Response-ability in the era of AIDS

Building social capital in community care and support

Edited by:
Wenche Dageid, Yvonne Sliep,
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To all those visible and invisible actors
who make the real difference to people
living with HIV/AIDS.

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ARV/ARVs	Antiretroviral(s)
CBC	Community-based care
CBO	Community-based organisation
CD4	Cluster of differentiation 4, a glycoprotein expressed on the surface of immune cells. CD4 count is used to assess the immune system of HIV-positive patients
CHW	Community health worker
CSES	The collective self-esteem scale
FBO	Faith-based organisation
HBC	Home-based care, home-based carer
HBCV	Home-based care volunteer
HIV/AIDS	Human immunodeficiency virus/acquired immune deficiency syndrome
IFRC	International Federation of Red Cross and Red Crescent Societies
MSF	Médecins Sans Frontières (Doctors Without Borders)
NF	Narrative Foundation
NGO	Non-governmental organisation
NPO	Non-profit organisation
NSP	National Strategic Plan
PhD	*Philosophiae doctor*, a postgraduate academic degree
PLWHA	People living with HIV and AIDS
RSA	The Resilience Scale for Adults
SOCAT	The Social Capital Assessment Tool
STI	Sexually transmitted infections
TAC	Treatment Action Campaign
TB	Tuberculosis
UNAIDS	The Joint United Nations Programme on HIV/AIDS
VCT	Voluntary counselling and testing
WEMWBS	The Warwick-Edinburgh Mental Well-being Scale
WHO	World Health Organisation
ZAR	South African Rand

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Wenche Dageid, Yvonne Sliep, Olagoke Akintola & Fanny Duckert,
Durban and Oslo,
June 2011

Chapter 1: Introduction

The role of social capital in promoting community-based care and support for people living with HIV/AIDS in KwaZulu-Natal, South Africa

Wenche Dageid, Yvonne Sliep, Olagoke Akintola & Fanny Duckert

The background for this volume is a four-year research project on social capital and HIV/AIDS. With the number of South Africans infected with HIV/AIDS soon exceeding six million, care and support for people infected and affected are becoming increasingly more important. Community members within a highly stigmatised environment with little government support carry out most care and support in the communities. It is therefore crucial to strengthen community capacity to provide care and support for the ill.

Most studies in this field have focused on individuals, families, caregivers and organisations separately, with little focus on how these work together. In our study, we have explored the levels, elements and mechanisms of social capital in relation to care and support for people living with HIV/AIDS (PLWHA). Social capital is defined as "the norms and networks that enable people to act collectively". We have examined the three forms of social bonding, social bridging and social linking at the levels of individuals, families, community-based organisations and external/governmental agents. To our knowledge, this is the first study that addresses all these levels in an HIV/AIDS context.

The aim of this volume is to disseminate the results of our research, and to further inform, inspire and create a platform for debate between practitioners, academics, researchers, trainers and facilitators interested in addressing community needs in terms of HIV/AIDS and support. The volume is mainly written for a graduate and professional public, but will be interesting and useful for practitioners and care workers in the field as well. We hope that the lessons learnt by us during our research will also inspire others working in the field.

The research project titled *The role of social capital in promoting community-based care and support for people living with HIV/AIDS in KwaZulu-Natal, South Africa* was conducted as part of an academic collaboration programme between Norway and South Africa, which was initiated in 1997 and financed by the Norwegian and South African governments. The programme aims at academic capacity-building through the development of conjoint research projects and research networks. The education of Masters and PhD candidates and the exchange of students and academics between Norway and South Africa are also important. The research project that is documented in this volume was conducted by a multidisciplinary team of researchers, students and assistants from both countries.

Background to the study

In South Africa, the province of KwaZulu-Natal has the highest overall HIV-infection rate in the country. An estimated 15.8% of the population older than two years is infected, and almost one in three women aged 25–29, and over a quarter of men aged 30–34, are living with HIV (Shisana *et al* 2009). It is not only the infection rate that is alarming but also care and support has moved into a crisis mode. Although HIV/AIDS affects all sectors of society, results from previous studies show that the most severe effects occur at household and community level. Studies suggest that the care of sick people account for a substantial part of the household expenditures, with much of these expenses going towards the impact of HIV/AIDS (Bachmann & Booysen 2004; Steinberg, Johnson, Schierhout & Ndegwa 2002). Further, caregivers, who mostly consist of female family members and volunteers, experience a considerable burden in providing care to the ill (Akintola 2006; Orner 2006; Steinberg *et al* 2002). Despite the increasing demand for assistance in HIV/AIDS care and support, there is an alarming lack of government leadership and support in South Africa (Lewis 2006). In light of the lacking governmental leadership and lack of resources, communities have had to find their own ways of providing care and support for PLWHA and their families. Consequently, families and local communities are responsible for the majority of all care and support activities (Akintola 2006; Swaans, Broerse, Van Diepen, Salomon, Gibson & Bunders 2008; UNAIDS 2009).

Our research project explored the social aspects of care and support for PLWHA through a social capital framework and lens. We hoped that the study would provide a better understanding of the social norms, mechanisms and practices related to HIV/AIDS care and support in the communities.

Social capital as framework

At the onset of the study it was thought that the term ‘social capital’ had become a focus of interest in health research over the last decade and offered an interesting framework for the overall study. It has been argued that communities characterised by high levels of social capital enjoy better health, well-being and development, and a more widespread and efficient delivery of health services (Campbell 2000; Grootaert & Van Bastelaer 2001).

The concept of social capital has been used to describe a number of phenomena pertaining to social relations at individual and societal levels (Macinko & Starfield 2001). Social capital has been thought of as a web of cooperative relationships between people that facilitates resolution of collective problems (Coleman 1990). Several scholars have described social capital in terms of resources that are embedded in and can be accessed through an individual's social network (Foley & Edwards 1999; Lin 1999). Such roles, networks and accompanying rules, procedures and precedents could be described as structural social capital (Grootaert & Van Bastelaer 2001). Further, social capital has been conceptualised as those features of social structure, such as level of trust, norms of reciprocity and solidarity, which act as resources for collective action (Putnam 1993). These shared norms, values, beliefs and attitudes constitute cognitive social capital (Grootaert & Van Bastelaer 2001).

Social capital may be considered as a useful tool for community revitalisation and development. Through the channels of information sharing, collective action and decision-making, one may build social capital and thereby social capacity (the ability of individuals to organise themselves, their assets and resources in ways which enable them to achieve objectives that they consider important). However, this concept refers to community access as well as resources, both of which need to be built externally and internally. For the purpose of this study, we defined social capital as "the norms and networks that enable people to act collectively and bridge divisions".

Using the social capital framework enabled us to work with concepts such as trust, shared values and norms, social cohesion and participation in civic groups and networks, collective action, reciprocal support and positive identity (Bordieu 1986:241-258; Coleman 1990; Putnam 1993) to improve the lives of PLWHA in South Africa (Campbell 2003; Ishtiaq & Roberts 2004). We hope that the results of our study will help create a platform for greater responseability from a community perspective, in South Africa and elsewhere.

Bonding, bridging and linking social capital

There are three main forms of social capital that were used in this study:

- *Bonding social capital* refers to intra-community networks (links individuals together along horizontal lines) that bring integration and cohesion through trust, reciprocal support and a positive identity (Campbell

2003; Woolcock & Narayan 2000). The links at a bonding level are made up of individuals of relatively similar status, and are characterised by homogeneity, loyalty, social support and exclusivity, for example a family unit. This level is important for residents in disadvantaged communities, where high levels of mutual support are primary mechanisms for 'getting by' (Kawachi, Subramanian & Kim 2008).

- While bonding social capital allows people to 'get by', *bridging social capital* provides a way for people to 'get ahead' (Woolcock & Narayan 2000). Bridging social capital integrates the levels and nature of contact and engagement between different social groups or communities linking diverse groups with varying levels of access to material and symbolic power. It brings people in contact with resources and benefits that are accrued from having a wide and varied range of social contacts (Gitell & Vidal 1998; Putnam 2004).
- *Linking social capital* has more recently been defined as an important conceptual distinction and refers to connecting people across explicit vertical power differentials. It is especially in relation to the role and responsibility of representatives of government institutions for delivering key services (Putnam 2004) and for influencing relevant policies. With regard to working in poor communities, powerful institutions such as governments, large NGOs and international donors, need to provide support for bridging social capital in order to make it possible for community members and groups to 'get ahead' (Kawachi *et al* 2008; McKenzie & Harpham 2006; Silva, McKenzie, Harpham & Huttly 2005).

Social capital as it applies to HIV/AIDS care and support

It has been argued that networks are the sources of the social capital we use for various purposes (Cook 2005). Within the South African context, social networks, which arise from social capital, have been essential in providing care for those who are needy during hard times at community, family and individual levels (Foster 2007). It is argued that HIV/AIDS has caused these networks to decline, particularly with reference to family and community networks (Barnett & Whiteside 2002; Marshall & Keough 2004). However, Ishtiaq and Roberts (2004) argue that this decline may be alleviated and that active mobilisation of social capital could reduce the impact of HIV/AIDS. Table 1.1 presents a schematic overview of the three levels of social capital pertaining to HIV/AIDS care and support in a South African context. It is indicated which actors and networks could be involved, and what kinds of concepts, mechanisms and challenges (which could overlap) could be met at each level.

Table 1.1 A social capital framework for HIV/AIDS-related care and support

Social capital levels	Actors involved	Main concepts and mechanisms	Main challenges
Social bonding	Infected individuals Affected individuals and households, family carers, neighbours General community members involved and not involved in care activities Wider community at horizontal level	Neighbouring Trust Reciprocity Social norms and communal values	Stigma Burden Mistrust Decline of social norms and values Inadequate availability of and access to resources at individual and horizontal level
Social bridging	Local HIV/AIDS CBOs, e.g. volunteer caregivers/HBC groups, support groups, garden projects and orphan care groups Local NGOs Churches and FBOs Transport owners' association Saving groups/*stokvels* Burial/funeral societies Traditional healers' association	Participation Voluntarism Networks Collaboration and coordination Local opportunities Social cohesion Solidarity Group identity	Low levels of participation Lack of collaboration and coordination Exclusion versus integration Insufficient diversity in local networks Inadequate availability of and access to resources within and outside of the community Decline of networking norms such as social cohesion and solidarity
Social linking	Municipalities Local, provincial and national authorities, government and ministries External NGOs External donors, researchers, agencies	Policies and programmes Legislation Grants Treatment Service delivery Values and norms underlying policy, programmes and service delivery	Lack of reinforcements Lack of synergy Inadequate resource allocation, accessibility and accountability Challenges of overall coordination of activities, cooperation, and flow of information Inability to translate values, norms and policies into sound practice

HIV care and support at a bonding level

Life with an HIV infection represents an unremitting, uncertain course involving several stressors that drain intrapersonal, interpersonal and material resources. The many stressors facing PLWHA are likely to be accompanied by psychological reactions like distress, worry, anxiety, self-blame, guilt, depression and shame as well as feelings of isolation, rejection and denial, to mention a few. Seeking support is a way to cope with life as an HIV-positive individual. Good quality and continuity of social support can promote health or offer some protection from illness, and there is a positive association between social support and psychological resources that help the individual cope with illness (Wolf *et al* 1991).

The term 'social support' includes –

1. the existence, quantity and type of interpersonal relationships;
2. the functional content of these relationships; and
3. the perceived quality or adequacy of this support (Green 1993; Lazarus 1990).

Social support for PLWHA promotes cognitive and behavioural coping, facilitates a sense of meaning, enhances self-esteem, fosters a sense of belonging, and increases available coping resources at individual, inter-personal and contextual levels (Namir, Wolcott, Fawzy & Alumbaugh 1987; Wolf *et al* 1991). The social representation of HIV/AIDS as a shameful and stigmatising disease could profoundly shape coping and the seeking and receiving of support. PLWHA might fear social isolation and becoming a burden to their family and communities as they need progressively more care and support. The HIV-positive person has frequently been cast as a "useless" person who cannot contribute (Bolton & Wilk 2004; Dageid & Duckert 2008).

At an individual level, care and support can foster a sense of hope, belonging, and self-efficacy and self-worth; help the individual break through cycles of negative coping; promote disclosure; and encourage 'positive living' and empowerment. Involving PLWHA might help combat the stigma and silence surrounding HIV/AIDS. Establishment of care and support for PLWHA can also act to reduce fear and stigma, and to inform and mobilise the community (Dageid & Duckert 2007; Sewpaul & Mahlalela 1998). While support is critical for PLWHA, it is often difficult to access the kind of support they require. For example, PLWHA and their caregivers have difficulties in accessing support from other family members because of stigma and discrimination directed at both of them (Akintola 2008; Mwinituo 2006). In addition, support from men is often lacking and when available, is limited to certain activities – usually financial support and transportation, which do little to relieve the burden on women who constitute the majority of the caregivers (Akintola 2006). In many societies, HIV/AIDS adds to household costs, endangers livelihoods and food security, and deepens poverty, increases the vulnerability of women and children, and leads to selling of household assets, which can result in irreversible destitution (UNAIDS 2009). These processes may strain community safety nets, undermine extended kinship ties, and alter civic and cultural norms, including values linked to reciprocity and collective action. In cohesive, closed networks, social capital might also prove to have negative effects such as mistrust and exclusion of individuals or groups. There is a need to explore how various aspects of social capital can strengthen social cohesion, norms and horizontal relations in relation to HIV/AIDS care and support.

HIV care and support at a bridging level

The recent years have seen a mushrooming of community-based organisations (CBOs) delivering HIV/AIDS care and support at grassroots level (Swidler 2006). Most of these local initiatives have sprung out of a desire to relieve illness and suffering and to mitigate the impact of HIV/AIDS on the communities. They consist of women's groups, support groups, faith-based initiatives, etc. Many of the groups are small and not registered with government as non-governmental organisations (NGOs). Local groups and organisations have knowledge of available resources in the community, needs and expectations of PLWHA, and how to reach populations most at risk or in need of services. Even the joint resources of governments, NGOs, international organisations and donors cannot substitute on any significant scale for the care and support activities of families and communities, especially those within communal cultures such as in Africa. The care and support offered by families and CBOs are crucial contributions to the formal health services, especially in rural areas where healthcare coverage and service delivery are often poor.

Efforts in turning informal obligations to family and neighbours into more organisationally distinct HIV/AIDS care and support groups have proved to be quite successful (Swidler 2006). However, CBOs face several challenges like funding, training, collaboration among similar and diverse organisations within a community, monitoring and evaluation of projects and not being very well co-ordinated (Dageid & Duckert 2007; Kelly *et al* 2006; Yamba 2002). Access to adequate training, emotional and material support is usually lacking as many organisations have yet to appreciate the emotional burden and the workload of caregivers and HIV/AIDS volunteers which is often enormous (Akintola 2008; Dlamini 2010). There is a need to explore these community-based organisational aspects of social capital to improve the provision of HIV/AIDS-related care and support.

HIV care and support at a linking level

In the HIV/AIDS arena, complex networks of international, governmental and locally based organisations define issues, carry out projects, mobilise local activists and lobby in international forums. There is often a lack of ‘cultural match’ between external policies and local, traditional methods of understanding and dealing with problems (Swidler 2006). The considerable amount of global funding for HIV/AIDS responses has done little to address the ‘implementation gap’, which is the inability of countries to use available resources promptly and effectively (Poku & Whiteside 2006). In many instances, large governmental bodies or NGOs receive vast amounts of money, and the money often does not benefit or even reach the communities (Ntetha 2010; Swidler 2006). There is also some evidence of coordination and cooperation difficulties, as well as difficulties in conforming to or keeping up with policies and regulations made by NGOs, governments and external donors (Kelly *et al* 2006; Rau 2006). It is a paradox that the areas with the highest need for HIV/AIDS services often do not receive them. PLWHA often live in hard to reach, poor, rural areas and are not aware, or do not have the means to travel to district offices where services are offered (Foster, Mafuka, Drew, Mashumba & Kambeu 1997). Within the South African context, government welfare services, such as social grants, are difficult to access because patients have difficulty in accessing, understanding and preparing the necessary documents and because of long queues at the issuing offices (Akintola 2004, 2005; Community Agency for Social Enquiry 2005; Steinberg *et al* 2002).

It must be noted here that, although it is possible to academically differentiate the levels at which social capital functions, in a practical setting it is very difficult. Bonding, bridging and linking networks, for example, are intertwined and may exist simultaneously. Diagram 1.1 demonstrates the different groups within the levels of social capital as explored in the overall study.

To be effective, work in connection with HIV/AIDS should be based in the community where people are drawing on community resources in a way that is recognisable and culturally sensitive. Efforts to improve support at a community level should simultaneously focus on different perspectives and levels of social capital in relation to HIV/AIDS care and support. It is essential to make use of all resources within the community, for example family authorities and traditional healers, as well as organisations and institutions at a macro level. These issues point to a need for a contextual and broad evaluation of social capital.

The main research objective of the study was to identify, understand and promote the multilevel elements and mechanisms of social capital at especially a social bonding and a social bridging level that would improve HIV/AIDS care and support in a local community in South Africa.

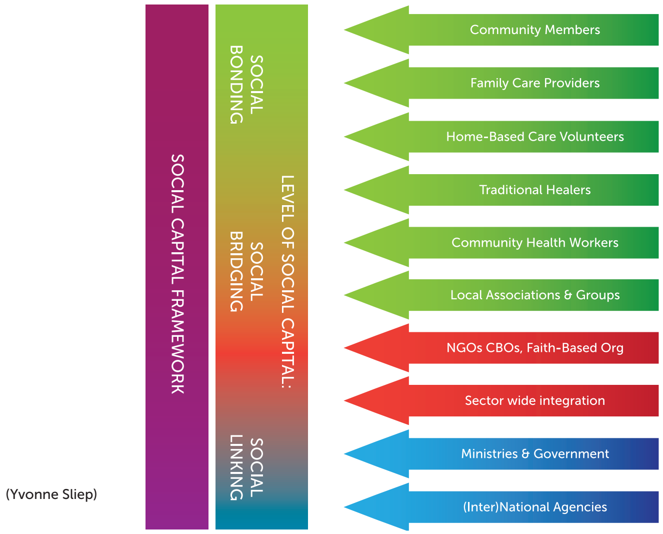

Diagram 1.1 Social capital framework within the research project[1]

The community in which the overall research project took place

Our research project was based in a semi-rural and hilly community in KwaZulu-Natal (cf. Photo 1.1), just 40 km outside of Durban. In the 2001 national census, the planning unit where our community of study is located consisted of 12 285 people (Statistics South Africa 2004). Almost the whole population in this community is isiZulu-speaking and black Africans; 47% male and 53% female. It is quite a young population, with 74% being younger than 34 years. The area is poverty-stricken and HIV/AIDS is rife. In 2001, 12% of the community members held paid jobs, and as many as 30% reported having no household income.

The community lies on a hilly slope with an inland water source at the bottom of the landscape. The nearest town centre, with post office, shopping complexes, health clinics and other facilities, is found at the top of the hill and is not within walking distance of the community. There is little infrastructure and only one main road going through the community. Driving or walking in the hilly landscape outside the main road could be challenging, especially during the rainy season. Most of the houses are small and built of soil and metal. Half of the population lives in traditional dwellings. The major community facilities located in the planning unit are one clinic, two community halls and four schools.

Photo 1.1 The community in which the study took place

The overall research project consisted of several separate studies. Most studies reported in this volume were based in the community described, however, the studies reported in Chapter 4 and Chapter 9 drew on samples from different, yet similar, locations within the greater Durban metropolitan area.

Overall methodology

We used a holistic, multi-method, bottom-up, longitudinal approach, aimed at exploring all levels of social capital simultaneously – within one geographic context. Several authors have called for such an approach (Campbell 2000; Gregson, Terceira, Mushati, Nyamukapa & Campbell 2004). Quantitative and qualitative methods were mixed, as recommended by the World Bank Social Capital Initiative group (e.g. Dudwick, Kuehnast, Jones & Woolcock 2006; Grootaert, Narayan, Jones & Woolcock 2004). Participatory action research (PAR) and ethnography were central methods throughout. PAR is a collaborative approach to research that enables people to take systematic action in an effort to resolve specific problems through critical reflection and analysis (Berg 2001; Cornwall & Jewkes 1995). Ethnography typically relies on observations, informal interviews, and the researcher's own experience of events and processes (Rossman & Rallis 1998). Ethnography allows the researcher to tap into the intensive local knowledge available to the study population, which also relates to issues of data quality and accuracy, the multiple kinds of data that can be collected, and the ability to observe key social processes as they occur (Axinn, Fricke & Thornton 1991).

Methods and instruments

Our specific methods included surveys, questionnaires, in-depth interviews, focus group discussions, participatory observation, field notes, flow charts and drawings, and narrative theatre. Narrative theatre was a central method, and is discussed in detail in Chapter 13 in this volume. The social capital instrument was another central measure. Items from this instrument informed most of the studies reported in this volume. The instrument was compiled after a literature review on social capital and measurement, and was in particular based on the Social Capital Assessment Tool (SOCAT) (Grootaert & Van Bastelaer 2001; Krishna & Shrader 1999). The SOCAT was designed on the results from 12 extensive studies in different countries and settings (Grootaert & Van Bastelaer 2001). All instruments were adapted to the local context, translated into isiZulu, and isiZulu-speaking assistants and university students were trained to conduct the field work of the different phases of the project. More information on the different methods and instruments can be found in each chapter.

Participants

The participants in the study were isiZulu-speaking adults of minimum 18 years of age of relatively homogenous ethnic, cultural and socio-economic backgrounds. We aimed at recruiting equal numbers of men and women where possible. Participants included randomly or purposefully selected individual community members; community members involved in HIV/AIDS care and support; PLWHA; family carers; volunteer care workers, grassroots groups and organisations; NGOs and external agencies operating in the area. The number of participants in each separate study ranged from 9 to 969. More information on the number and characteristics of participants in the separate studies can be found in each of the chapters.

Procedure

The whole research project took place over a four-year period 2007–2010. Yvonne Sliep is a founding member and Director of the Narrative Foundation, which has been working in the research community for ten years. This relationship with the community enabled smooth community entry for the research project and facilitated the continuous follow-up work that emerged through the taking-back practices in relation to the dissemination of the research results.

The first step of the research project involved a mapping of characteristics of individuals, households, associations, organisations, and agencies involved in HIV/AIDS-related care and support in the area. This was accomplished by searching the internet and examining publicly available resources, such as statistics and livelihood surveys/population census, visiting the community of study, and by conversations with different stakeholders. From this information, a list of possible groupings and organisations working with HIV/AIDS-related issues in the community was developed. The mapping exercise was repeated for different parts of the study, and informed the development of individual studies and questions.

Secondly, we tried to identify how elements of social capital in relation to care and support for PLWHA in the community manifested themselves and were inter-related through an exploration and evaluation of individual community members' perceptions of social capital in the area. This included individual involvement in social capital-related activities. A survey instrument on social capital was used for this part of the study, and a total of 969 randomly selected community members took part (cf. Chapter 2). The results from this community survey were then compared to the mapping done in the first phase of the project.

After analysis of these preliminary data, more visits to the community of study, and a pilot study on volunteer care workers (cf. Chapter 5) we developed interview guides and narrative theatre frameworks that would elicit in-depth information about selected networks and groups involved in HIV/AIDS-related care and support. These would be the groups identified through the mapping exercise, the pilot study, and the community survey as being the most relevant and important to HIV/AIDS care and support in the area. As will be seen in the volume, the main focus was on volunteer care workers (also known as home-based carers, HBCs), but other groups such as traditional healers (cf. Chapter 13) were also seen as important.

The next step of the overall project was to investigate the properties of a range of community-based organisations working with HIV/AIDS in the community. This included quantitative as well as qualitative investi-gations. Groups targeted in this part of the research included faith-based organisations (FBOs), HIV/AIDS support groups, saving groups, burial societies, HBCs, gardening groups and youth groups. For this part of the research, we used questionnaires, focus group discussions and flow charts/diagrams. (The reports from this part of the research project are, by the time of publishing this volume, still not completed). We looked into the extent and nature of links and collaboration between CBOs and associations and external agencies (cf. Chapter 3). Based on the findings of the research project as a whole, some overall policy implications were drawn and conclusions and recommendations are given (cf. Chapter 12 and Chapter 14).

All ethical protocols of anonymity, confidentiality and voluntary participation were observed throughout the project period. The research protocols were approved by the regional research ethics committees in Norway (REK), the Ethics Committee of the University of KwaZulu-Natal South Africa, and the Norwegian Social Science Data Services (NSD). If not otherwise stated, all quotes from respondents in the different chapters are given verbatim.

Structure of the volume

Apart from the editors who formed the research team, an additional ten post-graduate students contributed to the research completed for the project. We recognise the challenges that writing across so many different levels brings up for both the authors and the readers. For most of the students contri-buting to the volume, this is their first experience of publishing – something that we want to encourage as editors. We also hope that the volume helps to make the work done by the students more likely to be disseminated. The chapters consist of contributions made by the team of researchers and the students who completed their research under the umbrella of the overall project.

In Chapter 2, Wenche Dageid explores community perceptions and participation in HIV/AIDS care and support activities. She reviews some of the factors implicated in community participation before reporting on a study aimed at identifying potential spaces for involvement by ordinary community members in HIV/AIDS care and support. The study conducted a questionnaire-based survey with 969 respondents in order to understand and enhance the response-ability of the community members. Overall social capital was rated as moderate based on the finding that most people held government and traditional leaders responsible for addressing community problems due to post-apartheid promises. It was concluded that the high level of group activity in the community was confined to a limited number of people. Dageid observes that the building of social cohesion requires a diverse and sufficient pool of resources that are not available in this community. In addition, specific conditions, which are described, should exist for social capital to emerge through community-based capacity-buil-ding processes.

In Chapter 3, Fanny Duckert and Staale Vaage examine the organisational challenges in creating care and support services for PLWHA in rural South Africa. In their study, the leaders of 7 organisations in the community (three formal and four informal) were interviewed on how care and support were perceived, and the coordination and cooperation between various organisations were explored. Specific attention was given to the provision of ARVs. Of special importance were the lack of coordination and communication in the distribution of resources at the bridging level, and the lack of cooperation at the linking level between the community and government institutions. The chapter concludes that the challenge of human resources is still an overwhelming and unresolved problem in rural areas in South Africa.

In Chapter 4, Wellington Mthokozisi Hlengwa reports on the burden of care among 130 volunteer caregivers of PLWHA in the study area. He argues that there has been a host of studies that investigated the burden of care; however, most have had a qualitative focus and none have used quantitative measures to look at the degree of stress experienced by caregivers. In his study, he found that the 'overwhelming nature of the disease' and death among patients was found to be the cause of the most intense stressors amongst volunteers. Despite the levels of stress, the participants interviewed expressed a commitment to work voluntarily for a five-year period. An unexpected finding was that high social capital was associated with high levels of stress. Hlengwa speculates that this might be due to the high level of community stigmatisation of PLWHA and their caregivers.

In Chapter 5, Annette Kezaabu Kasimbazi and Yvonne Sliep focus on the perceived obstacles of volunteer HBCs in ensuring care and support for PLWHA. Interviews were done with 13 volunteer workers on their views of care and support that they provide to the community in relation to care and support of HIV/AIDS. The study found that there was growing apathy within the community, and limited knowledge and awareness of AIDS care and support. There was a general lack of resources for care and support exacerbated by poverty and lack of social cohesion. Kasimbazi and Sliep conclude that the burden of care is becoming increasingly overwhelming for households and volunteers. There is an urgent need to promote and increase social capital with community solidarity, moral and reciprocal support.

In Chapter 6, Sharl Fynn reports on various aspects of support at the different levels of social capital. The results of her study demonstrated that support received depended on the personal relationships that the 10 volunteers had with members of different groups at a social bonding level. Social cohesion was found to be lacking at this level, which made the work more difficult and family members were also not really supportive. The volunteers spoke clearly on the subject of needing structural support in the form of transport or a hospice. Training was also specified as an urgent need as volunteers felt unprepared for the challenges they encountered in dealing with patients. Volunteers requested that they be paid salaries/stipends to ameliorate the burden of care. The general lack of support from government is discussed in more detail as voluntary HBC is still identified as the most feasible option for the provision of care.

In Chapter 7, Fatimah Dada and Yvonne Sliep focus on family members and friends as caregivers. The 9 informal caregivers faced some particular challenges in their role as carers. Often, they had no choice on volunteering, and usually they had no formal training or access to basic amenities. This study demonstrated that the informal caregivers perceived very low levels of support, apart from the HBCs who were perceived as the strongest resource available.

In Chapter 8, Nicole D'Almaine De Klerk reports on the potential untapped resources for care and support in her focus group study of men and women of various ages who were at the time of the study not involved in caring for PLWHA. In all, 6 focus group discussions with 4 to 8 participants in each group were held. The perceived lack of care and support was attributed to negative perceptions towards the ill person, as well as to a general lack of trust and the prevailing stigmatisation. Participants differed in their opinions on what form of care and support should be provided, although it was generally assumed that all acts of kindness would increase support rather than only looking physically after a patient. Mutual mistrust among patients, family members and community members, as well as care organisations and government were indicated as major obstacles, which hinder people from becoming involved in care and support.

In Chapter 9, Anette Arnesen Grønlie, Kjersti Nesje and Wenche Dageid focus on how resilience and social capital are related to good outcomes and well-being. Their study sample consisted of 269 participants, mostly women. All participants were adult, isiZulu-speaking, and HIV positive, and also members of local Treatment Action Campaign (TAC) support groups for PLWHA. Their results demonstrated that resilience was related to cognitive social capital, and also to the quality of networks. Interestingly, for those people who had optimistic views and hope for their future, subjective well-being was in fact a central part of their stories. It was found that support group members valued their group highly, identified group membership as important to their identity, and held trust to the group, health system and organisations at a linking level.

In Chapter 10, Mbekezeli Mkhize and Thulasizwe Khuzwayo share their observations and reflections on their fieldwork activities. They have been collecting data in various forms including questionnaires, interviewing and facilitating focus groups. Descriptions are given of the practical and logistical challenges encountered especially in terms of suspicion. Among the locals there was a lack of trust towards outsiders, usually government officials and researchers that was historically based and which had been enhanced by unfulfilled promises. The experiences encountered include the threat of potentially dangerous dogs and snakes, poor geographical accessibility of houses, illiteracy among participants, and poor communication within the community. The account is of particular interest in terms of the field workers' identification with community members as well as being academic researchers.

In Chapter 11, Thirusha Naidu explores the concept of generative metaphor as a method of raising critical consciousness around identity amongst 15 home-based care volunteers (HBCVs). The role of metaphor in language and community action research is used as a frame to review the generative metaphor *umqondo kamama* ('the mind of a mother') that had been chosen as the common identity for the HBCVs. Naidu highlights that AIDS care work is predominantly gendered and the nature of the work disadvantages caregivers and is likely to produce negative identity associations. The connection of a generative metaphor to the element of motherhood offers the potential for positive identity associations to emerge. Finally, the efficacies and perils of using a generative metaphor are explored with reference to wider related communal and social narratives on motherhood.

In Chapter 12, Olagoke Akintola provides a conceptual analysis of the links between HBC and social capital using a feminist economics lens. His contribution suggests that while community/home-based care imposes severe burdens on families and communities (predominantly women), there are at the same time benefits that accrue to PLWHA, families and community members. Drawing on feminist economics, AIDS care and social capital literature, he argues that HBC is a public good. His contribution suggests that HBC generates community social capital and that social capital could also be mobilised to improve access to resources. He however cautions that community social capital could be depleted in the absence of external support. He advocates for massive government investments in care organisations, public healthcare systems and cash transfer/welfare programmes to sustain community social capital and preserve this public good.

In Chapter 13, Yvonne Sliep and Annette Kezaabu Kasimbazi explore how the results of the social capital research can be disseminated. The dissemination is interactive and tailored to the target audience. The emphasis of the chapter is on the creation of reflexive spaces to increase response-ability, and explores ways in which this could be done. Through creative ways, the feedback can form part of the research; it can promote critical forms of self-reflection as well as push the understanding of the research. A case study is included in the chapter to illustrate how the results of the study done by Annette Kezaabu Kasimbazi (cf. Chapter 5) was taken back to a wider audience through narrative theatre. An explanation of narrative theatre and an example of how the participants themselves were actively drawn in to highlight the results through participatory drama are given. The case study also explored how traditional healers through the dissemination process got a voice at both a social bridging and a social linking level. The feedback of the results forms a platform for possible future interventions.

Chapter 14 is the concluding chapter by the editorial group and pulls together the contributions made in the volume. It focuses on how to build social capital in community care and support. As such, this chapter represents a state-of-the-art declaration. We draw lines from our situated KwaZulu-Natal study to other situations and contexts, and share our passion and vision with the readers.

In addition to the chapters included in the volume, the study also comprised a few more research projects of students. The titles of all completed theses and the names of students involved are compiled in the Appendix where individual work from relevant libraries can be requested. Dissertations that formed part of the study, but which were not included in the volume, will be discussed briefly as part of an orientation to the overall project.

Therese Saeberg explored what motivates women to do voluntary care work and found that the women had a strong sense of community concern. The 12 interviewees expressed a sense of satisfaction with their work and appreciation of gained knowledge. Despite the hardships of volunteer work, they also told of personal rewards and growth. They found their strength in networks of social support, as well as in *ubuntu* (a sense of social cohesion).

Lungi Myeni picked up on observations done by fieldworkers while collecting the quantitative data that related to the concepts of trust and respect, which were items on the community survey, and revealed interesting perceptions. She interviewed 5 fieldworkers on their observations and compared the qualitative results with the results of survey data on the same values. It became clear in this study that results from a mixed design with both quantitative and qualitative data could yield more comprehensive understandings of a phenomenon than results based on one method alone.

In addition to the work described above/in this volume, further studies are underway. At the time of writing this volume, the analysis and write-up of field work by two PhD candidates (Annette Kezaabu Kasimbazi and Thirusha Naidu) were still taking place. In addition, policy reports are being developed to inform the actors at a linking level. It is known that the more levels involved interactively through dissemination of the research results, the greater the impact could be. The levels could include participants in each study, and inhabitants in the wider community the participants are drawn from, but also students, practitioners, policymakers, researchers, academics, service users and general citizens (Keen & Todres 2006). Effective provision and implementation of comprehensive policies and programmes from government are crucial to facilitate the growth of social capital in HIV/AIDS-affected communities. Recognising that HIV/AIDS care and support initiatives are initiated both from bottom-up and top-down, we also need to sensitise all partners to each other's activities, visions, fields of service delivery, possibilities for coordination and for working together.

Notes

1. Adapted from work done in Burundi (Sliep, 2008).

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Chapter 2

Spaces of response-ability: A mapping of community members' perceptions of and participation in HIV/AIDS care and support activities

Wenche Dageid

Introduction

For years, South Africa has had the highest rate of HIV infections in the world (UNAIDS 2009). Instead of a strong national healthcare response, communities, social networks and extended families have been left with the responsibility for the majority of care and support activities for people living with HIV/AIDS (PLWHA) (UNAIDS 2004). In the HIV and AIDS and STI National Strategic Plan of the South African government (RSA DoH 2010), strong cooperation between governmental groups and non-governmental organisations (NGOs) is emphasised. The civic community and grassroots groups are in other words encouraged and expected to take initiative. This requires knowledge, willingness and ability of ordinary community members to get involved in activities that can mitigate the impact of HIV/AIDS at a communal level.

Social mobilisation through community participation and strengthening of community responses has been promoted as one of the cornerstones in the efforts to deal with the HIV epidemic (Abdool Karim, Churchyard, Abdool Karim & Lawn 2009; Campbell, Nair, Maimane & Sibiya 2005; Nair & Campbell 2008). Some literature exists on those already heavily involved in HIV/AIDS care and support, such as family carers, home-based carers (HBCs), health volunteers, community-based organisations (CBOs) and NGOs. Less attention has been paid to factors that facilitate participation from less involved community members, and the role such participation has for the capacity of groups and organisations as service providers within the network of HIV/AIDS care and support (Campbell *et al* 2005; Russel & Schneider 2000). Capacity here refers to the ability of individuals, groups or organisations to organise their assets and resources to achieve objectives they consider important. The rationale behind participatory community-level approaches in this context is to not only provide better care and support for PLWHA, but also to foster an empowerment process in order to bring about social changes that will benefit the community as a whole (Campbell 2000;

Laverack 2001). Several factors influence peoples' participation in activities that serve to mobilise and build community capacity.

Structural factors are implicated in community participation. The structural level refers to the broader context of social, political, historical and economical forces that represent the 'collective life chances' of groups of people (Rutten 1995). In South Africa, economic disadvantage, and social and historical injustices help sustain health inequalities (Coovadia, Jewkes, Barron, Sanders & McIntyre 2009) and have an impact on the possible space of participation. Clearly, the community context plays a crucial role in terms of what constitutes realistic and possible opportunities for participation and empowerment.

Another factor that is implicated in participation and capacity building is social capital. Social capital can be considered a tool in community revital-isation and development, focusing on building social capacity. Several scholars define social capital in terms of resources that are embedded in and can be accessed through an individual's social networks (Foley & Edwards 1999; Lin 1999). The resources further include norms and mutual trust of civil society that facilitate cooperative action among members of society and institutions (Coleman 1988; Putnam 2000). A sense of community may be considered a catalyst for organised participation (Perkins & Long 2002), and networking behaviours are motivated both by social cohesion (community bonds) and perceived problems in a community (Perkins, Hughey & Speer 2002).

The trust, expectations and satisfaction individuals have in groups and organisations in their own community influence their decision to participate in collective action. The expectations, relations, and ultimately trust, are governed by underlying sets of norms, values and understanding. Trust develops where there are relatively stable expectations supported by norms (Reimer, Lyons, Ferguson & Polanco 2008). Just knowing about the existence of groups and organisations might contribute to social capital, because organisations may be considered institutions in which communal norms and resources are embedded (Reimer *et al* 2008; Wollebæk & Selle 2002).

Collective action may be considered a behavioural component of social capital, and is thought to depend on the presence of mutual trust and solidarity among community members, and a sense of collective efficacy. Bandura (2000) states that people exert collective agency through shared beliefs that they have the power to produce desired effects and forestall undesired ones by their actions. Otherwise, they would have little incentive to act. Low collective efficacy could result in assigning responsibility for solving community problems to actors outside of the community. In South Africa, the poor are disproportionately affected by HIV/AIDS. Living in a context of poverty, illness and social and political marginalisation may make people feel powerless in addressing their life situations (May & Norton 1997).

This chapter reports on ordinary community members' perceptions of HIV/AIDS-related activities in their local area, as well as to the extent to which they are willing to, and already do, participate in these activities. The overall aim of the study was to observe what potential spaces there are for involvement by ordinary community members, and to discuss ways that the response-ability of the ordinary community members in the context of HIV/AIDS support and care can be understood and enhanced.

Methodology

Study location, procedure and participants

This study took place in a semi-rural community in the eThekwini municipality of the KwaZulu-Natal province. Participants were isiZulu-speaking, black South Africans. The participants were randomly recruited by an interviewing team who went from door to door in the community during a period of four months in 2008. A sample of 319 males and 650 females (n = 969) ranging from 18 to 95 years old (M = 38 years) participated. Of these, 66% defined themselves as single, while 20% reported being married. In terms of education, 60% had completed secondary or high school. Only 21% held paid jobs. In this survey, only 5.5% reported no monthly household income, half of the sample had a household income of between 500 and 2 000 ZAR (100 ZAR = approximately US$15), while almost 10% had a monthly household income of 3 000–6 000 ZAR. Of the sample, 40% received their income from grants, mainly child grants (n = 193) and old age pensions (n = 121).

Instrument

The health and social capital survey used in this study was compiled from an extensive literature review, and in particular from the Social Capital Assessment Tool (Grootaert & Van Bastelaer 2001; Krishna & Shrader 1999). The instrument included in total 53 questions on demographics (categories of gender, age, education, employment status, marital status, source of income, and total household income), general health issues, knowledge and use of HIV/AIDS-related groups and services, trust and expectations related to HIV/AIDS services and providers, satisfaction with HIV/AIDS service provision, agents considered responsible for addressing community problems, and the degree to which community members already were participating and would participate in volunteer action for the HIV/AIDS cause. Some items were answered with 'yes' or 'no'; others were qualitative ("What would you say are the three main reasons for the change in quality of life since 2004?"), while most items were answered on a 5-point Likert scale, where 1 represented a negative attitude towards the question/statement (e.g. very dissatisfied/totally disagree) and 5 represented a positive attitude (e.g. very satisfied/totally agree).

Findings

Health status and overall quality of life

While almost half the sample reported good or excellent health, as much as a quarter reported poor health ($M = 3.03$, $SD = 1.451$). Women, widowed and married people, older people (older than 50 years), those who were unemployed, those who lived from pension or disability grants, and those who had no monthly household income or who had a monthly income of 500–999 ZAR (which would equal what is paid out as sick and pension grants), were significantly more likely than others to report poor health (all significant at $p < .05$). The most noticeable result was found for education, where more than 50% of those with no education at all reported poor health, while merely 14% of those who had completed secondary or tertiary education reported poor health ($p < .001$). Almost half of the respondents (48%) stated that the overall quality of life in the community had become worse since the 2004 elections. The three main reasons given were unemployment, inaccessible health services and a lack of clean water. The respondents who reported that overall quality of life had improved since 2004, were significantly more likely to be men ($M = 2.69$, $SE = .071$) than women ($M = 2.41$, $SE = .052$), (t (935) = 3.089, $p <. 005$), having tertiary education [F (3, 930) = 3.485, $p < .05$], and a total monthly household income of more than 2 000 ZAR [F (5, 914) = 15.339, $p < .000$].

