KwaNgcolosi Clinic. All focus groups that mentioned the Formal Health Workers in the community felt that they were extremely judgemental, that they were not doing their jobs properly, and that they could not be trusted. As a result, none of the participants felt that any community members would trust any Formal Health Workers to assist in care and support for those who are ill.

Focus group participants felt that in some cases, the Home Based Carers are trusted more than family members, and generally more than community members - however, this is not universal, and focus group participants also felt that

sometimes the Home Based Caregivers may also breach confidentiality, talking about those who are ill.

Unfortunately, the social assessment survey did not make a distinction between Home Based Caregivers and *uNompilo*, and did not ask about the latter. 18.3% of survey respondents felt that Home Based Caregivers could be trusted only to a very small extent, 11.8% said to a small extent, 21.1% said average, 29.1% said to a greater extent, and 19.4% felt that they could be trusted to a very great extent.

There is also a large discrepancy between focus group participants' responses concerning clinic staff, and survey responses. The survey questions asked separately about clinic staff (counsellors and nurses), and hospital staff (social workers, doctors, and nurses), however there was very little variation in the frequency of answers given. Approximately 8% felt that these two respective groups could only be trusted to a very small extent, approximately 4.7% to a small extent, around 16% felt average, 45.5% felt that counsellors and 40.4% felt that hospital staff could be trusted to a greater extent, and 25.4% felt that counsellors and 30.7% felt that hospital staff could be trusted to a very great extent.

Two tentative explanations may be offered for the discrepancy noted between focus group discussions and survey response frequencies regarding the clinic. Firstly, that as noted by focus group participants, those with HIV/AIDS who visit the KwaNgcolosi clinic are treated differently to those who have other illnesses, and as such, although individuals who visit the clinic with HIV/AIDS related issues may receive negative treatment from clinic staff, individuals who visit the clinic for other reasons may then feel that the staff can be trusted, as their experiences may be positive. Unfortunately, the ratio of HIV-related clinic visits as compared to other illness-related visits is unknown, and so it is unknown how many survey responses were drawing on experiences related to HIV/AIDS, and how many for other illness-related experiences.

Secondly, the issue of social desirability may have played a role in responses given, particularly if respondents perceive that they are what researchers want to hear, particularly when respondents feel that they are in a state of relative powerlessness (Ross & Mirowsky, 1984). This may be considered the case when considering whether or not respondents trust clinic staff, especially if respondents feel that researchers have some link to the health care sector, which may be the case when researchers are asking questions about such. Additionally, since KwaNgcolosi is an area of low socioeconomic status, researchers will be seen as in positions of relative power and authority. This explanation is backed up by the focus group of women aged 26-45, where one participant spoke of her sister who had a negative experience – unrelated to HIV/AIDS - with a clinic nurse.

Trust in the Government

Trust in government results in improved mental and physical health (Whetten, Reif, Whetten, & Murphy-McMillan, 2008). Although within South Africa, the government has been attempting to expand access to protective and beneficial services, the majority of South Africans are still excluded, primarily because of the amount of monthly contributions required (Veenstra, 2006). Members with poor socioeconomic status, such as those living in KwaNgcolosi are excluded from these resources. The focus group of women aged 46 and older also spoke about a mistrust in the government in providing resources such as Antiretrovirals and social grants. The perception was that the government was delaying money, and they explained this by saying that the government does not care about them. Such perceptions and attitudes may result in a decreased inclination to make use of governmental services and resources provided, and therefore lead to decreased health. However, again there was a discrepancy between what was said by focus group participants and survey respondents regarding trust in government officials: 19% of respondents said that they did not trust national government officials at all, 13.4% said to a small extent, 17.4% felt neutral, 35.5% said to a great extent, and 13.2% said that they trusted the government totally.

6.5.2 Destructive Social Norms

According to Pronkyk *et al* (2008), not all Social Capital is health promotive – in fact, in some instances Social Capital may result in the promotion and adoption of destructive social norms. Within KwaNgcolosi, it appears that destructive social norms are present in the form of alcohol and dagga consumption.

Traditional gender role expectations for men is that they will provide the income for the household, but also that they are expected to go out and consume alcohol (Wolff *et al*, 2006). According to focus groups of men 26-45 and 46 and older, this is why men are uninterested in assisting with care and support for those with HIV/AIDS. The men aged 18-25 also spoke about drinking among the youth of KwaNgcolosi causing a hinderance to any community initiatives or activities.