Knowledge of and use of HIV/AIDS-related groups and services

Approximately 50% of the sample knew of specific groups involved in HIV/AIDS activities in and around the community groups, and although 451 of the 969 respondents to this question did not name a single group, the ones who did, named a total of just over 100 groups. In this context, "HIV/AIDS-related activities" were broadly defined and included, for example, prevention and awareness, treatment, care and support, cultural and spiritual activities, and income-generating projects. The types of groups are displayed in Table 2.1. Most of the groups mentioned could be defined as home-based care (HBC) groups, faith-based groups, burial societies (a form of volunteer funeral savings group), and general HIV CBOs. Only approximately 50 community members specifically mentioned NGOs, despite the fact that several of these big and influential organisations exist and operate in the community. Those who had a monthly household income of between 1 and 499 ZAR were significantly more knowledgeable than others about HIV/AIDS-related groups operating in the area [*F* (5, 944) = 5.516, *p* < .001].

Table 2.1 Knowledge of types of groups conducting HIV/AIDS-related activities in the community

Type of group	**Number of respondents**	**%**
HBC groups	191	36.9
Faith-based groups	110	21.3
Burial societies	98	18.9
HIV CBO awareness/prevention/support/self-help groups	71	16.0
Savings groups/*stokvels*	15	2.9
Youth groups	11	2.1
Other	10	1.9
Total	**518**	**100.0**

A total of 33% of the community members "very seldom or never" used the services of the reported groups, while 11% reported using the services "almost every day". There were big differences in frequency of use between the types of groups. The most frequently used groups were faith-based groups with more than 85% attending these groups daily or once or twice a week. Between 70 and 80% of the respondents used the services of burial societies and savings groups on a weekly or monthly basis. Around 70% attended youth groups on a daily, weekly or monthly basis. On the other hand, between 10 and 15% used the services of HBC groups and HIV CBO awareness/prevention/support/self-help groups on a daily, weekly or monthly basis. Those who reported using the services of groups most frequently were more likely to be in the age group of 70 years or older [*F* (5, 509) = 2.407, *p* < .05], more likely to be employed (*M* = 2.90, *SE* = .148) than unemployed (*M* = 2.51, *SE* = .068), (*t* (938) = 2.497, *p* < .05), and to have a household income of between 1 000 and 2 999 ZAR [*F* (5, 504) = 14.420, *p* < .001].

The importance ratings of groups followed the patterns of frequency of use, were the groups scored "very important/having a high impact" being faith-based groups (80%), burial societies and savings groups (73%), HIV CBO awareness/prevention/support/self-help groups (57%), youth groups (54%), and HBC groups (19%). Those who had no monthly income were more likely to report that the groups were of "very high importance/impact" [*F* (5, 506)

= 21.105, *p* < .001]. HBC groups were the only groups rated as "predominantly of no or little importance".

Knowledge on the subject of HIV/AIDS-related services in the community mainly came from three information channels, namely radio (29.5%), relatives, friends and neighbours (21.5%), and national newspapers (21.5%). Only 3.6% got HIV/AIDS-related information from clinics, hospitals and other health institutions, while only a small number of people got information from community-based groups (four people, 0.4%), *Imbizos* (a Zulu word meaning 'mass meeting' or 'gathering', often signifying a forum for discussion of policy) (12 people, 1.2 %), NGOs (two people, 0.2%) and churches (five people, 0.5%).

Expectations and trust in different agents' provision of HIV/AIDS-related services

The respondents were asked to what degree they expected different actors to provide services for PLWHA in the community. Overall, the respondents held low expectations towards all providers. Highest expectations were offered to traditional healers and traditional leaders, while clinic staff and hospital staff were the least expected to provide HIV/AIDS services. The mean scores and standard deviations are provided in Table 2.2

Table 2.2 Scores on "To what degree do you expect these different actors to provide services for HIV-positive people in this community?"

HIV service providers	M	(SD)
Traditional healers	2.49	(1.596)
Traditional leaders	2.47	(1.532)
Local government	1.95	(1.355)
Community-based groups and organisations	1.89	(1.192)
NGOs and international donors	1.79	(1.204)
Provincial government	1.69	(1.236)
Family members, friends and neighbours	1.65	(1.112)
National government	1.56	(1.178)
Clinic staff and hospital staff	1.40	(0.966)

Note: Scores ranged from 1 (no expectation at all) to 5 (very high expectation)

The most marked differences in expectations from different service providers were found between income groups, where having a monthly household income of 3 000 ZAR or more was associated with significantly higher expectations from all service providers (all at *p* < .005) except clinics and hospitals, provincial government, and national government. Expectations were significantly higher among women (*M* = 1.97, *SE* = .049) than among men (*M* = 1.74, *SE* = .060) for service delivery from community-based groups (*t* (964) = –2.809, *p* < .005). Women (*M* = 2.56, *SE* = .063) also tended to have higher expectations towards traditional healers than men (*M* = 2.33, *SE* = .088), (*t* (964) = –2.107, *p* < .05). Those in the age group 30–39 were more likely to expect service provision from traditional leaders [*F* (5) = 4.328, *p* < .005]. Having a tertiary educational attainment was associated with significantly higher expectations from traditional healers [*F* (3) = 4.328, *p* < .005]. Those with no education expected significantly more from the national government in terms of service provision [*F* (3) = 2.755, *p* < .05] than the other educational groups.

When asked how much the respondents trusted different actors to do a good job with HIV/AIDS service delivery, the results were more positive than those regarding expectations (cf. Table 2.3). The most trusted providers were family, friends and neighbours, while the least trusted providers were traditional leaders and traditional healers. While not being expected to do much, hospital staff, clinic staff and governmental officials were moderately trusted to provide good service.

Table 2.3 Scores on "How much do you trust these different actors involved in HIV/AIDS activities in the community to do a good job/provide services?"

HIV service providers	**M**	**(SD)**
Family, neighbours and friends	3.83	(1.164)
Hospital staff	3.81	(1.159)
Clinic staff	3.76	(1.124)
National government	3.67	(1.314)
Provincial government	3.64	(1.170)
Local government	3.28	(1.372)
HBCs	3.19	(1.370)
Community-based groups and organisations	3.13	(1.334)
NGOs	3.11	(1.301)
Traditional healers	2.77	(1.341)
Traditional leaders	2.62	(1.309)

Note: Scores ranged from 1 (to a very small extent) to 5 (to a very great extent)

For trust, significant differences (*p* < .05) between income groups were found for all providers, except volunteers and workers in CBOs, where there were no differences. Family, friends and neighbours, HBCs, traditional healers, traditional leaders and local government were most trusted by those with no total monthly household income or an income of between 0 and 499 ZAR. Clinic staff was most trusted by those with no income and those with an income of 3 000 ZAR and more, while hospital staff was most trusted by those with an income of more than 3 000 ZAR. NGOs were most trusted by those who had an income of 2 000 ZAR plus, while trust of service provision from provincial and national government was highest in the income group of 3 000 ZAR and more ($p < .001$). Women trusted clinic staff ($M = 3.83$, $SE = .043$) more than men ($M = 3.60$, $SE = .065$) did ($t\ (964) = -3.033$, $p < .005$). Women ($M = 3.89$, $SE = .044$) also trusted hospital staff significantly more than men ($M = 3.65$, $SE = .069$) ($t\ (964) = -3.068$, $p < .005$). The difference in trust towards national government was also significantly higher ($t\ (950) = -2.618$, $p < .05$) among women ($M= 3.75$, $SE = .051$) than among men ($M = 3.51$, $SE = .077$). In terms of age groups, the only significant difference for trust towards different service providers was found for the category "traditional leaders". These were more trusted by people in the age group 60-69 [$F\ (5) = 2.557$, $p <.05$]. Those who had completed secondary school were significantly more likely than other educational groups [$F\ (3) = 2.654$, $p < .05$] to trust service provision from HBCs.

Satisfaction with HIV/AIDS-related groups and service provision

The overall health service provision in the community was rated as poor or fair by 51% of the respondents, whilst 10% thought it to be excellent. Overall service provision was rated most favourably by those with a total monthly household income of 2000 ZAR and more [$F\ (5) = 4.772$, $p < .005$] and those who had completed primary education [$F\ (3) = 3.413$, $p < .05$]. Results were mixed regarding satisfaction with HIV/AIDS work conducted by local community groups (cf. Figure 2.1). Almost one third of the respondents answered "very dissatisfied", while a quarter of the respondents were "moderately" or "very satisfied". Those most satisfied with the HIV/AIDS-related work carried out by community groups tended to be in the age group of 30–39 [$F\ (5) = 5.731$, $p < .005$] and having tertiary education [$F\ (3) = 5.731$, $p < .001$].

Community members were also asked how well different HIV/AIDS groups and organisations were working together in their community. Half of the sample was unsure or neutral in response to this question, while a quarter had the opinion that cooperation was "good" or "very good". The degree of cooperation between groups and organisations was considered most positive by those who had a monthly household income of 1–499 ZAR [$F\ (5) = 2.580$, $p < .05$].

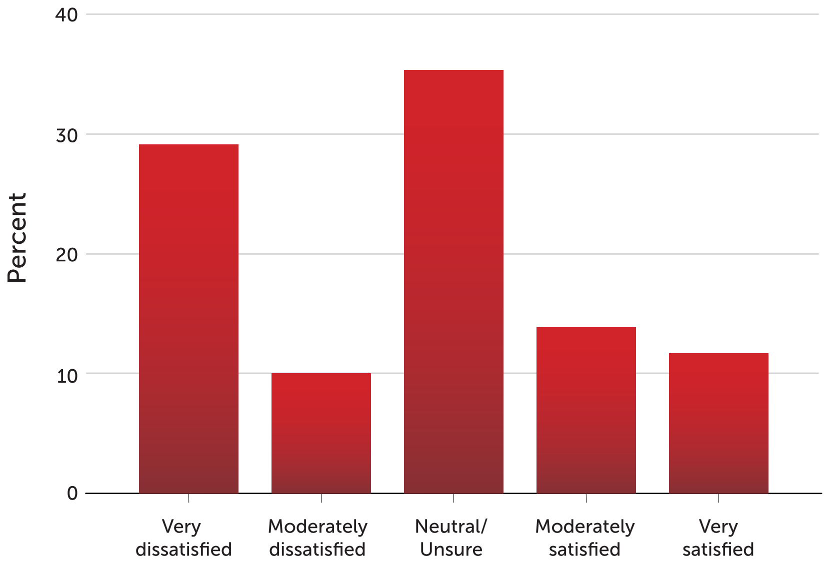

Figure 2.1 Satisfaction with groups working on HIV/AIDS-related issues in the community in %

Of the respondents, 27% agreed that government provided adequate support for community-based groups, while almost 50% had no opinion on this matter. Also, 30% agreed that HIV-positive people received adequate service provision (irrespective of service provider), yet almost half of the sample was unsure or neutral in response to this question.

An encouraging 42% stated that access to HIV/AIDS care and support had improved somewhat or a lot since the 2004 elections. However, close to four in ten respondents answered that it had "stayed the same", while almost 20% felt it had deteriorated. Those who have a monthly household income of 3 000 ZAR or more [$F(5) = 4.877$, $p < .001$] and those with a secondary education [$F(3) = 3.271$, $p < .05$] were significantly more likely than others to report that HIV/AIDS care and support in the community had improved.

Norms and values influencing participation

To investigate whether social norms were influential in perceptions of community cohesion, respondents were asked to what extent community members would get together to help a family who had lost a family member to AIDS and who could not afford a funeral. A total of 40% said that this is "likely" or "very likely". However, close to 50% said this was "unlikely" or "very unlikely". For the social norm of helping out in case of a funeral, the only significant difference was found between income groups, where those with an income of between 2 000 and 2 999 ZAR were significantly more likely to report that they would help out [F (5) = 2.953, $p < .05$].

The belief in the importance of the social norm of *ubuntu,* which in this study was used to represent a sense of social cohesion or sense of community, in motivating people to join volunteer work and HIV/AIDS activities was moderate, with 53% believing it was quite or extremely important, 26% being neutral or unsure about the question, while 21% said it had no or little importance. There was a significant difference between genders in terms of perceptions of the social norm of *ubuntu* (t (963) = −2.1989, $p < .05$), with women ($M = 3.56$, $SE = .049$) perceiving it to be more influential than men ($M = 3.37$, $SE = .069$). Household income of more than 3 000 ZAR was also significantly more associated with positive views of *ubuntu* than a lower income or no income at all [F (5) = 9.876, $p < .001$].

Collective efficacy, participation and responsibility to act to mitigate the effects of HIV/AIDS

A sense of collective efficacy or agency is crucial for collective action to take place. When asked who should address community problems, almost half of the respondents (46%) responded that government was the appropriate agent. Approximately 22% mentioned traditional leadership, while 17% selected community groups and associations as the agents responsible for addressing community problems. Less than 15% believed that they or their families and friends should be addressing community problems (cf. Figure 2.2).

When asked on the subject of general community participation in HIV/AIDS activities, almost four out of ten respondents claimed it was low or very low, while 36% were not sure or remained neutral about the question. The remaining 9% seemed to be highly active in participating in HIV/AIDS activities in and for the community. Those who had a monthly household income of 2 000–2 999 ZAR were most likely to perceive that there was high community participation in HIV/AIDS activities [F (5) = 3.274, $p < .05$].

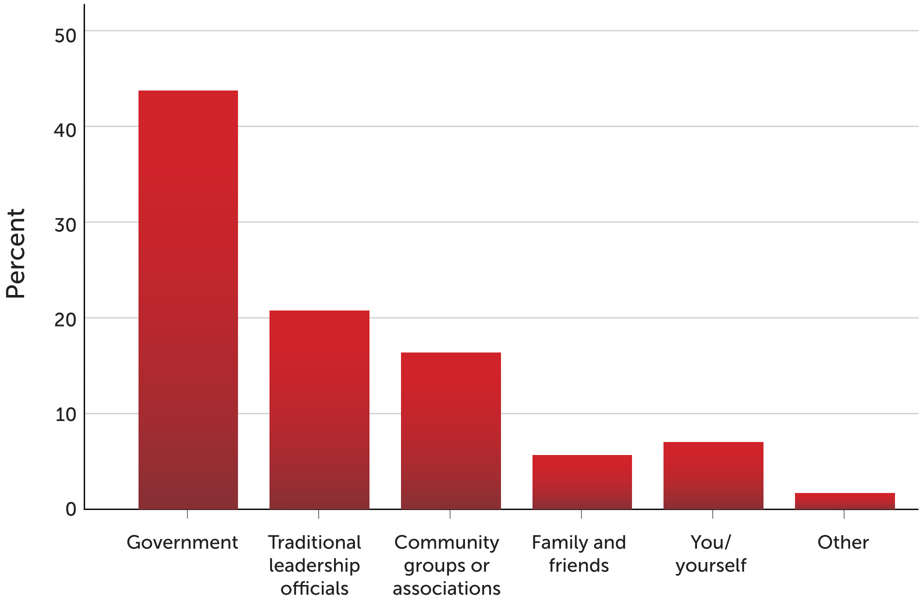

Figure 2.2 Respondents' views about who should address community problems in %

Seven out of ten respondents said they would "probably" or "definitely" volunteer to join a group or organisation providing HIV/AIDS services in the community. Young people between the ages of 18 and 29 years [F (5) = 29.138, $p < .001$] and those who had tertiary education [F (3) = 29.557, $p < .001$] were significantly more likely than others to report that they were willing to join volunteer community activities for the HIV cause.

Summary of findings

The demographic profile of respondents showed that this was a disadvantaged community. Levels of unemployment were high, educational attainment low, general health was rated as poor by a substantial proportion of respondents, and total monthly household incomes were on average no more than 1 000–2 000 ZAR. Unemployment, lack of access to health services, and lack of clean water were the main complaints in the community, which contributed to a general perception that quality of life had stagnated or worsened during the previous four years. Despite the high HIV infection rate in the community, half of the respondents could not name a single group working with HIV/AIDS-related issues in the community. For those who did know of such groups, HBC groups, faith-based groups and savings groups were most frequently mentioned. Even though community members generally made use of these groups, and the importance of the groups were rated as “medium” to “high”, satisfaction gained from the job done in terms of HIV/AIDS-related services, was at best “moderate”. Half of the respondents were neutral or unsure about the question of whether HIV-positive people received adequate services, about whether community-based groups were working well together, and about whether government support towards community HIV/AIDS activities was sufficient. However, community members did report an increase and improvement in HIV/AIDS care and support activities over the previous four years since 2004. Looking at the norms and values that were thought to underlie perceptions of and participation in HIV/AIDS-related activities, community expectations towards different service providers were surprisingly low. In particular, the formal health system was the least expected to provide HIV/AIDS-related services. Trust toward different service providers was much higher, with the formal health system, as well as family, friends and neighbours, most trusted. The social norm of *ubuntu* was considered an important value underpinning acts of solidarity and cooperation in the community, with more than half of the respondents quoting it as “very” or “quite influential”. However, responding to a scenario of considering contributing towards a funeral for someone who had died of AIDS, half of the respondents said it was unlikely that community members would make such contributions. The level of collective agency and responsibility seemed low. General community participation in HIV/AIDS-related activities were perceived to be moderate or low, with few community members actively involved in HIV/AIDS-related activities. On the other hand, a majority of respondents claimed they would be willing to volunteer in HIV/AIDS-related community activities and groups. Almost half of the respondents held government responsible for addressing community problems.

Discussion

The sheer magnitude of the HIV/AIDS epidemic in South Africa in general and in the KwaZulu-Natal province in particular has necessitated the combined efforts of individuals, families, communities, local and international organisations, and governments to mitigate the impact of HIV/AIDS. The South African government has initiated impressive legislations and plans for health care and HIV/AIDS treatment, care and support; however, implementation of the plans is seriously lacking in most areas (Chopra *et al* 2009). Without clear leadership and direction from the government how will it be possible for local communities to solve the imminent needs created by the HIV epidemic, and what role can ordinary community members play in care and support activities?

Structural and socio-economic boundaries for participation

As noted in the introduction, community participation requires a general population that is active, interested and informed (Prilleltensky & Nelson 2002; Wollebæk & Selle 2002). With the poor socio-economic and health status of many of the residents in our study area, energy and resources that could have been used for participation were most likely used for mere survival and 'getting by' on a day-to-day basis. Low socio-economic status and a high level of self-reported poor health have been connected with low levels of collective participation for communal benefits (Thomas 2006). The results of this study indicate that employment, having at least secondary education, and having a stable income are related to better health, more optimistic views on participation and service provision, and higher levels of trust. These individual assets can be used in creating and accessing resources and they are related to increased stocks of social capital. However, as noted in other chapters in this volume (cf. Chapters 3, 6, 7 and 12), structural constraints and lack of community resources may hamper creation, availability of and access to social capital. Based on the lack, and even de-terioration of community assets, it could be even harder for community members to access resources and opportunities outside of the community, something that would reinforce a negative spiral of disadvantage. The socio-economic and structural context of today has its roots in South Africa's history of political, social and economic injustices. The collective life chances and spaces of response-ability are in other words constricted by factors largely outside of community members' control.

The structure and functioning of HIV/AIDS networks in the community: 'Getting by' or 'getting ahead'?

Wollebæk and Strømsnes (2008) note that strong and visible voluntary associations are standing proof of the rationality and utility of collective action. Generally, the level of civic participation and number of civic organisations has been described as high in many South African communities (Campbell *et al* 2005; Habib 2005; Russel & Schneider 2000). Taking the high number of PLWHA in the study area into account, it was surprising that as much as half of the sample did not know of any group or organisation dealing with HIV/AIDS in the community. The people who named most groups were probably more knowledgeable as a result of participating more actively, by having less resources and thus needing more help from community groups, or by spending more time in the community (for example, as a result of lack of outside employment), thus being more aware of overall community activities.

Not surprisingly, HBC was the type of group most frequently mentioned. This highlights the magnitude of the epidemic, as well as the central role of HBCs in providing care and support for PLWHA in the community. However, it may also be an indication that the general public may start looking for HIV/AIDS-related services when severely ill rather than seeking information and assistance when still healthy. This assumption is compatible with studies showing that HIV-positive people in South Africa generally do not test or disclose their status until they are manifestly sick (cf. Almeleh 2006; Dageid & Duckert 2007). In addition, the relatively high number of people who named burial societies as HIV/AIDS-related groups supports this assumption. HIV/AIDS is still associated with stigma and premature death. The groups that were involved in HIV awareness, prevention and support were only third on the list of groups that community members knew of. This may suggest a disadvantage to preventive and public health promotion efforts at a community level, as community members would more likely be reached or approach information when in advanced stages of an HIV infection, and not before. Of course, the reason for HBCs being mentioned most frequently could also be because of their visibility and hands-on work in the community, as opposed to the more vague and often externally initiated process of informational and educational services.

Faith-based groups were the second most frequently mentioned type of groups related to HIV/AIDS in this community. This study did not look into what kind of HIV/AIDS-related services faith-based groups provide; however, it is likely to be a holistic approach of prayers, social support, different material support (e.g. gardening and donations), care for orphans, and funerals. Faith-based groups are in many instances important and valued providers of HIV/AIDS care and support throughout Africa (Birdsall 2005; Liebowitz 2002), as seemed to be the case in this study. However, faith-based groups face many challenges in terms of creation and access to bridging social capital. Religious congregations have by some researchers been characterised as “bound”/“restricted” groups into which a person is born or brought by association (Cross, Mngadi & Mbhele 1998). A potential challenge with “bound”/“restricted” groups is that they may be less outwardly active and less accessible to outsiders than “achieved”/“open” groups (such as savings groups or HIV-awareness groups) where members have to make a conscious decision to join and in which membership is relatively open (Cross *et al* 1998). Faith-based groups may thus provide more of an opportunity of ‘getting by’ (a bonding quality) and less of an opportunity of ‘getting ahead’(a bridging quality) in terms of social capital. This was, for example, the case in a study from Lusaka (Zambia) and Durban (South Africa), where

Thomas (2006) found that marginalised women living in informal settings almost exclusively participated in church groups, where they received social support and spiritual comfort, yet little in terms of tangible resources. Our study could not determine to what extent this was relevant for this community; however, this creates an opportunity for further research, as faith-based groups are major providers of HIV/AIDS care and support in many countries in sub-Saharan Africa (ARHAP 2006).

Networks may or may not create or promote social capacity relevant for a particular purpose. For example, a reading group might promote social capital, but not necessarily social capital relevant to the purpose of mitigating the impact of HIV/AIDS. The functions and goals of a particular group are also important in understanding the usefulness of social capital created for certain purposes. In some instances, the involvement in community groups may even prove to be detrimental to a person's health (Ziersch & Baum 2004). For example, savings groups offer community members an opportunity to access a lump sum of money on a rotation basis, something that could prove beneficial for a household affected by HIV/AIDS. Despite the usefulness of the saving schemes, these groups may in some instances not only fail to provide relevant social capital, but actually provide 'anti-social capital' in relation to HIV/AIDS (Campbell, Williams & Gilgen 2002). This phenomenon is particularly related to money being spent in *shebeens* (unlicensed establishments that sell alcoholic beverages) instead of on household necessities. Heavy drinking, particularly among men, was considered a hindrance to involvement in HIV care and support in the community of this study, as discussed in Chapter 8 of this volume.

In this study, relatively few community members specifically mentioned NGOs, despite the fact that several of these big and influential organisations exist in areas around the community and operate in the community. Again, this could be explained by the structural and socio-economic conditions that hinder mobility and access to information between the community and the outside areas. It might also indicate a lack of adequate and (culturally) relevant information efforts from the NGOs themselves. Community members might also not be aware that several of the community-based groups actually receive various kinds of support from NGOs.

Religion is an integral and important part of life for many South Africans (Dageid & Duckert 2008; Garner 2000); thus, it is not surprising that faith-based groups were used most frequently by community members, and also rated as most important. HBC and HIV CBO awareness/prevention/support/self-help groups, which arguably are the most directly relevant HIV/

ADS groups operating in the community, were not widely used and also scored surprisingly low on perceptions of importance. This is in contrast to all other HIV/AIDS-related groups mentioned, which were seen as important and of high impact by a majority of respondents. This could signify a general reluctance to acknowledge the impact of HIV/AIDS in the community. Several studies have shown that stigma, silence and secrecy around HIV are still rife and have detrimental effects on individual and communal possibilities to deal with the epidemic in adequate ways (Hosegood, Preston-Whyte, Busza, Moitse & Timaeus 2007; Maughan-Brown 2010). It could also reflect community knowledge and disapproval of the ongoing tension between different HBC groups in the community, as documented in several chapters in this volume. Another possibility is that the majority of community members find the work done by these groups inadequate in the face of a growing HIV epidemic. Again, the community members who presumably needed the services of community-based groups most, those with little income and thus few other options of accessing resources of HIV/AIDS care, gave all groups more favourable ratings.

It is necessary that the general population be active, interested and informed in order to create civic engagement and community participation (Prilleltensky & Nelson 2002; Wollebæk & Selle 2002). Ideally, community members should be able to access a range of resources and choose between different information channels to get the best and most relevant information concerning HIV/AIDS. In this study, information mainly came from mass media or from relatives, friends and neighbours. Paradoxically, community-based groups were hardly mentioned as sources of information concerning HIV/AIDS services, despite the fact that they were providing such services to the community. Few people mentioned the formal health system as a source of information, despite the fact that a government-owned clinic existed in the community. A possible explanation for this could be that the broad definition of what constitutes HIV/AIDS-related care and support at a community level indicated a marked difference between these services and those provided by government (which would be distributed through media, clinics and hospitals). Care and support activities mentioned by community members would cover 'survival needs' such as food from garden projects, spiritual care, funeral arrangements and palliative care, whilst the formal health system could be regarded as providing more medical and treatment-based care. Since many people in South Africa first visit traditional healers when sick (Babb, Pemba, Seatlanyane, Charalambous, Churchyard & Grant 2007), and the community clinic was struggling with lack of resources at the time of the study (cf. Chapter 3 of this volume), the formal health system might have been regarded as difficult to access and thus not the first choice for obtaining healthcare information.

Norms and values that influence perceptions of and participation in HIV/AIDS-related groups and activities

Reimer *et al* (2008) as well as Wollebæk and Selle (2002) argue that groups may be regarded as institutions in which communal norms and resources are embedded. This could be particularly true in a homogenous society (in which people share many or most of the characteristics) such as the one in which this study took place. Since trust to an extent is based on people having reasonable expectations regarding what others will do (Reimer *et al* 2008), one would assume that expectations of and trust towards HIV/AIDS service providers would show overlapping patterns. However, in this study, expectations towards service delivery were low while trust was consistently higher, and the service providers that were expected to provide care were not the ones that were most trusted. This finding may have been related to accessibility: the South African public health system is understaffed and underperforming, while traditional healers are numerous, easily accessible and used for many ailments (Peltzer 2009). The low trust displayed towards traditional healers and leaders could be due to the information from government, media and other sources that traditional healers cannot cure HIV/AIDS; rather, HIV/AIDS is a disease to be handled by the formal health system. The fact that women are more trusting of clinics and hospitals could be ascribed to the healthcare system's prioritisation of mother–child health (Coovadia *et al* 2009).

As in many other communities in South Africa, health service provision in our study area was insufficient. This was reflected in the low ratings of satisfaction with overall service provision and especially service provision from specific groups. The numbers of respondents who were unsure or negative towards the adequacy of HIV service provision were surprisingly high, as one would expect most families in the area to have been affected by HIV and thus having experienced or being in need of the care and support efforts of community-based groups. This finding might speak of the stigma and secrecy that keep families from accessing available HIV/AIDS care and support, as noted in several chapters in this volume.

The multitude of HIV/AIDS-related groups and organisations make a valuable contribution to mitigating the impact of the epidemic at community level. However, several studies have shown that community-based initiatives may face challenges such as lacking physical and financial resources, skills and knowledge; being small and not well documented; and being initiated ad hoc and not very well coordinated (Kelly *et al* 2006; Rau 2006). Community-based groups may therefore not have the capacity to reach out or to inform others of their existence. As a consequence, many community members might have been unaware of the multitude of groups that actually existed in the community. The low levels of satisfaction could reflect the inadequate level of functioning of many of the groups, thus confirming the statement of Putnam, Leonardi and Nanetti (1993:78) regarding the functioning of institutions as the sole consistent predictor of citizen satisfaction. Higher education and higher household income generally coincided with higher levels of satisfaction with service provision. People in these categories would probably have better access to information on community services and to alternative sources of healthcare services; thus, not being restricted to services offered in the community. On the other hand, those most satisfied with the functioning of community-based groups were perhaps also the ones most involved with and most in need of the types of services offered in the community (e.g. food parcels).

In the social capital framework, norms and values are thought to underlie and influence collective behaviours. In this study, the value of *ubuntu* was seen as very influential in instigating collective action, especially by those who had a relatively high income. Having a sufficient income might mean a person is less dependent on others, being able to draw on more resources, being more mobile and able to find information. This could explain why people who earned more reported being more likely to assist a family who had lost a family member to AIDS and who are not able to afford a funeral. Those with fewer resources would most likely have less space to manoeuvre in terms of assisting others, and fewer opportunities for accessing services for their own benefit.

Collective efficacy and agency in addressing community problems

In many local communities, HIV/AIDS adds to household costs, endangers livelihoods and food security, increases the vulnerability of women and children, and leads to the selling of household assets that can result in irreversible destitution (Bachmann & Booysen 2006; UNAIDS 2004). These processes may strain community safety nets, undermine extended kinship ties, and alter civic and cultural norms, including values linked to reciprocity and collective action. Stigma, secrecy and silence may in itself prevent PLWHA from asking for or receiving the support and care that they need (Paxton 2002), and may also discourage community members from joining volunteer community activities and groups. This was reported in a survey concerning community-based HIV/AIDS care and support in South Africa.

Russel and Schneider (2000) found that, even though many communities were willing to mobilise, they were unable to do this as they were lacking resources, skills and basic necessities. Most participants in our study lived in a context of poverty, illness and social and political marginalisation, which could have contributed to feelings of powerlessness and despondency. Social cohesion was at best rated as moderate.

According to Perkins *et al* (2002), communities are not empowered by service and advocacy done on their behalf, but rather by residents themselves engaging in collective action. Most of the respondents in this study held governmental structures and traditional leaders responsible for addressing community problems. With the most pressing community problems (e.g. unemployment, limited access to health services, lack of clean water) being caused by factors operating at a systemic macro level, this is not surprising. The governments after the end of apartheid have promised, and also partly delivered improved services to local, previously disadvantaged communities (Coovadia *et al* 2009), yet much remains wanting. As a result, community requests for service delivery are well founded. However, the results could also be suggesting a sense of low collective efficacy and agency at grassroots level. This was supported by the observation that only few community members were actively involved in HIV-related activities and that community involvement in general was reported to be low. The former apartheid government's active discouragement of social and political activism and development among blacks (Campbell & MacPhail 2002) might have accounted for some of the feeling of low efficacy and agency in the community. This study did not measure self-efficacy or collective efficacy as such, so the suggestion remains tentative. Since four out of ten of the respondents lived from government-provided grants, there might have been a sense of dependency yet also a sense of reliance on authorities.

The perceived low numbers of highly active community members suggest that the high activity level found at a group level was performed by certain small groups of active individuals. Some community members are more powerful, privileged, have the 'right' connections and networks, and are more aware of opportunities than others, enabling a higher degree of participation and ownership. These assumptions are supported by other findings from this project, as reported in the volume. It is also reflected in findings from a support initiative in Limpopo Province (Dageid & Duckert 2007), and points towards a sense of power and agency among some, but far from all, community members. Connected to this observation is the finding that those who claimed they were very likely to volunteer to join a group or organisation providing HIV/AIDS services in the community, were more likely to be young and having a tertiary education.

Conclusion: Suggested spaces for increased community response-ability

In community psychology, local contexts and local knowledge are the starting points for any meaningful action. The focus is on competence building and growth through active participation in community-based self-help or development initiatives. The ultimate goal for such health initiatives is to promote health and well-being through collective action for social change that promotes ownership and empowers communities (Prilleltensky & Nelson 2002).

There was no doubt a lot of activity at grassroots level in the community taking part in the study. Many individuals and groups were doing a tremendous job in mitigating the impacts of the HIV epidemic, despite difficult circumstances. Swidler (2006), in a study done in Botswana and Malawi, pointed out that formalising family and community care by creating HIV/AIDS care and support groups has proved rather successful. However, poor areas are often characterised by having more bonding groups than bridging groups (Ferlander 2007) and groups and associations are generally more geared to meeting immediate survival needs than working towards long-term community development. The provision of adequate resources, training and upgrading of skills, better coordination and cooperation among community-based groups, and improved relations between groups and organisations at bonding, bridging and linking levels within and outside of the community will no doubt increase community capacity.

Bridging and linking social capital represents a way of getting ahead. This requires a diverse and sufficient pool of resources, which is rarely found in communities such as the ones in which this study was conducted. The importance of focusing on improvement of socio-economic and structural conditions for disadvantaged communities cannot be overestimated. The collective life chances of community members must be addressed. What is needed to bring community HIV/AIDS work into a ‘get ahead’ mode, is a concerted effort from national leaders. Government should provide clear leadership in focusing on redistributive growth; in upgrading infrastructure, human resources, management and systems of health care; and in increasing accountability and transparency in decision-making processes (Abdool Karim *et al* 2009; Coovadia *et al* 2009).

According to Harpham (2008), collective action is only useful if a significant amount of social capital is available to the members of a community. Reimer *et al* (2008) argue that there is a weak association between the availability of social capital and the use of social capital; thus, increasing the availability of social capital does not necessarily lead to it being used. This indicates that without a proper presence and mix, social capital will neither emerge nor generate positive community change (Perkins *et al* 2002). In particular, further studies should address the bridging social capital of diverse groups and organisations at community level. People must be empowered to use services, and services must be tailored to meet the needs of the people. This requires information about the availability of services provided, as well as opportunities to access these.

Resourceful individuals are better able to generate and access various resources, including social capital. Improving the socio-economic status of individuals will broaden the individual space of response-ability and agency, which will most likely produce ripple effects at community level. However, there is a danger that social capital may in some instances be restricted or privileged to certain individuals and groups in a community, potentially creating power differentials and conflict. Any community-based capacity-building process should therefore address issues of power and power differentials, and lead to not only perceived, but also to actual control over events and outcomes, as well as to an understanding of decision-making processes that have an influence on peoples' lives (Zimmerman 2000).

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Chapter 3

Organisational challenges in creating care and support services for HIV-positive individuals in rural South Africa

Fanny Duckert & Staale Vaage

Introduction

In 2007, the South African government came up with a national and concrete strategic plan for fighting HIV/AIDS, namely the National Strategic Plan (NSP 2007–2011) (RSA DoH, 2007). The plan focuses on access to treatment and care for HIV-positive individuals and emphasises strong co-operation between governmental organisations and non-governmental organisations (NGOs). The NSP's main goal was to reduce the number of new HIV infections by 50% and to give access to an appropriate package of treatment, care and support to 80% of all people diagnosed with HIV. In 2008, a report analysing the consequences of implementing the plan was published (Walensky *et al* 2008). The study concluded that a rapid growth in antiretroviral (ARV) provision, as the NSP 2007–2011 suggested would reduce the number of AIDS-related deaths by 1.2 million in the five-year period. On the other hand, the study concluded that full implementation of the plan would mean enormous financial and human cost for the South African society (Walensky *et al* 2008).

A full implementation of the NSP seems unrealistic as the South African health system is suffering from a lack of human resources, poor admini-stration and expanding demands related to the HIV/AIDS crisis (Benatar 2004). Constraints for implementing the health plan are also related to the brain drain as thousands of educated healthcare personnel are leaving the country for the USA and European countries which offer better working conditions or higher salaries (Kober & Van Damme 2004). The healthcare personnel remaining in South Africa face the risk of increased workload and burnout as many of their colleagues go abroad. In addition, Achmat and Simcock (2007) have drawn attention to the problem that healthcare workers, who play an important role in the fight against AIDS and in the implementation of NSP, comprise one of the professions in South Africa which has the highest rates of HIV infection, with a prevalence rate of 35% among student nurses and 15.7% for healthcare workers in general.

As a result of the overwhelming pressure the AIDS crisis has placed on the formal healthcare system, the South African government released a national guideline for home-based care (HBC) and community-based care (CBC) in 2001 where reasons for promoting HBC/CBC were given:

- a shortage of hospital beds;
- an inadequate number of health professionals in the public sector;
- a lack of resources for treatment and drugs;
- the cost of institutional care; and
- crowded hospitals not able to give adequate care to people who are dying from terminal or long-term diseases (RSA DoH 2001).

For a successful implementation of HBC/CBC, the government guideline also highlighted the support of education programmes, social development, local government, traditional healers, faith-based organisations (FBOs), NGOs and community organisations.

South Africa's healthcare system

The introduction of HBC/CBC as a national healthcare strategy came in the challenging period of reconstruction and rebuilding in South African after apartheid (Benatar 2004). The new democratic South Africa inherited one of the least equal healthcare systems in the world, (Braa & Hedberg 2002), with 60% of the resources in private hands, serving only 20% of the population. During the apartheid years, South Africa built a high-technology, hospital-based health system, neglecting preventive medicine. All over the country, hospitals, rather than clinics, were accredited to administer ARV treatment. Bottlenecks developed almost immediately, and thousands of sick people were put on waiting lists. Thousands of others would never turn up at all. Their local clinics, often within walking distance, remained neglected, understaffed and without drugs (Steinberg 2008). This has created a heavy pressure on primary care, in addition to inadequate facilities and a shortage of personnel and basic medicines. Simultaneously, the reconstruction has reduced the availability of care in the tertiary sector, and hindered effective interactions between various health sectors (Benatar 2004).

The transformation of the healthcare system has particularly affected the interaction between governmental organisations and NGOs. The NGO sector became weaker after 1994 as personnel and skilled members found their way to the new state-run institutions. At the same time, the NGO sector lost much of its independence as the financial support from abroad, which previously had been distributed directly to private organisations during the apartheid period, were given to the South African government and channelled further through this (Habib 2005; Habib & Taylor 1999). In 1998, there were 98 920 civic organisations in South Africa and 53% of these were community-based organisations (CBOs) operating in poor and marginalised communities (Habib 2005). The more formal NGOs were in the minority even though they received the largest portion of aid support from the government and foreign donors. Another study (Ballard, Habib, Valodia & Zuern 2005) showed that the majority of CBOs, who worked in poor communities, were entirely dependent on a few key supporters to uphold the organisations. These studies reveal a gap between government and the majority of CBOs in South Africa.

Though HBC in marginalised communities is supported by government, most HBCs in South Africa are family members and volunteers who receive little or no support and who work under tough physical and psychological conditions (Akintola 2006; Campbell & Foulis 2004; Russel & Schreider 2000:1-41). Campbell and Foulis (2004) have highlighted three types of challenges connected with the use of HBC/CBC as a substitute or reinforcement of the formal healthcare system:

- challenges in terms of providing adequate and effective care;
- challenges in terms of providing HBCs, and their patients, with sufficient resources and equipment; and
- challenges in terms of empowerment and strengthening of communities to give them greater resilience against the HIV/AIDS epidemic and future epidemics.

Campbell and Foulis (2004) have recommended a better linkage between the formal health sector and informal health care to increase the flow of resources and information, to improve the condition for HBCs and to increase the quality of treatment, care and support for people living with HIV/AIDS (PLWHA) in South Africa.

Rowe, Makhubele, Hargreaves, Porter, Hausler and Pronyk (2005) outlined a series of criteria for how to establish a good service with maximum adherence to treatment. Among these are the need for visible leadership and clear policy guidelines, combined with adequate training, supervision and support of health providers. There is also a need to create a welcoming clinic environment for HIV-positive patients, to maintain confidentiality, to encourage staff to be friendly and supportive, and to streamline services to avoid long waits. In addition, patients need to come to terms with their HIV status before initiating medical interventions requiring close supervision, and enrolment criteria should be initiated before commencement of complex care regimes. Health workers must be aware of how to facilitate access to existing social security grants while transport costs must be covered, and user fees for HIV patients be removed. Patients need adequate nutritional support and the provision of dietary supplements. HIV patients on intensive medical regimens should be linked to community tracing or treatment support programmes and encouraged to disclose to family and close friends, and to attend support groups. Finally, traditional healers must be incorporated into clinic services.

This chapter reports findings from a study that investigated the extent to which the requirements for good HIV treatment and a care and support programme are achieved in a semi-rural setting in South Africa.

Methodology

A qualitative method was used in order to get an in-depth and first-hand experience of the research topic. The National Strategic Plan (NSP 2007-2011) focuses on improved access to treatment and care for PLWHA, and emphasises strong cooperation between government organisations and NGOs. The research team wanted to learn more about the current situation for HIV/AIDS-affected communities and health workers who were trying to implement the plan.

We focused on the following research questions:

- In what ways do formal and informal organisations provide treatment, care and support to PLWHA in the community?
- How do the formal and informal organisations cooperate and coordinate their work?
- To what degree do organisations working in the community cooperate and communicate with formal structures of government?
- What are the main constraints for providing efficient treatment, care and support for PLWHA in the community?

Semi-structured interviews were conducted over a period of four weeks in 2009 by the second author. Prior to the conduct of the interviews, he had visited the community for two months as part of the research team in order to get accustomed to the area, the culture and the atmosphere, and to map out which organisations were working with HIV/AIDS-infected and -affected people in the community.

The mapping process was conducted in three stages:

1. It was observed which organisations were included in other parts of the larger project, as described in Chapter 1 in this volume, and the type of tasks these organisations did in connection with HIV/AIDS work.
2. The internet was used to search for organisations in the area that provide treatment, care or support for HIV/AIDS-affected people. It turned out that all the organisations found on the internet were organisations with whom the team had already been in contact or whom they had noticed during the observation period.
3. Snowball sampling: The organisations were interviewed and asked about other organisations they were cooperating with, or knew in the area. Three organisations were recruited by the snowball sampling method. A total of seven organisations were included in the study. The organisations were chosen because they were administering ARVs, provided medical care, and/or provided care and support for patients' physical symptoms.