It has also been recognised that levels of alcohol misuse and drunkenness may be on the increase, particularly among black men, as there is a shift away from the home-brewed, low-alcohol content beer, to commercially produced and purchased alcohol products (Parry, Plüddemann, Steyyn, Bradshaw, Norman, & Labuscher, 2005). Alcohol consumption levels within South Africa are estimated to be one of the highest in the world (Parry, 2008).

It may be assumed that KwaZulu-Natal follows the trend of the rest of South Africa. As such, from these statistics it may therefore be inferred that alcohol consumption among men in the KwaNgcolosi is prevalent enough to be considered another obstacle to mobilisation of care and support for those who are ill within the HIV/AIDS community, particularly among men, as mentioned by the two male focus groups, aged 26-45 and 46 and older.

6.5.3 Restrictive Social Norms

Social norms have a significant impact on the way that HIV/AIDS is viewed, and consequently how it is dealt with. Such norms are demonstrated in how individuals with HIV/AIDS are viewed within KwaNgcolosi, and is

communicated through gendered norms regarding sexuality, and also inadvertently through media messages.

Gendered Norms and Sexuality

Gender plays a large role in sexual dynamics. Conversation between partners is generally poor, with men largely acting as decision-makers, and women having little power (Varga, 2003). In addition, young people's sexuality is shrouded in secrecy, kept away from parents (Campbell *et al*, 2005).

Such attitudes towards sexual norms may result in a relative comfort of men and discomfort of women to discuss sexual matters. This may explain why men in focus groups wish to visit and talk to those who are ill, whereas women – in addition to wishing to physically care for those who are ill – expressed a wish to be taught how to converse with them. The only exception to this was the men aged 18-25, who when discussing education needs within the community, expressed a wish for training on counselling. However, counselling was seen as different to simply visiting and talking, encompassing more formal topics and manners of conversing.

The differing levels of comfort/discomfort of men and women towards those with HIV/AIDS also indicates an ongoing cognitive association of HIV/AIDS with sexual matters. Although it is recognised that the majority of HIV cases within South Africa are as a result of sexual encounters (Airhihenbuwa & Obregon, 2000), focus groups expressed that although HIV/AIDS was initially introduced as a disease contracted through sexual encounters, they said that they now knew it could be contracted “other ways”. Such statements may therefore be seen as efforts to express an acceptance rather than blame of the individual who is sick, rather than an understanding that the person who has HIV/AIDS has not, in fact, been “bad”. None of the focus group participants offered any specific alternative “ways” that they knew of that HIV/AIDS could be contracted. This has important implications for current understandings of HIV/AIDS, as there is presently no

alternative explanation being offered which can cognitively replace the notion that HIV/AIDS has been contracted through promiscuity or other “bad” behaviour. As such, consideration may then be given to the media campaigns in South Africa around HIV/AIDS, as the women aged 18-25 said that apart from community resources, media was a source of information about the disease.

The Effect of Media

Media campaigns focusing on HIV/AIDS tend to adopt an individualistic approach to the disease (Airhihenbuwa & Obregon, 2000). These are based on an assumption of a linear relationship between understandings and behaviour – that is, increased information and knowledge directly affects behaviour. However, such campaigns are also problematic in that they do not take into account the social and relational dynamics not context in which HIV/AIDS is embedded, and therefore may be inadvertently perpetuating the perception that those who have contracted HIV/AIDS have behaved “badly”, not paying heed to knowledge and information provided.

6.5.4 Reciprocity: The Expectations of Expectations

Reciprocity is still a key feature of traditional African culture (Foster, 2002), in which if something is given, it is expected that the favour will be reciprocated at a later date when needed. In addition to affecting interpersonal relationships, this may also affect other issues, such as community organization. Community initiatives such as a youth centre therefore may not be successful, as noted by focus group participants, as an initiative solely for the benefit of community members with nothing asked in response will not be taken seriously.

6.6 Perceived Enabling Factors to Meeting Identified Care and Support Needs

Social networks as a gateway to potential resources were identified as potentially rich resources within the KwaNgcolosi community that are currently not being

utilized. These consist of both organizations such as the Home Based Caregivers, as well as of friends and neighbours within the community.

6.6.1 Social Networks

Social networks are important in that they provide access to both information regarding HIV/AIDS, as well as resources to assist in care and support for those with HIV/AIDS. Focus group participants identified two potential sources of information and care resources that are currently not being harnessed, but that could become enabling factors in community care and support for those with HIV/AIDS.

Access to Information

All focus groups expressed a desire for more information regarding HIV/AIDS, indicating that they felt the current pool of information within the KwaNgcolosi community was insufficient to meet perceived needs regarding care and support for those ill with HIV/AIDS within the community. Burt (1997) notes that in communities where all are likely to have access to the same information, no new information is introduced. Structurally equivalent contacts will all have access to the same information and therefore only be able to provide information that is already accessible. As such, those individuals within the community who are structurally on different levels to the community members, may be able to provide new, beneficial information to community members about how to care and support one who is ill with HIV/AIDS. Within the KwaNgcolosi community, according to focus group participants, currently the Home Based Caregivers appear to be the perceived source of new information. Perceptions of the Home Based Caregivers as the primary source of care external to the family was common in all focus groups, and is discussed in further detail in chapter 5.

Access to Resources

According to Burt (1997), Social Capital refers to opportunity. As such, higher levels of Social Capital within a community will result in greater opportunity, in

this case, for access to resources that will assist in care and support. Within KwaNgcolosi, because of the lack of trust surrounding issues related to HIV/AIDS, potential social networks remain untapped.

Additionally, within a traditional African context, it is considered a social norm for one to provide resources such as food for neighbours if one is aware that they do not have sufficient (Van der Geest, 2000). The focus group of men aged 26-45 noted that when visiting someone who is ill with HIV/AIDS, one should bring healthy food, or food that the ill person enjoys. Friends and neighbours may be an extremely helpful resource in terms of physical provisions, particularly since HIV/AIDS often results in economic loss within a household (Demmer, 2006). However, within KwaNgcolosi, this is currently not occurring. According to community members, as a result of mistrust, friends and neighbours find it difficult to visit, being blocked by either the ill person themselves, or by his/her family members.

6.7 Conclusion

From the above, it appears that lack of trust still functions as a major barrier to access to care and support for those with HIV/AIDS. Stigma is still prevalent within the KwaNgcolosi community, and results in a lack of trust in family, community, and other care providers, acting as a barrier for those who wish to become involved in care and support. Triangulation with the social assessment survey, however, reveals a discrepancy between what is found in this study in terms of trust and social cohesion, and what was found in the survey. Tentative explanations have been given in the form of social desirability of survey responses, and assumptions that others still hold negative perceptions of the disease, even if participants do not personally hold such views. This points to a lack of communication concerning issues related to HIV/AIDS. Furthermore, gender roles influence social dynamics regarding how individuals feel they can interact with one who has HIV/AIDS, as well as what activities individuals are inclined to undertake in order to assist in care and support. Expectations of

reciprocity negatively affect providing care for those who are blamed once becoming ill if they did not contribute to the household while still working. Although focus group participants articulated an awareness of blame as wrong, it appears no alternative explanation for the disease has been provided. Reciprocity also affects the social credibility of community initiatives, which are not taken seriously if nothing is expected in return. All of this has resulted in potential social networks and resources through these networks remaining unharnessed, although gateways to identified sources for information, such as the Home Based Caregivers and the KwaNgcolosi Clinic have been identified.

CHAPTER SEVEN

CONCLUSION AND RECOMMENDATIONS

7.1 Introduction

This study explored care and support for those with HIV/AIDS by community members who are currently not involved in care and support, within the area of KwaNgcolosi, South Africa. Social Capital was used as a theoretical framework through which to understand their current situation, particularly with reference to the elements of trust, reciprocity, social norms, and social networks, and how these functioned on levels of Social Bonding, Social Bridging, and Social Linking.

The area of KwaNgcolosi, in which this study was done, is characterised by poor infrastructure, low income and poor socio-economic status, high levels of poverty and unemployment, low levels of access to electricity and running water.

Social Capital has been used to explain community cohesiveness and solidarity and to understand the community collective action taken in response to any necessary situation. Specifically in this study, Social Capital is seen as a vital resource in care and support, particularly as other resources are limited or lacking. As such, within this community it was used to explore and understand community members' perceptions of the disease and its associated social dynamics.