The seven organisations interviewed:

- Organisation 1: Formal. ***The health workers***. Home-based care group in the community
- Organisation 2: Formal. ***The clinic*** in the community
- Organisation 3: Formal. ***The district hospital*** outside the community
- Organisation 4: Informal. ***The volunteers*:** Volunteer home-based care group in the community
- Organisation 5: Informal. ***Church group*** outside the community
- Organisation 6: Informal. ***Community group*** inside the community
- Organisation 7: Informal. Group of ***traditional healers*** in the community

The leader of each of the organisations was interviewed and for the CBOs, the leaders and counsellors were interviewed separately. The interviews with traditional healers were conducted with both the leader and the six members simultaneously.

The respondents decided on the time and location for the interviews to take place and the language in which it would be conducted. Seven of the eight interviews were conducted at the organisations' facilities. The remaining interview was conducted at the home of the respondent (the leader of the health workers). Six of the interviews were conducted in English. The interviews with the traditional healers and the leader of the health workers were conducted in isiZulu; the questions and answers were translated by a field-assistant in the research team who speaks isiZulu as his first language.

Six of the leaders and the counsellor were women and one was male (the leader of the district hospital). The range of the duration of the interviews was 30 minutes to one hour with an average of 45 minutes. The interviews were audio recorded and transcribed by the interviewer. The two interviews conducted in isiZulu were transcribed by the interviewer using the English translations. All the interviews were phonetically transcribed from the audio recorder.

Findings

Formal healthcare structures

Formal health care was defined as healthcare organisations governed and funded by government and working in accordance with the national health-care plans. Three of these organisations were found in the area:

- *The district hospital* was the biggest central health unit in the area, serving approximately 750 000 people. Patients came from the village and surrounding areas. According to the statistics, one third of the population– approximately 250 000 people – were HIV positive. An estimated 10% of these, approximately 25 000 people, had advanced HIV infections needing medical treatment. The head of the hospital informed us that approximately 80% of the patients sought medical help due to HIV/AIDS-related problems. The hospital had 200 beds and was treating more or less 4 000 HIV-positive patients with ARVs, which amounted to approximately 20% of the HIV-positive individuals needing treatment in the area surrounding the community. In addition, more or less 3 000 HIV-positive patients were receiving treatment from other government facilities, according to the hospital leader. Together, this brings the number of PLWHA in the area, who receive ARV treatment, close to the national estimate of 28% (UNAIDS/WHO 2008).
- *The clinic* was the only source of formal medical care inside the community. The clinic was operating without doctors or pharmacies. There were 13 staff members working in the clinic and only five of them were professional nurses. According to the leader, the clinic was the first stop for medical help for close to 10 000 people in the area, and served an average of 2 200 patients every month. When asked what kind of work they did, the clinic leader explained that they were mainly treating chronic illnesses and HIV-positive patients not yet ready for ARVs, or who had opportunistic infections. The clinic nurses treated patients with both physical and psychological problems, but referred more serious conditions to the nearest hospitals. The clinic conducts HIV testing and CD4

counts. However, in order for HIV-positive patients to start on an ARV programme, they have to travel outside the community to surrounding hospitals or initiation sites. Approximately 90 patients who were already enrolled in an ARV programme received their ARVs from the clinic.

- *The health workers* consisted of 28 health workers stationed in the community conducting HBC. They work for and receive their salaries from government. However, the leader informed us that in reality they had minimal contact with government and were mainly connected with and reporting to the clinic. Nevertheless, they were defined as a formal group because of their formal connections with government, and their close cooperation with the government clinic. The group was started in 1981 to help poor people in the community suffering from malnutrition and diarrhoea. The leader stated that their work at the time of the study mainly consisted of caring for people who were suffering from HIV/AIDS and tuberculosis (TB).

Informal health groups

We identified three organisations inside, and one organisation outside the community which are defined as informal groups because they were working independently from the formal healthcare organisations and did not receive any funding from the government.

- *The volunteers* were a group of 30 members. The organisation was started in 1996 as an initiative from the leader who wanted to help her community. They had been working without remuneration, but since 2007, government has been providing a monthly compensation of 500 ZAR (approximately US$75). According to the leader, the members of the volunteer group were conducting house visits in the community and caring for people who were sick, especially people who were sick from HIV/AIDS. In addition, they often helped elderly people who were taking care of orphans. When asked how many people they were caring for the leader told us that they had visited 586 patients in the month preceding the study. Divided by 30 that would be approximately 20 patients per home-based carer each month. The patients were spread out over a fairly big area, the landscape was hilly and rocky, and the volunteers had to do their home visits on foot because of the lack of roads and transport vehicles.
- *The community group* was started in 1994 as an outreach programme from an FBO outside the community. They had started out as a soup kitchen feeding the hungry and poor in the community, until the organisation was formalised in 2000. According to the leader, they had

then realised that there were other challenges in the community that needed attention. One of the problems was that HIV-positive people and families with orphans, who qualified to receive grants, did not know how to apply for such grants or which procedures to follow. The CBO counselled PLWHA, provided them with information on testing and treatment, and helped them to apply for and receive their grants. The CBO also aided orphans who had lost their parents due to HIV/AIDS, and provided them with school supplies. In addition, they supplied HIV-positive patients with food parcels and taught them how to grow their own vegetables. The majority of people who were coming to the organisation did so in connection with HIV/AIDS.

- *The church group* had started as a volunteer FBO in 1990, and had been formalised in 1996. The leader's vision was to care for the members of the HIV/AIDS community in a way that would empower and uplift them rather than moralise. The FBO ran a centre outside the community where they provided information and education, testing, CD4 counts and from where they referred HIV-positive patients to ARV sites. They also ran an HBC group in the surrounding area, and a 23-bed hospice that had opened in 2008. Five nurses and 41 health workers cared for AIDS-sick patients from the area. In addition, approximately 50 volunteers were working for the organisation. The leader stated that independence and sustainability were very important for the organisation. They received income from a garden project, a handicraft project, and from private donors.
- *The traditional healers* were a group of traditional South African healers (*sangomas*) who provided traditional medicine to the community, as well as giving care and support to the ill. The South African government had focused on traditional healers in the fight against HIV/AIDS because of the important role they play in the society. The traditional healers used their traditional healing skills to treat physical and psychological conditions, but they also referred patients with HIV symptoms or other serious conditions to the nearest clinics. According to the leader, they grew herbs used for traditional medicine in the community, but in terms of more formal healthcare equipment, they lacked the most basic necessities such as gloves and bandages.

Three of the seven organisations were licensed to provide formal medical care as well as other forms of health care, while four of the organisations mainly focused on providing care and support.

All the leaders of the informal organisations reported that the wish to help the community had been the main motivation behind building their organisations. The members of these groups had different backgrounds and various levels of education ranging from qualified nurses and administrative leaders to volunteers with no formal education. None of the members received funding from government, except the volunteers who were scheduled to receive a monthly stipend of 500 ZAR per member. Members of the other organisations were either working as unpaid volunteers or they received salaries funded by private donors or private income projects.

Cooperation and coordination between the community-based organisations

Cooperation

Upon asking the organisations about the kind of groups they were working within the community, most organisations mentioned at least two or three of the other organisations in this study. The clinic leader stated that they were cooperating with both the volunteers and the health workers, and were meeting with them monthly at the clinic to share problems and ideas. The clinic also cooperated with and referred patients to the district hospital. The community group assisted them, and helped patients by way of feeding schemes. There was a high degree of poverty and malnutrition in the community and the community group provided people with food and put them on feeding schemes, especially sick people who needed a healthy diet.

> *There is also ... (Community Group). They also provide HIV-positive people, though they don`t know if they are HIV positive. They look at the weight of the person. They provide them with food. So they help us with bedding, because sometimes we do run short of beds, porridges ...* (Leader, Clinic)

In addition to cooperating with the clinic, the leader of the community group reported that nurses from the church group outside the area were coming to the community group to assist them with HIV testing. The leader of the health workers mentioned the community group inside the area and the clinic as two of the organisations they were cooperating closest with. The leader of the community group highlighted cooperation with the church group as a way to empower the community and to save time and resources connected to their HBC work:

> *So, the last years or so we had quite a good relationship with the social workers [the health workers], where we can finally see that … we do know all the families here … they can just come to us and say: "Where is*

> *this family?" We can show them, we can tell them. Everything we know that can help them with their investigation … sometimes they come down here, they only come once a month and they don't know where the families are or … they are wasting a lot of their time. So now they are working with us.* (Leader, Community Group)

The clinic leader reported that she got help from the volunteers to trace patients who had missed appointments at the clinic. The community group highlighted their cooperation and communication with the health workers as a tool to make the HBC work in the community more efficient. According to the organisations, it seemed that even the organisations that were quite similar and which provided the same kind of care and support to the community, like the community group/church group and the HBC groups, were cooperating and supporting each other. The leader of the community group highlighted cooperation among the organisations as an important factor to avoid duplication of work.

> *And there are different resources. So now there are other organisations with food, so what is important is that we are not all doing the same. Like if that family is getting food from them they shouldn't be getting from us. Or, at least, it they are getting from us, then we should know what the others are doing and that's why the networking it is quite important.* (Leader, Community Group)

Even the clinic and the traditional healers seemed to have close cooperation despite representing two very different healing paradigms. The traditional healers were referring patients to the clinics, and the leader of the clinic reported that she was working with the traditional healers to gain their trust.

> *Yes. I even attend their meetings, because I should gain their confidence. I even attend their meetings, if they do have meetings. Otherwise, if I don't attend, there would be friction.* (Leader, Clinic)

Constraints for cooperation in the community

The organisations were mainly focusing on positive interactions with one another. Only a few of the organisations mentioned problems related to cooperation and communication. For example, the leader of the community group and the leader of the district hospital identified constraints as competition for resources, and misunderstandings in the community related to the kind of role the various organisations played and the kind of resources they provided.

> *Yes, I think there is a bit of competition out there. With the community they kind of compare, "I go to ... (Community Group) for that, but I go to them for that" or "they gave me this but they didn't". I suppose it is just lack of understanding of a community. Sometimes a community expects something and then we can't provide it. Or they can say: "why did they get it and not us?" We don't have never-ending resources. So, yes, there are those challenges.* (Leader, Community Group)

The district hospital leader also described how the limited resources facilitate competition instead of cooperation among the organisations:

> *Yes, and remember at the end of the day it is a dog-eat-dog world out there and there is a final amount of resources and we are all scrambling for a piece of the pie.* (Leader, District Hospital)

According to the leader of the district hospital, there seemed to be a general lack of strategic response to the AIDS crisis in the province. The lack of coordination and the lack of sustainability in the provision of treatment, care and support in the communities were the biggest obstacles for efficient cooperation among the organisations.

> *There are a lot of structures that are supposed to be there: clinic, committees and community health forums, and all those sort of things that just are not. And even when they do get created they are very fluent. Because different people see them as opportunities for political power and the community structures are continuously changing. So you never really know who you are dealing with, what sort of mandate they got and if they have personal access to grants or if they are genuinely interested in health? It is a very tough place to work in community structures in South Africa.* (Leader, District Hospital)

The leader of the community group also highlighted the lack of common criteria for community health care work. Because of the lack of a co-ordination strategy in the community, all the organisations had to meet regularly in order to synchronise their work. But there were not enough time and resources to do this.

> *Each one has their own criteria. So we might decide that this granny needs … but another organisation might decide that that granny doesn't need. So it's just depending on your criteria and your resources at the time and you can't actually have a meeting every time, with every organisation to make a decision.* (Leader, Community Group)

Cooperation between community organisations and government

Provision of care and support

The cooperation between organisations working in the community, both informal and formal, was generally reported as good. However, none of the informal organisations providing care and support reported working closely with government. When interviewing the organisations, many of them were focusing on the lack of coordination and communication between government and the community. Some reported that their relationship with government was very unreliable, and that they received some sort of support one year, but not the next year, etc. Among the community organisations there was a strong wish to have more reliable and reciprocal connections with the government.

> *Before we got it. Department of Health they gave us the home-based care, life skills, counselling. Now this year: No money from the Department of Health. So there is no training.* (Leader, Volunteers)

The district hospital leader also emphasised the need for more stability and better coordination between government and different community organisations.

> *There are a lot of people out there that do need food. But you can't do it the way the government does it. They got money, so "I give you food now reliably for three or four months" and then: "I don't give it to you for six months." Then you can just as well not give it.* (Leader, District Hospital)

All the informal organisations in the area cooperated and reported to the government-funded clinic, but this cooperation seemed to have been created by initiatives inside the community in order to fill gaps in healthcare provision.

> *It is better than it was, but there are always gaps, you know. If they were doing their job (government) then we wouldn't have … we wouldn't be needed. But you know the extent of the epidemic is so large …* (Leader, Church Group)

Both the councillor of community group and the leader of the health workers expressed the wish that government could come to the area in order to see with their own eyes the extent of the epidemic and the conditions under which the health workers were operating. According to the two organisations, government needed to have a bottom-up approach and work closer with the community to grasp what had to be done and what needs had to be addressed.

> *Yes if the government can come and visit the ... (Community Group), like you are here today, then say: "Take me to one of the families that are struggling." Then for you to visit that family and see exactly what is happening on ground. And so the government could take the steps. Because if I am reporting it is not like when I am at that family facing the sick people laying down with the old granny, maybe the mother with a four-year-old child sitting next to the mother who is between dead and alive ...* (Councillor, Community Group)

However, both the community group and the church group reported that the lack of cooperation with government also partly stemmed from a wish to remain independent, in combination with the fact that neither did trust the government as a sustainable funder. Even the health workers, who were working in the community, and who were funded by government, reported that they had little connection with government.

> *We are cooperating with the government and we get information from the clinic, but there is no information given in regards to HIV. Government is going to put out buses on the World AIDS day the 1st of December, but they are not going to address the issue of AIDS. It is only on that particular day. Otherwise there is no intervention.* (Leader, health workers)

Provision of ARV treatment

When asking the organisations in our study what kind of changes or formal interventions have been most important for PLWHA in the community, a substantial number of them focused on the provision of ARVs. The clinic in the community could not initiate ARV treatment, and only 90 patients received their ARVs through the clinic. Yet, the clinic leader still highlighted the positive effects of ARVs in the area. Before ARVs became available, there were only a few HIV-positive people coming to the clinic, and the nurses were uncertain on how to consult and support patients who tested positive.

> *Those years they were very difficult. And by that time there were no ARVs except in private organisations. So it was just like telling a person ... giving a person a death sentence if you are saying a person is HIV positive. You don't know how to help him or her.* (Leader, Clinic)

Many of the organisations mentioned how the introduction of ARVs had made it easier for people to come forward and disclose because there was treatment available.

> *Well, it has brought hope into this situation, in some cases it is starting to reduce stigma. I am not so sure about behaviour change. Now, in a consultation a patient is more likely to say up-front: "I am HIV positive, I know, and my last CD4 count was 350 or ... " So you are getting more of those sorts of consultations where people are more open about it.* (Leader, District Hospital)

However the district hospital and the church group also highlighted the structural challenges connected to implementing the ARV roll-outs and how the ARVs had distorted and extended the pressure on the health sector.

> *Well there is treatment available now and the AIDS movements. It is improving. It is more ARV roll-out. The roll-out in some cases is becoming more efficient. In some cases they just become overloaded and they can't cope. So their quality of care is going down. It just depends.* (Leader, Church Group)

> *It has brought huge challenges in terms of ... it is a fairly technical intervention and it has distorted healthcare funding, and it has distorted this hospital's operation.* (Leader, District hospital)

The general impression was that government administrated ARV roll-outs, which had brought hope in the situation for HIV-positive people in the community, and had made people come forward for testing because they knew that treatment was available. While some organisations mentioned in-creased workload as a negative effect of the ARV intervention, the hospital also focused on how the introduction of ARV had freed resources in the hospitals.

> *The one advantage it has given is that there are people out there that would have been using a big chunk of other resources and then dying who are now well and out of the system.* (Leader, District hospital)

The constraints for efficient health care in the community

All the organisations reported serious challenges and constraints making their work difficult.

Lack of human resources

The problem most often mentioned by the organisations was lack of human resources to provide care and support, and to administer more extensive ARV roll-outs. Especially acute was the need for HBC and support in the community.

> *There are just not enough hospital beds in South Africa for the number of sick patients that are coming. So that is a reality. So those patients have to be attended to by home-based carers or by their families with no support from home-based carers ...* (Leader, District Hospital)

According to the leader of the volunteers, they were 30 members caring for approximately 586 patients in the community. When the 28 members of the church croup were added, there were a total of 58 HBCs to care for more than 500 people in a fairly big area.

> *We need support because the community they need us. They need us too much. Even the home-based carers that did not come. They phone to me: "I didn't see your lady today! Where is she?" I must phone to her, go to that house. They need you.* (Leader, Volunteers)

The district hospital also referred to the lack of human resources in the South African health system as the main barrier for implementing the NSP and its intention of providing 80% of all HIV-positive people access to treatment, care and support. Although less than one third of all PLWHA who needed medical treatment in the area had access to ARVs, the district hospital leader reported that this was the maximum number of patients that the hospital was capable of attending to with its current staff and resources.

> *So we are all overwhelmed! And there is no way, if you look at the resources available to the sub-district at the moment and the personnel, that we can cope with the theoretical number of patients that need treatment. It is sad, but in some ways it is actually good that they are not all coming knocking at our door. Cause we wouldn't be able to attend to them.* (Leader, District Hospital)

The church group was also stating the lack of staff as a barrier for implementing the NSP and that the pressure on the understaffed healthcare system resulted in burnouts and brain drain. The leader of the church group reported that an ARV roll-out in the area had raised the number of patients from 100 to 6 000 patients, without an increase in the number of staff.

> *... but that is the biggest problem, they got this lovely plan but they have not increased staff. And so that is why it is not working.* (Leader, the Church Group)

According to the clinic leader, they did not only need more staff, but also qualified health personnel to treat serious conditions and to initiate ARV treatment.

> *... because we are not accredited to initiate, so even in other clinics they refer to initiative sides, the accredited sides. Because it should be a doctor, pharmacists, occupational therapists or social workers so here we don't have those people.* (Leader, Clinic)

Lack of material resources

The lack of human resources was part of the general lack of material resources in the community. Most organisations referred to the lack of service delivery as a major barrier to providing treatment, care and support.

> *You may be willing to help, but the main problem is that we don't have the necessary resources to do our support to this people. So if it's beyond our power we don't do anything.* (Leader, Traditional Healers)

When asked what kind of resources they needed to be able to carry out their work, both the volunteers and the traditional healers stated the need for a home or a unit facility where they could provide care to the sick in the community.

> *So let's say ... because we haven't got resources, so they need resources because we want to take them to stay at our place, in the morning, afternoon we must take them to their house. Now we haven't got anything for the time being. We need help.* (Volunteers)

Both the community group, who had received help from private donors in the area to build a house, and the church group, who had built a respite unit in 2008 focused on how the new facilities improved the quality of their health care significantly. The leader of the community group reported that they had realised the need for treatment and care in a communal setting when they saw more and more people were left in their houses, dying alone and not cared for because other family members were dead. In addition, they saw that children were taken out of school to care for sick family members.

> *So admitting people into a controlled environment where you are giving them love. You are giving them a bed, you are giving them three meals a*

> *day and giving them whatever medicine they need. They take it regularly. It is incredible. What happened is: In that first year; from February to December, 53 patients that were actually admitted to die got up and went home and they are still doing well. What we realised then is that there is a place for respite care.* (Leader, Church Group)

The councillor of the community group and the leader of the district hospital also highlighted the need for restructuring the clinic in the community, and for giving it more resources in order to help the community.

> *The first thing I would make sure … because it is not easy to build a hospital. I can make sure that the clinic has all the things that are needed by the community.* (Councillor, Community Group)

> *… the district hospital should also be a resource for the district. But the people should be treated closer to their homes. In other words there is no reason ... (the district hospital) should be treating all 25 000 people. There should be government ARV initiation sites started throughout our sub-district ...* (Leader, District Hospital)

Lack of access to transport

Transportation was a big problem in the community as a result of inefficient roads, a steep and hilly landscape, and long distances to surrounding hospitals and clinics. The problem was also connected to a lack of public transport and a lack of money to pay for the mini-taxis, which was the only way of transport for the majority of people living in the community.

> *We got big challenges in the communities. Because the others are too far. There are no roads; we are just going these small places. So it is too much of a challenge.* (Leader, Volunteers)

> *Remember the trip to a hospital for some people is a big issue; it costs them a lot of money. And some might prefer to die at home actually. If some of the issues around stigma and other things can be addressed or can be looked after.* (Leader, District Hospital)

The community group reported that if somebody became ill and that person was not able to travel to hospital it could take days before an ambulance arrived. Also, that they had started giving HIV-positive people money for transport because they had experienced that people had been defaulting treatment because of a lack of money to pay for the mini-taxis.

> *... we then get them into ARVs and they do very well. Their CD4 then gets over 200 – the government takes their disability grant away. Because they are well now, they can work. But they are unemployed and they can't get work. So what happens is without that thousand rand they have no money to get to clinic. They have no bus fee. So they default on treatment. They end up back in the unit. They develop resistance and they die. And that we are seeing a lot of.* (Leader, FBO)

Stigma

Most of the organisations focused on the stigma and shame connected to disclosure as a barrier to accessing treatment, care and support for PLWHA. Even after education programmes, awareness campaigns and the introduction of ARVs, stigma remained a major problem in the community.

> *Well it seems like the clinic is supposed to be the first step, but a lot of people would miss that step, because of community, I think. Because it is a small community. People that live here they have lived here their whole life and they all know each other and just about everyone is related. And I think the stigma ... and maybe there has been some gossip or whatever. So some people would prefer to go out for an initial test.* (Leader, Community Group)

On the other hand, the clinic argued that stigma was a fading problem and that more HIV-positive persons would come to the clinic if only the ARVs were accessible.

> *The challenges are those who still fear to go forward. Even if they suspect they might ... there are those who still fear. But with persistent consoling and telling them that there is ARV that does work. You better test early. Because if you start ARV when your CD4 is very low you are likely to become very sick.* (Leader, Clinic)

The community organisations that provided care and support to patients in their homes were more concerned about stigma as a serious problem in the community than the leader of the clinic. The health workers reported that stigma was a serious problem for them because their patients did not want to reveal what kind of condition they were suffering from. In addition, many patients were hidden in their houses because their families did not want to be associated with having an AIDS-sick person in the house.

> *It is difficult with AIDS because many people do not like to disclose their status. So the only way you get treated, get medical attention, is when*

> *you disclose. The ... (health workers) take you to the clinic and they check your CD4 counts. In many cases, when they find your status it is below 200 because many people do not disclose their status. They keep quiet and by the time when they decide to disclose their CD4 counts have already dropped.* (Leader, Health Workers)

When HIV-positive individuals finally were coming for treatment either on their own initiative or with the help of the HBCs or family, it was often too late to start efficient treatment. This point was also mentioned by the district hospital leader.

> *Although I am still concerned about stigma and all the barriers for people to get care because we still get people who present CD4 counts that are less than 50. They are coming very late in the disease. And there are multiple reasons for that, but it is concerning.* (Leader, District Hospital)

Summing up

The overall results in our study indicated a fundamental lack of staff, qualified health personnel and resources needed for implementing the NSP and to reach the targets as to treatment, care and support in the community. The organisations interviewed, highlighted the need for upgrading the infrastructures in the community and for improving the quality of treatment for PLWHA. Building more healthcare units and providing the clinic with staff and resources were some of the suggestions to achieve this.

Transport, money constraints, and a lack of staff at hospitals and clinics were perceived as the major constraints for receiving efficient treatment, care and support outside the community. Lack of resources and stigma were considered the most serious challenges for providing HIV-positive people with treatment, care and support within the community. Another challenge was a lack of coordination and role confusion between the various organisations. However, the level of community participation and the cooperation between organisations seemed to be high and were generally reported as good. Cooperation and communication between the community and government were generally reported as poor or non-existing, with the exception of cooperation with the government-funded clinic and the community health workers.

Discussion

Participation, volunteering and health care in the community

In our study, the various CBOs were all volunteers or informal groups who worked with little tangible support from government. This is similar to the findings in a study by Russel and Schreider (2000) who analysed 20 different communities and support projects in South Africa. They also found that the majority of the activities were run with little or no external support. The most common tasks for the community groups were funding and support, facilitation of welfare services, education, counselling, income generation and HBC. Such tasks resemble what we found in our study. This congruence indicates that the results found in our research area that relate to community participation and healthcare structure are similar to many poor and marginalised communities in South Africa.

It has been suggested that South Africa's inefficient reaction to the HIV crisis and the slow roll-out of ARVs in the country is a result of the existing burden on the health structures and the lack of fiscal resources available (Achmat & Simcock 2007; Benatar 2004). According to this view, a government focus on HBC and CBC in poor and marginalised communities is the best strategy to cope with the HIV/AIDS epidemic. The use of HBC allows patients to be treated in their homes surrounded by family and loved ones, and frees resources for transport and hospital admissions. Many of the organisations interviewed in our study reported a need for HBC, and underlined the important role the HBCs played in providing the sick with care and support in the community. On the other hand, the HBCs reported that they needed resources to carry out their work, and that they were exhausted from the heavy workloads and the long distances they had to walk. Akintola (2006) has also questioned government's hypothesis about HBC being more cost-effective and cheaper than hospitalisation.

The majority of the organisations in our study underlined the need for a house or a unit where they could treat their patients. Chopra *et al* (2009) recommend a stronger focus on district models of care, to bring care closer to the communities, and a more equal distribution of resources between primary community care and tertiary-level hospital care. Achmat and Simcock (2007) have also suggested that community care workers must be given more resources and training to ensure higher levels of specialisation and responsibility at the level of primary care. Increased mobilisation of communities and the scale-up of mid-level workers could be one way to solve the bottlenecks in the health system and increase healthcare provision in poor and marginalised communities according to Chopra *et al* (2009).

A healthcare unit would solve the problems connected with transport and long distances, and would assure supervision and care of the patients at all times. According to the leader of the church group, this strategy had showed great results in their organisation, and she reported that many patients who had been admitted to die actually had recovered and gone home. She highlighted the need of 'home-based care in a controlled setting' because ARVs were becoming increasingly more accessible at the same time as there were fewer people to care for the sick in their houses. The combination of formal treatment and HBC in a controlled setting is in line with successful results in projects by Medecins Sans Frontieres (MSF) in rural areas of the Western and Eastern Cape and in Khayelitsha near Cape Town (Achmat & Simcock 2007; Coetzee, Boulle, Hildebrand, Asselman, Van Cutsem & Goemaere 2004).

Cooperation and bridging in the community

All the organisations located in the community reported that they were cooperating and communicating relatively well. However, they were lacking resources to work efficiently and to coordinate their work. This indicated that high levels of participation and volunteering are not enough to provide efficient care and support if the organisations involved are not supported from the outside, in particular by government. This is in line with Foley and Edwards (1999) who argue that social capital may be defined as access plus resources, and that social capital in a community has to be built both 'internally' through increased participation and volunteering, as well as 'externally' through resources, support and coordination of healthcare programmes.

According to our results, the cooperation between organisations seemed to follow a horizontal level of groups and people who were similar in background and status, while there seemed to be a lack of cooperation between groups and people across vertical structures in the healthcare system. According to the social capital theory, the results indicate a high level of bridging in the community and a low level of linking between groups that were dissimilar in background and status (Derose & Varda 2009). In congruence with the social capital theory, the high level of bridging seemed to contribute positively to the level of health care access in the community (Derose & Varda 2009). However, the problems such as a lack of resources and coordination, as reported by the community group and the district hospital leader, decreased the level of bridging in the community. Whether the community group and the district hospital were the only organisations that experienced difficulties related to cooperation and communication or whether the other organisations were unwilling to discuss this issue with an outsider, is an open question.

Coordination of the community work was often found to be a problem leading to a lack of standardisation, monitoring and possible duplication of work and activities in a majority of the 20 communities that Russel and Schreider (2000) investigated. In this study, we found that the provision of support and stipends from government varied a great deal between the various volunteer groups. The struggle for resources and the potential conflicts, envy and misunderstanding created because of this were also something that was highlighted by several of the organisations in our study.

Cooperation and linking between community and governmental health care

The results of our study indicate a lack of communication and cooperation between the community and government institutions. Many of the organisations interviewed reported that their distant or irregular relationship with government was an obstacle to efficient work in the village. According to the social capital theory, the lack of cooperation across different horizontal structures in a society can hinder efficient health care and decrease social capital in a community (Putnam 1995).

Government support and increased responsibility for informal organisations have been reported to be factors in Uganda's successful HIV/AIDS policy (Parkhurst & Lush 2004). These authors argue that Uganda and South Africa chose different strategies in relation to their use of NGOs and CBOs (Parkhurst & Lush 2004). Uganda's success in reducing its HIV prevalence was related to close cooperation with NGOs, FBOs, donors and self-help groups in the country. Since Uganda lacked a strong management and a national bureaucracy, much of the responsibility for HIV/AIDS work was transferred to NGOs and local groups. These groups received economic and political support from the government but were otherwise working independently. The AIDS policy in South Africa however had little connection with the NGOs and CBOs in the country. The AIDS interventions were based on the old health systems were doctors and hospitals were the focus areas. The system weakened the autonomy and influence of clinics, NGOs, nurses and other health personnel, at the same time as the growing AIDS crisis increased the need for a broader response. The pressure on hospitals and expertise created bottlenecks in the South African healthcare system as the numbers of sick people increased (Benatar 2004; Schneider & Stein 2001).

The lack of hospital beds, health personnel and ARV treatment, and the gap in the healthcare system as a result of this, was also something that was highlighted by both the organisations in our study, as well as the Department of Health (RSA DoH 2001). The high level of participation and volunteering in the interviewed organisations seemed to fill some of the gaps, but the organisations still reported a need for human resources and qualified healthcare personnel, especially to treat serious conditions and initiate ARV treatment in the community. For instance, the community clinic reported that they were unable to initiate ARV treatment because the clinic lacked doctors, pharmacists, occupational therapists and social workers.

The projects by MSF in Lusikisiki (a poor town in the Eastern Cape) have demonstrated greater access and adherence in primary care clinics than in secondary care clinics, according to Achmat and Simcock (2007). This was related to the lower levels of cost and travel time for patients using the primary care facilities. Similar factors had been highlighted in an earlier study of the MSF project in Khayelitsha where Coetzee *et al* (2004) concluded that the excellent adherence rate found in the study was related to services being situated close to patients' homes and family environment. They concluded that first-hand knowledge of patients is especially important, due to the complex nature of ARV treatment. As a consequence, they recommended that small health facilities should be spread out in the districts with a manageable number of patients, rather than a few centralised, big initiative sites and hospitals where patients disappeared in the system. The MSF projects demonstrated no differences in treatment provision and adherence rates in the clinics mainly staffed by nurses compared to hospitals or clinics staffed by doctors. All the professional nurses in Lusikisiki were trained to initiate and monitor ARV treatment, and community-based health workers were used as HIV/AIDS educators and adherence counsellors (Achmat & Simcock 2007).

The clinic leader in our study met with the HBC groups once a month and used them for tracing patients who were not coming to the clinic. If the clinics increased their ARV stock, and the nurses were given education and permission to initiate ARV treatment, the HBCs could take the ARVs with them during house visits to patients who were either too sick to come to the clinic or who were lacking money for transport. In addition, this could give HIV-positive individuals who were afraid of the stigma connected with going to the clinic an opportunity to receive ARVs in their homes.

The success in Lusikisiki and Khayelitsha in giving nurses increased responsibility in initiating ARV treatment in primary care clinics, and the high access and adherences rates after using community health workers as councillors, demonstrate that it is possible to empower a community to tackle the challenges connected to HIV/AIDS, despite the lack of professional health-care workers and limited access to transport.

The results of the MSF projects in Lusikisiki and Khayelitsha are in line with the social capital theory, and the postulate that increased community participation, bridging and linking will lead to higher levels of health care and health in a community. On the other hand, the results could also be read as an indication that community participation would need to go hand in hand with external support and coordinative strategies (bridging and linking mechanisms) to empower the community.

Constraints for efficient health care in the community

In our study, the four major constraints for efficient health care in the community were a lack of human resources, a lack of material resources, limited access to transport, and stigma. Most of the problems in providing efficient services to PLWHA in the community were connected with the lack of staff and resources for providing care and support, and the lack of qualified health personnel to initiate and provide ARV treatment. This is in line with a study by Kober & Van Damme (2004), who analysed access to ARVs in Southern Africa (Malawi, Mozambique, Swaziland and South Africa). This study concluded that human resources were the single most important factor for successful implementation of the countries' HIV/AIDS plans (Kober & Van Damme 2004). A problem often discussed in relation to extended ARV roll-out in South Africa is the challenge of distributing medicines in poor and marginalised communities with little infrastructure. If the HIV prevalence in the community where our study took place was the same as the provincial average, then 2 000 of the 10 000 inhabitants were HIV positive and in need of treatment, care and support at some stage. As only 90 patients received ARV treatment from the clinic, the rest would have to travel long distances to the nearest hospital or other initiative sites in order to get treatment. A wider distribution of ARVs to local sites would probably solve the transport problems reported on in our study. The leader of the FBO reported that many of the patients, who they had successfully managed to admit to a treatment programme, later developed resistance and died because of a lack of money to go for their treatment appointments. The same has been found in other studies (Campbell, Nair, Maimane & Sibiya2005).

Achmat and Simcock (2007) argued that extended ARV roll-outs will be cost-effective because persons who otherwise would have stayed sick for a long period, and who would have been a burden for families and health facilities, will get an opportunity to live a relatively long and healthy life.

Especially important is the consequent decrease in the number of orphaned children. This point was also stressed by the district hospital leader, when he highlighted the need for more ARV initiative sites spread around the district to relieve the pressure put on the district hospital. Studies from Brazil, which in 1996 already started producing cheap generics of ARVs and granted free treatment to PLWHA in that country, are supporting the assumption that extended ARV roll-outs will be cost-effective (Achmat & Simcock 2007).

Our results unfortunately indicated that stigma was still a major problem in the community. Even if the clinic leader reported stigma to be a fading problem, the HBC groups perceived stigma to be a major problem in the community, and that many of their patients still refused to disclose their status and remained hidden in their houses. This was also found in a similar study in KwaZulu-Natal where Campbell *et al* (2005) conducted 60 in-depth interviews and focus group interviews with different local residents who were either HIV positive or doing healthcare work. As in our study, they found stigma to be a major constraint for receiving treatment and care. Many people would not talk openly about their status and health workers were unaware of the conditions patients were suffering from, as was also reported in our study.

However, a substantial number of the organisations interviewed in our study were reporting on how ARVs had been an important tool in the fight against stigma. According to the clinic leader, disclosure seemed to be easier for many HIV-positive people when AIDS was no longer regarded a death sentence. Several of the organisations mentioned that people were more motivated to go for testing when they knew there was treatment and care available. On the other hand, some of the organisations interviewed were focusing on the tendency for people to seek help outside the village because they were afraid of gossip or the risk of meeting people they knew at the clinic. Increased access to ARVs from the clinic, as many of the organisations recommended, would not be efficient if people still had to travel long distances in order to retain secrecy about their HIV status. Dealing with stigma therefore still has to be a central ingredient in future strategies.

Recommendations

In order to strengthen local participation, programmes mapping informal groups in marginalised communities, and development of support systems for such groups might be a way of upholding and sustaining the important civic participation found in many South African communities (Campbell *et al* 2005; Russel & Schreider 2000).

Better coordination and communication, and more information available in the community on how the resources are distributed would probably reduce many of the problems (Russel & Schreider 2000). Interventions to help the community with coordination of work, either by educating the organisations in administrative work or by hiring persons from outside in order to help the community with coordination could be a way to increase bridging in the community and increase the level of social capital.

As the formal healthcare sector is suffering from a heavy workload because of HIV/AIDS, brain drain and the high prevalence of HIV among health personnel, a broad recruiting of other healthcare workers in South Africa seems necessary (Benatar 2004; Chopra & Ford 2005). Strengthening cooperation and linking the level between community and government, including special programmes to empower and educate volunteers and healthcare workers in the communities, could be one way of meeting the increased demand for more qualified healthcare personnel in the community, according to Campbell *et al* (2005). These authors argue that there has been too much focus on medically trained personnel, such as doctors and nurses in South Africa, in the quest for human resources needed for implementing the roll-out of ARVs. They have also highlighted the importance of grassroots community representatives in the implementation processes, and in bridging the gap between poor and marginalised communities and formal health services.

Interventions to increase the local access of ARVs would need to go hand in hand with programmes fighting stigma and promoting acceptance in the community. The combination of up-skilling and empowering nurses and healthcare workers, and promoting openness toward and acceptance of HIV/AIDS are also significant factors for successful interventions to improve treatment, care and support for those living with HIV/AIDS.

Our results revealed resistance from some of the organisations to work closer with government. The wish from some organisations to work independent from government may be reasonable after government's previous controversial stands on HIV/AIDS and its many shifts in strategies concerning HIV/AIDS. However, in order to achieve a better coordination in the healthcare sector it may be necessary for NGOs and/or CBOs to sacrifice some of their independence and to work closer with the government, thus improving social capital through linking mechanisms. At the same time, government also needs to give independent organisations, working with HIV/AIDS, more responsibility and resources in order to sustain their work (Parkhurst & Lush 2004; Schneider & Stein 2001).

Concluding remarks

Already in 2004, Kober and Van Damme highlighted the lack of human resources for health as the single most serious obstacle for implementing the national treatment plans in Southern Africa. They underlined the urgent need for a comprehensive human resource strategy, and practical changes in the organisation and running of healthcare systems. The results of our study demonstrate that the challenge of human resources still is an overwhelming and unresolved problem in rural areas in South Africa. South Africa's healthcare system still has a long way to go in order to meet the requirements for good treatment listed by Rowe *et al* (2005).

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Chapter 4

The burden of care: A study of perceived stress factors and social capital among volunteer caregivers of people living with HIV/AIDS in KwaZulu-Natal

Wellington Mthokozisi Hlengwa

Introduction

Caring for a person who is terminally ill is a stressful activity associated with negative physical and emotional outcomes. These outcomes include carers becoming stressed or reaching the stages of burnout. Documentation of the experiences of stress related to being a caregiver is fairly extensive (cf. Akintola 2006; Maslanka 1996; Mohammad & Gikonyo 2005; Ncama 2005; Pearlin, Mullan, Semple, Marilyn & Skaff 1990; Van Dyk 2007). In sub-Saharan Africa, we still lack adequate information from quantitative measurements of the stress that volunteer caregivers experience. Therefore, while the majority of studies capture the experiences of stress among volunteer care-givers, little is known about the degree to which volunteer caregivers are stressed.

The study being reported here was aimed at exploring the degree of stress, as well as the predictors of stress among volunteer caregivers of people living with HIV/AIDS (PLWHA) using quantitative measures. In addition, the study wanted to find whether social capital would have any influence on the stress levels of volunteer caregivers.

Caregiver stress

Informal, home-based and volunteer caregivers are people, usually women, who provide care outside of the formal healthcare systems such as hospitals, clinics as well as private practices, who are not employed or receiving any remuneration for the service they provide (Akintola 2006; LeBlanc, London & Aneshensel 1997). Studies report that the burden of HIV/AIDS care-giving produces mental and physical health problems for the caregiver (e.g. Pakenham, Dadds & Terry 1995). Socioeconomic and demographic characteristics that have been associated with physical and mental health problems in caregivers include low income, education and social status; female gender; age-related life transition (older and younger age of caregiver and younger age of PLWHA); and single marital status (unmarried) (Brown, McDaniel & Birx 1995; Flaskerud & Tabora 1998; Sher 1993; Wardlaw 1994). Pakenham *et* *al* (1995) also added that for caregivers, anger, loneliness and stigma have been associated with health problems. Most female caregivers report that no one in their surroundings wants to talk about PLWHA; hence, they feel alone even when they are surrounded by friends and family (Flaskerud & Winslow 1998). In a study conducted in South Africa, Van Dyk (2007) identified several factors that contributed to caregivers' stress: the overwhelming nature of the disease, failure to deal with a patient's death, lack of social support, and lack of organisational support. Pearlin, Aneshensel and Leblanc (1997) focused on among others, role overload and role captivity as important stress factors for caregivers in a US setting.

The role of social capital in mitigating stress

Social networks constitute important elements of social capital because the flow of information within and between groups facilitates informed action that an individual can use as a source of support from members of those groups and networks (Coleman 1990). While one needs strong social networks to generate social capital, those networks could yield both positive and negative results (Portes 1998) in terms of alleviating stress. Social norms and values such as trust and reciprocity may also influence the level of stress experienced by volunteer care workers.

The study being reported here was aimed at exploring the degree of stress, as well as the predictors of stress among volunteer caregivers of PLWHA. In addition, the study wanted to find whether social capital would have any influence on the stress levels of volunteer caregivers. The chapter concludes with recommendations for stress alleviation for volunteer care givers for PLWHA. The study also provided insight into how social capital can be strengthened.

Methodology

The study site

The study was conducted in 13 semi-rural communities (townships) located in an area approximately 30 km from the city of Durban in KwaZulu-Natal, South Africa. The communities in the area are serviced by a hospital owned by Catholic missionaries. In 1997, the missionary hospital started a community-based organisation (CBO), which provides home-based care (HBC) services to communities in the area. The organisation recruits and trains volunteer caregivers who in turn assist PLWHA and their families in the provision of HBC services. At the time of the study, there were approximately 300 volunteer caregivers working with the organisation. There were approximately 15 coordinators and one project manager. Two of the coordinators were retired nurses who were working at the hospital designated to provide nursing care to patients as well as providing voluntary counselling and testing (VCT).