Focus group participants in this study felt that there was still significant levels of stigma, distrust and discrimination within the KwaNgcolosi community. Fear and mistrust arose largely from stigma, blame and shame surrounding the disease, and negatively affected the ill person's sense of identity and trust of those around him/her, and also influences perceptions of family, community members, and other care providers. Participants said that the Home Based Caregivers appeared to be competent and doing their jobs well, although they seemed to be more prominent in some areas of KwaNgcolosi than others. The other resources noted

were Formal Care Workers (known as *uNompilo*) and the KwaNgcolosi clinic, both of which were seen to reflect and perpetuate mistrust and stigma associated with the disease. The mistrust and stigma within the community also serves as a barrier for those who wish to become involved in care and support for those who are ill, as they will be turned away either by the person who is ill, or by his/her family members.

Focus group participants felt that care and support should be motivated by unconditional care for those who are ill, and showing them that they are still loved and accepted. Care and support should be about physically providing for those who are ill, but also about providing social and emotional support according to their needs. However, the roles that focus group participants were prepared to undertake differed significantly according to gender, and somewhat according to age. Men wanted to visit and show acceptance through talking and social support, whereas women were more focussed on physically seeing to the needs of the ill person, with a secondary focus on emotional and social support. Additionally, focus groups of men and women aged 18-25 felt that collaborative care efforts would be beneficial, with a centre where the youth could group and organize, and where those who are ill could stay if necessary.

A large stumbling block, however, was perceived by all focus group participants. All felt that the social norm of alcohol consumption would be a large barrier to organizing care and support, firstly because those who consumed alcohol would be disruptive to other activities, and secondly because those who consume alcohol are simply too drunk to be interested in becoming involved in care efforts.

Social and gendered norms regarding care and support for those with HIV/AIDS were evident, however both men and women identified differing but important ways in which they felt that they could contribute for care and support for those with HIV/AIDS.

All focus group participants expressed a desire for more education surrounding the disease, and identified sources of information as the Home Based Caregivers and the KwaNgcolosi clinic. They felt that as trust increases and social norms and perceptions surrounding the disease changed, so it would become easier for those who wished, to become more involved in assisting in care and support for those who are ill with HIV/AIDS.

7.2 Limitations of the Study

The issue of recruiting participants for focus groups proved to be challenging, particularly for men aged 26 and older. Although random sampling was done, several individuals who agreed to participate in the focus groups did not arrive at the scheduled day and time. Of those who did participate in focus group discussions, all expressed a desire to be involved in care and support, being prevented by external factors such as mistrust. As such, it is possible that this study represents a sample of caring members from the KwaNgcolosi community, and that those who are uninterested in becoming involved in care and support were also uninterested in participating in focus groups.

It is also acknowledged that within the KwaNgcolosi community, the issue of neglect, particularly blatant neglect, may be more conspicuous and striking than instances where care is, in fact, sufficiently occurring. This may have led to an inflation and misrepresentation of the perceived amount of instances of blame and neglect, as compared to instances within the community where caregiving needs are sufficiently met.

Additionally, although all participants spoke about care and support for those with HIV/AIDS being about love and acceptance, it is acknowledged that the potential for social desirability to affect responses given is a possibility.

The use of a translator in this study may have led to personal interpretations of situations and expressions by focus group participants, which may have

influenced responses given. Additionally, it was necessary to repeat one focus group after it was later discovered that the group had inadvertently included two Home Based Caregivers. Unfortunately, at the time of this focus group, the translator used for all other focus groups was overseas, and so another translator was used, which may have influenced the tone of the group. Some responses given during this focus group differed from other group discussions – including this being the only group that mentioned the KwaNgcolosi clinic. However, as many other responses and discussions were consistent with data obtained from other focus group discussions, this is not deemed to significantly negatively impact the trustworthiness of this study.

7.3 Recommendations

This study identified several gaps which are currently acting as barriers to providing care and support for those with HIV/AIDS in the area of KwaNgcolosi, South Africa. These can be addressed through the implementation of projects, further research, and a change in policy.

7.3.1 Project Recommendations

Projects that seek to address and improve the current situation regarding care and support for those with HIV/AIDS should move away from a focus on current barriers, to rather focus on the potential that exists within the community for contributing to care and support for those with HIV/AIDS.