Participants

A convenience sampling method was used. Participants were volunteer caregivers of HIV/AIDS patients and AIDS orphans working for the CBO mentioned in the previous paragraph. The organisation consisted of 300 volunteer caregivers; however, only 130 volunteers (3 males and 127 females) participated in the study. All volunteers were contacted and asked to participate in the study but due to prior commitments and relocation, only 130 volunteer caregivers responded to the request.

Method of data collection

A structured questionnaire was used to obtain the following information from the volunteer caregivers of PLWHA. The questionnaire comprised three sections:

- Section A contained demographic questions;
- Section B contained questions related to stress factors; and
- Section C contained questions related to social capital as described below:
    - *Section A Demographic information* refers to information on age, sex, marital status, academic qualifications, grade and level of responsibility, whom they care for, how many years they have been in volunteer work, how many years they intend to do the work, how many patients they care for. Respondents were also asked to indicate how many of their patients have passed away.
    - *Section B Stress factors of volunteer caregivers of HIV/AIDS patients*: constructs that are specifically related to stress associated with HIV/AIDS care ('overwhelming nature of the disease', 'lack of organisational support', 'lack of social support', 'role overload', 'role captivity' and 'failure to deal with patients' death') were measured using a 15-item Likert-type scale. All stress constructs were taken from Van Dyk (2007) except for 'role overload' and 'role captivity' that were taken from Pearlin *et al* (1997). Participants were asked to indicate their responses on a 5-point scale ranging from 'strongly disagree' (1) to 'strongly agree' (5). The range of scores was 15–75, with a higher score indicating higher stress levels.
    - *Section C Social capital*: Social capital was measured in two dimensions, namely structural (networks) and cognitive social capital

(norms and values). Each dimension was measured on three levels – bonding, bridging and linking. Examples of questions and statements included in the measure are:

- For 'trust' at different levels: "How much do you trust different types of people involved in HIV/AIDS activities in the community you are working in to do a good job/provide services?" (the question was followed by a list of specific groups and organi-sations at the level of bonding, bridging and linking respectively).
- For 'social action bridging': "Most HIV/AIDS organisations/groups are doing a good job in providing HIV/AIDS-related services".

In some of the questions, respondents were asked to list their answers, to answer yes/no, whereas in other questions they were expected to respond on a 5-item Likert-type scale ranging from 'definitely not' (1) to 'to a great extent' (5). A higher score indicates higher levels of social capital.

Scale measurement

Factor analysis was used to validate the stress scale. This was done because the scale that was used had not previously been validated. Therefore, it was important to determine before further analysis whether the stress scale actually measured the hypothesised stress construct. Although the alphas for 'fear of dealing with patients death' and 'role overload' were low (.554 and .514 respectively), the factor loadings were well within acceptable limits (Pallant 2007). In addition, inter-item correlations ranged between .2 and .4, indicating an acceptable level of co-linearity (Briggs & Cheek 1986:115). Table 4.1 shows factor loadings and content of the stress scale. The final 15-item stress scale had a Cronbach's alpha of 0.80.

Table 4.1 Factor loadings on stress factors associated with caregiving

Scales and items	Factor loading	α
Fear of dealing with patients' death		**.554**
Bereavement becoming too much to handle	.758	
Stress of dealing with distressed relatives	.794	
Overwhelmed by grief when doing volunteer work	.640	
Overwhelming nature of disease		**.722**
Absence of cure for AIDS makes me feel hopeless	.863	
Feelings of disappointment because I can't see the light at the end of the tunnel	.832	
Volunteer workload making it hard to cope	.702	
Lack of organisational support		**.610**
Insufficient support for caregivers from government and private agencies	.805	
Feelings of working in the dark without proper supervision	.704	
Insufficient help for all people with HIV/AIDS	.741	
Lack of social support		**.636**
Friends and family do not understand what I'm going through	.856	
Not getting enough support from friends and family	.856	
Role overload		**.514**
Not being able to finish a day's work	.820	
Too much work causing a lack of leisure time	.820	
Role captivity		**.635**
Feeling trapped by patients' illness	.856	
I wish I could run away from care-giving work	.856	

Results and discussion

Demographic profile

Of the total number of volunteers (*n* = 130) who participated in the study, 129 questionnaires were completed. Table 4.2 provides the demographics of the sample.

Table 4.2 Demographic characteristics of the volunteer caregivers

Items	N	%
Total sample	**130**	**100**
Men	3	2.3
Women	127	97.7
Age groups		
20–29	25	19.2
30–39	70	53.8
40<	35	26.9
Marital status		
Married	29	22.3
Not married	91	70
Widow/Widower	5	3.8
Engaged	5	3.8
Level of education		
Primary	6	4.6
Secondary/high school	121	93.1
Tertiary education	3	2.3
Level of responsibility		
Coordinator	5	3.8
Facilitator	69	53.1
Caregiver	56	43.1

Items	N	%
Type of volunteer work		
HIV/AIDS patients	49	37.7
Orphans	18	13.8
Both	62	47.7
Missing	1	0.8
Source of income		
None	120	92.3
Domestic work	1	0.8
Street vending	2	1.5
Salary	4	3.1
Temporal jobs	3	2.3
Years in volunteer work		
1–4yrs	23	17.7
5–8yrs	69	53.1
9 yrs<	38	29.2
Number of deceased patients		
None	6	4.6
1 person	16	12.3
2–4 people	65	50.0
5<	43	33.1
Years caregiver wants to continue work		
Not sure	16	12.3
1–5yrs	53	40.8
6–10yrs	13	10.0
11yrs<	43	33.1

The degree of stress among volunteers

The minimum score on the stress scale was 31, while the maximum stress score was 75. The standard deviation was 10 with a mean stress score of 52. Only 10 participants (8%) scored below the mean of the total stress score and 119 participants (92%) scored above the mean. It was expected that volunteer work in this context was stressful, so a moderate stress level could be considered 'normal'. However, a stress level as high as the one found in this study could indicate that stress could lead to burnout and attrition in this sample.

The findings were not surprising because a number of studies have supported clinical observations that high levels of stress experienced by caregivers, especially those of patients with dementia-related disorders, lead to negative outcomes, including fatigue, burnout, extreme burden, social isolation, depression and health problems (e.g. Haley, Levine & Brown 1987). For HIV/AIDS caregivers, these stress outcomes were also influenced by the nature and progression of the disease (Pakenham *et al* 1995). A number of factors may be responsible for high levels of stress among HIV/AIDS volunteers. Pearlin *et al* (1997) have attributed high stress levels among volunteer caregivers to the fact that these caregivers are exposed to the unprecedented death of young people and that many caregivers are also HIV positive themselves. A large number (42%) of the volunteers reported being highly stressed. This was almost half of the total sample. A number of factors may be responsible for high levels of stress among volunteers. UNAIDS (2000) reported that the most commonly mentioned reasons for high stress levels among volunteer caregivers was an oppressive work load, over-involvement with PLWHA and their families, and personal identification with the suffering of people with AIDS. The high stress levels thus indicated that caregivers in this organisation needed special attention and support in their care-giving work by acknowledging that care-giving work is hard and stressful. The high stress levels, if left unattended, may result in volunteer caregivers reaching burnout stages (UNAIDS 2000).

The 'overwhelming nature of the disease' was found to account for most of the stress among volunteer caregivers, contributing to 49% of the variance of stress. This variable was measured by the absence of a cure for the disease and feelings of hopelessness experienced by caregivers and the poor access to antiretroviral treatment and other medication for PLWHA. The 'overwhelming nature of the disease' obviously seemed to be a major contributor to high stress levels among volunteer caregivers (UNAIDS 2000).

Another contributory factor is the fact that the volunteer caregivers in this study were working in communities where they lived. Therefore, the pain of witnessing people they know, family members and peers, going through excruciating pain, exacerbated by extreme poverty, might have proved to be too much to bear.

The second most salient stress factor was 'failure to deal with patients' death' which accounted for 32% of the total variance of total stress score. Volunteer caregivers seemed to find it difficult to deal with issues of be-reavement, death and dying among patients, resulting in high stress levels. As evidenced in other chapters in this volume (cf. Chapter 5 and 6), when patients die, the responsibilities for the removal of the body, funeral arrangements and everything pertaining to the burial proceedings sometimes fall on volunteer caregivers. Evidently, this burden has negative impact on volunteer caregivers considering that most households where these caregivers work have limited resources even to bury their loved ones. Therefore, the shifting of responsibility by the household members to volunteer caregivers is the easiest route out of distress for the family. This, however, has a negative outcome for the volunteer caregiver. In addition to this, volunteer caregivers often have to comfort and help by counselling the bereaved family members, which in itself has a great potential to increase stress levels (Van Dyk 2007).

Surprisingly, despite the high stress levels reported by volunteer caregivers, 41.1% reported that they were willing to work as volunteer caregivers for more than five years still. This is consistent with a previous study among volunteer caregivers (Uys 2001). Uys (2001) reported that, despite the fact that caregivers have high stress levels, they still felt that they were making a difference in the lives of other people who needed help and who were satisfied with their work. Akintola (2011) provides some insights into the motivations of volunteer caregivers. His study suggests that volunteer caregivers continue with their work in spite of stressful working conditions for a variety of reasons, including strong altruistic concern for others and the community, hope for future employment and for training leading to professional work, avoiding idleness and increasing personal growth.

The influence of demographic characteristics on stress

On the question of whether stress is influenced by demographic characteristics, results showed that none of the demographic characteristics had any significant influence on volunteer caregivers' stress levels (cf. Table 4.3).

Table 4.3 The influence of demographic characteristics on stress

Variables	Value	df	Sig (2-tailed)
Age	.379	2	.829
Marital status	.355	1	.551
Type of volunteer work	2.063	2	.356
Years in volunteer work	5.645	2	.060
Years to continue volunteer work	.185	3	.980
Number of deceased patients	.401	3	.940

The fact that there was no significant association between years of experience in volunteer work and stress levels is interesting because other studies suggest that the number of years in volunteer work gives enough experience to handle stressful situations (Claxton, Catalan & Burgess 1998). Hence, inexperienced and experienced caregivers would react to and handle stress differently. Also, young caregivers experience higher stress levels than their older counterparts (Claxton *et al* 1998). However, the findings of the study being reported here were consistent with those found in a study conducted in South Africa by Van Dyk (2007) who found that demographic characteristics were not predictive factors of stress among professional caregivers. Studies conducted in Western contexts have suggested that age, experience, level of education and economic status are major predictors of high stress levels (Claxton *et al* 1998; Pearlin *et al* 1990). The question that arose then was whether there is difference in the way stress is handled between volunteer caregivers in Western countries and those in sub-Saharan Africa. It is noteworthy that the sample in this study was homogeneous and dominated by women; hence, it lacked variation. Therefore, it is difficult to draw conclusions about the predictive value of demographic characteristics on stress, and the findings should therefore be treated with caution.

The relationship between stress and social capital

In the total model, social capital explained 19.1% of the total variance of total stress scores (R-squared = 0.191, sig. = 0.008). This implied that the total model was statistically significant. Of the items that were significant, 'Social action at the bridging level' (β = 0.311, sig. 0.002) was the strongest variable explaining 10.2% of the total variance of total stress scores. Trust at the bridging level of β = 0.280, sig. = 0.010 was the second strongest variable explaining 5.7% of the total variance of total stress scores. This meant that when social action at the bridging level increased, stress among volunteers also increased, and when the levels of trust at the bridging level decreased, stress increased (cf. Table 4.4).

Table 4.4 The relationship between general stress and social capital

Model	β	t	sig.
1 (Constant)	4.550	.000	
Group bonding	–0.87	–1.014	.313
Group bridging	.115	1.246	.215
Group linking	–.123	–1.316	.215
Social action-bonding	–.002	–.021	.983
Social action-bridging	.311	3.139	.002
General trust	–.012	–.136	.892
Trust bonding	–.004	–.136	.892
Trust bridging	–.280	2.602	.010
Trust linking	–.209	–1.894	.061
Social cohesion			
Bonding	.022	.189	.850
Social cohesion			
Bridging	.029	.316	.753

The results could be interpreted that the increase in collaboration and working agreements between different groups, organisations and society causes an increase in stress levels. It is also possible that volunteers who are active in trying to collaborate with other stakeholders in the field of HIV/AIDS care become more stressed because of competition, rift and struggle for proper coordination, knowledge sharing and collaboration among HIV/AIDS care and support organisations (Kasimbazi 2009; see also Chapters 3, 5 and 6 in this volume). The lack of proper coordination between non-governmental organisations (NGOs) and HIV/AIDS care and support groups is partly caused by the lack of visibility of government participation.

The low level of 'trust at the bridging level' is related to high levels of stress. Low levels of trust may arise from previous failure to get results when engaging in social action. In Chapter 2 in this volume, community members' expectation and trust towards HIV/AIDS service providers were rated as low to moderate, and half of the respondents rated HIV services as poor or fair. It was also shown that very few community members were actively participating in communal activities. Thus, there is probably a lack of a support system from the top, e.g. government, hospitals and clinics. The Department of Health (RSA DoH 2007) reported that while volunteers and other healthcare workers work at the primary care level, nurses in clinics and paid health workers often deride volunteers. Other issues related to these results could be linked to referral systems whereby volunteer caregivers complain that clinic staff and paid health workers do not have the necessary sense of urgency when dealing with ambulances and referrals to hospitals (Kasimbazi 2009). All these could contribute to increasing stress levels among volunteer caregivers.

The predictive nature of social capital was also measured against subscales of the total stress scale, which included 'failure to deal with patient's death', 'overwhelming nature of disease', 'lack of social support', 'lack of organisational support', 'role overload' and 'role captivity'. Only role overload and role captivity had significant results.

Social capital explained 17.1% of the total variance of 'role overload' (R-squared = 0.171, sig. = 0.022). The model was statistically significant with some individual variables within the model being significant. 'Trust at a linking level' was the strongest with β = –0.310, sig. 0.006 explaining 3.2% of the total variance of 'role overload'. The second strongest variable was 'social action at a bridging level' with β = 0.219, sig. = 0.031 explaining 2% of 'role overload' (cf. Table 4.5).

Table 4.5 The relationship between role overload and social capital

Model	β	t	sig.
1 (Constant)	.567	.572	
Group bonding	.029	.328	.743
Group bridging	.045	.478	.633
Group linking	.031	.322	.748
Social action-bonding	–.097	–.822	.413
Social action-bridging	.219	2.180	.031
General trust	–.052	–.560	.576
Trust bonding	.155	1.688	.094
Trust bridging	.143	1.311	.192
Trust linking	–.310	–2.774	.006

Model	β	t	sig.
Social cohesion			
Bonding	.215	1.850	.067
Social cohesion			
Bridging	.018	.194	.847

The final model made up of 'role captivity' and social capital variables was statistically significant with R-squared = 0.187, 18.7% with sig. = 0.010. Individual variables that were significant included 'social action at a bridging level' which was the strongest with β = 0.275, sig. 0.007 explaining 7.3% of the total variance of 'role captivity'. The second strongest variable was 'trust at a bridging level' with β = 0.246, sig. = 0.024 explaining 3.2% (cf. Table 4.6).

Table 4.6 The relationship between role captivity and social capital

Model	β	t	sig.
1 (Constant)	.131	.896	
Group bonding	−.166	−1.928	.056
Group bridging	.142	1.529	.129
Group linking	−.018	−.196	.845
Social action bonding	.091	.779	.437
Social action bridging	.275	2.769	.007
General trust	−.003	−.036	.971
Trust bonding	.012	.131	.896
Trust bridging	.246	2.284	.024
Trust linking	−.199	−1.798	.075
Social cohesion			
Bonding	.006	.055	.956
Social cohesion			
Bridging	.137	1.489	.139

The overall models of 'general stress', 'role overload', 'role captivity' and 'social capital' are significant with the increase in 'social action at a bridging level' predicting high levels of stress. The variables dealt with issues surrounding groups working in the field of HIV/AIDS and problems associated with this work. These have been discussed above. ‘Role overload’ is characterised by the scope of work that is beyond what the volunteer caregiver can handle. This results in a lack of family and leisure time for volunteer caregivers. However, based on the finding that trust at a linking level is related to a decrease in stress, volunteer caregivers in this sample might trust that government participation and involvement with all its resources can reduce the amount of work that they handle. Russell and Schneider (2000) argued that the Department of Health guidelines of HBC are regarded as well conceptualised; however, they are insufficiently implemented, leaving the burden of care-giving with volunteer caregivers. In spite of the discouraging implementation, results showed that volunteer caregivers still believed that government has the potential to come up with strategies and programmes that can assist volunteer caregivers in reducing the burden of care. Therefore, government mobilisation at this level should be considered a high priority.

Conclusion

The study being reported here aimed at identifying the levels of stress of volunteer caregivers and to explore the relationship between stress and social capital. Findings revealed that volunteer caregivers are highly stressed. There were only eight volunteer caregivers who scored below the average on the total stress scale, with 92% of the volunteer caregivers scoring above average. In trying to identify the sources of stress, it was found that demographic characteristics did not have any influence on the high stress levels. Volunteer caregivers reported being overwhelmed by the nature of the disease. Based on the findings, it was concluded that stress levels were attributable to the nature of HIV/AIDS care-giving work. This supports previous findings from studies on stress among volunteers (Akintola 2008; UNAIDS 2000; Van Dyk 2007). The fact that there is no cure for HIV/AIDS and that the number of people who are being infected is not decreasing seems to cause major concerns. Literature reveals that most volunteer caregivers are also HIV positive themselves (Claxton *et al* 1998; UNAIDS 2000). Hence, volunteers may be faced with the challenge of dealing with their own HIV status as they witness difficulties faced by their patients and the hopelessness of the immediate solution (Akintola 2004).

When stress was measured against social capital, the expectation was that the relationship between the two variables would be negative, indicating that the presence of social capital would mitigate high stress levels of volunteer caregivers. However, most of the significant social capital variables were positively correlated with either the general stress factor or the different subscales; indicating that an increase in the social capital variables induces high stress levels for volunteer caregivers. The most significant variables were 'social action at a bridging level', 'trust at a bridging level' and 'trust at a linking level'. This may suggest that communities in which these volunteer caregivers work may still have a high rate of discrimination against PLWHA and their caregivers. Also, it is possible that there are still no proper relations and coordination between groups and organisations working in the field of HIV/AIDS in these communities; hence, the strife between the groups and organisations (Kasimbazi 2009) (see also Chapters 2, 3, 5 and 6 in this volume).

Lastly, government has failed to implement proper coordination of resources to support HBC. The findings of the study suggest that trust could increase among volunteers if government agencies play an active and coordinating role in HBC services. Therefore, government's participation through the distribution of resources to HBC organisations as well as implementation of programmes that are directed at improving partnerships between organisations could provide better understanding and management of stress levels.

Notes:

1. The name of the community has been withheld due to ethical reasons.

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Chapter 5

Unpaid volunteers and perceived obstacles in ensuring care and support for people living with HIV/AIDS

Annette Kezaabu Kasimbazi & Yvonne Sliep

Introduction

The purpose of this chapter is to analyse how volunteer community workers perceive the HIV/AIDS care and support that they provide to the community.[1] The broader theoretical framework of this chapter is social capital as it applies to community care and support. This chapter intends to provide an understanding of what volunteer community workers perceive as the available care and support in the community, and to investigate the challenges impeding the implementation of care and support. It specifically has objectives such as to explore and describe how volunteer community workers perceive care and support around HIV/AIDS provided by them to the community, the perceived challenges they face in implementing care and support, and to make recommendations on how to improve care and support provided by the volunteers for those infected and affected by HIV/AIDS.

The chapter is structured into five main sections. The first section describes the methodology. The second section contextualises qualitative research into the wider social capital framework. The third section explains the theory of social capital and volunteerism and reports on the analysis of findings of the study in the context of care and support for people living with HIV/AIDS (PLWHA), based on existing literature. The fourth section presents the main findings of this specific study on how volunteer community workers perceive the care and support regarding HIV/AIDS that they provide to the community. This chapter further identifies some of the challenges/obstacles hindering care and support. The final section presents the conclusion.

Methodology

The study used qualitative methodology and aimed to understand the perceptions of volunteer community workers on care and support around HIV/AIDS in a semi-rural community in KwaZulu-Natal. The participants were purposefully selected based on their recognition as volunteer community workers and their willingness to be interviewed. The research used semi-structured interviews and focus group discussions. The first author conducted the interviews with the assistance of an interpreter, since she does not speak isiZulu (the language of the interviewees) fluently. The one-on-one interviews with each of the 13 selected volunteer community workers took place over a period of three weeks plus another week of focus group discussions. The interviews covered the themes of trust, reciprocity, social networks and norms and the way these relate to care and support for those infected and affected by HIV/AIDS. From the forty isiZulu speaking volunteer community workers, thirteen with most experience were selected. All the interviewees were women between the ages of 28–56 years old. Women were selected because there were no male volunteers. The interviews were audio recorded and transcribed for analysis.

Findings and discussion

The context of care and support for people living with HIV/AIDS

It was estimated in 2008 that 5.2 million people of the population of 47 million people were living with HIV/AIDS in South Africa, more than in any other country in the world (Shisana *et al* 2009). The impact of the HIV/AIDS epidemic on families and communities is unspeakable. In an attempt to deal with this impact, some community members volunteer for care and support to aid the affected households.

Care literally means to address physical needs, help or comfort (Orner 2006). In the context of this study, care denotes addressing physical needs, and providing moral support, spiritual support, help or comfort to those infected and affected by HIV/AIDS. These are usually acts through which people demonstrate their sentiments of care and love. These acts may also extend well beyond daily nursing tasks to include any activity that contributes towards the welfare of others. Examples include sharing money and food, providing labour and time, attending funerals, and visiting others, all of which are acts of care through which people mobilise sentiment in order to strengthen or heal relationships (Klaits 2002; Livingston 2003).

Social support on the other hand, according to Ogden, Esim and Grown (2004), means to give aid and courage. This may take the form of social or material provision of support whereas care means to have regard or consideration for another. As opposed to care, support for those infected and affected by HIV/AIDS is normally provided by non-medics, often in the home, embracing psychosocial, spiritual, and other non-medical forms of care (Akintola 2004). It involves the physical, emotional, spiritual and moral comfort given to those infected and affected by HIV/AIDS by the volunteer community workers and other community members. Social support is vital for those affected and infected by HIV/AIDS to give them hope and courage to face the effects of HIV/AIDS.

Volunteers also provide spiritual support by praying with the patients. They further provide moral support by showing patients love and compassion, and by talking and listening to them. In addition, volunteers provide basic nursing care, including mouth care, cleaning pressure sores, skin care, turning bedridden patients, support for adequate nutrition, and monitoring drug adherence, among other things (Ogden *et al* 2004). The caregivers also assist patients with daily activities such as feeding, bathing, dressing, walking and going to the toilet and they assist with household chores, shopping, making of porridge for the sick, organising transportation to the hospital, and making telephone calls for referral. Social support provided by volunteers also involves connecting those infected and affected by HIV/AIDS to wider community resources and information. These may include support groups, faith-based groups, welfare services and material assistance. However, social support is normally weakened in communities with wide-spread denial, stigma and discrimination (Akintola 2005; Population Council and Health Systems Trust 2006).

Care and support in households affected by HIV/AIDS

The family has formed the crucial social and economic unit on which most human societies have been based throughout history (Poortinga 2006). The extended family safety net has been the most effective community response to the AIDS crisis (Mukoyogo & Williams 1991). Relatives and friends may provide both moral and material support to the sick on the assumption of future reciprocation and sometimes out of sheer lack of alternatives. Preparation of food, work on land or overseeing livestock is done by another family member or neighbour in addition to their own tasks (UNAIDS 1999).

HIV/AIDS affects families in a number of ways, from additional financial strain and increased care demands to bereavement and orphanhood. Care and support activities extend well beyond the needs of PLWHA and often include complex dynamics involving the larger family. Family members sometimes demonstrate negative attitudes, like stigma and discrimination, and may refuse to provide care and support to a family member with AIDS, or refuse to disclose a family member’s status to others who may provide assistance despite the clear need for care and support. Care is even further compounded by the nature of HIV/AIDS being a long-term illness in which patients require more attention, so that productive time is spent looking after them and sometimes household items are sold to generate income which in turn leads to impoverishment (Ogden, Esim & Grown 2006). This goes to show that over time the ability of families and social networks to absorb these care and support demands will decrease as more adults die young as a result of HIV/AIDS hence the increasing need of more volunteers from the community (Ogden *et al* 2006).

Care and support at a community level

Care and support at community level emerge from local conditions. It is driven by community members, responds to local needs, reflects local forms of organising and acting, and draws upon available resources (Campbell, Nair, Maimane & Sibiya 2008; Gitell & Vidal 1998). According to Foster (2004), spontaneous and informal actions that are undertaken to care for and support those infected with HIV/AIDS and orphans and vulnerable children are some of the community responses to HIV/AIDS. He notes that community initiatives are usually started by small groups of motivated individuals who are driven by a sense of obligation to care for and support those infected and affected by HIV/AIDS where there is limited or non-existent government services.

Foster (2004) further notes that these initiatives generally share the same fundamental principles of social cohesion, namely reciprocity, community solidarity, social trust, consensus-based decision-making, self-reliance through local mobilisation of resources, local leadership, volunteerism (altruism emanating from a sense of community ownership), innovation and problem-solving, and association with faith-based organisations (FBOs). Birdsall and Kelly (2005), however, note that the most successful and sustainable initiatives are those that operate in communities with high levels of social cohesion; which in the community in which this study took place, was always referred to as *ubuntu*.

Ubuntu (a Zulu word) serves as the spiritual foundation of African societies. It is a unifying vision or worldview enshrined in the Zulu maxim *umuntu ngumuntu ngabantu*, literally meaning "a person is a person through other persons" (Shutte 1993). *Ubuntu* describes a human being as being-with-others and prescribes what being-with-others should relate to. In effect, the values articulated in *ubuntu* are consistent with the elements of social capital, which makes this evaluation of social capital nothing but an endorsement of the African *ubuntu*. It emerged in the study, that the ideal of *ubuntu* was deemed to be on the decline in the community, also highly undermined by many factors such as poverty, high rates of unemployment, rural–urban migration, and the advent of HIV/AIDS; hence, these factors led to apathy that was seen to be suffocating the community spirit. The community follows practices that have encouraged togetherness. These practices include cultural ceremonies, art and craft groups, sewing clubs, *stokvels*, communal gardens, and poultry farms. The study being reported here also discovered that poverty has been compounded by the high number of orphans and child-headed families. This in effect has escalated the spread of HIV/AIDS because young girls resort to commercial sex so as to be able to support their families. In addition, the meagre pension earned by the few individuals is not sufficient to sustain these impoverished families. Therefore persons infected and affected by HIV/AIDS look to volunteers for the provision of financial support that volunteers can hardly afford. In this study, the volunteers were only able to get by with a meagre 500 ZAR (approximately US$ 75) stipend from government, which they call ‘soap money’ that only half the group received. In addition, they were using some of their personal funds and provisions from their own homes to care for sick people.

Social capital and HIV/AIDS

Social capital has been applied in various disciplines and more recently to understand the impact of HIV/AIDS (Perry, Williams, Wallerstein & Waitzkin 2008; Pronyk 2002). Several authors have linked the HIV/AIDS pandemic to social capital, usually indicating how factors related to the disease such as stigma, discrimination and the costs posed by care for the sick as well as orphans erode and put pressure on social capital (Campbell, Williams & Gilgen 2002; Foster 2004). Communities with high levels of social capital are more effectively able to implement health interventions like care and support for those infected and affected by HIV/AIDS (Campbell 2001). This is possible with increased information channels, community interaction, mutual support and care that are facilitated by social capital. These interactions enable people to build communities, to commit themselves to each other, and to knit the social fabric. It is important to note however that the utility of the concept of social capital lies in its flexibility and its consequent capacity to explain the negative spill-over of certain social relationships.

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

Elements of social capital

The study being discussed here used the core elements of social capital as described by Putnam (1993), which include social norms, trust, social networks and reciprocity. These elements and the study findings are concurrently discussed in the following section.

Social norms

Norms are defined as a set of behavioural models and rules that are assimilated within a society (Elster 1989). Social norms consist of rules of conduct and models of behaviour prescribed by a society. Regarding HIV/AIDS in South Africa, social norms determine the level of participation in voluntary support and care-giving. Voluntary care-giving is left mainly to females, since it is a cultural belief that it is the duty of women to take care of the sick. The few male volunteer caregivers are regarded by their peers as deviants doing unmanly duties (Akintola 2005). Such perceptions influenced by social norms have inevitably undermined the magnitude of care and support due to the disproportionate low number of volunteers providing care and support for people infected and affected by HIV/AIDS who are in dire need of such care and support.

In the community where this study took place, the social norm of altruism was demonstrated by the desire of the volunteer community workers to work without any form of payment for the good of others. This was cited by the volunteer community workers as the main reason for volunteering to provide care and support to those infected and affected by HIV/AIDS. Despite the existing altruism and social norms that encourage it, volunteerism was estimated to be declining. In the focus group discussion with the volunteer community workers, they retrospectively noted that the African togetherness, *ubuntu,* on which people relied in times of crisis in rural and semi-rural areas such as their community, was declining because of factors such as rural–urban migration, urbanisation, globalisation, poverty and unemployment.

Reciprocity

In social psychology, reciprocity refers to responding to a positive action with another positive action, and responding to a negative action with another negative action (Dickhaut & McCabe 1995). Different societies have different social norms of reciprocity. In most African countries, norms regulate interpersonal relationships, for example, those who do not contribute for funeral expenses may not get any contribution in terms of money and labour when they lose a member of their household to HIV/AIDS or any other causes. Mutangadura, Mukurazita and Jackson (1999) assert that for individuals infected and affected by HIV/AIDS, norms have been used as coping mechanisms to cushion the difficulties associated with this scourge through assistance from members from other households. Mutangadura *et al* (1999) assert that 80% to 90% of bereaved households were likely to receive assistance in cash or kind from members of other households.

It emerged in this study that reciprocity existed in the community, especially where community members borrowed from one another and family relations played an important role in care and support of those affected by HIV/AIDS. Community members also made some material contributions but their contributions were often affected by factors like poverty (lack of material things to contribute), self-centredness in addition to the fact that HIV/AIDS was a new and mysterious disease. The fear of contagion in this case weakened social cohesion and hindered effective care and support from community members. Apart from the reciprocity in the community, volunteers also noted that community members expected reciprocity from government. They noted that most people join the volunteers expecting that government will return the favour and pay them.

Trust

Trust refers to the level of confidence that others will act as they say or are expected to act, or that what they say is reliable (Putnam 1993). Although people can 'invest' trust in others, a person's level of trust in another depends largely on such person's perception of the other's trustworthiness. Volunteer community workers, for example, have to prove that they will not exacerbate stigma in order to earn the trust of the community members (Gilson 2003). In the community where the study was carried out, trust has facilitated volunteerism in the care and support for people infected and affected by HIV/AIDS, and the lack thereof has led to negative consequences that have undermined social bonding. Volunteers' views suggested that people affected and infected with HIV/AIDS had lost trust in their neighbours and as a result there was mistrust and shame, stigma and discrimination, and denial on the part of PLWHA. According to the volunteer community workers, lack of trust on the side of the sick person and the family is usually generated by self-stigmatisation and feelings of guilt and may also be perpetuated by the norms of fear, denial, stigma and discrimination that are associated with HIV/AIDS. This lack of trust of the community members by PLWHA and their families has led to the breakdown of social cohesion in most communities. In a few isolated cases, however, family members leave their patients with trusted neighbours. In effect, those infected and affected by HIV/AIDS do not get the much needed care and support from community members.

Networks

A network is an interconnected group of people who usually have an attribute in common (Productivity Commission 2003). An individual may be a part of separate networks of relationships based on his or her neighbourhood and could also be part of several networks simultaneously. Being part of a network provides individuals with benefits such as a greater pool of social support when needed, access to information and a wider range of opportunities (Gitell & Vidal 1998; Jamil & Muriisa 2004). Regarding the role of social networks, the findings of the study revealed that some community members made material contributions such as food to facilitate care and support activities. These contributions have encouraged care and support for those infected and affected with HIV/AIDS and even motivated volunteer community workers. However, the study also revealed that social networks and specifically horizontal networks amongst community members existed though they were reported to be weak. Horizontal networks included networks among friends, peers, people who attend the same churches, people in the same associations and clubs such as burial societies, *stokvels* and garden projects. Factors that advance weakness in the networks included lack of time to get together, the divisions fuelled by religious and cultural beliefs, limited awareness regarding volunteering and HIV/AIDS and inadequate government support for volunteers. The networks amongst groups that operate in the study area were undermined by competition and uncoordinated groups which all provide overlapping kinds of care and support.

Volunteerism

Volunteerism is the willingness of people to work on behalf of others without the expectation of pay or other tangible gain. A volunteer is defined as someone who gives time, effort and talent to a need or cause without profiting monetarily. The White Paper for Social Welfare (RSA DoW, 1997:98) defines a volunteer as “a professional or non-professional person who provides a service to a welfare or development organisation, usually without reimbursement”. The nature and activities of volunteers differ from context to context. Volunteers in the Western world differ from those in sub-Saharan Africa, where HIV/AIDS is endemic. In addition, material and psychological demands placed on volunteers in the context of the HIV/AIDS epidemic is different from what may be required under normal, or pre-epidemic, circumstances (Mutangadura *et al* 1999; Uys 2002). According to Dingle (2001), voluntary action creates a bond of trust and encourages cooperation, and in that sense, enhances social capital. It also empowers individuals who cannot make substantive contributions to get involved in care and support for the affected households, for example unemployed people who undertake to do household chores for those infected and affected by HIV/AIDS. Volunteerism adds value to the services that governments provide. For example, volunteers offer complementary services in the care and support of PLWHA especially when hospitals and other healthcare institutions cannot cope with the increasing number of patients either because of limited personnel and/or funds or infrastructure (Fox, Fawcett, Kelly & Ntlabati 2002). Volunteers are also considered by the community as a guarantee for social welfare, especially in the care and support of those infected and affected by HIV/AIDS, namely the elderly, orphans and vulnerable children and the disabled in the communities (Carter & Maluccio 2003). In essence, volunteering is not simply a one-way act with one giver and one receiver; it has multiple benefits for those people involved and for society at large.

Volunteering provides crucial learning opportunities and leadership development for those who volunteer. It is a means by which marginalised people, such as those who are HIV positive, the elderly, orphans and vulnerable children, can assert their own value and power. This is important for care and support for those infected and affected by HIV/AIDS as it provides a forum through which they can claim their needs.

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

Challenges to volunteering in HIV/AIDS care and support

The challenges that volunteers face, include the secrecy that many families maintain regarding the status of the family member they are caring for, which leads to their alienation from potential care and support from volunteer community workers (Campbell *et al* 2008). At an emotional level, patients and volunteer community workers feel isolated in a community where stigma makes people reluctant to disclose their HIV status, often even to their carers. This means that both patients and carers often battle on with no emotional support. Fear of disclosure also limits people's access to what little care or support might be available (Campbell *et al* 2007). Most PLWHA do not want their families to know that they are HIV positive; for fear that their family members will be afraid to look after them (Uys 2003). Family members sometimes demonstrate negative attitudes, like fear of stigma and discrimination, and they may refuse to provide care and support to a family member with AIDS, or refuse to disclose a family member's status to others who may provide assistance despite the clear need for care and support. This undermines volunteer efforts to care and limits care and support from the families of PLWHA. In the community, fear of rejection by family members was reported as one of the biggest challenges in volunteering. The volunteers noted that it not only leads the PLWHA to self-stigmatisation, but also leads family members to chase away volunteers as nosy people who should have no business with their sick person.

The fear of getting infected with HIV/AIDS is yet another challenge that has negative implications for care and support of PLWHA (Campbell *et al* 2008). Family members are reluctant to help their sick persons because of fear of contracting the disease through such means. In our study, volunteers reported that many community members would not join the volunteer community workers because they fear contracting HIV/AIDS through the risky modes of transmission such as direct contact. HIV/AIDS is still confusing people because the symptoms and the process of the disease are not well understood by most people in the community.

Studies (Campbell *et al* 2007; Campbell *et al* 2008; Uys 2003) indicate that, due to the increased interest in caring for patients in their homes and the use of volunteers, the community health workers (CHWs) who are salaried government workers are beginning to examine volunteers as potential healthcare workers who are poised to take their jobs and are therefore not cooperating with them. In the community where we undertook our study, the volunteer community workers reported a strained relationship between them and the CHWs, which seemed to stem from competition between the two groups. According to the volunteers, the CHWs feared that the volunteers who were relatively new were poised to take their jobs; therefore, they had to alienate them. This competition affected the performance of both the volunteers and CHWs, leaving the patients' needs of care and support unmet.

Volunteer caregivers are subjected to constant worry concerning the pain and suffering of their patients, which causes them to have sleepless nights and nightmares. Their inability to provide a cure for the illness causes them guilty feelings, which is exacerbated by the eventual death of the patient (Akintola 2005; Campbell & Foulis 2004). In the community, the effect of this has been to discourage reciprocity by volunteers. According to the volunteers, this explains why there is apathy among the community members towards volunteering to give care and support to people infected and affected by HIV/AIDS. There is consequently a high and unmet demand for caregivers and a need for more staff and volunteers (Birdsall & Kelly 2005).

Fear and distress regarding the state of patients also confront the volunteers caring for terminally ill patients. Bathing them, cleaning their sores and changing their nappies produce intense emotional distress because it highlights the deteriorating state and imminent demise of the patient. Patients may cry and express pain and agony when being bathed, which results in constant emotional trauma to the volunteers (Akintola 2005; Bachmann & Booysen 2004). Almost all volunteers in our study reported being emotionally affected by the situation in which they find the sick person.

The effect of myths and traditional/cultural beliefs coupled with theories of denial was apparent from the various responses, for example that some PLWHA are reluctant to take antiretrovirals (ARVs) under the honest but mistaken belief that ARVs are dangerous and poisonous, preferring traditional healers. This explains why in some instances volunteers are shunned for fear that they are going to encourage PLWHA to take ARVs.

Summary of main findings

The research for this chapter identified that the main gaps in achieving adequate care and support around HIV/AIDS in the community of study include growing apathy, self-centeredness, limited awareness, limited social cohesion, the mystery of the disease causing fear and denial of HIV/AIDS infection, general lack of resources for care and support services, and challenges of abject poverty and volunteering.

Most respondents noted that there was a need to raise awareness on HIV/AIDS care and support in the community. HIV/AIDS comes with distressing symptoms and any long-term illness is baffling to community members. The respondents felt that most HIV/AIDS programmes reported on in the media concentrated on prevention, while care and support were not given the attention it deserved. As a result, denial, stigma and discrimination were still rife in the community and even those who loved their patients and wanted to care for them did not know how to go about it. The volunteer community members were of the view that community members' response to care and support would be improved through regular community meetings and sensitisation to issues regarding HIV/AIDS. They also stated that community contribution could take the form of providing food to the sick and forming knowledge-sharing groups. The volunteers also affirmed the need to be resourced in order to promote the exchange of effective responses and to facilitate their participation in the bottom-up design of policy and programmes related to the HIV/AIDS care and support initiatives.

The participants identified an urgent need to revive the philosophy of *ubuntu*, community solidarity and moral and reciprocal support. According to them, revival of those notions will lessen the volunteers' workload since community members will be in a position to render a helping hand to those who are in dire need of support and care as a result of HIV/AIDS. The participants also asserted that volunteers and other community members need to be trained to ensure that barriers to care and support such as denial, stigma and discrimination are diminished among those who are infected and affected by HIV/AIDS.

In the volunteer organisation taking part in our study, half of the volunteers received a small stipend from government while the other half did not receive a stipend. The participants therefore proposed standardisation of the stipend, with the aim of each volunteer receiving a monthly salary. This is because they work hard and are often as poor as the households they are serving. A salary would enable grassroots volunteers to sustain the work they have been doing informally over the years. In addition, volunteers affirmed that they need assistance with emotional support and may have medical needs of their own, including access to treatment. They noted that the responsibility of volunteering imposed financial burdens as it required expenditure on meals, medicines, costs for transportation, as well as diverting their time from other productive chores.

Volunteers also identified self-centeredness by some community members as a hindrance to care and support. Self-centeredness affects the role a person would play in activities of social support for members in need of it. The volunteers identified self-centred people as those uncooperative individuals who only approach volunteers when they have a problem but lack the necessary community spirit of helpfulness, which contravenes the social norms. Another challenge that was mentioned was the bad attitude that community members have toward volunteers. A large number of the community members perceived volunteerism as "work for those who lack things to do", which also greatly demoralised the volunteers. Some of the volunteers stated that poverty and/or harsh economic conditions were creating a significant departure from the original thinking of volunteerism. Hence people expect remuneration or some sort of compensation, such as transportation, to do volunteer work.

Conclusion

Many households in South Africa barely survive, through casual work, subsistence gardening or trading, old age pensions or mutual borrowing and assistance. Individuals concerned for their friends, neighbours and members of their extended family often organise to provide moral support and material relief to households affected by HIV/AIDS. The burden of care and support in the community of study fell heavily on the shoulders of households and volunteers. There were many impoverished families in the community as family members infected with HIV/AIDS returned when they can no longer work or care for themselves. With the increasing number of persons in need of care and support, volunteers have come out as the best option. However, it is dangerous to assume that volunteers and community members have limitless resilience and capacity to care for dying people and to provide for those they leave behind. Preserving extended family and community ties is an important insurance mechanism because such ties allow families to share risks and gain access to additional resources. There is therefore an urgent need to promote and increase social capital with community solidarity, moral and reciprocal support.