Trust and Social Cohesion

There is a need to promote trust and social cohesion within KwaNgcolosi around care and support for those with HIV/AIDS. Currently, this appears to be the largest obstacle to involvement in care and support, for those who have a desire to do so. Interventions could work towards addressing the reasons for mistrust, encourage dialogue around such issues, and work at rebuilding weak social ties, noted as a decline in *Ubuntu* within this community. Interventions may possibly be in the form of narrative theatre, as it is based on the actual life stories of people

who work collectively to find a way forward that will strengthen everyone. As trust and social cohesion increase, it is anticipated that opportunities will develop for the organization of willing community members prepared to become active in care and support, possibly both reciprocal and altruistic. Additionally, the presence of psychosocial care and support within this community will decrease stigma within this community, therefore removing one of the largest current obstacles to care and support within KwaNgcolosi.

Social Networks of Information

As trust, reciprocity and social cohesion are developed, information channels should be encouraged such that sharing information regarding HIV/AIDS becomes a social norm. Identified sources of information, such as Home Based Caregivers, should be encouraged and trained on how to share information and skills with family members and interested community members. This will potentially lead to a decrease in the stigma and silence surrounding the illness, and facilitate opportunities where community members can become involved in care and support for those with HIV/AIDS.

HIV/AIDS and Caregiving

Current gender norms and roles dictate that it is the women who will adopt the role of primary caregiver of those who are ill, and shoulder most of the responsibility. Much literature has criticised such gender divisions, and recommendations have been made to encourage men to become more active and share what is currently primarily a woman's burden. However, such change initiatives will be met with resistance as they conflict with traditional and culturally accepted gender roles. Rather, the involvement of men according to what they feel they can offer and what would be appropriate for them – which, according to focus group discussions in this study, is mostly social and emotional support primarily through visiting and talking – should be encouraged. Such an approach is consistent with traditional and cultural gender norms, and will also be

advantageous in that it allows for a more holistic approach to care and support for those with HIV/AIDS.

Clinic Building

Focus group participants mentioned that the current use of the KwaNgcolosi clinic structure is such that the ARV clinic is separate from the other areas of the clinic, such that anybody who is seen walking towards the ARV clinic door is known to be there for an HIV/AIDS-related issue, and acts as a hinderance for those who wish to make use of clinic HIV/AIDS resources. It was felt that this is promoting the continuation of the notion of segregation and discrepancy for HIV/AIDS related issues. The way that the building is utilized for HIV/AIDS facilities and services should therefore be reconsidered and possibly restructured, such that there is no obvious difference between areas for HIV/AIDS related issues, and other illnesses.

Explanations of HIV/AIDS

Although many focus group discussions mentioned awareness that HIV/AIDS is not necessarily contracted through “behaving badly” and that it can be contracted “other ways”, none offered any elaboration on this. It therefore appears that although there is a cognitive recognition that HIV/AIDS should not be a shameful disease, this has not been internalized, as no alternative explanations for contraction of the disease have been given. Future initiatives should therefore give consideration to this issue.

7.4 Research Recommendations

Owing to the discrepancy found in this study between the data obtained from focus group discussions and triangulation done with overlapping social assessment survey data on trust and social cohesion within the KwaNgcolosi community, this research would benefit from further one-on-one interviews and focus groups to better understand trust and social cohesion in general within this

community, and as it relates to HIV/AIDS. A more extensive study is therefore needed to fully understand these dynamics and differences.

Research is also needed, in the form of one-on-one interviews, to follow up with those community members who were recruited for focus group discussions but did not participate, to understand the reasons behind this, and their views on care and support for those with HIV/AIDS.

7.5 Policy Recommendations

Currently, policy regarding care for those with HIV/AIDS emphasises few individuals as being primary caregivers who tend to be older women, which leads to overburden of this particular group. Policy needs to address the potential that is possible by involving other sectors of the community, which could decrease the burden felt by caregivers of those with HIV/AIDS.

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Appendix 1(a): Focus Group Questions in English

- What do you understand under care and support for people who are suffering from HIV/AIDS in your community?
- What are the reasons for it being the way it is?
- Could it be any different?
- In what way would you be able to be more active?
- What would get in the way of you becoming more active in care and support?
- What would help you to become more active?
- What would make it possible to be different?
- Do you think that caring for somebody who has HIV/AIDS might be different to caring for somebody who is, for example old, or has another illness such as flu? How so?

Appendix 1(b): Focus Group Questions in IsiZulu

- Yini oyaziwo mayelana ngokunaka abantu abagula ngeciwane lengculaza emphakathini?
- Iziphi izizathu ezenza kube nje?
- Ungaba khona umahluko kungehluka na?
- Iyiphi indlela wena ongasiza ngayo?
- Yini engenza ukuthi ungakwazi ukusiza?
- Yini engakusiza ukuthi ukwazi ukulekelela kakhulu?
- Yini engaza umahluko uma usiza?
- Ucabanga ukuthi ukusiza umuntu onegciwane lesandulela ngculeza kunomahluko kunomuntu, umasifamisa omdala noma onokunye ukugula njengo mkhuhlane? Kanjani?

Appendix 2(a): Consent form in English

UNIVERSITY OF KWAZULU-NATAL
MSOCSCI HEALTH PROMOTION IN PSYCHOLOGY
FOCUS GROUP CONSENT FORM

I, Nicole Helene D’Almaine (Student number: 203509600), am currently working on a Masters in Health Promotion research project, the topic of which is *Exploring Perceptions of Informal Care and Support by Community Members not currently involved for those with HIV/AIDS in the KwaNgcolosi area, KwaZulu-Natal, South Africa*. The project necessitates focus groups discussions with community members who are not currently involved in care for any person with HIV/AIDS. Participation in these focus groups is voluntary, with the understanding that:

- Strict confidentiality of each individual will be maintained
- Anonymity will be respected and if desired, no real names nor identifying characteristics 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 MSOCSCI project being undertaken by Nicole Helene D'Almaine and that I voluntary participate in said research.

Name

Signature

Date

Appendix 2(b) Consent Form in IsiZulu

Invume yokubuza iqoqo labantu imibuzo

Mina, Nicole Helene D'Almaine (Student number: 203509600), owenza izifundo zeMasters kwezokuthuthukiswa kweZempilo, osihloko sithi *Exploring Perceptions of Informal Care and Support by Community Members not currently involved for those with HIV/AIDS in the KwaNgcolosi area, KwaZulu-Natal, South Africa.*

Lezifundo zimaqondama nomphakathi ongazihlanganisile nezempilo kwabanegciwane Legculaza Nesandulela Ngculaza (HIV/AIDS).

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 kwalwezifund o

zeMasters ngu Nicole Helene D'Almaine nokuthi angipheqelelwe
ukuzibandakanya kulezifundo.

Igama

Signature

Date

Appendix 3(a):
Excerpts from the General Social Capital Survey used for Triangulation in this Study

16. About how many close friends do you have these days? These are people you feel at ease with, can talk about private matters, or call on for help.

Close friends you have these days-people you are at ease with when discussing private matters

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	203	19.8	20.3	20.3
	1	310	30.3	31.0	51.4
	2	222	21.7	22.2	73.6
	3	84	8.2	8.4	82.0
	4	43	4.2	4.3	86.3
	5	22	2.1	2.2	88.5
	6	6	.6	.6	89.1
	10	6	.6	.6	89.7
	12	1	.1	.1	89.8
	14	1	.1	.1	89.9
	18	1	.1	.1	90.0
	22	1	.1	.1	90.1
	30	1	.1	.1	90.2
	Not applicable	98	9.6	9.8	100.0
Total	999	97.6	100.0		
Missing	Missing	17	1.7		
	System	8	.8		
	Total	25	2.4		
Total		1024	100.0		

18. If you suddenly needed to borrow a small amount of money (enough to pay for the expenses for your household for a week), are there people beyond your immediate household and close relatives to whom you could turn and who would be willing and able to provide this money?

Definitely not 1
 Probably not 2
 Unsure 3
 Probably 4
 Definitely 5

Friends beyond immediate family where you could borrow money

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	4	.4	.4	.4
	Definitely not	346	33.8	33.8	34.2
	Probably not	116	11.3	11.3	45.6
	Unsure	85	8.3	8.3	53.9
	Probably	194	18.9	19.0	72.8
	Definitely	269	26.3	26.3	99.1
	Not applicable	9	.9	.9	100.0
	Total	1023	99.9	100.0	
Missing	System	1	.1		
Total		1024	100.0		