Notes:

1. The insights and discussions in this chapter are drawn from the qualitative research study carried out for an MA dissertation that was submitted for a Master of Arts in Psychology at the University of KwaZulu-Natal.

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Chapter 6

Experiences of social support among volunteer caregivers of people living with HIV/AIDS

Sharl Fynn

Introduction

Social support is associated with positive health outcomes among family caregivers of people living with HIV/AIDS (PLWHA) (Cohen & McKay 1984:253-267). Despite the high numbers of people needing care, the role of social support for volunteer caregivers of PLWHA has received little attention in Africa. The South African Department of Health policy states that home-based care (HBC) is a viable option to hospital care and recommends that the public health system discharge patients early to be cared for at home (Akintola 2005; RSA DoH 2007). It is hoped that this will release bed space within hospitals for people with other illnesses and, furthermore, decrease the cost to public health establishments. In a study by Fox, Fawcett, Kelly and Ntlabati (2002) on integrated community-based care and HBC in hospices conducted in South Africa, HBC was said to decrease the amount of time spent in hospitals from approximately two weeks to three and a half days (Fox *et al* 2002).

HBC may be described as the provision of healthcare services by caregivers in the home of the patient with the objective of ensuring utmost levels of comfort and dignity of the ill (Campbell & Foulis 2004). Volunteer caregivers are individuals, mostly women, who care informally for the sick without receiving compensation or a formal salary for the service they provide (Akintola 2004). Despite the obvious relevance of voluntary care-giving in the lives of PLWHA, HBC programmes come with many challenges, such as the daily burden of care work, the stigma attached to caring for someone with HIV/AIDS, the type of support provided to the volunteers, the support needs of the volunteers, the possible reasons behind the lack of support, and the support experienced by the volunteers. These programmes often receive little support from government (Steinberg, Johnson, Schierhout & Ndegwa 2002) and care organisations have to rely mainly on volunteers to provide care for PLWHA.

This chapter begins by discussing the theoretical background of the study, namely various aspects of the social support theory as well as aspects of the social capital framework. Drawing on a qualitative Masters research project, the study being reported here explored the experiences of social support among volunteer caregivers of people with HIV/AIDS in a semi-rural community in the eThekwini municipality in KwaZulu-Natal. The chapter concludes by considering possible interventions in an attempt to mobilise social capital and ultimately promote the social support that is needed by the volunteers.

Social support

Social support is described by (Ross & Mirowsky 2000) as various types of support that people receive from others whereas Cohen (1992:109-124) discusses perceived social support as being represented as the "function of social relationships" with the notion that these relationships may provide beneficial resources. The definitions presented by all three authors suggest that social support involves give-and-take relationships between people for the purpose of improving certain social conditions. Cohen, Underwood and Gottlieb (2000) go on to describe the presence of social support as reducing the effects of stressful events on one's health through supportive actions of others or one's belief that support is available.

Taylor (1999) argues that social support may take on forms such as appraisal support, tangible assistance, information and emotional support. According to Taylor (1999), appraisal support refers to help provided to an individual to comprehend a stressful experience and adopt the necessary resources and coping skills to deal with the experience. An example of this type of support may be the provision of counselling.

Cohen *et al* (2000) further reinforce Taylor's view on social support by describing appraisal support as shielding an individual against the effects of stress by encouraging the individual to interpret stressful situations less negatively. Cohen and McKay (1984) and Cohen and Wills (1985) further explain this approach by discussing the buffering effect that the appraisal perspective has on stress and, in turn, health outcomes when there is a presence of perceived support and when stress-buffering is only evident when there is a match between the needs elicited by stressful experiences and the functions of social support that are recognised to be accessible.

Although this study took the views of several authors into consideration, the views of Taylor (1999) and Cohen and McKay (1984) took main focus. Making use of aspects of the social support theory as the conceptual framework of the study allowed the researcher to link the experiences of social support thematically with stress and health outcomes of the volunteer caregivers.

Social capital

The social capital framework, according to Blakely and Ivory (2006:614), has been described as being made up of three levels, namely social bonding (relationships of trust and collaboration between networks of a similar nature), social bridging (relationships of respect between people of an unrelated nature) and social linking (involves norms of respect and networks of trust which connect people of authority). Putnam's (1993) theory of social capital encompasses the elements of trust (between people), reciprocity, social norms and social networks, which may filter into the levels of social capital as described by Blakely and Ivory (2006). Although all the levels and elements of the social capital framework pertain to the social dilemmas of HIV/AIDS, this study focused on the elements of trust and social networks at all levels (i.e. bonding, bridging and linking).

The interplay between social support, social capital and volunteering

The social support theory provides a lens through which issues relating to volunteer caregivers' support could be understood. Tangible support refers to support provided through material entities such as financial assistance, services, being taken to the doctor by someone, etc. Informational support is a more cognitive type of support as it may be provided by relatives or friends with the aim of providing an individual with information regarding an experience by someone who has experienced the same or a similar event (Taylor 1999). Emotional support may be provided by supportive friends or family members and is carried out by reassuring the individual of his/her worth and value to them and to society (Taylor 1999).

The study being reported here highlighted the interplay between social capital and social support in terms of the relationships and networks between community members and volunteers and the support provided to the volunteers by the community, friends, family and other non-profit organisations (NPOs). The above-mentioned levels and elements of social capital theory suggest an affiliation between volunteers and other stakeholders such as NPO's, non-governmental organisations (NGO's), community members etc. with the objective of mutual benefit. For example, by improving social bonding, bridging and linking as described by Blakely and Ivory (2006), relationships of trust, social networks and reciprocity as described by Putnam (1993) will be improved, which in turn will create opportunities of support for the volunteers, such as better social cohesion and the coming together of communities, NPOs and other voluntary organisations to improve the accessibility of social support. Volunteers may be able to access or resource support from NGOs, NPOs, community members, etc. provided that the abovementioned levels and elements of social capital are operational. Furthermore, the presence of social support and social capital may benefit the volunteers by lightening the burden of care as well as strengthening the relationships between volunteers and stakeholders. It stands to reason then that community cohesion (coming together) and solidarity (unity) become part and parcel of the aspects of trust, reciprocity and social networks. These relationships between the volunteer, the community and other stakeholders play a key role in the provision of social support to the volunteer caregiver. When necessary, volunteers may be able to access support in the form of resources from NGOs, certain kinds of support from their community members and support from the family of the patient. For example, tangible support in the form of basic working materials, food (porridge for the patient), etc. may be resourced from NGOs, neighbours of the patient as well as the family of the patient when necessary. This process, however, may only be successful granted that the give-and-take relationships as described in the social capital framework are operational.

The social capital framework may be used as an intervention mechanism in conjunction with the social support theory to mobilise support. For example, at an individual level, social linking and bonding may enable the volunteer to receive adequate training and skills to prepare for care work. At an interpersonal level, social bonding and bridging may encourage relationships of trust and respect between the volunteer caregiver, the patient and his or her family members. At an organisational level, social bonding and linking may encourage volunteers to openly share experiences among themselves in order to gain support from each other. In this case, social linking and social networks play an important role in bridging potential gaps between volunteers and government in order to facilitate the support process. At community level, social trust and social bridging play a role in improving the relationships amongst community members and between the community members and the volunteers.

Methodology

A qualitative research method was used for the purpose of the study as it enabled the researcher to understand the findings from the volunteers' experiences, behaviours and context and to investigate the many relations between them (Ulin, Robinson & Tolley 2005). Volunteers' experiences allowed for an understanding of the caregivers' experiences of social support from the volunteers' point of view. The sample selected for this study consisted of 10 female volunteer caregivers residing in the study location. Purposive homogenous sampling was used, with participants being strategically selected "for their ability to provide rich information" (Ulin *et al* 2005:56). This meant that the volunteers were those in a good position to provide rich information.

All participants in the study were middle-aged, married or widowed women that had formed their own care organisation in response to the need for care within the community. They also belonged to a local registered NPO. This organisation was founded in 2002 with the objective of offering support to the volunteer caregivers by providing working materials and basic training. The volunteer caregivers were meant to receive a monthly stipend of 500 ZAR (approximately US$75) from the Department of Health.

Interview schedules containing open-ended questions were used to guide the individual interviews. The main themes covered in the interview schedule were that of the burden of care, social support needed, social support provided, unmet support needs as well as social capital issues such as relationships of trust, social networks, social bonding, bridging, linking and cohesion between the volunteers and stakeholders. Interviews were conducted in isiZulu, the local language spoken in the area, and were administered in the presence of the researcher by an isiZulu-speaking interpreter. Interviews lasted between 40 and 50 minutes each and were audio recorded, transcribed and translated into English. All ethical protocols of anonymity, confidentiality and voluntary participation were observed and necessary approvals received, as described in Chapter 1.

Findings

The findings in this study revealed the aspects of social support received by the volunteers, the lack of support experienced from the various stakeholders as well as underlying social capital issues that may have hampered the accessing of social support.

Social support received by the volunteers

The coordinator as a provider of support

The volunteer coordinator played a pivotal role in the provision of support. She was often seen not only as an authority figure but also, in some cases, as a confidant. Due to confidentiality constraints between volunteer and patient, the volunteers were unable to talk openly to anybody except the coordinator about their care work experiences. Volunteers then turned to their coordinator for guidance when faced with emotionally disturbing experiences. However, the coordinator was only able to provide limited support due to factors such as limited experience and lack of training as a counsellor. As a result, even though support was provided, some volunteers, such as Participant 1 in the following quote, found her help to be of little use to them as the effects of the informal counselling were short-lived.

> *We report to our coordinator, and she would say we should persevere and try to understand the pains that come with the job … there is nothing else that she comforts us with.* (Participant 1)

Emotional support provided to the volunteers

Family support played a vital role in encouraging the volunteers. In some cases, volunteers obtained useful support in the form of reassurance and encouragement from their own family members and discussed positive experiences on the support provided. In other cases, volunteers referred to the support from their families as "encouraging" and "being the reason for them continuing with their care work".

Volunteers shared a special relationship based on trust and commonalities with each other. They suggested that by talking with each other they ultimately felt better about their experiences as they were not bound by confidentiality toward each other. The volunteers revealed that talking about or sharing their difficult experiences with each other provided them with immense support and comfort. Most of the volunteers stated that they tried to have regular meetings with each other. During these meetings, they shared their experiences with each other and provided possible solutions to dealing with stressful encounters. As one volunteer put it:

> *We come together and talk or share our experiences with each other. That's where we express our sorrow and sadness of working with a person for so long. You bath them and feed them and your hopes are raised and you get excited thinking that they will recover and then they just die.* (Participant 10)

Social support needed by the volunteers

Although volunteer meetings acted as a safe haven, volunteers expressed their need for more support of different kinds. A feeling of neglect or a lack of support was experienced by all participants. The support needs of the volunteers were immense due to the nature of their care work. Volunteers felt as if their communities isolated them and government had forgotten about them. This affected their morale in a very negative and demoralising way.

> *Say for instance I get to a house and I wasn't well received or felt exploited. I have to report the incident in the meeting but it has proved useless to do that because you don't get any help at all, you just have to go back there and hope things are better next time around.* (Participant 8)

This statement made evident the lack of support experienced by the volunteer. Volunteers expressed a need for emotional support and skills to cope with experiences of this nature.

The main forms of social support needed were tangible, informational, and emotional/appraisal support. The tangible support needed included that of financial support in the form of a salary, but they also needed a hospice, transportation to and from the patient's house and working materials in the form of protective gear, disinfectants and wound dressings. Informational support came in the form of the provision of first aid, patient care and counselling training. Emotional and appraisal support needs overlapped somewhat and took on the form of counselling provided to the volunteer.

Tangible support needed

Financial support and salaries

Poverty affected both patient and volunteer negatively. Patients often had empty cupboards and besides almost starving, needed to take their medicines with food. This kind of poverty put the unpaid volunteer in a situation where the volunteer had to take from their own empty cupboards in order to feed the patients and expressed a need for help in the form of a food sponsor to provide food parcels to their patients, as one of the volunteers put it:

> *We find ourselves as volunteers having to take from our own food which is barely enough for our own families.* (Participant 10)

All ten interviewed participants stressed their need for financial support in the form of a salary. This, they stated, would improve their quality of life by providing them with a means of providing for their families, running their homes and increasing their self-worth, as expressed by one of the volunteers:

> *If we can get financial support, as in salaries, it would make our lives much better and improve our conditions at home. We do this work because we*

> *love doing it. However, we might even end up resenting it because we don't get anything.* (Participant 2)

The lack of funding/finance had consequences on the daily functioning and morale of the caregivers. As previously mentioned, every volunteer received a 500 ZAR stipend from the government. This amount was meant to be provided on a monthly basis but instead, according to the volunteers, was provided approximately once every three months. The purpose of the stipend was for the volunteers to buy detergents to keep their uniforms clean (the reason why it is called 'soap money'). However, volunteers had to use this money to meet their basic needs. Transportation and groceries for their families and often for their patient (porridge) were paid for with the stipend and the volunteers, such as Participant 1 in the following quote, expressed their frustration with the irregularity of the provision of the money.

> *Sometimes you take from your own groceries at home, ask from your neighbours or use the very 500 ZAR that you get to buy soap to wash the clothes for the month. The thing is, patients cannot take their medication before they eat. They must have eaten something or even porridge before they can take medication. We are supposed to be getting the stipend every month, however, sometimes a month passes by and we enter the second month without getting anything. So it happens that sometimes you get it after three months or so.* (Participant 1)

Hospice

Six out of ten participants, including Participant 1 in the following quote, voiced their need for a hospice, stating that the presence of a hospice would help tremendously with regard to patient care. Volunteers felt that if all their patients were admitted into a hospice it would cut down on the time spent walking from patient to patient, all working material would be in one place and having the patient in a hospice would take away the negative experience of family neglect.

> *I would really appreciate it if there is a person who can build a place like a hospice where all the patients can be put together and we as volunteers can work at different shifts. This will give us time with our families and to do other activities that we are unable to do.* (Participant 1)

The volunteers also felt that working shift work at a hospice would remove the dangers of having to make unexpected house calls at night.

Transportation

Volunteers described walking long distances to each patient's house on a daily basis. Although all the volunteers had to travel to their patients on foot, in certain cases of emergency other arrangements had to be made. Many of the participants described how their fellow community members would not voluntarily transport them and their patient to the nearest clinic when needed. Instead, when asked by the volunteers, community members agreed to provide transportation on condition that they were paid for it. Volunteers were also forced to make use of taxis when transporting their patients and many requested that transport be provided to assist with such problems. The difficulties of finding transport are demonstrated in the following quote:

> *If we need a car we have to borrow money to hire it even if we don't have the money at that time because no one will take us for free, no one.* (Participant 9)

Working materials

The coordinator was responsible for providing basic working materials such as disposable gloves, disinfectants, ointments, etc. for the volunteers. Although initially useful, these materials were consumed quickly. Once depleted, the materials were not replaced, leaving the volunteers to make alternative arrangements with whatever materials they could find, for example, using plastic packets as a substitution for gloves. This placed a large amount of stress and feelings of vulnerability on the volunteers. As one of the volunteers put it:

> *We get working material from the coordinator even though it's is not sufficient. Even the gloves we get are not strong. You find that there is water inside the glove whilst you are bathing the patient.* (Participant 5)

The role of the community healthcare clinic in the provision of support

An interesting relationship of support being provided was the relationship between the volunteers and the other professional healthcare workers. Healthcare workers refer here to those, including nurses, who worked in the community healthcare clinic. During the interviews, some volunteers described the role of the healthcare workers as being twofold. The first role was that of data collecting in the form of surveying. It was described by the volunteers that healthcare workers would visit the homes of ill patients and gather information from the patient in order to ascertain the patient's state of health. The second role of the healthcare worker was described by the volunteers as first aid treatment provided by the healthcare clinic to community members in need of medical treatment. Although some support was provided in the form of basic working materials, it became evident that those volunteers who knew certain healthcare workers personally were given preference when it came to the provision of the necessary working materials. Those volunteers who did not know any healthcare workers on a personal basis were refused access to any working materials, as expressed by Participant 7:

> *If we don't have enough working material we ask the clinic to provide for us, for example, bandages and ointment for sores. I don't know how to explain it but they are not entirely comfortable with supporting us, it depends on who you are. If you know someone from the inside then they will help you, but if you don't know anyone they tell you to bring the patient for a consultation like everyone else. That is our biggest confusion because they promised to work with us and help/support us when we need them to. We used to go to the nearest clinic to ask for working material and they would give it to us, but they asked our community why we have to go so far for help when they can easily provide for us. So the head nurse here promised to assist us from now on, but we haven't received anything and whatever we get is based on whom you know on the inside. Otherwise we have to take them to the clinic with us so they can get the help they need.* (Participant 7)

Informational support needed

Training

It became evident from the data that volunteers felt unprepared when dealing with certain situations with their patients. Almost half of the interviewed volunteers stated that they needed some sort of healthcare-based training, especially first aid training, to prepare them for their care work as they found themselves in situations where it became necessary for them to practice those skills. Volunteers also found it necessary to have basic counselling training in order to provide better guidance to their patients, as expressed in the following quotes:

> *I believe that we need some training that will teach us how to handle different situations that we come across during our volunteer work.* (Participant 1)

> *We need more training. We have been trained before but this work is hard. You know when one of your patients die* [sic] *it gets so hard for*

> *me, because I have spent so much time with them and we had a bond between us.* (Participant 4)

Emotional/appraisal support needed

Although family members of the volunteers in some cases seemed to be supportive of the service the volunteers provided to the community, some found that they could not turn to their families for support. They disclosed that they could not talk to their families about the hardships faced as a consequence of their care work due to the fact that the family did not approve of the work done by the volunteers.

> *They think we are insane and call us stupid. The worst thing is that even at home, when I get night calls to come and attend to the sick patient, when I come back from those houses my sisters would say "Don't touch anything because you might be carrying this HIV in your nails." They even go so far as to saying* [sic] *that I should wash my hands with bleach.* (Participant 2)

The negative reactions as described in the above citation draw attention to the unsupportive nature of some of the family members of the volunteers. Such experiences may worsen feelings of isolation and despair on the part of the volunteers.

The need for support from government

Volunteers felt that they mostly needed support from local and national government. They felt as though government dismissed them, and they expressed their dismay at how none of the representatives from the Department of Health interacted with them or visibly acknowledged them and again looked to researchers to bridge the gap between the two groups. Volunteers saw researchers as a direct link to government and hoped that the work done by researchers in the study area would be shown to government representatives in order to change volunteers' working conditions. Although volunteers tried, through their coordinator, to arrange meetings with a government representative, they were unsuccessful. This added to their frustration. Volunteers stated that although support was provided in the form of some working materials, it was inconsistent and when the supplies were finished they had to wait long periods before they were supplied with more.

> *For me, it is the government that I would like to see giving us support. I just wish that the government can really do something to make our situations better.* (Participant 1)

The community role (lack of social support)

Six out of the ten volunteers stated that community members were particularly unsupportive of the care work done. Volunteers were mocked and their work frowned upon by most community members. When the volunteers were asked what they thought the reason was for not receiving any support from community members, one of the volunteers responded by explaining that the divisions among the community members ran deeper than those at a social level, meaning that the community was not only unwilling to help because of the stigma attached to care work but also due to the fact that the community was under the misconception that the volunteers earned a salary and that they were therefore not entitled to ask for help because they had money of their own. Participant 2 expressed it this way:

> *I think it is because the community have* [sic] *a perception that we earn a lot of money because we work for the government. They don't believe us when we tell them that we are not working for the government and we don't get paid but only get "soap money". Still, they don't believe us. Therefore they end up not helping us.* (Participant 2)

Community members were viewed as uncaring and spiteful. Cohesion between community members was also put in a negative light as caregivers were constantly faced with ridicule from the community members due to the nature of their work. When asked why this volunteer felt as if she could not trust her community members she responded by saying:

> *It is because they are the ones who laugh at us because of the work that we are doing. So! How can I trust them? The community is even disgusted by us saying that we have AIDS. How can they help us than because the only thing they do is to laugh at us?* (Participant 2)

This was disheartening for the caregivers, as they could not look to their fellow community members for any kind of support or help. Volunteers explained that the community members laughed at them, ridiculed them and even accused them of being infected with HIV/AIDS themselves:

> *We do feel stigmatised especially if it is the people who are not sick saying these things to us. Sometimes when you try to share some of your food or fruit with them, they will say "No thank you, we don't want it". This is all because we touch people with AIDS. Therefore, I don't trust them that they can help us with anything.* (Participant 2)

> *People just don't care about each other; you are more likely to get help from a relative. Neighbours don't usually help each other out here.* (Participant 9)

On the question whether volunteers trusted their community members to provide support such as taking care of their children (if necessary) while they were at work or providing the volunteers or their patients with food, if necessary, most of the volunteers interviewed said that they did not trust the community members whilst others admitted that they had never asked for any help from their community.

Interviewed volunteers described instances where their patients had succumbed to their illness and passed away but the patients were not acknowledged by their community nor were their family members supported by the community. In some cases, guardians of the patient did not show any empathy and refused to arrange a proper burial for the deceased. One particular volunteer stated that, after her calls for help had fallen on deaf ears, she had no alternative but to turn to the Minister of Social Development for support with regard to arranging a burial for her patient:

> *There is one girl that passed away two months ago and no one came to help until the old lady she was staying with called me and said that I should deal with this mess because she doesn't want to have a heart attack and anyway this is my patient. When I asked her whether she had covered this girl on her burial scheme she said no. When I asked her why she didn't because this girl has being staying with her for so many years and helping her out she said that it wasn't her child; she did not give birth to her. I then called the Ministry of Social Development to come and help me out with this situation because he stays in [name of location just outside the area of study]. He then came and saw the girl lying there because she was still in the house. He then organised everything for her funeral. That is how she got buried.* (Participant 2)

In this particular case, help was provided but from an outside entity. Help did not come from the community or family or even from friends of the patient, and even though help was provided in this case, it was not a regular occurrence. The volunteer did not have a personal relationship with the minister nor had she ever contacted the Minister prior to this incident but she felt a desperate need to help the deceased patient. This incident speaks volumes on the breakdown of relationships of community spirit in this community.

Discussion

The findings of this study provide insight into the social support needs of the volunteers as well as the social issues/relationships regarding the experiences of such support. The study confirms and extends knowledge on the burden of care, the daily care work routine of the volunteers and social issues such as poverty, and also highlights the need for social support and improvement of the relationships between members of the community. Social capital issues such as a breakdown of trust, lack of social cohesion and of social networks are discussed as precursors to the volunteers not being able to access support adequately. It became evident in the findings that both stakeholders (voluntary organisations) and volunteers played a key role in the accessing and provision of support. The findings of this study point toward a lack of social cohesion amongst community members in the study site.

Social support provided

The findings on the role of the coordinator as a provider of support were two-fold. On the one hand, the provision of working materials were consistent with the study by Mabude, Beksinska, Ramkisson, Wood and Folson (2008), which focused on the improvement of HBC kits. However, what this study found was that, although there was a great demand for the kits, the contents of HBC kits were poorly available. Basic working materials were made available to the volunteers on a very irregular basis and were not sustainable. This forced the volunteers to find alternative materials when providing care. The implications of such a finding are that the lack of working materials placed extra strain on the volunteers and created the need for tangible support. On the other hand, the unrealistic expectations of one person, albeit a leader, to sustainably provide the kind of support needed, are highlighted. It is impractical for the coordinator to be expected to provide tangible and emotional support to all volunteers without receiving any sort of support herself or training to better prepare her for such a task. It is essential that social networks such as NGOs, NPOs and the Department of Health recognise the role of the coordinator and provide her with the skills needed to cope with demands made by the volunteer and ultimately to provide the volunteers with the counselling that is needed by them. Perhaps the role of the coordinator should in future be that of coordinating a team of subordinates with the combined skills, such as dispensing materials, providing on-site counselling and training, educating the communities about the role of the volunteers, etc. which are necessary to provide adequate support to the volunteers. This would empower the coordinator and eventually enable her to provide the emotional support that is needed by the volunteer.

In some cases, the volunteers received emotional support from their family members as well as from each other. These volunteers were able to share certain experiences with their family members and draw the support needed. In these cases, it stands to reason that the relationships of trust between the volunteer and her family members might have been sound enough for the volunteer to share certain experiences in order to gain support. This also suggests that, in cases such as these, the family members of the volunteer perhaps acknowledged the importance of care work and as a result provided support and motivation where necessary. This suggested that some form of relief from the emotional and psychological burden of care was experienced when the volunteers were able to speak about their issues. It also suggested that the volunteers were able to provide each other with emotional as well as informational support in certain instances.

The support provided by the healthcare clinic was based on a complex relationship between the volunteer and the healthcare worker. Volunteers were not convinced that support was made available to all volunteers and felt that only certain volunteers, who knew the healthcare workers personally, had access to materials from the healthcare clinic. This suggested a breakdown in social cohesion between the two. The healthcare workers' behaviour might have been due to a resentment of the close-knit relationships shared between the volunteer and patient as opposed to the strained relationship between the patient and the healthcare worker. It seemed that the community favoured the type of hands-on care provided by the volunteers as opposed to the more observatory care provided by the professional healthcare workers and as a result the community turned the professional healthcare workers away. This may have been due to the nurturing and empathetic treatment provided by volunteer to patient. As a result, this might have had a negative influence on the volunteers receiving adequate social support from the healthcare workers. Interventions should be put in place in the form of improving social bonding and bridging by perhaps educating both the volunteer and healthcare worker on their individual roles within the community as well as the importance of providing each other with support in order to lessen the burden of care that would bring the volunteer and healthcare worker together.

Social support needed by the volunteers

Volunteers taking part in the study were under mental, emotional and physical strain due to the nature of their care work. They felt despondent when faced with ridicule and stigma from their own community members. The social support needed may have been accessed from various resources. However, important to note is that there was an issue of not asking for support from social networks/organisations among some of the volunteers. Volunteers did not seem to be able to identify with organisations such as faith-based groups as a source of support and they rather associated with these organisations at face value, i.e. they saw churches as solely for praying and other religious practices. This raises issues around social capital. Support could have been provided if the volunteer asked for it. For some reason the volunteers did not regard this social network as a source of support. Perhaps the volunteer did not trust that support would be provided.

The reason for this was possibly a lack of social trust and social cohesion between volunteers and social networks, which resulted in a lack of support. The volunteers might not have trusted that the organisations would be able to provide support and as a result, they did not ask. Regardless of the possible reasoning behind this issue, it is evident that there is an urgent need to bridge the gap between the volunteers and surrounding social networks. Relationships between social networks and volunteers need to be at a position where volunteers are able to identify these organisations as resources or sources of support. The findings of the study being reported here suggest that the volunteers would have liked to be better informed with regard to their duties and the accessing of working materials. Relevant NGO's, NPO's and community members could make use of the volunteer meetings as a platform to educate the volunteers as well as the coordinator about their roles as stakeholders and possible sources of support. It is then that volunteers would become more aware of their possible sources of support as well as gain some sort of feeling of validation for their care work.

The majority of support needed fell under the ambit of tangible support, in the form of financial remuneration, working materials and that of a hospice. Most of the participants voiced their need for a hospice. They justified this by explaining that a hospice would cut down on the time walking from patient to patient and increase the time spent providing care for each patient. Volunteers also felt that they could work shifts and ultimately spend more time with their own families this way. Whether feasible or not, such a hospice may however lead to complete isolation of both volunteer and patient. People who are admitted to a hospice or who work there may face damning stigma due to the fact that a hospice may become known by the community as 'the place where people with AIDS are'. The issue of no financial remuneration places strain on the survival of volunteers. The volunteers all voiced their love for their care work, but not being able to provide for their families often added to their poverty and ultimately their feelings of hopelessness. It is suggested that government acknowledge the work of volunteers in the form of payment.

Conclusion

This chapter discussed the social support issues of the volunteers in this particular community where the study was undertaken, and the reasons behind a perceived lack of support. In light of the results of this study, the volunteers battled daily obstacles while providing care for the ill. Although their circumstances were disheartening, the determination of the volunteers to provide care against all odds was admirable. However, the evident breakdown in trust and cohesion within the community was at a critical point and needed urgent attention from the relevant stakeholders. It is imperative that coordination at all levels of social capital, but particularly focusing on the bridging level, be improved. Being identified as the most feasible option to the provision of care (Akintola 2005), the work and the socio-economic challenges of the volunteers need to be acknowledged by government with the objective of improving the social support structures of volunteers. The volunteer coordinator plays a key role in the support experiences of the volunteer. Strengthening her role could increase cooperation and knowledge about other social networks and support opportunities. However, more pressing is the need for interventions to be done with the community in order to improve the social capital among the community and to mobilise social support. It is only through the improvement of these relationships that social support may become more readily available and, more importantly, more easily sourced by the volunteer.

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Chapter 7

Those without the choice to care

Fatimah Dada & Yvonne Sliep

Introduction

HIV/AIDS has had disturbing consequences for the people of Southern and South Africa. One of the most significant is the increasing burden of caring for the sick. An estimated 1.2 million AIDS orphans and over six hundred thousand AIDS sick in South Africa (Treatment Action Campaign 2009), have placed care work in an unprecedented crisis (Peacock & Weston 2008). Whilst stakeholders are still in the process of developing the right HIV/AIDS policies and interventions, the immediate needs of the sick and dying have spawned grassroots responses to the care work crisis (Ogden, Esim & Grown 2006). These responses are centred primarily on community members – friends, family and volunteer care workers (Campbell & Foulis 2004). Currently, home-based care (HBC) is largely non-clinical, providing a range of care and support services to affected persons and families by informal carers or volunteer care providers (Ogden *et al* 2006). Yet this response is not sustainable as under-resourced communities are battling to cope under the strain, and the demands of care work – monetary, physical and emotional – are playing a huge role in perpetuating the difficulties that are already experienced by members of under-resourced communities (De Jong 2003).

This chapter reports on a qualitative Masters research project that sought to create greater understanding of the support perceived by informal care providers in their care work of a friend or family member ill with HIV/AIDS. Informal carers refer to friends and families of the sick who are untrained in clinical care and are expected to care for those who are ill. For the purposes of this study, such informal care workers are distinguished from community health workers (CHWs) and home-based carers (HBCs) (two groups of volunteer care workers) who have had some rudimentary training, and from clinically trained care providers. Informal care providers face particular challenges in their role as carers. Having to respond to these additional tasks as well as dealing with people about whom they often care deeply, but who may die while under their care creates additional stress. In addition, informal care providers are vulnerable to burnout, infection and illness (Akintola 2008a). They often do not have access to basic amenities (Steinberg, Johnson, Schierhout & Ndegwa 2002), do not receive much support themselves, and may be ostracised and discriminated against due to the stigmatised nature of the epidemic. Often carers are themselves HIV-infected and in need of care. They suffer economic costs (Akintola 2008a; LeBlanc, London & Aneshensel 1997) and reduced food security (Opiyo, Yamano & Jayne 2008) and face exacerbated levels of poverty as their care work detracts from other productive activities (Akintola 2008a). They are restricted from opportunities for personal development as they often have to be removed from school or employment (Akintola 2008b; Peacock & Weston 2008).

Being in the domain of 'women's work', care work has often gone unrecognised, and so too, have care workers (Conrad & Doss 2008). The HIV pandemic has, however, strained the capacities of many under-resourced settings to provide care, and has brought to the fore many of the previously unacknowledged dimensions of care work. These new insights challenge previously accepted ideas of the value of care work and care workers. In recognising the plight of care workers, one is made aware of the huge input they are making in the HIV/AIDS response. At present, insufficient attention is paid to the experiences of caring for a sick individual from the perspectives of informal caregivers (Ogden *et al* 2006).

Our research was informed by the social capital theory of Putnam (1993). The social capital theory asserts that collective action can be made easier through certain societal elements, namely social norms, norms of reciprocity, trust which gives rise to reciprocal relationships, and networks which facilitate interaction.

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

The specific study objectives were:

- **On a social bonding level:** How do caregivers perceive the accessibility and availability of support they receive from individuals in their immediate environment (family members, neighbours)?
- **On a social bridging level:** How do caregivers perceive the accessibility and availability of support from various groups and organisations, such as churches and community-based organisations (CBOs)?

- **On a social linking level:** How do care workers perceive the availability and accessibility of support from government structures, businesses, and institutes external to the environment? What support would caregivers like to have available to them?

Research methodology

Study sample

Those who participated in our research were purposefully selected, based on their residence in the study area, informal care work with HIV-positive friends or family members, and being women. Participants were recruited by the various HBCs operating in the area and with whom they had frequent contact. The ages of the 9 participants ranged from 20 to 67 years, with a mean of 34 years. These women were caring for friends or family members on an informal basis, rather than as volunteer care workers (HBCs and CHWs). This band of care workers were rather more disjointed and isolated than the volunteer care workers in the area, who meet regularly. With many of the participants, their only contact with any kind of formal support group was through the HBCs. All but three of the participants responded in isiZulu, and an interpreter thus facilitated the interviews.

Data collection procedures

Collected data was on the perceived support available to participants in their capacity as carers. The data was obtained through interviews with participants using a semi-structured interview schedule. Interviews were conducted by the first author at the participants' homes. She was accompanied by an interpreter and the HBC assigned to the area. All the interviews were recorded on audio-tape, with prior consent from the participants, and later transcribed. A semi-structured interview schedule and open-ended questions facilitated the interview, and allowed a free range of responses to emerge from the participants on their experiences and perceptions of the kinds of support available to them in their capacity as informal caregivers. Questions in the interview schedule were general, tapping into perceived support within the various levels of Putnam's (1993) social capital theory. Further exploration was an essential component of the interview.

Findings and discussion

Poverty weakens social capital

Our research found the effects of poverty to be extreme, hampering the creation of beneficial social capital. These effects are discussed in terms of the bonding, bridging and linking levels. Poverty affected the extent to which individuals in social networks were able to provide assistance; the contextual effects of poverty increased the burden of caring on the carers by, for example, transport costs and difficulties in transportation; and the problems of poverty were not addressed sufficiently at governmental level.

Poverty and social bonding

The study found that poverty coalesced with stigma and misperceptions of the disease to sustain the participant's isolation: Individual community members might not have the resources to help carers or they may conserve money and/or energy for their own struggles. Poverty influenced the support of the carer because it reduced the individual's networks' ability to provide assistance or the ability of the carer to reciprocate. The community where this study took place is steeped in poverty, with basic survival necessities such as food and medicines being unavailable in many households, which inhibits the potential of householders to be of assistance to others

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

> *Some of them do not work; they are suffering, some people do not go to hospitals to collect the treatment, because they don't have money to go there.* (Participant 9)

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

> *… so what I think in my case personally is that my neighbour is also very troubled. She lost her daughter who was feeling ill and her child … she had a baby so she must look after the baby. I don't think it's anything personal when she doesn't look my way when I'm having a hard time, 'cause she has a lot of troubles of her own.* (Participant 3)

> *In my family, there is* [sic] *a lot of people, so it happens like this people are caring for their children, but they are always supportive, so I cannot rely on them, we cannot rely on them … because they are caring for their families, for their children and mothers, you know.* (Participant 9)

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

> *… this child has had to get out of school, I made her to stop* [sic] *going to school, because if I am not here who would stay with her, so she had to stay here at home* [to look after patient]. (Participant 3)

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

Poverty and social bridging

Adler and Kwon (2002) state that an individual's network of social ties creates opportunities for social capital transactions, yet Adler and Kwon (2002) do acknowledge the importance of the network's ability to provide resources, the lack of which does not equip individuals in a particular network to invest in social capital. Ability refers to the competencies and resources at the nodes of the network (Adler & Kwon 2002:26). In Bourdieu's (1985:241-258) discussion of social capital, he forces us to consider not only the existence of community social networks, but also the resources (potential or actual) possessed by the networks, and the individual's ability to draw upon the network for those resources. In our study, there was a clear inability of the networks to provide assistance, based on poverty and their own struggles with daily living. Theorists are divided as to whether ability should be considered a source of social capital or a complement to social capital, with the former suggesting that social capital theory loses some of its utility when the resources of networks are not considered, and the latter suggesting that incorporating resources makes social capital theory too broad. The data in this research does suggest that a lack of resources was a significant impediment to accessing beneficial social capital.

In the study being reported here, almost all participants mentioned transport problems. The difficulties revolved primarily around transport costs and inadequate transport, either because the public transport points were too far or because the roads were inaccessible. The inability to meet transport costs reflects the poverty of the community, and poor road quality reflects the apathy of local leadership and/or government to develop infrastructure.

> *There is a lot of money that get* [sic] *spent, especially on transport, because when she is sick and needs to be taken by car to the clinic the people charge approximately 200 ZAR* [approximately US$30] *to take her to the clinic. If it happens at night then we are in trouble, because it is hard to find cars at night.* (Participant 3)
>
> *Roads must be closer, make transport easier, even if you want to do something you cannot because the roads are not here. Besides that I cannot think of anything else.* (Participant 3)
>
> *… sometimes there isn't money to take her to the clinic. Like today she's going to the clinic, but it's been two days since she went out of her ARVs, but because there was no money to go to the clinic she couldn't go.* (Participant 7)
>
> *… and we also went to the clinic, so if we had to go from home to the bus stop, of which it is a long distance and we don't have a car, yes, that was the toughest thing. Maybe they would say we must come tomorrow and then it's the following day, the following day, that was the worst thing;* [transport] *was the biggest one and still it's the biggest problem.* (Participant 9)

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

> *The taxis do not go in to our home* [it is very isolated]*, so we need to travel and it's a long distance from my place to the bus stop, more especially to someone who is very sick, it is very, very difficult, sometimes we need to take a wheelbarrow or something, because she cannot move for herself, yes it's the toughest thing.* (Participant 9)

What this translates to is an increase in the burden of care on the carer. One questions whose responsibility it is to ensure good infrastructure, and then why the informal carers of this community are not supported in a way that eases daily difficulties, such as transport, and also why the ill are cared for at home when they clearly need hospital attention. This draws attention to the function that should be fulfilled by the organisers of society. Similarly, in highlighting the inability of a social network to provide assistance, attention is drawn to the role of those in the community who are more powerful and who can create contexts that would relieve carers. In this regard, it is significant that there was no mention of local leadership in the participants' responses to the perceived help that they are currently receiving. This discussion draws attention to a criticism aimed against Putnam's social capital theory – that it is excessively bottom-up and there is insufficient attention being paid to top-down processes, both in their ability to promote or impede the creation of social capital (Evans 1996; Ostrom 1994; Woolcock 1998). Campbell and Foulis (2004) question the utility of emphasising AIDS-related home care when the environmental context that patients are discharged into cannot support them. While the research by Campbell and Foulis (2004) specifically pointed out a lack of food and water, our study pointed to inadequate transport and the related poverty, which significantly increased the cost of care on the carer – physical, financial and emotional.

Poverty and social linking

Social grants and ARVs

All participants in this study reported receiving some money from government in the form of disability grants, child care grants or pensions, but this in most cases was money that was intended for other people in the carers' immediate family, including in some cases the ill.

Six of the nine informal carers reported that their patients were being treated with ARVs. The patients who were not treated with ARVs did not require it because their CD4 count was not low enough. Yet of the six participants, five actively cared for their patients, as the ARVs did not bring them back to their original state of health. The carers of the two HIV-positive persons who were not on ARVs also reported much difficulty in caring for them. The primary medical input (as reported) for these patients was the ARVs, and this in itself was inadequate. It became hard to differentiate, in this context, between help for the carer from help for the ill. ARVs and proper medical attention directly relieved the carer, and lack of same further burdened the carer. Despite concerns that the main medical input did not translate into complete relief for the carer and the ill, it should be noted that there was general consensus among the carers in this study that medical attention was sufficient, and participants did not have complaints regarding the care provided by clinics and hospitals (apart from access to them because of transport difficulties, discussed above).

Primary input from government is understood as being inadequate

The discussion on grants and ARVs summarises the main contributions that participants reportedly received from government. However, both appeared to be inadequate in addressing the needs of the ill that impacted on the carer. Perhaps what is more important is that none of the participants reported any contribution from government in addressing their particular concerns in their capacity as carers.

Nsutebu, Walley, Mataka and Simon (2001) note that lack of government involvement may be explained by the lack of an adequate home-care model that may be applicable to a resource-strapped government, and lack of government technical expertise or motivation for developing and implementing HIV/AIDS home care. Campbell, Nair and Maimane (2007:358) suggest further that government involvement is hampered by transformational processes, lack of resources, heavy workloads, low salaries, limited skills, a large volume of social regeneration projects, and finally bureaucratic red tape that inhibits public servant involvement in non-standard activities. Despite this, a central theme running through the literature is that the HBC and non-governmental organisations (NGOs) cannot do it alone. For an effective response, greater involvement from government is imperative. An important conclusion in much of the literature is that the key to an effective response is the active participation and networking of the various stakeholders ranging from individual community members to government policy makers.

Stigma and social norms that weaken social capital

In our study, it became clear that the informal carer's HIV-positive status, or the association with an HIV-positive individual, contributed to the weakened networks at a bonding level. This appeared to be related to HIV/AIDS-related stigma and discrimination which are still rampant in the community, creating a climate of mistrust, denial and fear, and a situation of isolation and exclusion of the ill and their carers. Social norms that suggest that individuals must 'take care of their own' further isolated the ill and their carers.

Shame, misperceptions and mistrust

There is much shame associated with HIV/AIDS. According to the participants in our study, this inhibited open disclosure of a positive status, which then affected the extent to which carers could expect help from others or whether patients would disclose their status and seek help. HIV-positive individuals, their families and care providers were in this way ostracised and isolated. The apparent conclusion is that being HIV positive, or being associated with someone who is HIV positive, significantly weakened the informal carers' social networking.