19. If you suddenly had to go away for a day or two, could you count on your neighbours to look after your children?

Definitely not	1
Probably not	2
Unsure	3
Probably	4
Definitely	5

Could you count on neighbours to look after your children when you are away

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	5	.5	.5	.5
	Definitely not	138	13.5	13.5	14.0
	Probably not	85	8.3	8.3	22.3
	Unsure	92	9.0	9.0	31.3
	Probably	224	21.9	21.9	53.2
	Definitely	473	46.2	46.2	99.4
	Not applicable	6	.6	.6	100.0
	Total	1023	99.9	100.0	
Missing	System	1	.1		
Total		1024	100.0		

20. Generally speaking, would you say that people can be trusted or that people cannot be trusted?

- People cannot be trusted 1
 Some people cannot be trusted 2
 Unsure/neutral 3
 Some people can be trusted 4
 All people can be trusted 5

Generally,would you say people are trusted or not

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	3	.3	.3	.3
	people can not be trusted	220	21.5	21.5	21.8
	Some people can not be trusted	164	16.0	16.0	37.9
	Unsure/neutral	133	13.0	13.0	50.9
	Some people can be trusted	392	38.3	38.4	89.2
	All people can be trusted	105	10.3	10.3	99.5
	7	1	.1	.1	99.6
	42	1	.1	.1	99.7
	55	1	.1	.1	99.8
	Not applcable	2	.2	.2	100.0
	Total	1022	99.8	100.0	
Missing	System	2	.2		
Total		1024	100.0		

21. In general, do you agree or disagree with the following statements?

B. In this community, you have to be alert or someone is likely to take advantage of you	
Disagree strongly	1
Disagree somewhat	2
Neutral	3
Agree somewhat	4
Agree strongly	5

o you agree/disagree in this community you have to be alert or someone is likely to take advantage of you

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	2	.2	.2	.2
	Disagree strongly	56	5.5	5.5	5.7
	Disagree somewhat	56	5.5	5.5	11.2
	Neutral	106	10.4	10.5	21.7
	Agree somewhat	265	25.9	26.1	47.8
	Agree strongly	525	51.3	51.8	99.6
	Not applicable	4	.4	.4	100.0
	Total	1014	99.0	100.0	
Missing	Missing	9	.9		
	System	1	.1		
	Total	10	1.0		
Total		1024	100.0		

25. Would you say that most of the time people in this community try to be helpful, or are they mostly looking out for themselves? They are

- Mostly looking out for themselves 1
- Not very helpful 2
- Neither helpful nor unhelpful 3
- Somewhat helpful 4
- Mostly very helpful 5

Most of the time people in this community are very helpful or look out for themselves

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	12	1.2	1.2	1.2
	Mostly looking out for themselves	358	35.0	35.1	36.3
	Not very helpful	100	9.8	9.8	46.1
	Neither helpful nor unhelpful	134	13.1	13.1	59.2
	Somewhat helpful	323	31.5	31.7	90.9
	5	90	8.8	8.8	99.7
	99	1	.1	.1	99.8
	Not applicable	2	.2	.2	100.0
	Total	1020	99.6	100.0	
	Missing	Missing	2	.2	
System		2	.2		
Total		4	.4		
Total		1024	100.0		

44. How strong is the feeling of togetherness or closeness in your community?
Use a five-point scale where 1 means feeling very distant and 5 means feeling very close.

- Very distant 1
Somewhat distant 2
Neither distant nor close 3
Somewhat close 4
Very close 5

Rate feeling of togetherness in your community on a five point scale where 1 is very distant

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	16	1.6	1.6	1.6
	Very distant	59	5.8	5.8	7.4
	Somewhat distant	126	12.3	12.4	19.8
	Neither distant nor close	170	16.6	16.8	36.6
	Somewhat close	386	37.7	38.1	74.7
	Very close	246	24.0	24.3	98.9
	Not applicable	11	1.1	1.1	100.0
	Total	1014	99.0	100.0	
Missing	Missing	9	.9		
	System	1	.1		
	Total	10	1.0		
Total		1024	100.0		

52. In the past 12 months, how often have people in this community got together to jointly request something from government officials or political leaders that could be benefiting the community?

- Never 1
Once 2
A few times (three or less) 3
Many times (six or less) 4
Very often (seven and more) 5

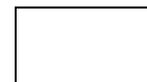
In the past 12 months how often have people in this community got together to jointly request something from government officials or political leaders to benefit community

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	14	1.4	1.4	1.4
	Never	379	37.0	37.6	38.9
	Once	371	36.2	36.8	75.7
	A few times (Three or less)	196	19.1	19.4	95.1
	Many times (Six or less)	36	3.5	3.6	98.7
	Very often (seven and more)	9	.9	.9	99.6
	NOT applicable	4	.4	.4	100.0
	Total	1009	98.5	100.0	
Missing	Missing	14	1.4		
	System	1	.1		
	Total	15	1.5		
Total		1024	100.0		

Appendix 3(b):
Excerpts from the Social Capital and HIV/AIDS Survey used for
Triangulation in this Study

11. How influential do you think the norm of *ubuntu* is in motivating people to join activities of volunteer care and support for HIV positive people in this community?

Extremely influential	1
Quite influential	2
Neutral/unsure	3
Not very influential	4
Not influential at all	5



How influential is ubuntu in motivating people to join volunteer activities & support for HIV (sic)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not influential at all	83	8.4	8.5	8.5
	not very influential	123	12.4	12.5	21.0
	Neutral /Unsure	258	26.1	26.3	47.3
	Quite influential	254	25.7	25.9	73.1
	Extremely influential	260	26.3	26.5	99.6
	101	4	.4	.4	100.0
	Total	982	99.3	100.0	
Missing	Missing	7	.7		
Total		989	100.0		

12. How much do you trust different types of people involved in HIV/AIDS activities in the community to do a good job/provide services? Please rate them on a 1 to 5 scale, where 1 means you trust them minimally and 5 means you trust them a lot.

A. Family, neighbours and friends	
B. Home based carers	
C. Clinic staff: counsellors, nurses	
D. Hospital staff: nurses, doctors, social workers	
K. National government officials	
To a very small extent	1
To a small extent	2
Average	3
To a great extent	4
To a very great extent	5

How much trust in family,neighbours and friends involved in HIV/AIDS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	To a very small extent	54	5.5	5.5	5.5
	To a small extent	75	7.6	7.7	13.2
	Average	207	20.9	21.1	34.3
	To a greater extent	287	29.0	29.3	63.6
	To a very great extent	354	35.8	36.1	99.7
	101	3	.3	.3	100.0
	Total	980	99.1	100.0	
Missing	Missing	9	.9		
Total		989	100.0		

How much trust in Home based careres involrd in HIV/AIDS(sic)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	To a very small extent	179	18.1	18.3	18.3
	To a small extent	116	11.7	11.8	30.1
	Average	207	20.9	21.1	51.3
	To a greater extent	285	28.8	29.1	80.4
	To a very great extent	190	19.2	19.4	99.8
	101	2	.2	.2	100.0
	Total	979	99.0	100.0	
Missing	Missing	10	1.0		
Total		989	100.0		

How much trust in clinic staff:counsellors involved in HIV/AIDS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	To a very small extent	78	7.9	8.0	8.0
	To a small extent	48	4.9	4.9	12.9
	Average	157	15.9	16.1	28.9
	To a greater extent	445	45.0	45.5	74.4
	To a very great extent	248	25.1	25.4	99.8
	101	2	.2	.2	100.0
	Total	978	98.9	100.0	
Missing	Missing	11	1.1		
Total		989	100.0		

How much trust in hospital staff:nurses,doctors,social workers involved in HIV/AIDS

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	To a very small extent	80	8.1	8.2	8.2
	To a small extent	45	4.6	4.6	12.8
	Average	156	15.8	16.0	28.7
	To a greater extent	395	39.9	40.4	69.1
	To a very great extent	300	30.3	30.7	99.8
	101	2	.2	.2	100.0
	Total	978	98.9	100.0	
Missing	Missing	11	1.1		
Total		989	100.0		

16. Would you volunteer to join a group or organization that is providing HIV/AIDS services in the community?

- Definitely not 1
- Probably not 2
- Unsure 3
- Probably 4
- Definitely 5

Would you volunteer to join in a group/organisation providing HIV/AIDS services in community

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Definately not	124	12.5	12.7	12.7
	Probably not	99	10.0	10.1	22.8
	Unsure	62	6.3	6.3	29.1
	Probably	223	22.5	22.8	51.9
	Definately	470	47.5	48.0	99.9
	101	1	.1	.1	100.0
	Total	979	99.0	100.0	
Missing	Missing	10	1.0		
Total		989	100.0		