> *Because there are people who are … like right now they are … not coming to visit us here as usual, they are not coming here because … I am not sure, but I think they are not coming here because they think we are all HIV positive.* (Participant 8)

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

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

Trust is an essential element of social capital (Putnam 1993). Social capital rests on the cooperation between various stakeholders or parties, and trust lubricates that cooperation (Putnam 1993). It was apparent in this study that inhibitions on disclosure of one's status or the status of one's ward were strongly related to mistrust. Community members' mistrust stemmed primarily from fears of gossip, creating a bad name (reputation) and being ridiculed, shamed or ostracised. This relates directly to fears of stigmatisation and discrimination. Put differently, perceived stigma (Scambler & Hopkins 1986) created a mistrustful climate in the community, and this limited the extent to which the existing networks could be called upon for assistance, limiting reciprocity, and ultimately inhibiting the creation of social capital.

> *No I don't trust them* [neighbours]*, because you know sometimes when you have a tiff with people, they would shout most confidential information about you for the world to hear. So no, I wouldn't trust them.* (Participant 6)

Participants reported enacted stigma (Scambler & Hopkins 1986), or that they were actively discriminated against. This contributed significantly to inhibitions to open disclosure.

> *It's very painful, because they call me names; they say everything that they want to say.* (Participant 8)

Stigmas still existed in the community and fears of same, both perceived and enacted, created a climate of mistrust. A network or tie can be said to contribute to the creation of social capital if trust exists in that relationship (Putnam 1993). In the case of our study, trust was clearly missing. Mistrust, created by stigma, inhibited disclosure. This inhibition has far-reaching consequences, the most destructive possibly being that the virus will continue to be passed on. For our purposes, inhibitions on disclosure quite simply meant that individuals could not draw on existing sources of assistance, and they were increasingly isolated and ostracised.

HIV/AIDS stigma and the associated discrimination are impeding efforts to provide adequate care and support for the sick (Bond *et al* 2002; Brown, Trujillo & Macintyre 2001). This has been recognised for some time now, as evidenced in the literature on HIV/AIDS stigma and discrimination. A lack of complete success in preventative intervention has resulted in more attention being placed on the social constructs of the epidemic, including the role that stigmas are playing in blocking preventative measures and in providing adequate care (Campbell, Foulis, Maimane & Sibiya 2005; Hayes & Vaugham 2002). However, stigma arises from much more than misinformation. It is a complex social process that is shaped by meanings and explanations for sickness, ideas concerning disease transmission and sexual behaviour, and fears associated with illness, disease and sex (Bond *et al* 2002). It has also been suggested that stigmas function to preserve existing power differentials in society, and that the stigmatisation of others serves as a source of self-esteem in an under-resourced environment where material access to that respect is not possible (Campbell *et al* 2005). The conclusion is that there still is a greater need to create awareness, and that stigmatisation as a complex social process deserves more research in its own right.

Social norms that weaken networks through their isolating effects

Social norms, generally discussed in the literature as being beneficial to social capital, played a role in further isolating participants. The fact that participants would not solicit help from others appeared to be rooted in the way that the community functions. These norms can be regarded as lacking in reciprocity. Reciprocity rests on the trust that is inherent in a network, and the ability of that network to reciprocate (Putnam 1993). The community of study was lacking in both these dimensions (with regard to HIV/AIDS care work). The expectation (or norm) that individuals in the community 'must take care of their own' served to isolate the carers by reducing the strength of their networks.

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

The HBCs as important resources that strengthened social capital

The HBCs emerged in the data as possibly the strongest resource that the informal carers could rely on. The support the informal carers said that they received from the HBCs overlapped on an emotional, instrumental and educational level. On a personal, or bonding, level, the HBCs were important sources of emotional and instrumental support, and on a social bridging level the HBCs imparted HIV/AIDS-related knowledge.

Emotional and instrumental support

In the HIV/AIDS literature, 'emotional support' often refers to moral, spiritual and psychosocial support that is provided to the ill by the carer (Akintola 2008b; Peacock & Weston 2008). In our study, it can be said that this was the same support that the HBCs offered the informal carer. The HBCs went some way in helping the informal carers 'carry their emotional burdens' and this support from the HBCs was possibly the strongest result that emerged in the data. This by no means undermines the instrumental support received, but rather highlights the emotional burdens carried by informal carers. The HBCs assisted emotionally by being supportive, offering advice, being welcoming and open to participants, listening to them, and providing an avenue of release for the carer from their daily burden of care, simply by their presence.

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

The HBCs were invaluable sources of instrumental support, assisting with cleaning, bathing and cooking. For many participants, this was the only instrumental assistance received.

> *When I have to go away I ask her* [HBC] *to look after the house and the kids. She is the only person whom I can trust, 'cause she knows how sick she is. Even when I'm away she sees that it is getting bad, she will call me to say that it is getting bad and if she has the money she will take her to the clinic or something. So she is the person that I can go to and talk about my problem, I look at her and liken her to my mother, 'cause she is the one who is around here whom I can turn to.* (Participant 4)

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

Relationship between the HBC and informal carers is propped up with trust and reciprocity.

What was it about the informal carers' links to the HBCs that allowed them (HBCs) access to their homes, thoughts, and troubles? The relationship that existed between the HBCs and the informal carer was one in which stigma, perceived or enacted, was absent. Participants could rely to a large extent on the HBCs because this was a relationship that they could trust.

The literature on networks in general suggests that networks may provide social support, self-esteem, identity and perceptions of control for an individual (Cattell 2001). Social capital literature states further that trust is an essential element in these networks (Putnam 1993). The HBC networks are more likely to provide these (social support, self-esteem, identity and perceptions of control) to informal carers in a context where they are isolated and ostracised, and cannot approach others. The trust inherent in this relationship allows for the activation of support (and information), as well as mutual interaction which would further strengthen this relationship, and may provide the leverage to further increase the informal carer's support and knowledge base by the HBCs' links to other stakeholders.

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

The HBCs as sources of informational support

At a bridging level, the HBCs provided access to information and knowledge of HIV/AIDS to the carers in this study. The assertion by some participants that the community needs to be informed on HIV/AIDS attested to the knowledge of the disease that the HBCs were seen to have. Some participants in this study explicitly stated that this knowledge came from the HBCs, and a fairly safe assumption may be that this knowledge gained by other participants was also due to their contact with the HBCs.

> *The home-based carer comes and she reminds me. She reminds me about a lot of things and she also speaks to my mother to tell her to stop drinking, but my mother still swears at her when she comes to say that.* (Participant 7)

> *There is this mother* [HBC] *who comes to tell us about HIV, they teach us and they talk to her and they talk to us, they teach us how to look after her.* (Participant 8)

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

> *… the neighbours they wouldn't even touch the baby, because they could see that the mother was sick, so they wouldn't even want to touch the baby.* (Participant 2)

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

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

The HBCs are networks or relationships that bring in new information and knowledge to the community. The primary importance of this finding, however, is not that this knowledge is available, because as stated media campaigns have attempted to reach even rural communities, but suggests rather that the HBCs provides a more efficient manner of disseminating HIV/AIDS-related knowledge. Diffusion of innovation is defined as "the process by which an innovation is communicated through certain channels over time among the members of a social system" (Rogers 1983:11). The HBCs may provide these channels of communication, having access to the homes of affected families, and more importantly, holding their trust. This puts the HBCs in an ideal situation to diffuse new information into the community by teaching and engaging community members in critical dialogue.

Informal care givers' perceptions of what support for the carer should entail

Participants' reports of essential support that is required included monetary assistance. Assistance in the form of monetary resources is understandable and may even be expected considering that adverse effects of poverty emerged strongly in the data. This is a very desperate and immediate need of the participants, and indeed of the community as a whole.

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

> *If they could fence like a small area here so that I can have a vegetable garden and have food to eat.* (Participant 6)

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

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

> *It is not as if I never think about work, about going to work although that would make things seem much easier, but then I start to think about what about this child – who will I leave her with when I go to work … it's not that I don't want work or that I cannot find work, I can find work, it's just that even if I do find work in a place that is not close by so I will have to be not here.* (Participant 4)

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

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

A conclusion that may be drawn from the responses of participants is that they may appreciate interventions that might allow them greater ability to take care of themselves. A further suggestion that may be drawn from the above-mentioned is that participants would like opportunities for empowerment. The term empowerment was initially understood at an individual level, relating to the intra-psychic world of the individual and referring to greater feelings of control and actual control (Rappaport 1981).

With regard to this study, the participants' expressed wishes for education, employment and self-subsistence farming suggested that members of this community were looking for opportunities to be more self-sustaining.

Later constructions of the term 'empowerment', and its application to health promotion literature prompted a more critical understanding: Individual empowerment needs to take place in the context of transformative changes that addresses contextual inequalities (Rissel 1994). Perkins (1995) defines empowerment as a construct that links individual strengths and competencies, natural helping systems and proactive behaviours to social policy and social change. Community well-being and health are thus directly related to individual members' perceptions of control or psychological empowerment (Rissel 1994). This control should work in coalition with raised levels of consciousness (Campbell & Murray 2004) and includes a socio-political aspect, which involves the active participation of community members as well as a redistribution of resources (Rappaport 1981; Rissel 1994). Empowerment is an important dimension of this discussion because, as mentioned, it reflects the perceived needs of the participants. It is also important as it addresses the sustainability of an intervention – grassroots participation and the strengthening of local resources may be more likely to ensure that the correct needs are identified and met. Yet another reason for its importance is because it provides a vehicle with which to address some of the contextual problems that hamper care work, these including, but not limited to, gender and class inequalities, poverty and apathy in leadership. Psychological and community empowerment is useful also for its transferability: as community members, and the community as a whole, are empowered in one aspect, their ability to address other issues affecting their lives is strengthened.

The emphasis on the redistribution of resources (as suggested by Rissel 1994) once again highlights the fact the any initiative requires the inputs of those who do hold more power (and thus more resources, monetary and otherwise). In this regard, Campbell *et al* (2007:361) conclude that it is a myth to regard the mobilisation of grassroots community participation as a cheap way of delivering services and addressing social problems in deprived communities, and that those seeking to implement such approaches need to recognise that they are extremely resource-intensive to initiate and maintain.

Conclusion

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

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Chapter 8

Untapped resources for HIV/AIDS care and support

Nicole D'Almaine De Klerk

Introduction

Within the South African formal health sector, there is a marked shortage of health professionals and resources for those who are ill (Lewis 2008; Naidoo 2008). This situation is exacerbated when considering care and support for people living with HIV/AIDS (PLWHA), since South Africa has the highest HIV/AIDS burden globally (UNAIDS 2008). As a result, the onus currently falls mainly on the shoulders of community members and caregivers who are given the responsibility of caring for HIV/AIDS patients – either voluntarily or because they are obliged to – to secure and provide adequate care and resources for those for whom they are responsible. Research points 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 a great burden – emotional, physical and financial – being placed on the caregiver (Akintola 2005; Kipp, Nkosi, Laing & Jhangri 2006; Swaans, Broerse, Van Diepen, Salomon, Gibson & Bunders 2008; Wight, Beals, Miller-Martinez, Murphy & Aneshensel 2007).

The study being reported here focused on exploring the current perceptions of present HIV/AIDS care and support within a semi-rural community, by those who are uninvolved in such care. It then explored the untapped potential within this community regarding care and support, and the way the needs of those who are ill can best be met.

Methodology

Procedure and participants

The community members who participated in this study came from different semi-wards of the larger community, and so contributed and commented on happenings and things that they had noticed within their own areas – generally, observations and perceptions were the same in all areas. Information was gathered by focus group discussions, with divisions made according to age and gender.

Participants in this study were homogenous in terms of language, ethnicity, culture and socio-economic background. They spoke isiZulu and the minimum age was 18 years. This age was decided, since it is adults who are usually expected to adopt care-giving roles, and the study was aimed at those who would be in a position to provide care, but currently are not, and who have no perceived obligation to do so. Since this research formed part of a larger body of research, as described in the introductory chapter (Chapter 1), orientation to the context by other members of the research team occurred prior to the outset of this study.

Members of the community who are not currently providing care, and those who have no current perceived obligations – social, familial or otherwise – to be doing so, were identified. Focus group participants were identified and recruited by the field coordinator for the project, and were randomly sampled from participants who had filled out the social assessment survey conducted for the overall project (see Chapter 2 in this volume). Initially approximately 13 participants were identified and recruited for each of the six focus groups; however, between four and eight participants arrived for each focus group discussion. 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 an isiZulu-speaking interpreter, who was also a member of the research team and therefore familiar with the area as well as the community. Discussions were audio recorded, transcribed and then translated into English. Prior to each focus group, consent forms were given to participants, confidentiality explained to them, as well as the process and reasons for the study. Ethical issues were also covered both verbally and in the consent form (see the introductory chapter for more details on ethical clearance).

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 46 and older. For each age group, both males and females were interviewed. More females than males took part in the focus groups. 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 was at a different developmental stage and could have had different views regarding the topic. Different priorities were set according to the life situation, and focus group discussions aimed at exploring HIV/AIDS perceptions 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 one hour. The discussions were largely unstructured, but were guided by a number of preset questions informed by the research theme.

Focus group discussion was 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. In addition, focus groups provide formal examples of everyday speech within the community (Denzin & Lincoln 1998:1-34), 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 initially be perceived as homogenous (Terre Blanche, Durrheim & Painter 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 four to eight participants who were recruited from various areas of the larger research location 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 under-stood and discussed between community members, and its associated emotions, as well as to explore perceptions surrounding psychosocial support.

Focus group discussions

All focus group discussions began with the researcher greeting everyone in isiZulu. It was explained to the participants that the researcher was learning isiZulu and that the focus group would be continued in English with the interpreter assisting between the two languages. The interpreter explained this language aspect to the participants in isiZulu.

Right from the start there were very noticeable differences between groups. In general, the male participants seemed to be much more at ease with the researcher and the process than the female participants. Female participants, upon arrival to the venue where the focus groups were to be conducted, usually waited to be greeted first by the researcher. On the other hand, in the focus group of men aged 26-45 years, the interpreter left briefly after everyone had been seated but before the focus group began. The men used the interim to ask me to introduce myself, and to introduce each of themselves by name and to ask me questions such as where I was from. The female focus groups also did not flow as easily as the male focus groups, and were more difficult to start. Most notably, with the women aged 26-45, there was a period of silence after the first question was asked that was long enough for the interpreter to feel the need to reiterate and re-explain the question that she had translated. In all-female focus groups, there were pauses between responses, and women waited for one another to finish before speaking, whereas in the male groups, people spoke right after each another, even on one or two occasions interrupting one another to speak. Most notably, in the group of men aged 18-25, they became quite animated regarding the ideas they were discussing.

Findings and discussion

Although the information gained was similar across focus groups, the emphasis was placed on different issues between groups. Men felt that problems and obstacles for care and support were primarily attributed to those who were sick and their family members, whereas women took more time expressing frustration concerning organisations within the community that they felt were not functioning as they should. Although respondents spoke to the interviewer and translator rather than conversing with one another, they did build upon one another's comments. No dissenting opinions were expressed that differed from the general consensus of the group; with one exception, relating to past experiences with the formal group of community health workers (CHWs). This will be discussed later in this chapter.

"It is a shameful disease": The current situation

A deeper exploration of the dynamics of the current situation with regard to care for those who have HIV/AIDS revealed that community members of this area felt that the current situation regarding care and support for those who are ill with HIV/AIDS was less than ideal. Most notably, the respondents stated that care and support should be about unconditional love, whereas it appeared that, at the time of the study, many people who were ill were 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.

Community members recognised that there were obstacles preventing the ideal situation from occurring; most notably a lack of trust from the person who was ill and his/her family members, and negative perceptions towards the ill person, including stigma which was still prevalent within the community where the study was undertaken and which resulted in a lack of trust in family, community and other care providers. This acted as a barrier for those who wished to become involved in care and support. Community members also conceptualised and suggested solutions to these difficulties, namely education and changing social norms and perceptions.

It may be deduced that there was low social cohesion within this community at the time of the study, which was conceptualised according to Hseih (2008:152) as the abundance of moral support, which, instead of leaving individuals to rely on their own resources, lead them to share in the collective energy and supported them when their individual resources were exhausted. According to focus group participants, such sharing and support were not occurring at the time of the study – those who were ill were largely isolated from other community members, and in extreme cases from family members as well, the degree of such seeming to vary from family to family.

Reasons for this varied, but appeared to stem largely from stigma, fear and lack of trust; the latter two both from the person who was sick with HIV/AIDS who mistrusted others and feared what they would say, as well as from family members who mistrusted and feared the perceptions of other community members. Community members who wished to provide care and support also often found themselves prevented from doing so by these same reasons.

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, for example traditional gender roles which dictate that women will only provide care and support for the person who is ill and discomfort and secrecy surrounding all sexual matters and, by association, HIV/AIDS-related issues. Additionally, focus group participants felt that any initiatives to increase social cohesion within the community should not be taken seriously, or might be met with a general lack of interest. All of the above has lead to the individual who has HIV/AIDS lacking support, and as a result, feeling stressed and isolated.

The role of social support and social capital in HIV/AIDS care and support

There is substantial evidence to suggest that social support helps individuals to maintain their health (Hudson, Lee, Miramontes & Portillo 2001), as well as positively influencing the self-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, mobilising social support and collective community action should be regarded as highly important, and should receive due attention and encouragement.

McKenzie, Whitley and Weich (2002), and Helliwell and Putnam (2004) note that the social context significantly affects an individual's mental and physical health. As such, the emotions and perceptions of an individual who is ill with HIV/AIDS may be considered 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.

The perceptions of stress as it related to HIV/AIDS were also 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 and 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, Grobbelaar, Sikkema, Vandormoel, Bomela & Kershaw 2008); thus, negatively affecting their health status. Secondly, the focus group participants spoke about the person who is ill with HIV/AIDS thinking that they were 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 and disadvantaged areas (Lewis 2008), such as the community in this study. A perceived lack of access to formal health care and resources may also be a cause of stress. Stafford, De Silva, Stansfield and 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 people of this community, as the majority of individuals residing there would fall into this category.

According to all of the focus group participants in this research, care and support for those with HIV/AIDS 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. All of the women, although speaking of a desire to visit and show love and support for the person who is ill, focused mostly on meeting physical needs through cleaning the home, bathing and tending to the person who is ill. The women aged 18–25 and 26–45 also spoke of wanting to form an organisation with the purpose of doing such, while all the men spoke about meeting psychosocial and emotional needs through visiting the sick person and expressing love, support and acceptance. However, the men aged 18–25 also mentioned meeting physical needs, but through exercise, according to the interests and activities of those providing care, such as replenishing physical strength through walking, lifting weights and such. Additionally, all then mentioned needing to visit and taking care of the person who is ill, and the necessity to assist in meeting physical needs. However, it was also noted that this was not happening at that stage. 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 the way these influence care and support for those who are ill.

Taylor, Williams, Dal Grande and Herriott (2006) found that lower levels of trust, community involvement, and social activities were seen in poorer communities. Given that the community where this study took place is an area characterised by poor socio-economic status and few resources, it could therefore be expected that this community exhibited trust, social activities and involvement consistent with what was observed in other poor communities. Mistrust was evident in the social interactions between those who were ill, family members and other community members, home-based carers (HBCs), and other healthcare workers because, according to focus group participants, both those who were ill and their families were unwilling to trust the motives of any individuals who wished to provide any form of care and support.

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 fewer. 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, Laibson, Scheinkman & Soutter 2000). As such, isolation through mistrust acts as a destructive force for social networks. This appeared to be the case in the semi-rural area where the research was done. Focus group participants also noted that people with HIV/AIDS were largely isolated from the rest of the community.

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 cooperation 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. In the community where the study was done, there was also a perception that those who were not treated well once they require care and support were perceived as deserving by family members. In such cases, care was provided out of duty, or because there were perceived benefits, such as social grants.

However, it is important to note that trust and reciprocity are different to altruism (Carter & Castillo 2002). Focus group participants noted that in cases where the family neglected the ill person, there would be one individual who would provide care for him/her, adopting the role of informal primary caregiver. This may be seen as the result 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.

"It's about giving love and hope": What can we do?

Community members also discussed ways in which they would be able to assist in care and support, including forming an organisation and working together, such as taking care of the physical aspects of care-giving and cleaning a person and his or her immediate environment, providing support through visiting and talking, collaborative care efforts according to each individuals' own interests and strengths, and the way these could be used to meet the needs of the person who was ill, and additional structural support in the form of a hospice, clinic or youth centre.

Social networking as a means to meet the needs of those with HIV/AIDS took two forms in focus group discussions, namely forming care organisations, and creating a youth centre within the area that would function either as a meeting place for such young organisations, or as a place of support where those who had HIV/AIDS could reside and receive the necessary care and support. These could be understood by considering the social norms regarding care-giving roles at the time of the study. It appeared that social norms surrounding care and support for those with HIV/AIDS were largely influenced by prevailing gender norms, which influenced dynamics in the community regarding care-giving, whereas research pointed towards care-giving being primarily undertaken by women (Campbell, Nair, Maimane & Sibiya 2008; Wight *et al* 2007). The majority of HBCs were furthermore women (Akintola 2005). This may have resulted in a social norm according to which women involved in care-giving efforts do so as part of an organisation. Such a norm was reflected in the suggestions of women in the focus groups, particularly those aged 18–45 – the age of most home-based caregivers – to form organisations in order to assist in care. The women aged 26–45 even mentioned that they have a uniform to identify themselves as being part of a group.

Moreover, traditionally it is still expected that women will take care of domestic chores (Kipp *et al* 2006). All of the female focus groups also mentioned caring through bathing and cleaning the home of the patients, for instance. Although these suggestions 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, Grellier & Barnett 2004), as well as to frequent local *shebeens* where drinking, but also a great amount of socialisation is done (Wolff, Busza, Bufumbo & Whitworth 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 the psychosocial needs of those who were ill.

It must be noted at this point that in my study, participants were divided into focus groups according to age and gender. While many commonalities were presented throughout focus groups, specific differences were noted, such as men appeared to favour providing support by demonstrating acceptance of the person who is ill – visiting, talking, and perhaps bringing needed physical resources, whereas women seemed more inclined to take care of physical needs in the form of bathing, feeding and physically assisting the person who is ill, as well as cleaning his/her home. There were also differences noted across age groups, in that both younger men and women (aged 18–25) were more favourably disposed towards care efforts that were collaborative and undertaken according to the expressed (as opposed to anticipated or perceived) needs of the sick person.

Perceived obstacles to providing care and support

Although the desire to become involved in care and support for those with HIV/AIDS existed among focus group participants, it was also noted that there existed several obstacles to doing so at the time of the study – the greatest of these, according to focus group participants, being a lack of trust. According to Skinner and Mfecane (2004), stigma counteracts trust. Therefore, those who experience stigma, or who are aware of stigma in the community, are less likely to trust others. A lack of trust in 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 became apparent that stigma and mistrust were major obstacles to providing care for those with HIV/AIDS, particularly according to focus group participants. Although much research has been done into stigma surrounding HIV/AIDS, it appeared that the situation at the time of the study was still the same as it had been years ago (see, for example, Caldwell, Caldwell & Quiggin 1989; Chiu *et al* 2008).

It appeared that those who were ill still feared the gossip, which could be attributed to the stigma associated with the disease. The silence that existed as a result of stigma was demonstrated both by the individuals who were ill, as well as their family members who were unwilling to disclose their status. Moreover, participants felt that family members of those who were ill also exhibited mistrust and an unwillingness to disclose to other community members.

Mistrust therefore acted as a significant barrier to providing care and support. This was also demonstrated in perceptions of healthcare services available to the respondents taking part in the study – namely the HBCs, the CHWs, and perceptions of healthcare workers at the local clinic. All focus groups that mentioned the CHWs in the community felt that the CHWs were extremely judgemental, that they were not doing their jobs properly, and that they could not be trusted to maintain confidentiality when ill community members disclosed their status to them, or to maintain confidentiality about what occurred within community members' households.

As a result, none of the participants felt that any community member would trust CHWs to assist in care and support for those who were ill. There was however one exception: one participant from the focus group of women aged 18–25 knew of one CHW who had significantly helped with her uncle when he was ill, and as such, she felt more loyalty towards the formal health workers than other participants. She had to be encouraged to participate when the rest of the focus group participants were complaining and criticising the CHWs – although it must be noted that common consensus among participants seemed to be that in the past the CHWs had done their jobs properly; now they did not seem to be doing much for the community.

However, concerning the HBCs, focus group participants felt that in some cases, the HBCs were trusted more than family members, and generally more than community members – although this was not universal – and focus group participants also felt that sometimes the HBCs may also breach confidentiality, talking about those who are ill.

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

In addition to trust in family, community members, and those providing healthcare services within this community, research shows that trust in government results in improved mental and physical health (Whetten, Reif, Whetten & Murphy-McMillan 2008). Although the South Africa government has attempted 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 for individuals to access these services (Veenstra 2006). Members with poor socio-economic status, such as those living in the area where the study was undertaken were excluded from these resources. The focus group of women aged 46 and older also spoke about mistrust in government to provide resources such as antiretrovirals (ARVs) and social grants. The perception was that government was delaying payment of money, and they explained this by saying that government does not care about them. Such perceptions and attitudes could result in a decreased inclination to make use of governmental services and resources provided, and therefore a deterioration in health.

Social norms also play a significant role in care and support for those with HIV/AIDS. According to Pronyk *et al* (2008), not all social capital aspects promote health – in fact, in some instances social capital may result in the promotion and adoption of destructive social norms. Within this community, social norms had a significant impact on the way that HIV/AIDS was viewed, and consequently how it was dealt with. Such norms were demonstrated in the way individuals with HIV/AIDS were viewed within the area where the research was done, and were communicated through gendered norms regarding sexuality, and also inadvertently through media messages, as well as social norms and practices of men within this community that may hinder interest and participation in care and support for those who were ill.

It also appeared that destructive social norms were present in the form of alcohol and *dagga* (colloquial term for marihuana) consumption. Traditional gender role expectations for men are 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 male focus group participants, 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 this area causing a hindrance to any community initiatives or activities. This attitude appeared to apply particularly to endeavours around HIV/AIDS. The social norm of alcohol indulgence and what was seen as an increase in alcohol abuse and drunkenness, particularly among black men, was also a perceived obstacle for any joint endeavours in the community. 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.

Based on the fact that it was only males who mentioned alcohol and *dagga* as a barrier, it seemed that this was an obstacle for men rather than for women in this community. According to Wolff *et al* (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).

It has been recognised that levels of alcohol abuse and drunkenness in South Africa 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, Steyn, Bradshaw, Norman & Laubscher 2005). Alcohol consumption levels within South Africa are estimated to be of the highest in the world (Parry 2008). It may be assumed that KwaZulu-Natal follows the trend in the rest of South Africa. As such, from these statistics it may therefore be inferred that alcohol consumption in the area where the research was done, was prevalent enough to be considered another obstacle to mobilisation of care and support for those who were ill within this community, particularly among men.

In addition, social norms as they apply to men and women regarding sexual matters may impact upon the nature of care and support provided by men and women for those who have HIV/AIDS. Gender, for instance, plays an important 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 and kept away from parents (Campbell, Foulis, Maimane & Sibiya 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 the focus groups wished 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 men aged 18–25, who when discussing educational needs within the community, expressed a wish for training on counselling. However, counselling was considered to be different from 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 indicated an ongoing cognitive association of HIV/AIDS with sexual matters which are seen as taboo in conversation. Although it is recognised that the majority of HIV cases within South Africa are the result of sexual encounters (Airhihenbuwa & Obregon 2000), focus group participants expressed that, although HIV/AIDS was initially introduced as a disease contracted through sexual encounters, they now knew it could be contracted in 'other ways'. Such statements may be considered efforts to express an acceptance rather than blame of the individual who is sick, 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 known to them by which 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 media campaigns in South Africa around HIV/AIDS, as focus group participants said that, apart from community resources, media was a source of information concerning the disease.

Perceived enabling factors

Within the community where the research was done, social networks were identified as the resource that would provide what is needed in order to facilitate care and support for those with HIV/AIDS within this community. 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. It emerged that access to information and access to resources were considered the two main factors that would increase and improve care and support for those with HIV/AIDS.

Focus group participants expressed a desire for more information regarding HIV/AIDS, indicating that they felt the current pool of information within the 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. As such, those individuals within the community who are structurally on different levels may be able to provide new, beneficial information to community members on how to care for and support one who is ill with HIV/AIDS. Within the community, according to focus group participants, the HBCs currently appear to be the perceived source of new information. This is potentially an extremely useful source, as focus group participants noted that in many cases, community members see HBCs as the primary source of care for those who are ill.

In addition, 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 this community, 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 are in need (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 the community involved in the study, this was not happening at the time of the study. According to community members, as a result of mistrust, friends and neighbours find it difficult to visit, being blocked by either the ill persons themselves, or by their family members.

Conclusion

Participants of this study saw care and support as multi-faceted. Each community member had different interests, and the form which care and support took had to be according to these interests. Additionally, the situation at the time of the study resulted in potential social networks and resources through these networks remaining unharnessed, although gateways to identified sources for information, such as HBCs and local clinics, had been identified. There did appear to be optimism that an ideal situation could be achieved, although community members were looking to outside sources for training and development.

Future endeavours seeking to include community members in care and support activities for PLWHA should therefore be undertaken and pursued according to interests and strengths of local interested community members, and should, as far as possible, be in line with positive social norms and perceived possible contributions. Consideration should be given to potential differences across age and gender groups as they relate to potentials of care and support, as in this study it was found that younger people were more inclined to favour collaborative care efforts. Social networks of information and resources should be identified and encouraged in order to increase and improve current care and support for those with HIV/AIDS. Although focus group participants expressed a desire for a new venue to be built, dedicated solely to HIV/AIDS care and support initiatives, consideration should also be given to infrastructure that currently exists and how this may be utilised for such purposes.

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Chapter 9

Improving the response-ability of people living with HIV/AIDS: Individual and group factors

Anette Arnesen Grønlie, Kjersti Nesje & Wenche Dageid

Introduction

Most South Africans infected and affected by HIV/AIDS live in poverty-stricken areas characterised by sub-standard housing, scarce supply of electricity and running water, high crime rates, high unemployment, and low educational achievement rates (Hirschowitz & Orkin 1997; Williams, Williams, Stein, Seedat, Jackson & Moomal 2007). Such socio-economic constraints shape how people are able to respond to adversities in their lives. Yet, individual characteristics and group factors also play a part in the process of dealing with HIV/AIDS. In this chapter, we focus on individual and small-group capacities. We discuss ways to promote HIV-positive people's ability to respond constructively to a life with HIV/AIDS through examining the roles of well-being, optimism and hope, resilience, social capital, support group motivations and support group identity.

Well-being, optimism, hope and resilience

Well-being comprises objective and subjective well-being, and while objective well-being describes the circumstances and external elements of a person's life, such as education, income and housing standard, subjective well-being is the person's perceptions of these circumstances and the subjective reaction to them (Diener 2006). People infected with HIV view the illness in diverse ways and live with it differently. Some see HIV as a death sentence, while others view it as a chronic disease, which is manageable, and the latter group of people are able to see that they can live a long and good life with the illness (Barroso 1997; Farber, Schwartz, Schaper, Moonen & McDaniel 2000). Optimism and hope, including even unrealistically optimistic beliefs concerning the future, and believing that one's life has meaning and purpose, are psychological beliefs, which are known to increase well-being and be protective of mental health in the face of or following adversity (Taylor, Kemeny, Reed, Bower & Gruenewald 2000; Utsey, Hook, Fischer & Belvet 2008).

It is relatively common that HIV-positive individuals report a higher prevalence of other risks and traumatic experiences, than the general population and individuals with other chronic diseases (Leserman *et al* 2007; Olley, Seedat & Stein 2006; Whetten, Reif, Whetten & Murphy-McMillan 2008; Williams *et al* 2007). Several studies have shown that there are some common features among people who are able to live a good quality life despite, or in the midst of, strain and adversity, and these individuals can be considered resilient (Borge 2005; Bromley 2005; Friborg, Hjemdal, Rosenvinge & Martinussen 2003; Werner 1992). The common attributes can be divided into three dimensions, namely

- dispositional/psychological attributes of the person that predominantly elicit positive responses from the environment;
- socialisation practice/family support and cohesion, which elicit trust, autonomy, initiative and connection to others; and
- external support systems in the neighbourhood and community that can help to reinforce self-esteem and self-efficacy (Friborg *et al* 2003; Werner 1992).

One of the most important and recurrent attributes in resilient individuals is their valuation of social relationships to others, and the quality of these relationships (Morland, Butler & Leskin 2008:39-61).

Social capital, support group identity and membership

In addition to socio-economic and individual factors, social resources in the form of social networks are crucial for well-being. In this context, the concept of social capital provides a useful perspective. Social capital has been thought of as a web of mutual relationships between people that can facilitate resolution of collective problems, promote sustainable development, and increase quality of life and well-being. Structural social capital refers to the number of associational networks that link people together, both formal and informal, while cognitive social capital is the psychological aspect of the construct, which refers to the individual's perceptions of the quality of social relationships and social support, as well as trust, norms, values and civic responsibility (Kawachi, Subramanian & Kim 2008; McKenzie & Harpham 2006). Social capital consists of several elements, including groups and networks, trust and solidarity, and collective action and social cohesion, which are the elements our study focused on. The study also focused on these elements as they operate on the bonding, bridging and linking levels of social capital.

A possible way of dealing with the negative effects associated with an HIV diagnosis is to join HIV/AIDS support groups. Joining support groups may enhance well-being and self-esteem, establish feelings of shared identity and a sense of belonging, improve coping skills, and offer individuals resources they do not possess, like information and knowledge on how to handle their situation (e.g. Adams 2002; Dageid & Duckert 2007; Spirig 1998). Under circumstances where people living with HIV/AIDS (PLWHA) experience inadequate support from family and friends, support groups may represent a valuable additional source of social support (Iwelunmor, Airhihenbuwa, Okoror, Brown & BeLue 2006). For PLWHA in Southern Africa, sharing a common positive identity through membership in support groups could be especially important because these individuals often experience discrimination and neglect from their community (Greeff *et al* 2008).

Membership in dense, homogenous support groups could promote high levels of intra-group trust. Trust is a core element of social capital, and is described as a lubricant which makes social interaction smoother (Igarashi, *et al* 2008). Without trust, resources will not be exchanged and networks may not voluntarily be formed (Putnam, 1993) Trust is not a one-dimensional concept, and because the networks in social capital theory are structurally distinct, trust within different networks may be expressed differently. Investigating the level of trust will therefore be important when assessing the quality of social capital.

Our study

Previous research has found that resilience, social capital and membership in support groups are related to positive outcomes; however, most previous research has taken place in Western and more individualistic environments, where the socio-economic context is different from our study. In the current study, we explored how resilience was related to social capital and well-being in situations of severe adversity. In addition, we were interested in finding out how optimism and hope would be associated with well-being. We further examined the motivations for becoming members of HIV/AIDS support groups, the degree of shared identity, and the extent of trust group members held towards other groups and institutions. By investigating individual and social attributes in HIV-positive people's lives, we wanted to gain more knowledge on the psychological mechanisms and social resources that are central to increase well-being among HIV-positive South Africans living in a context of adversity.

Methodology

Procedure

Participants were recruited through Treatment Action Campaign (TAC), which is a national non-governmental organisation (NGO) with branches in local municipalities in South Africa. As the participants were mainly isiZulu-speaking, an isiZulu-speaking TAC employee was trained to act as interpreter. The instruments were translated into isiZulu. Members of a total of 14 HIV/AIDS support groups (which were either initiated by or had close contact with TAC) took part in the study. The support groups held weekly meetings, and the purpose of the study was explained at these meetings and the support group members' participation requested. They were asked to complete five questionnaires by ticking off the statements that best corresponded to their attitudes, thoughts and feelings. As most participants had never filled out questionnaires before, the interpreter assisted the groups, and read aloud all questions and response alternatives. If the questions were perceived to be ambiguous, the participants could address this via the interpreter and researchers, who were available to clarify any questions the participants had throughout the sessions. Each session lasted approximately two hours. Lunch, refreshments, and money for transport to and from the meetings were provided. All participants gave written in-formed consent to participate in the study.

Participants and setting

The participants in our study lived, like many black South Africans, in poverty-stricken areas. The study included a sample of 269 adults, recruited in the eThekwini municipality of the KwaZulu-Natal province. There were 84% women and 16% men. All were isiZulu-speaking, HIV positive, and members of support groups for PLWHA. The mean age was 35.5 years (*SD* = 9.60, range 18 to 67 years). The mean score on general health was 2.59 (*SD* = 1.18), with 5 being the maximum possible score, and the participants had on average known for four years that they were HIV positive, with a range from one month to 15 years (*SD* = 3.19). Marital status: 74% were single, 20% were married or engaged, 4% were divorced or separated, and 2% were widowed. Three quarters had completed the South African general education (Grade 0–9), and one quarter had further education (Grade 10–12). Only one person had university education. Nearly 90% lived in rural areas, while one tenth lived in urban areas. Approximately 60% had no monthly household income, 13% had an income of 1–499 ZAR (100 ZAR = approximately US$ 15), 13% had an income of 500–999 ZAR, 8% had an income of 1 000–1 999 ZAR, 3% had an income of 2 000–2 999 ZAR, and 4% had an income of between 3 000 and 5 999 ZAR.

Measures

Well-being

Subjective well-being was assessed with a scale consisting of six items. Three items were from the WHO (five item) Well-Being Index (1998 version), and the remaining three items were from the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) (Tennant *et al* 2007). These scales focus on subjective well-being and positive psychological well-being, and cover positive mood, vitality, general interest, how one deals with problems, how one feels about oneself, and if one has been feeling loved. Participants were asked to rate how they had felt in general over the previous two weeks, and items were rated on a 6-point scale, from 1 = all of the time to 6 = at no time. Internal consistency approached a satisfactory level, as indicated by $\alpha = .77$, and mean inter-item correlation, $r = .36$.

Resilience

Resilience was assessed using a version of the Resilience Scale for Adults (RSA) (Friborg, Martinussen & Rosenvinge 2006). Three items were removed from the original scale to improve internal consistency. The scale used for analysis consisted of 30 items, which measured five resilience factors: ‘perception of self’, ‘perception of future’, ‘social competence’, ‘family cohesion’, ‘social resources’, and ‘structured style’. Participants were asked to rate how they had been thinking and feeling about themselves in general over the last month, and all items were rated on a 7-point scale, with two semantically different anchors at each end. The sub-scales were added to gain a total resilience score. The total scale reached good internal consistency, with Cronbach’s alpha of $\alpha = .82$. The sub-scales of resilience also reached either a satisfactory Cronbach’s alpha or mean inter-item correlation. For analysis of variance, participants were divided into three groups, based on their total scores on resilience: Group 1 = low resilience ($M = 23.14$ or less), Group 2 = medium resilience ($M = 23.15$ to 27.27), and Group 3 = high resilience ($M = 27.28$ and above).

Social capital

Social capital was assessed using a questionnaire based on The World Bank Group’s Social Capital Assessment Tool (SOCAT) (Grootaert & Van Bastelaer 2001; Krishna & Shrader 1999). Items were extracted to produce a questionnaire covering the three elements of social capital we intended to measure, namely ‘groups and networks’, ‘trust and solidarity’, and ‘collective action and social cohesion’. For each element, the questionnaire included items that measured structural and cognitive social capital at bonding, bridging and linking levels. The measure of trust also included items assessing general trust. The final instrument consisted of 34 items, with some sub-items, including demographics. Most items were rated on a 5-point scale with various statement and response alternatives, and some items were open-ended. As the questionnaire consisted of three different sub-concepts at three different levels, it was not appropriate to test reliability.

Support group identity scale

This scale was adapted from the collective self-esteem scale (CSES), a 16 item, 7-point Likert scale (1 = strongly disagree to 7 = strongly agree) developed by Luhtanen and Crocker (1992). The CSES seeks to assess collective self-esteem in accordance with the social identity theory and is one of the most widely used scales measuring social identity (Aberson, Healy & Romero 2000). The CSES measures collective self-esteem using four subscales: 'importance to identity', 'private collective self-esteem', 'membership esteem', and 'public collective self-esteem'. The CSES was originally designed to assess collective self-esteem in relation to all major social groups that are important to the individual. In this study, however, only their collective self-esteem derived from the specific support group was of interest. The wording of the scale was therefore changed, from pertaining to plural groups to apply to the specific support group. Three items were excluded to improve reliability, that reached $\alpha = .68$. A high score on the total scale indicate high social identity.

Measure of motivations for support group membership

To measure the degree of homogeneity related to the motivation for group membership, a questionnaire consisting of one item with eight response categories was developed. The response categories were constructed based on two studies which identified motivations for group membership (Adams 2002; Trojan 1989). The item was: 'Why did you become a member of this support group?' with the following response categories:

1. to obtain knowledge about HIV/AIDS;
2. to receive support from fellow group members;
3. to learn from what others have experienced/experience;
4. to obtain feelings of being 'normal';
5. because my family/friends wanted me to;
6. to change how my family/friends think about HIV/AIDS;
7. to receive medical help;

8. because of fear of being stigmatised; and
9. to get access to grants.

The questionnaire was constructed as a 5-point Likert scale, where responses ranged from 1 = agree to 5 = disagree.

Results

Resilience, well-being, optimism and hope, and social capital

Resilience and subjective well-being

To determine the impact of resilience on subjective well-being, a one-way between-groups ANOVA was conducted. We found no statistically significant differences in subjective well-being among the three resilience groups [F (2, 160) = 1.443, *p* = .239].

Resilience and objective well-being

To explore what characterised the groups that were divided into low, medium and high on resilience, a one-way between-groups ANOVA was conducted to determine the impact of resilience on demographic variables at interval level. The variables were: general health, age, and the duration the informants had known that they were HIV positive. The results indicated that the difference between the resilience groups on self-reported general health was significant (*p* = .001). The effect size, calculated using eta-squared, was .08, which surpasses a medium effect size (Cohen 1988). Post-hoc comparisons indicated that there were significant differences between Groups 1 and 3 (*p* < .001) and between Groups 2 and 3 (*p* = .023).

Chi-square tests for independence were performed to test whether there were differences between the groups on demographic variables at nominal level, and the variables were: sex, marital status, education, household monthly income, and area.

The chi-square tests indicated a significant association between marital status and resilience group, χ^2 (2, *n* = 200) = 8.49, *p* = .014. The effect size reported, Cramer's V = .206, is approaching a medium effect size. In Group 1 (low resilience), 16% were in a relationship, while 84% were single. In Group 2 (medium resilience), 12% were in a relationship, while 88% were single. In Group 3 (high resilience), however, 31% were in a relationship while 69% were single (cf. Figure 9.1). The majority of people (53%) who were in a relationship were in the group that scored the highest on resilience.

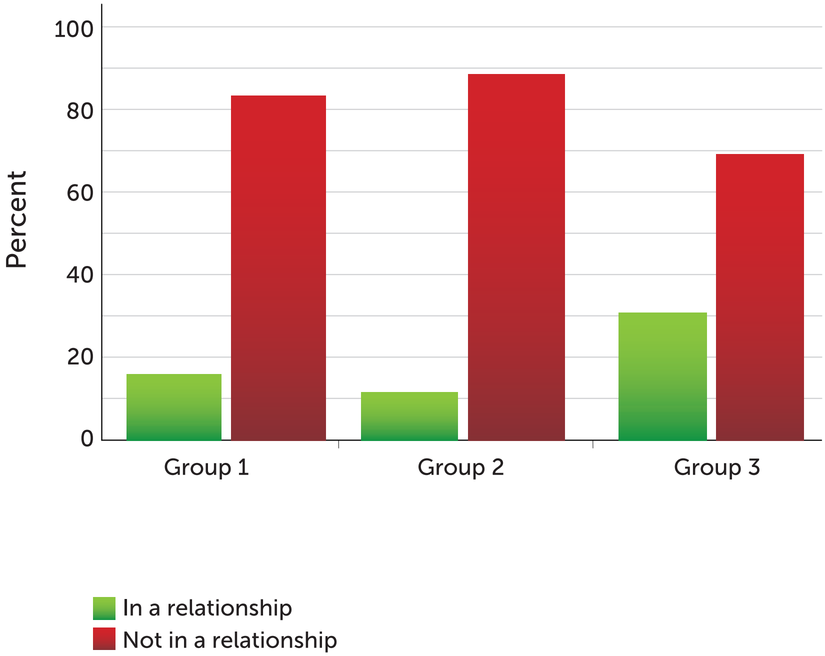

Figure 9.1 Marital status and resilience groups

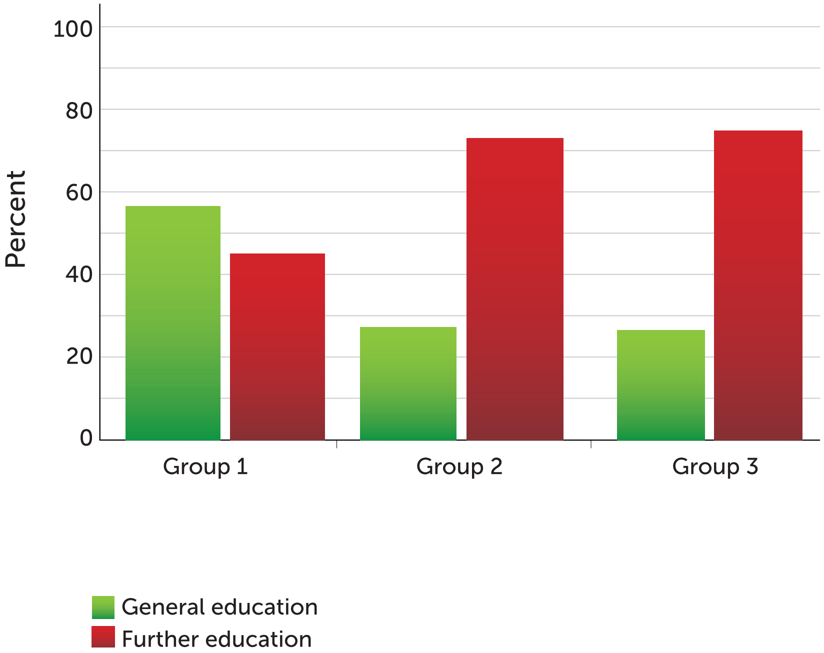

Figure 9.2 Education and resilience groups

The chi-square tests also indicated a significant association between education level and resilience group, χ^2 (2, n = 197) = 15.87, p < .001. The effect size, Cramer's V = .284, is approaching a medium effect size. The majority in Group 1 (56%) only had general education; however, the majority of the people in Group 2 (73%) and Group 3 (73%) had completed further education (cf. Figure 9.2). Of the individuals that only had general education, 50% belonged to the group that scored lowest on resilience. Nearly 78% of the people who had further education were either in Group 2 or 3.

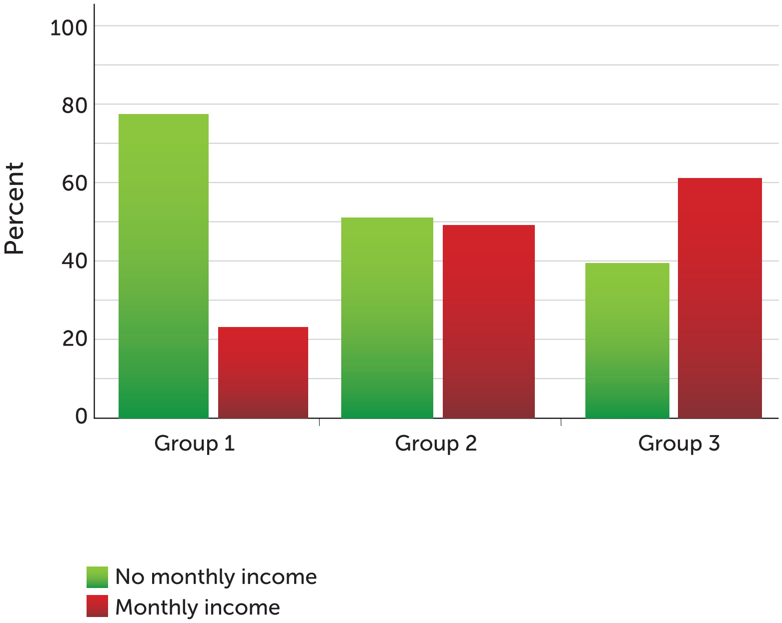

Figure 9.3 Household monthly income and resilience groups

There was also a significant association between monthly household income and resilience group, χ^2 (2, n = 195) = 19.01, p < .001. The effect size, Cramer's V = .312, is medium. The majority of individuals in Group 1 (77%) had no household monthly income. In Group 3, the majority of the individuals (61%) did have a household monthly income. In addition, nearly half of those who had no household monthly income (45%) were in the group that score lowest on resilience, while nearly half of the individuals who did have a household monthly income (46%) were in the group that scored the highest on resilience (cf. Figure 9.3).

Social capital and subjective well-being

To explore how social capital was related to subjective well-being, correlations were performed. There were four social capital factors that related to subjective well-being. 'Groups and networks' on the bonding level (r = .181, p < .01), 'Collective action and social cohesion' on the bonding level (r = .180, p < .01), 'Trust' at the linking level (r = .185, p < .05), and 'collective action and social cohesion' on the linking level (r = –.146, p < .05). As it was expected that 'trust' at linking level would differ depending on the different institutions and groups, correlations between 'trust' at the different groups and subjective well-being were performed. Subjective well-being correlated positively with 'Trust in NGOs' (r = .411, p < .001), and with 'trust in the health system' (r = .157, p < .05).

Social capital and resilience

To explore the impact of resilience on the total social capital score, a one-way between-groups ANOVA was performed. The results indicated that there was a statistically significant difference for the three groups [F (2, 98) = 18.78, p < .001]. The effect size was .28, calculated using eta-squared, which is considered a large effect size. Post-hoc comparisons indicated that the mean score for Group 1 (low resilience) (M = 21.90, SD = 3.25) was significantly different from Group 2 (medium resilience) (M = 25.05, SD = 2.74, p < .001), and from Group 3 (high resilience) (M = 26.75, SD = 3.35, p < .001). Group 2 did not differ significantly from Group 3; however, the difference nearly reached statistical significance (p = .053). We were interested in finding out what specifically differed between these groups in terms of social capital, and a one-way between-groups ANOVA was performed where the sub-factors at all levels of social capital were included, and all were divided into cognitive social capital and structural social capital.

In 'groups and networks', there was a significant difference between the groups in cognitive social capital at the bonding level [F (2, 198) = 4.705, p = .010]. The effect size was .05, which is approaching a medium effect size. Post-hoc comparisons indicated that there were significant differences between Group 1 and Group 3 (p = .008). At the bridging level there was a difference between the groups in cognitive social capital [F (2, 196) = 5.749, p = .004]. The effect size was .06, which is medium in size. The differences were significant between Groups 1 and 3 (p = .003). There were also significant differences in cognitive social capital on the linking level [F (2, 195) = 3.633, p = .028] between Groups 1 and 3 (p = .037). The effect size was .04, which is approaching a medium effect size.

For the cognitive social capital element 'trust and solidarity', there were significant differences between the groups in general trust, as well as trust at bonding and bridging level. The differences were between those who scored low and those who scored high on resilience, with general trust at a significance level of $p = .010$ and effect size at .05, while at bonding level, the significance level was $p < .001$ and effect size at .13, which is considered large, and at bridging level the significance level was $p = .003$ and the effect size .05.

With regard to 'collective action and social cohesion', the groups were significantly different on cognitive social capital at bonding and bridging level. At the bonding level, the effect size was .12, and considered large. Group 1 was significantly different from both Group 2 ($p = .003$) and Group 3 ($p < .001$). At the bridging level, there was a difference between Groups 2 and 3 ($p = .005$), and there was a medium effect size of .05.

Optimism and hope and subjective well-being

The entire sample reported that religion was important to them ($M = 4.67$, $SD = 0.87$, range 1 to 5). As it was assumed that those who scored high on the resilience sub-factor 'perception of future' would also score high on subjective well-being, a separate ANOVA was carried out where participants were divided into those who scored low, medium, and high on perception of future. The results confirmed that there was a difference between the groups [$F(2, 195) = 3.636$, $p = .028$], where post-hoc comparisons indicated that the significant difference was between those who scored low ($M = 20.05$, $SD = 8.13$) and those who scored high ($M = 23.96$, $SD = 8.82$, $p = .021$) on 'perception of future'. The effect size, calculated using eta-squared, was .04, which is approaching a medium effect size. For further details of the results, refer to Grønlie and Dageid (2011).

Support group motivations, identity, and trust

The single most important motivation reported by the sample was 'to obtain knowledge on HIV/AIDS', where 97% agreed with this statement. The motivations 'receiving support', 'learning from other's experience', 'changing family/friend's attitude regarding HIV/AIDS', and 'receiving medical help' all had an agreement rate of over 90%. There was least agreement con-cerning 'access to social grants' (64%) as a motivation behind joining support groups. 'Obtaining feelings of being normal' (87%) and 'dealing with fear of being stigmatised' (71%) also had fairly high agreement rates. The mean score on the total support group identity scale ($M = 6.04$, $SD = 0.84$), and each scale item (M between 4.95 and 6.69) was high (cf. Table 9.1).

Support group identity was significantly correlated to three items measuring general trust. These were: ‘Generally speaking, people can be trusted’ ($r = .208$, $p < .05$), ‘do you have to be careful with most people’ ($r = .259$, $p < .01$) and ‘do you think that most people take advantage of you if they got the chance, or would they try to be fair?’ ($r = -.202$, $p < .05$). Support group identity explained 14% of the variance in the first general trust item ($p < .001$), 10% of the variance in the second general trust item ($p < .01$), and 5% of the variance in the ‘advantage’ item ($p < .05$). Support group identity was positively associated with trust in bonding networks, where higher collective self-esteem was associated with higher trust in the support group of which one was a member ($r = .202$, $p < .01$). Support group identity explained 9% of the variance in trust at a bonding level ($p < .05$), but was not significantly related to trust at a bridging level. At a linking level, support group identity was associated with ‘trust in the formal health system’ ($r = .206$, $p < .05$), ‘trust in the national government’ ($r = .202$, $p < .05$), and ‘trust in NGOs’ ($r = .221$, $p < .05$). In total, support group identity explained 10% of the total variance in ‘trust in the formal health system’, 5% of the total variance in ‘trust in national government’, and 14% of the total variance in ‘trust in NGOs’ (all at $p < .01$).

Table 9.1 Mean and standard deviation for total collective self-esteem scale (CSES) and each CSES item

	M	SD	N
Membership			
I am a worthy member of group	6.15	1.66	195
Cooperative participant of group	6.47	1.35	192
Private			
I often regret that I belong to the group	5.46	2.3	185
I’m glad to be member of the group	6.22	1.72	186
I often feel the group is not worthwhile	5.68	2.11	180
I feel good about the group	6.44	1.58	190
Public			
The group is considered good by others	5.89	1.95	188
People consider my group to be ineffective	4.95	2.54	186
Others respect my group	6.15	1.72	195
Others think my group is unworthy	5.73	2.15	192

	M	SD	N
Identity			
The group is an important reflection of me	5.95	1.98	191
The group is unimportant to my sense of self	5.33	2.45	186
Belonging to the group is an important part of self-image	6.69	1.1	196
Total CSES score	6.04	0.84	131

Note: The negatively worded items are reversed. A high score indicates high social identity.

Discussion

Well-being, optimism and hope, resilience, and social capital

Subjective well-being is believed to result from a feeling of mastery, optimism and hope, a progress towards one's goals, immersion in interesting and meaningful activities, as well as from positive social relationships (Constantine & Sue 2006; Pavot & Diener 2008; Utsey *et al* 2008). Research has shown that there are differences across individuals, cultures and nations with regard to what constitutes a good quality life (Borge 2005; Diener 2006; Grønlie & Dageid 2011; Kuppens, Realo & Diener 2008). In cultures where people's basic needs are generally met, and external elements of their lives are satisfactory, subjective well-being is central. In reality, this mostly translates to developed nations, and in particular to more individualistic cultures. In a majority of previous research, resilience is closely associated with subjective well-being, and an essential topic in the resilience research is the prevention of maladjustment in individuals at risk. In our study, the participants' levels of resilience and subjective well-being were comparable to levels in samples from Western cultures and contexts (Friborg *et al* 2003; Friborg *et al* 2006). Therefore, we expected to find a relation between resilience and subjective well-being, albeit weak. However, our results indicated that the typical positive outcome of subjective well-being was not associated with being resilient at all.

Resilience and well-being have not been widely researched among HIV-positive individuals in developing countries, and it is likely that subjective well-being, as it was operationalised in this study, is not central to how people in environments like the one where this study was done judge their quality of life. Rather, in this context, differences in resilience in people are more likely to be associated with differences in objective measures of well-being, such as general health, education, household income, and marital status, which is what we found in our study. One possible explanation is that for individuals who live in environments where they are struggling to survive, emotional experiences and subjective evaluations may be less relevant to overall well-being. Instead, more objective and external measures of well-being may be central for a good quality life (Diener & Diener 1995; Kuppens *et al* 2008; Pavot & Diener 2008).

Religion was overall important in this sample, and the individuals who had distinct hopes and an optimistic view on their own future, scored the highest on subjective well-being. Optimism has previously been found to mediate the relationship between culture and well-being among African-American samples (Constantine & Sue 2006; Utsey *et al* 2008). Engagement in religious and spiritual activities has been tied to better psychological adaptation in individuals with HIV (Simoni, Martone & Kerwin 2002). In many Southern African cultures, religion and spirituality are very important, and in such cultures, individuals may view their own role and fate differently from individuals in more individualistic and secular cultures. For example, when collective norms of conduct are observed, it is believed that individuals stay protected, healthy and on good terms with other people and with spiritual forces (Chalmers 1996; Dageid & Duckert 2008). It thus becomes imperative to strive for togetherness, harmony and optimism.

In our study, having a positive outlook on one's future was the only resilience sub-factor, which was related to subjective well-being. For those individuals who belonged to the group that was the most hopeful and optimistic regarding a better future, subjective well-being was more central than for individuals who viewed the future as more or less gloomy. An ex-planation for this finding can be that in our sample, and in this culture, a positive perception of one's future can be a form of optimism and hope, rather than a realistic perception and expectation towards one's own future. Møller and Saris (2001) found exactly this in their study on subjective well-being and more objective measures of well-being among poor black South Africans, where expectations for one's future ran opposite to how these South Africans evaluated their current and past subjective well-being. Resilient individuals who have marked optimism and hopes for the future may generally be better at pursuing positive adjustments and adaptation, and may also possess dispositional characteristics that enable them to find meaning and purpose in their lives, and evaluate their quality of life as generally positive, even in the face of adversity. This is supportive of the findings from Barroso's (1997) study of long-term survivors of HIV/AIDS, where a common feature in these resilient individuals was an existential ability to 'transcend' their illness.

The results revealed that for these individuals, the cognitive and psychological aspects of social capital were central to both resilience and subjective well-being, while structural social capital did not come out as important. The differences between the resilience groups were only along measures of cognitive social capital. In this sense, what mattered was the quality of the relationships people had at bonding, bridging and linking levels, while the number of friends, groups and networks one had did not seem to matter. This indicates that friends and groups mean much more to resilient individuals than to less resilient individuals, and that it is the quality rather than the quantity of networks that is crucial. The strongest associations between social capital and resilience were at the bonding level of social capital, which other studies also have found (Silva, McKenzie, Harpham & Huttly 2005).

One important objective of the study was to find out what specifically characterised resilient individuals in this context of adversity. The results showed that the more resilient an individual is the more social capital he/she possesses and takes advantage of. Vice versa, it is likely that by possessing more social capital and having a stronger support system in general, one is better equipped to handle stressful situations and conditions successfully (Borge 2005; Werner, 1992). Having a well-functioning external support system is an important resilience attribute.

Support group motivations, identity and trust

While the number of groups and network ties increase an individual's opportunities to access resources, the quality and significance of these ties are equally important, as one single tie might be sufficient to gain access to a crucial resource. Groups of which people are members can provide social support, sharing of information, and joint work to achieve goals that individuals in isolation would not be able to accomplish (Macinko & Starfield 2001). Literature has identified several motivations as to why PLWHA join support groups. Social support, need for information concerning the illness, access to medication and changing the attitude of family and friends towards the illness, all seem to be important contributors when people decide to join support groups (Adams 2002; Dageid & Duckert 2007; Trojan 1989). There was high agreement concerning motivations behind joining support groups in our study; the single most important motivation being 'to obtain knowledge on HIV/AIDS'. The results are in agreement with previous research regarding motivations behind joining support groups for PLWHA (Adams 2002; Brashers, Neidig & Goldsmith 2004; Dageid & Duckert 2007; Trojan 1989).

The participants in our study felt as valuable members of the support group. As well as feeling good about their group membership, they perceived other people to view their group positively, and perceived their group membership as an important part of their identity. When people join groups due to common motivations, tightened emotional bonds and identification with the group may occur (Castano, Yzerbyt & Bourguignon 2003). According to some researchers, collectivistic cultures often value in-group harmony highly, and make quite strong in-group–out-group distinctions. They also define themselves more often in relation to the in-group, than what is usual for individualistic cultures (Hui & Triandis 1986; Triandis, Leung, Villareal & Clack 1985; Triandis, McCusker & Hui 1990). The support groups in this study were homogeneous, operating in what may be described as a collectivistic culture, and sharing a strong social identity derived from the group. However, we can only speculate that the similarity and homogeneity of the support groups lead them to share a strong social identity. The setting under which they completed the study, may have contributed to the members identifying more strongly with the support group. The participants in this study were visited while attending support group meetings, and it was during this time that they participated in the study. Their identity as support group members could consequently be highly salient.

High social identity scores were associated with the participants perceiving people, more often than not, trying to take advantage of them. This indicates that a strong social identity is related to less trust. As some theorists have viewed distrust as a form of discrimination (Paolini, Hewstone, Cairns & Voci 2004; Voci 2006), the association emerging in this study, could illustrate a form of in-group bias. However, the association between social identity and general trust was ambiguous. Two of the associations were positive; pointing towards higher collective self-esteem being associated with higher general trust. This could indicate that the five items intended to measure general trust, possibly did not measure the same aspects of trust. To get a better understanding of the discrepancy between the general trust items, it is necessary to take contextual factors into consideration. The support groups were situated in the local communities of its members. This means that members who constituted the support group were neighbours, friends and family. They not only constituted the support group, they may also have constituted the community. Although some people travel to the nearest cities to work, few of the participants had the opportunity to travel far, in short their activities and opportunities were mainly restricted to the community they live in. This could have contributed to a sense of togetherness. In addition, the spirit of *ubuntu,* in short meaning “I am, because you are", was passed down through generations, and was of importance especially for people living in rural areas of South Africa (Bonn 2007). When the participants were asked if they perceive people to be trustworthy or not, they would most likely think of people in their own community. Their identity as community members might have been stronger than that of people living in individualistic societies, and thus the socially embedded attitude could be that most people in their community were trustworthy. The 'advantage' item on the other hand might have evoked different associations for the participants. This item could relate to the behavioural and risk-taking approach of trust. As South Africa suffers from high levels of crime and violence, it would be wise not to trust the actions of strangers, or even neighbours, as it might involve an imminent risk.

It might seem counter-intuitive that collective self-esteem was not associated with the other measures of trust in bonding groups, for example 'trust in family and friends'. However, the majority of the members of the support group reported that changing the attitude of family and friends concerning their HIV status, motivated them to join the support group. This might indicate that the participants experienced a lack of support from family and friends, as a consequence of their HIV status. Greeff *et al* (2008) found that many South African HIV-positive people felt reluctant to disclose their status to family and friends, because of stigmatisation and discrimination due to their HIV status. This could indicate that individuals who join support groups, do so in order to receive additional support, while simultaneously wishing to change the attitude of family and friends.

Support group identity was not significantly related to trust at a bridging level. Methodologically, this could be explained by the lack of variance in response to the identity scale, and does not necessarily mean that no relationship exists between the variables. However, the lack of association between social identity and trust in other support groups could come across as surprising. Other support groups would be the most clear-cut example of out-groups, similar in both structure and status to their own in-group. Tajfel and Turner (1979:33-47) originally argued that in-group bias would be especially strong in relation to groups that are similar to the in-group. Because of this, we could also expect to find less trust in these groups. However, there is a need to take the motivation for joining HIV support groups into consideration. The individuals joining the support groups do so because they are diagnosed with HIV. They have similar concerns related to the development of the disease, fear of social discrimination and their future. Deaux, Reid, Mizrahi and Cotting (1999) argue that people are not always motivated to join groups solely to enhance their social identity, which could lead to in-group bias. Motivations like insight and understanding, in-group cooperation and cohesion could also be important motivators. Thus, the different support groups do not necessarily have conflicting interests. In addition, many of the support groups in the area of KwaZulu-Natal were initiated by TAC, and their common identity as a TAC support group could be salient.

Stigma could also be implicated in the lack of trust at bridging levels. Hinkle and Brown (1990) argue that the group's status in relation to other groups and networks need to be accounted for when investigating the in-group dynamics. They argue that the groups are affected by the status they have in the society, which could make them mirror the views of society. In relation to society, HIV remains a stigma (Campbell, Foulis, Maimane & Sibiya 2005), which could result in HIV/AIDS support groups experiencing low status. The lack of association between social identity and trust in bridging networks could also indicate that there are in reality few existing bridging networks in the study areas, that the groups do not know of each other's existence, or that there is competition over resources and thus less trust. Many HIV/AIDS community-based groups in sub-Saharan Africa have few resources, which means they are struggling with day-to-day survival and functioning, and have little possibility for exchange of resources (Rau 2006; Swidler 2006).

One assumption of our study was that social identity was negatively associated with trust in linking networks. The positive association we found was therefore somewhat surprising. However, the fact that these support groups were closely associated with TAC might be one explanation of these findings. TAC could be characterised as a linking network at national level and as a bridging network at local levels. TAC has played an im-portant role in changing the government's attitude towards PLWHA, and in addition, TAC has worked for increased treatment coverage in South Africa (TAC 2009). By being members of a TAC-initiated support group, the participants in this study could have had a positive experience with TAC as an organisation at both bridging and linking levels. This positive experience could hence influence the trust shown by the participants towards NGOs, the government and the health system.

Trust is a relational phenomenon, which enhances cooperation and includes the expectation that individuals, groups or institutions will act completely fairly, openly and with concern (Mohseni & Lindström 2007). The social capital theory emphasises trust as one of the most important factors in allowing resources to be shared between groups and individuals (Bourdieu 1986; Portes 1998; Putnam 1993). Research in relation to social capital has revealed that dense and homogeneous groups may have high levels of intra-group trust, but may simultaneously display distrust to other structures in the society (Stolle 1998; Yamagishi, Cook & Watabe 1998). For example, Stolle (1998) explored how in-group trust in voluntary groups related to general trust. It was found that the level of in-group trust was high in voluntary groups, which could be characterised as homogeneous and tight. However, there was a negative association between in-group trust and trust in people in general. Thus, tight and homogenous (bonding) groups had high levels of trust within the group, but low levels of generalised trust. This association was reversed for heterogeneous (bridging) groups.

In relation to social capital, HIV/AIDS support groups can be characterised as groups at a bonding level. Even though tight and homogeneous groups obviously could be beneficial for the individual, for example in the form of strong emotional bonds, positive social identity, and enhanced self-esteem, it could have negative consequences as well. Where bonds between the members are tight, groups may become 'closed' or sectarian, there could be little or no acceptance of members joining other groups, and it can become difficult for outsiders to be included in or to access the group (Portes 1998; Wollebæk 2009). If support groups become too 'tight', it could affect the members' chances to draw on resources from individuals and institutions (bridging and linking networks) outside their group, resources that could be imperative for optimal coping with life with HIV/AIDS. In addition, access to resources at a linking level may mean that the support group can have the potential to influence wider social and political contexts, which could be of particular importance in South Africa, with its history of failed leadership and mismanagement in the HIV/AIDS field (Coovadia, Jewkes, Barron, Sanders & McIntyre 2009).

Limitations

Our study relied exclusively on self-reported data from participants. Several limitations of self-reported data have previously been established, including accuracy of recall, recall bias, as well as a tendency to embellish or minimise behaviour or attitudes (Judd, Smith & Kidder 1991). As this was a cross-sectional, correlation study, it precluded any inference of causality and directionality of the association between the variables investigated. To establish changes and causal directions and to explore the in-depth meaning of the responses given, prospective, longitudinal designs including qualitative investigations should be conducted. All scales used were developed in Western cultures and contexts, and might therefore not similarly apply to, or might have yielded different responses from, our sample as compared to Western samples. The language and translation aspects also need to be considered. The questionnaires were translated from English to isiZulu by an isiZulu-speaking Masters student, and later examined by an isiZulu-speaking TAC employee, however, we do not know for sure whether all the nuances of the scale were properly conveyed. The researchers' first language was neither English nor isiZulu, and the interpreter's first language was not English and, even though the interpreter was trained, the same limitations apply. However, these limitations will always be a concern when researchers and participants have different cultural backgrounds.

Conclusion

There is a tendency to see African societies as collectivistic – to such an extent that individual differences are deemed not important. This study showed that this is not necessarily correct, and also showed that individual factors do count with regard to resilience, social capital and well-being. Objective well-being and socio-economic factors were crucial for our sample, as they provided the boundaries within which people can manoeuvre their lives. Most of the people in this area will never achieve a high socio-economic status, due to macro-factors largely beyond their control. Based on our results, it is likely that the higher someone's socio-economic status, the more resilient he/she is and the more opportunities he/she has.

This study also shows that cognitive factors are more important than structural factors with regard to well-being and resilience, even in such an adverse environment as that within which our participants lived. Having an increased focus on improving the social environment and cognitive social capital of PLWHA in South Africa is important. In addition, interventions can be made that aim to strengthen and emphasise attributes common to resilient individuals. Focusing on and emphasising optimistic thinking and positive aspects of people's lives, possibilities and future can help to increase people's resilience and quality of life. This is particularly important for those who do not display these attributes to the same extent, so that individuals' levels of well-being and resilience may increase.

Social networks in the form of support groups for PLWHA are important sources of social support, shared identity, information exchange and access to medication. However, the results also indicated that a strong, shared social identity and in-group trust at a bonding level could obstruct chances of accessing resources from other and more powerful networks in society. This could happen through the negative association between social identity and general trust. General trust is a necessary requirement in order to access resources from other and more powerful networks in society. In this study, we had reason to believe that the support groups might have placed all or most of their bridging and linking trust in and through the powerful NGO TAC. The lack of other 'weak ties' (Granovetter 1973), or the lack of trust in such ties, could prevent new ideas and energy from permeating the support groups and the areas within which they operate. This could especially be devastating for PLWHA in rural areas of South Africa, where resources are scarce.

To enable HIV/AIDS support groups to respond to the needs of those living with HIV/AIDS, there needs to be continued focus on the psychosocial needs that make people join the groups in the first place. Secondly, to 'open up' the groups, there should be a continued focus on stigma at both individual and societal levels. Thirdly, government leadership, support and increased resources at macro-, meso- , and micro-levels will help the groups function better, open up for more and better cooperation, and also increase individual members' socio-economic status and space to respond to their own and others' life situations.

So what can be done to improve the ability of PLWHA to respond to their own life situations? Joint efforts at individual, group and societal levels simultaneously are needed to improve life situations for those living with HIV/AIDS, and to effect sustainable development and empowerment. At group level, both bonding and bridging ties should be encouraged, as they serve different yet complementary purposes. Groups consist of individuals, and by encouraging diversity between individuals and groups at community level, the groups may grow, find improved solutions to challenges, and benefit from each other in cooperative bridging networks. Forming a strong and interwoven bridging level, groups may gain enough power to make their voices heard and have an impact at the linking level. At a micro-level, individual talents and characteristics and high quality (rather than quantity) relations must be encouraged. At the same time, resilience and well-being are tightly connected to resources of more physical, objective nature. Multi-sectoral and multilevel (bonding, bridging and linking) approaches are necessary to improve the structural and socio-economic framework within which individuals find themselves.

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Chapter 10

Reflections on fieldwork

Mbekezeli Mkhize & Thulasizwe Kuzwayo

Introduction

This chapter begins by retreating to the phases of data collection at the study site. These phases included a survey investigation through which a questionnaire was used as an instrument, and group assessments through the use of focus groups interviews, questionnaires, diagrams and participatory observation. Challenges were clearly discernable from these phases. However, contingency plans were creatively devised to guard against these challenges. In this chapter, each phase will be briefly described in conjunction with its challenges and the solutions that were put in place to overcome challenges. Further, the lessons learned by fieldworkers while they were collecting data will be revealed here. The lessons will vary as the chapter aims to investigate the lessons from fieldworkers as a group, and from fieldworkers as individuals, respectively. Consequently, gains obtained will be discussed both at group and at individual level.

The first phase: Survey investigation through the use of questionnaires

This phase marked the end of training sessions and the beginning of what was seen as transfer of training into practice. After several weeks of intensive training, fieldworkers were strengthened to overcome any obstacle in the field. Fieldworkers started off by pre-testing (piloting) the questionnaires. Modifications to the questionnaires were made in accordance with how participants responded to the questionnaires. At this stage, the total number of fieldworkers was seven. This phase commenced around September 2008, and it went on until December 2008. The phase was reasonably manageable since the questions were constantly revised to ensure answerability and readability. The flexibility of the survey structure became an advantage for most fieldworkers, because they were able to finish their tasks slightly earlier than initially envisaged. Some, however, had started in a low gear, and they had grown effectively and progressively in confidence as the phase progressed. As a result, most fieldworkers were able to transfer the skills learned from the training to the workplace. Thus, the training proved relevant and the principles were easy to apply and understand. The households were readily available in the community, and there was no need to make a prior notice as the fieldworkers went from door to door.

Challenges

The research team encountered five logistical challenges during the first phase of the research project. These are described in the following paragraphs.

Not being properly introduced to the community by local authorities

Most definitely, fieldworkers encountered problems during data collection because they were not properly introduced to the local authorities. This was particularly so because a majority of the cases reported were based on issues of consent. Presumably, there was miscommunication between local authorities, such as the local chief (*inkosi*) and his hierarchy of traditional councils, headmen and their deputies. Fieldworkers had to explain how and from whom they obtained consent to conduct research in the area. As far as we were concerned, the project as a whole as well as the fieldworkers were in fact introduced to the local authorities; thus, the challenge was that this consent had not been relegated to the community. From the community's point of view, the research seemed somewhat strenuous and suspicious. Their motives were premised largely to previous researchers whom they did not trust. According to the community, these researchers had mischievously deceived the community by making a multitude of unrealistic and unfulfilled promises. In the community's perspective, this was done in order to make them feel at liberty to participate. Others argued that it was used mainly to coax them since rural communities are considered to be gullible when it comes to agreeing to something. As a consequence, these researchers never showed up again while the community was desperately waiting for them to fulfil their promises. These researchers, according to the community, were not necessarily specific about what they would do for the community except that they would attend to the challenges of the community. Based on this ground, one can conclude that other researchers who preceded the social capital project had inadvertently hampered our data collection process.

The challenge of dangerous and threatening animals

A majority of households tend to have dangerous dogs that are being domesticated for various reasons. Certain dogs were potentially dangerous in such a way that the fieldworker could not enter into the household without signalling his/her presence. As a result, he/she had to wait until someone came out from the house. Perhaps, the dog that bit the tyre of the car could possibly be the classic example of such dogs. After this incidence, dogs actually became a huge stumbling block to data collection. Traditionally, dogs are kept for a variety of reasons. Firstly, they are used for hunting purposes. These ones could be effortlessly identified owing to their tallness and physical shape. In comparison to other dogs, these ones are also healthy. Secondly, they are being kept for security reasons, especially at night when everyone is asleep. Consequently, some are kept for other reasons.

Apart from these experiences, incidences involving deadly snakes were reported. Traditionally, seeing green snakes was not a threat to the people living in the neighbourhood, but it was a big threat to the fieldworkers and the sight of one upset the smooth running of an interview. As far as the community is concerned, green snakes symbolise or signify ancestral presence. For example, one incidence took place when we were under the tree at one of the households. A snake was lying in the tree under which we were sitting. We, nevertheless, continued with the interview. Overall, fieldworkers regarded this as an exceedingly terrifying experience.

Poor infrastructure

There were no proper roads leading up to certain areas. In spite of the fact that fieldworkers had their own transportation at their disposal, they were unable to get to certain houses. In this instance, the fieldworkers had to walk long distances to places, where they have never been before and, occasionally, this happened in rainy weather conditions. This at times led to intolerable fatigue. Indeed, this invariably led to the postponement of fieldwork, which eventually prolonged the duration of the entire project.

Another similar hindrance was that a majority of places in the community were located in mountainous areas. Households were located near scary cliffs or in places where a car could not easily go. The community was however extremely happy with the location of their households. The majority of them tend to argue that they would not leave the place, partly because it is their ancestors who own the place; therefore, they have a sense of belonging and ownership of the place. If they leave the place, it would generally be considered a big insubordination and deception to their ancestors. The fieldworkers had to climb these mountainous areas in order to get to some of the households.

Lack of suitable locations for interviewing

The majority of households did not have suitable locations for conducting an interview without fear and pressure. Our main fear was the state of the houses due to their fragility and susceptibility to windy conditions since most of the houses were made up of mud and thatched with grass. Some houses could leak if it rained, which impinged upon the fieldworker's ability to conduct an interview in a proper manner. To avoid distractions, some of the interviews were held under trees. Under such circumstances, it was virtually impossible for the fieldworker to stop the children who were exceedingly disruptive at times. The children disturbed the interviewing process by making noises while the interview was in progress. Interference was also caused by neighbours who saw people sitting under the tree and decided to join them. The neighbours were conspicuously keen to witness what was happening in their neighbourhood. They contended that this was what they do if the neighbour was away; they keep an eye on his/her house. Actually, they referred to it as a moral obligation. This created a robust form of social cohesion.

Illiteracy

Finally, illiteracy also appeared to be an insurmountable barrier in the entire community, particularly to the elders who could only make a cross if asked to sign. This barrier essentially protracted the period of an interview. In fact, education continues to be a big problem even after democratic dispensation to the elders in the form of adult learning programmes. This is because illiterate people tend to avoid anything that is written. They would, for example, argue that it is aimed at deceiving them. As a result, the fieldworkers ended up wasting a lot of time trying to convince the respondents to participate.

Solutions

In response to the challenges in the first phase, the fieldworkers collectively and individually applied the skills obtained from the training they received prior to the first phase. As previously argued, this training was extremely useful because it made it possible to predict what was likely to happen under which circumstances, while at the same time, it provided mechanisms to deal with those circumstances. In addition to expertise obtained from the training, the fieldworkers had to apply their own cultural and personal experiences and backgrounds to overcome the challenges experienced. The following section deals specifically with the solutions that were used by the fieldworkers in phasing out the challenges that were met in the first phase.

Entering the community and gaining acceptance

In reaction to the issue of entering the community and gaining acceptance, the fieldworkers had to painstakingly explain the purpose of their research.

In doing so, the researchers explained how transparent their intentions were. For example, they willingly gave out the contact numbers of the organisers of the project so that participants themselves could contact the organisers for more information. Nevertheless, the community seemed unconvinced because they were used to receiving announcements from the chief. For them, it was rare or surprising to get a message which had not been approved by the chief either in writing or verbally. Finally, the community got the message from the chief that the research was approved.

Dealing with dangerous and threatening animals

The issue of dangerous dogs was a bit intimidating and time-consuming. It became a serious problem amongst the fieldworkers and a consensus was reached on how to deal with the dogs. Each fieldworker's frame of reference was shared and used in the group. Amongst the fieldworkers, there were a few who grew up in rural areas. They could differentiate between dogs that are used for hunting and those that do not have any specific role. The ones that are used for hunting purposes are generally quiet even to a stranger because they are familiar with strangers in the forest. The others tend to be quick in barking at strangers. We could then differentiate and try to avoid dogs that were known to bark and attack strangers. The issue of deadly snakes was overcome due to the fieldworkers' courage and love for their jobs, as we proceeded with interviewing even after seeing snakes.

Dealing with poor infrastructure

The lack of roads was one of the biggest obstacles. The fieldworkers' vehicles inevitably became useless because it had to be parked far away from the houses. Nevertheless, the fieldworkers were motivated by the fact that households were visible. Sometimes, the fieldworkers decided to use the small routes which often led to extremely dark forests. Traditionally, these big forests are kept in order to produce firewood. Fortunately, the fieldworkers did not get lost because they were able to see the houses at a distance. Occasionally, we were directed by whomever we encountered or alternatively we could simply direct ourselves. But either way, this worked out well.

Similarly, the issue of mountainous areas was an aspect over which we had no control and about which we could not do anything. The saying "accept what you can't change" motivated us. At first, climbing a mountain was hard for some of us. In fact, one the of the fieldworkers actually slipped and collaps-ed while we were climbing the mountain. However, it was not a serious injury but only bruises. In the end, we realised that if we do not include the households in this area, the results would not be a true reflection of what was happening in the area. We did not want to compromise the quality of the data collection, and we eventually got used to climbing the mountains.

Handling the interview process despite inadequate locations

The problem of dilapidated houses remained unresolved; nonetheless, we continued with the data collection. Since we were disturbed by children in certain households, we decided to lower our voices so that the children could not grasp the content of the conversation. This was so because some of them would interfere and answer the questions which were directed at their parents. Interference also came from the neighbours. Some of the neighbours would spontaneously take part in the discussion and share their opinions in the discussion. However, as time went by we were able to ask them tactfully not to interfere.

Handling illiteracy

The success with the illiteracy problem was dependent on fieldworkers themselves. In response to the illiteracy, the fieldworkers decided to administer the questionnaires themselves to avoid any delay. However, the fieldworkers had to be extremely vigilant and explain issues thoroughly because respondents needed more clarifications than was initially envisaged. These clarifications were important because we were able to elicit the answers that were relevant to the questions. Again, it was patience that worked to our advantage.

The second phase: Group assessments by using focus groups interviews, questionnaires, diagrams and participatory observation

In this stage, four research methods were used. The methods of focus group interviews, questionnaires, diagrams and participatory observation were effectively combined and collectively used to obtain the individual and group views of all the members, and consequently, to present the links that a particular organisation had to other organisations (networks) in a graphical fashion, and most importantly, to provide observations aimed at exploring and understanding the realities in the community.

Challenges

Five challenges were encountered during this phase. The challenges differed in terms of significance and relevance to the data collection. As previously stated, some challenges delayed and interrupted the process to such an extent that some appointments were postponed and others ultimately cancelled. The challenges are described in this section.

Unfamiliarity with research methods

This phase involved the drawing of diagrams of networking groups and organisations which seemed peculiar in the beginning. However, as time went by, the fieldworkers got used to them. The diagrams were quite easy to handle although they seemed difficult to the respondents. This was partly because they were more or less a repetition of content from the focus group discussion because organisations mentioned the names of other groups and organisations during the conversation. In addition to diagrams, participatory observations (in the form of field notes and follow-up questions) were constantly used to keep track of characteristics of each organisation and its membership. No significant problem was encountered in using field notes although they served a critical purpose in the data collection. This stage was quite helpful because we were able to establish links with organisations. This served as a snowballing approach.

The problem of setting up and keeping appointments with organisations

Most of the organisations did not keep scheduled appointments. Frequently, organisations would agree on a meeting for an interview, but never arrived at the venue. As agreed, the fieldworkers would be on time at the venue but only to find that the organisation was not there. When one made a follow-up call in an effort to establish what actually transpired, the leader would not answer the phone. Seemingly, when we made an appointment with the leader, he/she later consulted with other members of the organisation who perhaps changed the date and venue, or disagreed with the decision to hold the interview.

Some members of the organisations were not willing to give us their leaders' contact numbers. Leaders of these organisations were often treated with a high degree of respect. Mostly, they were the ones who tended to dictate the direction and vision of the organisation. Most of organisations that had relations with the *inkosi* seemed to have easy access to resources, distribution of land and materials. One organisation was headed by a sister of the *inkosi*. As far as we know, she still holds this position. This put other ordinary members in jeopardy or in an inferior position. If, by any chance, you met an ordinary member, he/she could hardly give you any detailed information concerning the organisation. Clearly, they always had to get approval from their principals.

A majority of the organisations comprised of members with various commitments, which, therefore, impacted negatively on the expected number of participants in the focus groups. The presence of respondents was constantly shaped by the activities and commitments the respondents were involved in. Again, it proved difficult to gather all members because some were working part-time or on temporary basis, or were involved in other activities. Increasingly, meetings became a tremendous challenge to put together partly because of varying activities. This not only led to the adjournment of particular appointments, but it also inevitably led to the cancellation of the meeting.

Community members' expectations of the researchers

Some members of the organisations regarded researchers as government officials. Since government officials rarely visit the area, the community was always cautious of them. A large section of the community actually referred to us as 'government officials'. The community came to us with mixed feelings, with high expectations and in a state of disbelief. Largely, this was motivated by the belief that government officials usually visit the village with job opportunities or alternatively with information related to social grants. They are consequently treated with a level of optimism and en-thusiasm. Some of the organisations had lost faith in researchers owing to unfulfilled promises by researchers who preceded the social capital project. As indicated previously, studies that were done by previous researchers had created big expectations in the community. The community accused them of wrongfully and wilfully conveying blatant lies in order for the community to comply. The community trusted them and complied while the researchers decided to abscond afterwards. It was this bad record that made the community approach us with a high a level of scepticism and criticism.

Challenges connected to illiteracy

It took long to conduct an interview in groups with high illiteracy rates. Generally, organisations that were predominantly run by elderly people were perceived as those that were more illiterate. The fieldworkers had to put in extra effort in terms of providing clarifications and repetitions, sometimes for each and every question. To manage the situation, the fieldworkers had to administer the questionnaires themselves. But even after these efforts, the interviews were discouragingly low in terms of pace and accuracy. However, the interviews with the youth groups proved to be extremely efficient and easy to handle. This was ultimately attributed to the fact that the youth were literate and seemed to understand their groups' challenges, and they were also efficient in articulating those challenges.

Preference for face-to-face interaction

Lastly, local people had not yet internalised the idea of telephonic appointments. Rather, they preferred a face-to-face conversation. This was premised upon the fact that it was hard to talk to a stranger, a person whom you had never met before. The community argued that there certainly had to be trust before one could enter into an agreement with a stranger. However, in a rural setting it takes a while for trust to be fully developed because of violent conflicts that broke out in the past. The community had been confronted with violence before, making it impossible for people to trust strangers. The most preferred method of communication was therefore face-to-face interaction. The local people said this based on the grounds that in a face-to-face interaction one can successfully interrogate the stranger.

Solutions

The challenges that were met at this stage of data collection were more severe than those that were met in the first phase. While the challenges that were met in the first phase focused on issues of consent, the challenges met in the second phase were more technical and difficult to manage. Typically, they required an ability to anticipate them before they actually occurred. Occasionally, poor anticipation by the research team and fieldworkers actually led to unnecessary wasting of resources. This section deals particularly with solutions that were adopted and implemented to address challenges.

Dealing with difficulties in setting up meetings with organisations

In reaction to the organisations that agreed but never showed up, fieldworkers found it difficult to distinguish between groups that were lying and groups that were not. As a result, fieldworkers had to confirm before they went to a venue that had been agreed upon. Even so, some organisations would convincingly confirm but frustratingly never pitch. This appeared to be the most frustrating exercise for the fieldworkers who had to consistently report back to the research team. Gradually, the fieldworkers began to know the groups that were not reliable through constant interaction with the leaders.

In terms of organisations that refused to provide contact details, the fieldworkers continued to search frantically for the details. After a long process of explaining the purpose of the research, the fieldworkers were able to access the information. The contact details would sometimes be obtained through different members of the organisation, because in certain situations it was only one member of the organisation and not the entire group who refused to give out contact details.

Correcting community members' expectations of researchers

As time went by, community members would see us often and understood that we were not government officials. Also, the necessary approval from the chief was obtained. The research observed ethical rules of research, and we also gave back results to the community.

Lessons learned

Besides the fact that there were challenges, the data collection has afforded many lessons to the fieldworkers. Lessons included, amongst other things, the importance of understanding culture, the importance of respect, attitudinal change, and the importance of perseverance. In rural areas, culture is being considered as a cornerstone, and anything that is in-consistent with culture is not allowed. In fact, culture and respect form the critical basis upon which rural communities are built. As a result, a researcher should ideally change his/her attitude in order to adapt to the rural communities. He/she must identify with the community. The researchers came to the area with predetermined ideas as to what the community looked like. Some of these ideas/frames of reference were enhanced or intensified while others were disapproved. So, some of the challenges could have been avoided before they occurred, but researchers were not aware of such challenges.

It is imperative to point out that culture should be respected and conformed to if one embarks on data collection in a rural area. For example, body language and the way one addresses the people are absolutely vital. These communities are able to recognise one's background by looking at the way you talk. Luckily, most of the fieldworkers came from backgrounds that are similar to this community. For example, the fieldworkers knew how to address and greet the elderly. In other words, we knew how to conduct ourselves at a funeral and at a big function where a cow or a goat had been slaughtered. In fact, we attended these events deliberately so as to acquaint ourselves with the entire community or to mingle. We interacted with respondents at these events. Most importantly, the researchers spoke isiZulu and that is why communication was never lost or broken.

Likewise, respect is something that is highly praised and valued in the community. We have learned that in order to conduct an interview, the interviewer needs to treat respondents with a high level of respect, integrity and honesty. We decided to address the respondents as ‘aunts’, ‘uncles’, ‘moms and dads’, ‘brothers and sisters’ to ensure that the respect was never lost. In doing so, the respondents felt comfortable with us. In addition, they felt at ease when they were called by their clan names. This was extremely important because they do not want to be called by their real names. If you call them by their real names, it signifies or shows under-estimation and insubordination. In other words, they are more accustomed to these names than their real names. Not only did this show that we knew their histories and backgrounds, but it encouraged them to speak out openly without any fear. Clan names encourage the community to talk because they feel that their surnames are known and popular in the community. It is this popularity that ensures active participation. In spite of the fact that fieldworkers were young and university students, the respondents showed a high degree of respect to the fieldworkers.

Admittedly, we also learned how significant it is to change your attitude if you conduct interviews in a rural setting. In the initial phases of data collection, some of the fieldworkers could not understand the dialects that were spoken in the area. So, they had to adapt to the languages of the area. Normally, the elders would prefer to use sayings and idiomatic expressions to put their points across. This requires a complete change of attitude in the interviewer because if he/she does not change, the respondents would feel shy to take part in the discussion. In fact, sayings are understood by both fieldworkers and almost everyone in the community because they are frequently used. The community relates easily to sayings, especially the elders. By change of attitude, we mean that fieldworkers had to apply their knowledge of sayings as opposed to speaking simple language. Even the dress code was a big problem. Females are generally expected to wear skirts as opposed to trousers. Although this was not accepted, it did not lead to the refusal of interviews.

At times, the fieldworkers had to work in conditions where, in many occasions, there was bad odour. The entire house would smell badly in such a way that one had to persevere in order to get to the crux of the matter. This, ultimately, proved that perseverance is the mother of success. In this case, perseverance has paid off because fieldworkers were extremely patient to collect data – even in places that were extremely unpleasant.

Afro-centric approach of collecting data

As previously argued, certain values tend to dictate how people react in certain situations. For example, rural communities persistently expect to be addressed in a particular way, especially when they are addressed by young persons. Ideally, one should give them a chance to express themselves fully regardless of whether they are out of context or not. This was particularly so because they liked to talk about stories that might (in a researcher's view) not necessarily have been relevant. There is also consensus among rural communities that under normal circumstances, a person would not freely and openly give out important and confidential information to the stranger. This was particularly true in the community where the research was done. In fact, it manifested in various ways. At first, we relied heavily on making telephone calls to make or to confirm an appointment. However, nearly more than half of the appointments made by telephone were not successful. Respondents argued that they could not enter into an agreement with a stranger whom they had never met before. This was further exacerbated by the fact that respondents did not understand completely what the research entailed. Even in their responses in the telephonic conversation, one could tell that the person on the other side was not comfortable with the discussion.

In response to this, we decided to use telephone calls mainly to plan a meeting with the respondents so that they could see us. It was only after seeing us that they would confidently and fluently give us their details. Indeed, they regarded face-to-face interaction as the most convenient and reliable method for them, given the circumstances they live in. After seeing them, the appointments actually started to bear fruit. So, in order to make successful appointments, fieldworkers had to drive around in the community and talk to whoever they met. This proved to be a great success. At this particular juncture, telephones and cell phones were merely used to confirm the appointment. In fact, some of the respondents would even go the extra mile by setting up appointments on our behalf.

Gains as a group

There were quite a number of gains that accrued to the fieldworkers. These included intellectual stimulation, a significant boost of confidence, and a holistic approach to the community. First of all, it is imperative to indicate at this stage that the fieldwork had actually come at the right time for most of the fieldworkers. This was particularly so because they varied in terms of the progress they had made in their own research projects. Some, through gaining first-hand experience, were able to effectively use the knowledge to add to their own projects. In this regard, the research know-how or expertise has hugely helped in terms of familiarising fieldworkers with the most current methods of collecting data. In other words, this was a highly intellectually stimulating experience.

Similarly, the fieldwork significantly improved the fieldworkers' confidence in terms of handling interviews and administering questionnaires. This was a remarkable experience since fieldworkers will be able to continuously apply the skills learned for the rest of their professional lives. Since organisations vary in terms of size and length of service, this is no longer an issue amongst fieldworkers who have now grown in confidence and in intelligence. Traditionally, the big organisations tend to be more terrifying than those that are small and new. This was particularly a big problem in the beginning because of the lack of required skills and the necessary level of confidence.

In addition, the fieldwork has also profoundly helped in terms of skills required for entering a community. Ideally, it should be said that gaining a perfect entry into the community makes everything hassle-free. We talked to the relevant authorities, including chiefs, local councils and traditional councils, who granted permission. Likewise, the interpersonal skills of the fieldworkers have grown exponentially through their exposure to different organisations and the way these organisations are run. This not only boosted the fieldworkers' self-esteem in terms of interacting with different people, but it also created an appropriate space for them to apply the knowledge and skills they have gained in the classroom to the community. In fact, the fieldworkers applied skills that were coherently brewed in various formal and informal educational cycles. In particular, their backgrounds seemed to match perfectly with the community's expectations. Further, the training that fieldworkers received also enhanced their level of self-esteem and understanding of essential research methods. Therefore, data collection has been a test or exercise for interpersonal skills in which fieldworkers have emerged victorious.

Admittedly, the fieldworkers' problem-solving skills have also been immensely boosted due to their exposure to various organisations. This happened because most organisations indicated how they resolve their issues. As far as the fieldworkers were concerned, this was a learning curve because they could easily take that experience and transfer it into their own situations. Problem-solving skills are critically important especially if one intends to become a future leader.

Finally, leadership skills were also acquired through working and interacting with different leaders of organisations. Their leadership styles and how they lead organisations were all benefits that accrued to fieldworkers. This is so because one cannot rely on one leadership, but it must be a synergy of different leadership styles in order to come up with an effective and productive style.

Gains as individuals

Mbekezeli Mkhize

Although this was not necessarily a first opportunity at fieldwork, it proved to be technically and tactically different from previous research I had been exposed to. It was different in terms of organisation/design, professionalism, academic excellence and length. These aspects appeared to be the cornerstone of any successful research project. So, these aspects will be explained briefly in terms of how they impacted on me as an individual.

The fieldwork proved to be splendidly and accurately organised. For example, transportation was made available to the fieldworkers, and the methods used in collecting data were flexible to allow the fieldworkers to add their observations. I think observations are essential because people do not always mean what they say. For instance, a person might say "I am poor" while he/she comes from a luxurious house. Therefore, it was appropriate to combine the observation method with focus group conversations. The intended respondents seemed to be in a situation that was anticipated in the research proposal since virtually 60% of them were extremely poor and they were faced with a challenge of diseases, including HIV/AIDS.

Professionally, the data collection phases have adhered strictly to the ethos of high professionalism and integrity. Fieldworkers were constantly encouraged not to compromise the quality of an interview for the sake of finishing early. The interviews were, therefore, handled with a high degree of vigilance and technical know-how. This taught me to be extremely prudent in terms of applying academic knowledge in the rural setting. This was done irrespective of the weather conditions.

Academically, the data collection phases were extremely important because we got to know the key research approaches and methods. Furthermore, we become familiar with applying those skills in real-life situations. In fact, we were able to put those research skills into practice without any significant adversity. It made us academically independent. In other words, we could handle academic work without any assistance from anyone. This is especially useful for young and aspiring researchers.

The length of the project taught me how to handle a longitudinal study. One must maintain good relations with the community. If the relationship was ruined in the first phase, it becomes difficult to gain entry into the second phase. The longitudinal study also creates opportunities for fieldworkers to know the community better, thereby making it easier to do other research activities in the area because they are already known and trusted in the community.

Thulasizwe Kuzwayo

The social capital and HIV/AIDS programme was research work that brought about extensive knowledge in conducting longitudinal studies. It further helped to improve personal understanding, to develop processes that seek just, equitable and integrative solutions, and to clarify interests and values, thereby informing deliberations that lead to the collection of high-quality information. The study helped me in terms of addressing issues of relationships, reciprocity, power and influence in the local community. It also enhanced my ability to discover common understanding, to identify mutual responsibilities and to negotiate shared principles among local community members of that rural area.

The social capital and HIV/AIDS project has exposed me to factors that include individual risk perceptions, social networks and organisational behaviours (reasons for the groups' failures and successes). Fieldworkers adhered to the culture of teamwork to make this study successful. It is imperative to mention that fieldworkers maintained teamwork even when things were going against our will and planning. The study taught me how to maintain good relationships with respondents who participated in the research programme. I learnt that a researcher could indirectly act as a mediator between two parties that do not see eye to eye. For example, in a focus group, a researcher can help participants laugh together and get to know and understand each other much better than they did before. The social capital project provided me with practical experience in data collection, professionalism and the importance of maintaining research ethics. The study taught me how to engage different people of different age groups. Sometimes fieldworkers would come across people who are impossible to deal with. Faced with such challenges, fieldworkers were required to use personal skills as an icebreaker to capture respondents' interests.

This research work has exposed me to ongoing social and cultural ties that shape and motivate local people in that rural area. An example here could be when there is a big function at one household. The community (especially the neighbours) would happily flock to the house. The culture dictates how each function should be carried out, and the entire community is well aware of cultural doctrines. Thus, the research work offered me insight into issues pertaining to gender and culture, patriarchy and matriarchy and influences of social structures in local human life. It also gave me an opportunity to develop an inquiring mind and interest in what gives rise to the lack of social capital and the spread of HIV/AIDS. The research skills that I acquired during this social capital and HIV/AIDS research project have enabled me to handle my own research work in a professional and systematic manner. However, it is also important to mention that I did not experience any culture shock during our stay in the local community. This is because the culture, norms and values that people practice in the rural area where the research was undertaken are almost similar to those that are practiced in my community.

Concluding remarks

To conclude, it is imperative to refer back to what was said in the beginning about the first and second phase. From the outset, it was argued that the first phase was relatively easy to handle because there was no need for appointments. Although this stage presented its own challenges, most challenges were relating to issues of consent. Mostly, the respondents were readily available. During this stage, the fieldworkers could ask the respondents to fill out the questionnaire even if they met each other in the road or in the recreational facilities. There was no planning involved except to consider the areas that had already been covered and those that had not yet been covered. The first phase was easy to handle as opposed to the second phase which required thorough planning and proper organisation of research work.

In the second phase, we had to make appointments with local organisations. As previously stated, appointments had to be either postponed or cancelled owing to various unforeseen circumstances. It is important to stress that the closing stage was highly demanding since it was during the time of the year when organisations resume and plan for the year to come. At this point, the field work was a bit tiring as we had to go back and forth picking up the remaining pieces, trying to meet the deadline. A few appointments with organisations were completed at first attempt. The majority, however, was not completed at first attempt because of unforeseeable circumstances, which included adverse weather conditions and the unavailability of respondents.

In spite of these challenges, fieldworkers have learned crucial lessons during the fieldwork. Although these lessons varied, they were after all extremely advantageous to the fieldworkers. The lessons as shown above varied from one fieldworker to another. But one can safely say that all the fieldworkers who participated in the project have gained immensely.

Chapter 11

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

Thirusha Naidu

Introduction

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

Women volunteers and unpaid care

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

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

Generative metaphor

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

Schon (1979) regards metaphors as ‘generative’. A metaphor is referred to both as a product (a perspective or frame, a way of looking at things), and as a process by which new perspectives on the world come into existence. Generative metaphors create a sense of imaginative play through which new meanings are created, transforming and increasing our understanding. Metaphors allow for a new organising schema on familiar and banal ideas in such a way that inestimable variations are/become possible. Lakoff and Johnson (1996) use the term ‘mapping’ in relation to metaphors, suggesting metaphors allow a meta-perspective in much the same way as a map would do in relation to physical geography. It offers an immediate mental picture where an explanation would be thin and inadequate. A generative metaphor facilitates the learning of new knowledge, creating the conditions for experiences that are outside the current frame of reference. Through a metaphor new perceptions of the world are possible and experiences of these new perceptions can be ordered and made sense of. Immersion in this experience, through active thought and experimentation, leads to the cultivation of new ideas and the expansion of cognitive frames (Modell 1997; Schon 1993; Winter 1989).

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

- How do HBCVs view themselves in terms of identity?
- How can the generative metaphor elevate and thicken pre-existing positive identity associations with the role of the HBCV?

Methodology

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

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

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

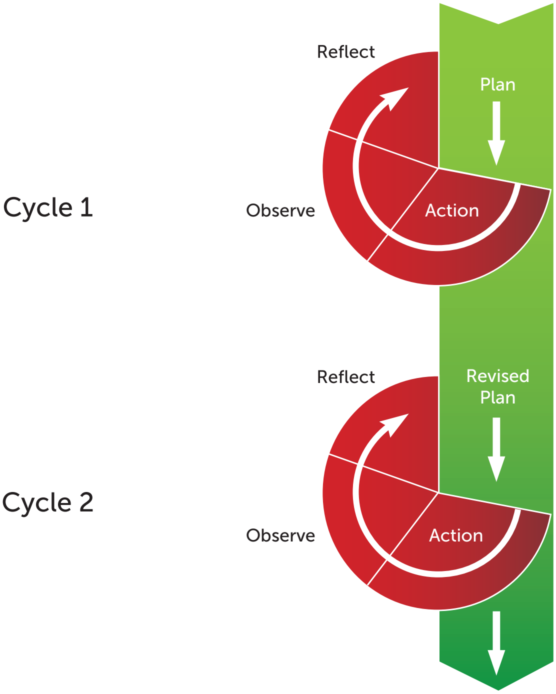

Figure 11.1 A simple action research model (MacIsaac 1995)

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

The women who took part in this study volunteered as part of a group who provided care services to community members who were too infirm to care for themselves. The women were approached through other researchers on the social capital project that had done preliminary work with the HBCVs. The group's leader contacted the women to arrange interviews. The participants lived in the community and were aged between twenty-five and sixty. None were formally employed. All had attended formal schooling and had completed between Grade five and Grade twelve at school. None of the group members had any formal training in nursing or care work, although three had experience of caring for sick relatives. Of the group, all but four had participated in the informal employment sector as domestic workers or doing other types of ‘piece jobs’ (a colloquial South African term for intermittent casual paid work). The women all spoke isiZulu as their home language and had some understanding of English. The women would begin by volunteering in the group for a period of six months or more after which they would receive a small government stipend as and when this was available.

Findings and discussion

Identifying the generative metaphor

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

> *It would seem that, besides being a ‘compassionate doer’ Mrs T had many other traits that contributed to her being able to help others. Those close to her (her husband and her mother) were also strong-minded, proud and positive people who were industrious and innovative.*
>
> *I was struck by the fact that the four women healthcare volunteers that I met seemed to be respectable and conservative matriarchs in the community. Their standards of dress and appearance conveyed this initially. Later it was also conveyed in Mrs T and Mrs N’s stories about their lives. In my chance meeting with the two HBCVs, this persona was also evident. The life stories of Mrs T and Mrs N conveyed the idea that they were aspirant people, ambitious, brave, unconventional and daring. The type that was willing to break the rules and take chances. Mrs N’s life story reflected that she was always trying to improve her situation in life. (TN Reflexive Journal 24/05/2009: p. 8)*

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

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

> *TN: What makes you as a person able to volunteer? Does it require a certain kind of people to be able to care for people?*
>
> *Mrs M: I don't think it requires a particular type of person, just as long as you are able to go to people and give them information and help them. So, I really don't think it needs a special person it just needs a mind of a mother.*
>
> *TN: And you don't think that is special?*
>
> *Mrs M: The mind of a mother is very important, because it could help you go through small spaces, like enlighten people who don't know.*
>
> *TN: I don't understand what it means when you say go through small spaces.*
>
> *TN: Okay! Can you give an example of when you have done that?*
>
> *Mrs M: When you get to a household and there is an old woman who cannot get up; maybe she has lost control over her excretion functions and when you get there, it is dirty. So, I would speak to the people around there who should be taking care of her. I would say: "This is not how it should be working … she shouldn't be dirty like this and these are the effects." So, that old woman would be very pleased, and very grateful for saying things to make these children realise what they should be doing.*

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

HBCVs belonged to in the community was called *uthando lomama* ('the love of the mothers'). This phrase was adopted as a generative metaphor.

The cultural, contextual and personal salience of the generative metaphor

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

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

The use of mothering as the basis of this generative metaphor was especially fortuitous. It is a communal metaphor, one that is easily recognisable and transferable across cultures. The fact that the researcher is also a mother resulted in the use of the metaphor strengthening rapport around the shared role of motherhood. From a social constructionist perspective, it could be said that it is particularly because I considered the motherhood aspect of my identity salient that I was drawn to this phrase and applied it as a generative metaphor. The HBCVs accepted the salience of this metaphor for themselves to varying degrees and certainly as a collective as reflected in their decision to name their group *Uthandolomama*. The broader cultural framework within the context held distinctive ideas concerning the values, roles, etc. of motherhood (Masuku 2005). In Modell's (1997) terms, this would then be a communal generative metaphor. A metaphor is usually consistent with a value system that is coherent with the metaphor's ontological stance. Within the cultural perspective of the participants (African collectivistic culture), motherhood is central to a woman's identity. From a collectivist view, motherhood is an inevitable role for all women in the community – a role they take on to varying degrees throughout their lives: mothering siblings, their own children and grandchildren (Masuku 2005). Older women in the community are referred to as *omama.* This is a collective noun meaning 'the mothers' and simultaneously reinforces the collectivist concept of motherhood. Children or younger people in the community are expected to afford the same degree of respect to all older women in the community as they would their own mothers. By the same token, older women should treat children with the same benevolence, care and concern they would treat their own children.

This metaphor allows for more meticulous examination of the concept it maps and the correlations between the mother identity and the home-based caregiver qualities or identity. The use of a metaphor is fairly common in care work. It is interesting to note that 'coming home' or 'home' is a metaphor that is often associated with palliative care (Dekkers 2009). This is a metaphor that is not out of place in this context where people literally return to their physical and ancestral homes to be cared for by their biological mother, a female relative all of whom are viewed as 'mothers of the community' (*omama*) in the terminal stages of illness. In a study by Berdes and Eckert (2007), nursing aides used metaphors associated with family relationships and attachment to describe their affective care and even contrasted it with uncaring families. The HBCVs in my study compared their caring to that of uncaring families, especially to uncaring mothers. Sharoff (2009a, 2009b) writes on the importance of the metaphor in nursing care work as creating possibilities for new meaning and providing new insight into the human spirit. In contexts other than caring, women have also attributed their volunteerism to an expression of their maternal nature (Petrzelka & Mannon 2006).

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

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

> *Mrs RM: They would describe me as the kind of person that I am [I asked what would that be] for example the mother-in-law sometimes she says to me – especially around sweeping the yard – when you die we will still see you in the yard with a hoe or with a broom … [Mrs RM LAUGHS] … because I sweep, I mean I sweep that side, I go outside and I pick things up. If I hadn't had the time to sweep the yard it is full of rubbish and I will be shouting and I would be like "Why does it have to be like this, just because I didn't have the time to clean up today does it mean it should be like this?" So she would describe me as that sort of person.*
>
> *TN: So you are the type of person who takes control of things and makes sure that it is done properly?*
>
> *Mrs RM: Yes.*
>
> *TN: And everybody knows you like this?*
>
> *Mrs RM: Yes, even my mother would tell you what kind of person I am. I am a mover.*
>
> *TN: And what about your friends, would they think the same thing? Your friends and your neighbours?*
>
> *Mrs RM: I think they would especially. People who come and visit at home, I don't sit, you won't find me sitting at home, because even inside the house I am always doing something. Like the dresser … it doesn't sit in one place for the whole year, I move it at least twice a year. I move things; I re-arrange things all the time.*
>
> *TN: Why do you do that?*
>
> *Mrs RM: I think I am used to it and also that sometimes it is hard to clean places that you cannot reach.*

The generative metaphor was suggested in each interview and all the women made sense of it and identified with it to varying degrees. Of significance is that metaphors in general resonate with what is familiar to the individual and what that individual relates to. According to Obeyeskere (1990), culture is the process whereby the symbolic forms of the metaphor existing at the cultural level get created and re-created through the minds of people. There is an intersection of private metaphor and cultural symbol. Simply stated it allows the person to connect the known with the novel. The generative metaphor provides a tool that allows for ideas to be expanded beyond their initial presentation. The generative metaphor, if used constructively, can be simultaneously challenging yet respectful of current perspectives as illustrated in the following excerpt:

> *TN: And also someone said that one needs a mind of a mother to be a HBCV? What do you think that means?*
>
> *Mrs RM: I wouldn't really say that you have to be a mother to do this; you just have to be someone who is hard-working, someone who is interested in helping people, because you can do that without being a mother. You can just … because some people are not mothers, but they can give what mothers can give, you just have to have the love of helping people.*
>
> *TN: Could it mean that the person meant you need to have the qualities of a mother even though you are not a mother yourself?*
>
> *Mrs RM: Yes, that is what it means, because when you are a mother you are like a chicken that protects its chicks. So if you are going to do this work you have to like that. You have to be like a chicken to the people you are caring for. When you arrive at the house they should feel that you have arrived, that you are going to protect them, they should feel warm in your presence.*

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

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

Are generative metaphors omnipotent?

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

All the HBCVs cited *uthando* ('love') as being their primary motivation for volunteering. This, combined with the decision to call their group *Uthandolomama,* could conceivably have a disempowering effect on group and personal identity. The value construct of 'love' is a central element of both volunteer and mother role identities as constructed by the HBCV group within the canons of the broader socio-cultural and historical narratives of the community. Love in the context of motherhood – whilst it is passionate and unconditional – can also be selfless and self-sacrificing. The expectation is created for the HBCVs themselves, the community and new recruits that no external reward should be expected, and those willing to do the work needed to create their own internal sources of reward. The connotation of the name (*Uthandolomama*) is also likely to establish expectations within the community as to what to expect of the HBCVs, namely loving, caring and doing tasks for the ill that mothers are expected to do. Mothering is commonly understood to be an unpaid position, definitely financially and possibly emotionally. When children are at their most needy (very young or very ill), a mother's work is at its most demanding, both emotionally and physically. Based on interview data, it would seem that the name thus epitomises the philosophy of the group. Those who are not motivated by love cannot and should not do the work. In so doing, the work is simultaneously defined as unacknowledged yet beyond the resources of ordinary people requiring only those who are able to love unconditionally without the expectation of a reward.

Notably, a key feature of HBCV groups is that they consist almost exclusively of women. In cases where men are involved, they serve as supervisors and spokespeople for the groups. When men are active in the physical sense, it is usually in the role of caring for a relative – most often a wife and not, as in the case of women, caring for extended family members and community members. Aita, McIlvain, Susman and Crabtree (2003) note that in the case of the nurturing parent as caregiver model, empathy is central. By mapping the nurturing parent metaphor onto a political perspective, a viewpoint that emphasises a morality of empathy and justice, looking after people in need, and caring for the self and others emerges. The strict father model espouses self-discipline, accountability, and self-sufficiency. Mapping this metaphor onto a political perspective, results in a conservative idea of subscribing to a morality of strength, self-sufficiency and self-discipline. A blaming rather than a nurturing attitude to patients is cultivated in the context of the father metaphor. This perpetuates the international, cross-cultural stereotype of women as caregivers. The idea that women are the best caregivers, that they do the best job, and that they are naturally predisposed to caring roles, contributes significantly to excluding men from the process. In the particular case of *Uthandolomama,* it is likely that, whilst the name may attract women to volunteer in the group, it is likely to have the opposite effect on male volunteers. Confronted by the implication that volunteering to care in this group requires a 'mother's love' many if not all men in the community are likely to be discouraged from volunteering. In terms of Modell's (1997) axes of metaphors, *Uthandolomama* would in this case signify a communal but foreclosed metaphor, which could serve to reinforce the gendered nature of care work (Akintola 2006). Whilst there is substantial criticism around men being less involved in caring than women, the case in point might be illustrative of a phenomenon where women either consciously or inadvertently discourage men from participating in community care work.

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

> *Mrs VM: So sometimes I tell my children we were raised by women. One woman. There was no grandfather there. Our mothers were not there, but we were raised. We could have done whatever we wanted to but all of us who were raised by granny are married. So I say to them: a mother and a father are raising you. You are very lucky yet you do not appreciate that you just go wherever you want to. People just govern themselves. I mean you come back and you say "Oh we were at H this weekend or we were in M" and yet you haven't told me that you were going to H or to M. What happens if you get hurt there? We could have done whatever we want with granny because she was a woman and she was old, but we respected her. These children don't respect what they have. So I talk to them a lot and sometimes I reflect and I think that being raised by Granny helped me a lot because I am in my home, there are bits of gravel here and there, but I am there and I tell them because now they are grown they can see things and I tell them, I say "Can you see that there are problems within this house, but I am still here?" Granny used to say, "You don't just live like that you can build a house a home as a woman just by yourself you can do that. There doesn't have to be a man for there to be a warm home." So yes, I tell them that if you listen to me you are also going to turn out to be strong women and strong men who are going to build strong homes, but if you don't then you'll end up roaming the streets and just be nothing.*

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

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

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

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

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

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

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

Conclusion

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

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

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Chapter 12

Home-based care and social capital: Exploring the role of social capital in resource creation and access

Olagoke Akintola

Introduction

Community participation in health care is a core element of primary healthcare programmes the world over. This is especially true for Africa where resources are not only limited, but where there is a romanticised sense of community. These notions of community among Africans seem to converge with those of international organisations such as the World Health Organization (WHO), which, approximately three decades ago, endorsed community participation as critical to community empowerment and for achieving health for all (WHO/UNICEF 1978). Community-based programmes have therefore been promoted widely, in the spirit of empowerment, in primary health care. This has taken root particularly in the developing world where people's willingness to contribute to community development has been tapped by community programmes. Although the degree of community participation varies in different settings, the most enduring form of participation has been that of community health workers/community-based health workers who provide a range of services in community healthcare programmes thereby helping with service delivery. With the advent of AIDS, the notion of community participation has been drawn upon widely by governments to promote home-based care (HBC) as a measure to reduce the burden of AIDS care on public hospitals. Yet, it is for its negative implications for women that HBC has come under the spotlight in recent times (Akintola 2008a, 2008b; Chen, Vanek, Lund, Heintz & Jhabvala 2005).

Researchers as well as gender activists have argued that home-based care imposes a burden on women who are predominantly poor and underprivileged, undermining small gains made in the development of women (Akintola 2006; Akintola 2008b; Chen *et al* 2005; Orner 2006). Further, as will be evident later, an overwhelming majority of care providers working with care organisations are volunteers and they also experience physical, emotional, social and economic stress highlighting the need for support. Regrettably though, care organisations comprising non-governmental organisations (NGOs), faith-based organisations (FBOs) as well as community-based organisations (CBOs), which provide the bulk of HBC for people living with AIDS in South Africa through volunteers (Steinberg, Johnson, Schierhout & Ndegwa 2002), confront enormous resource problems which undermine the reach and sustainability of these programmes as well as the quality of care provided (Akintola 2004; Russel & Schneider 2000).

A critical element in HBC policies is the need for collaboration and partnerships among various stakeholders. This will suggest the need for provision of various resources and support by different key stakeholders for effective HBC (Akintola 2004; Campbell & Foulis 2004; Russell & Schneider 2000). The stakeholders include the following:

- the informal sector: civil society organisations such as NGOs, FBOs and CBOs, families and communities;
- the private sector: private businesses and industries; and
- the public sector, including various government departments/institutions, notably the health department (public health facilities), social welfare department and other government departments.

However, there is little collaboration among these players and access to resources remains poor in HBC (Akintola 2008b, 2010b; Campbell, Nair, Maimane & Sibiya 2005). Given that resources are critical to the implementation of efficient, effective and sustainable HBC programmes, several authors have suggested the need for access to more resources by the key players in HBC (Akintola 2008a, 2008b; Campbell *et al* 2005; Russell & Schneider 2000). However, available studies focus on the burden of care, while other studies in this volume examine various roles of social capital on the burden of care. It is therefore unclear what potential role social capital could play in accessing resources to mitigate the burden of care on caregivers and for effective HBC. In this article, I assess the links between social capital and access to resources in HBC. Insights from this study could provide information that will inform policies aimed at improving access to resources in HBC.

The AIDS-care economy

Before discussing the AIDS-care economy, it is apt to first discuss the question: What is care work? Care work, according to England, Budig and Folbre (2002), is work that provides a service to people that helps develop their capabilities. Care work could be paid or unpaid and includes childcare, teaching and healthcare work. Unpaid care work refers to labour undertaken out of affection or a sense of responsibility for other people, with no expectation of pecuniary reward (Folbre 1995). It involves direct and indirect care as well as the provision of supportive services to persons, including children, the frail elderly, the sick and persons with disabilities, as well as able-bodied family members (Razavi and Staab, 2008). Care also requires, particularly in developing countries, an increasing amount of housework (Budlender 2004) such as meal preparation, cleaning of homes and utensils, washing and ironing of clothes, and shopping.[1]

Care economy is a term used to describe the unpaid care work performed within homes and communities, which facilitates the sustenance of physical, psychological and socio-economic well-being of family and community members (cf. Azari *et al* 2004; Elson 1999). Unpaid care has been a subject of interest among feminist economists (cf. for example Elson 1999; Folbre 1995; Van Staveren 2005), largely because women perform care work disproportionately across the globe. Time-use studies worldwide reveal women bear a much higher burden of care than men (Antonopoulos & Hirway 2010:1-21; Budlender 2004; International Labour Organization 2008). Elson (1999) argues that the unremunerated care provided mainly by women at home serves as substitute for the labour market. As Antonopoulos and Hirway (2010) point out, care work and indeed all unpaid work serve as subsidies to the business sector and public sector provisioning. In other words, care work helps sustain productivity in the paid economy because it allows family members to have 'free' time that they can use, for example, to participate in the labour market in order to generate income, to use for other subsistence activities, or to participate in schooling and other social activities. Without care work, these activities would not have been possible as family members would have to hire paid care workers to help fulfil this function in order to free up time for other activities. Care therefore contributes to the social and economic development of a country. Therefore, from this perspective, unpaid care produces 'public goods' since they help maintain the proper functioning of society. The notion of public goods is used in the economics literature to refer to goods that have benefits for those who pay as well as for those who do not pay for such benefits. The fact that one derives benefits from a public good does not preclude others from deriving benefits from it. It is also impossible to exclude those who do not pay for public goods from enjoying the benefits that come with them. Care is considered a public good because it produces benefits that are enjoyed by society at large. For example, a recipient of care enjoys direct benefits such as comfort, skills, values, good habits, etc. S/he is also able to pass on the benefits, such as increased productivity, good behaviour and proper conduct, to others such as the community or employers (England 2005; England & Folbre 1999). However, much of the available literature focuses on unpaid care in Western countries and emphasises mainly care provided by able-bodied persons for spouses, children and other family members.

Whilst AIDS care shares a number of similarities with other forms of care described extensively in the feminist economics and indeed the wider feminist literature such as child care and adult care, the AIDS-care context has some uniquely different features from other forms of care. First, much of the unpaid AIDS-care activities are a consequence of government's AIDS policies which serves to shift a substantial proportion of caring responsibilities to AIDS-affected families and communities. Governments in many sub-Saharan countries have promoted HBC policies as a means of addressing problems in the public health sector. These problems include a dramatic increase in the number of people living with HIV/AIDS making use of public health facilities, the dearth of human capacity in the public health sectors, a shortage of healthcare professionals and the lack of bed space in the public hospitals (cf. Akintola 2010b:112-139). HBC, which refers to the provision of care to chronically ill patients at home by family and community members, is the government's solution for dealing with the problems in the public health sector. Second, AIDS care is resource-intensive: the nature of the disease makes it imperative to draw on some essential resources normally available in public institutions and to highly skilled people such as human, medical and material resources, including bed space in the provision of home care. Third, patients are usually in the productive and reproductive ages, but many of the caregivers become caregivers by default rather than by choice, usually a generation older or younger than the patients (Homan *et al* 2005). These caregivers are therefore the least able to provide such care, given their age, health and socio-economic conditions.[2] This has implications for the quality of care of the patients as well as the health and well-being of the caregivers. Fourth, HBC policies largely impact on public health facility users who are normally less well off in society (cf. Akintola 2010b). As a result, care is provided in the context of poverty and a lack of resources. Fifth, care is often provided in secrecy due to the fear of stigma and discrimination. Finally, unlike many other non-infectious and infectious diseases, AIDS clusters in households. Thus, the additional burden on care providers are substantial and much more than providing regular care for children and other family members in countries that are most affected by AIDS, such as countries in Africa, Asia and the Caribbean.

In the context of AIDS, there has been a considerable increase in the amount of unpaid care carried out at home and in communities (Akintola 2010b). The provision of care to chronically ill family members is at the top of the list of pre-existing care responsibilities that caregivers have to carry. In addition to existing care activities, such as care for family members, caregivers have to undertake a range of care activities for people with AIDS. There is usually an increase in the demand for housework, such as washing dishes and clothes, including soiled ones, fetching water and firewood and running errands for the ill. As with other forms of care discussed in the feminist economics and feminist literature, AIDS care is a gendered activity (Akintola 2006, 2010b); women are the majority of family members and community members providing care. Together, these bring into sharp focus women's time burdens and the implications for women's well-being and development.

Community empowerment and access to HBC resources

Citizen empowerment is at the heart of primary health care, which has long been promoted by the WHO as a broad philosophy for attaining health for all (WHO/UNICEF 1978). This notion is echoed in various countries' policies on HBC. Community mobilisation is a major domain in empowering communities (Laverack & Labonte 2000) and is based on the notion that communities possess latent resources that could be activated through, amongst others, community participation. Empowerment is a process through which people experience more control over decisions that influence their health and lives (Laverack & Labonte 2000:1). Community empowerment is aimed at promoting equality in social relations of power (Laverack & Labonte 2000), defined in this case as access to resources necessary for HBC. Although community HBC is intended to mobilise communities to draw on potential resources with the ultimate goal of empowering communities, much of the literature on HBC paint a different picture that seems at odds with this goal. Although participation in HBC initiatives empowers communities to some degree, it often results in a systematic disempowerment of communities. At core is the general lack of access to resources necessary for effective HBC. There seems to be no clear guidelines on how to mobilise communities to take collective action aimed at accessing latent resources within the community and resources from outside the community. Whereas HBC policies are ostensibly aimed at empowering communities with skills and opportunities to partake in decisions concerning the ill, a critical lack of capacity among family members to cope with the care and related needs of the ill renders them ill-prepared and ill-equipped to provide care for the ill. This has created a care gap in many communities across the region (Akintola 2010b).

In practice, mobilisation for care and various arrangements are undertaken by various groupings with little help from governmental structures, with few exceptions. CBOs, FBOs as well as NGOs have in many cases shouldered the responsibility of mobilising community members to fill this care gap. These organisations recruit community members and provide training for them in order to provide care to the ill and support for family members. Although these organisations have been able to provide enormous support in AIDS care, studies reveal a number of problems with this arrangement. First, many AIDS-affected households are not reached by care organisations (Steinberg *et al* 2002); therefore these households are unable to access the services of these organisations. Second, many of these care organisations lack the requisite resources such as personnel, training, funding, supplies for the provision of care and food to supplement poor households that would help in providing comprehensive HBC. Closely related to this is the inequitable distribution of HBC resources by government institutions (Akintola 2010a). Third, care organisations confront a myriad of challenges in meeting the needs of their unpaid volunteers. There is a paucity of various factors that enhance satisfaction and retention of volunteers (Akintola 2010a) such as psychosocial, financial and material support. Community empowerment in HBC is thus restricted in many instances to the provision of care services by community members trained either by local or outside agents (Campbell, Nair, Maimane & Sibiya 2008; Russel & Schneider 2000). It is therefore questionable if and to what extent the romanticised changes in the configurations of power and community members' ability to access resources are achieved. Given these challenges, it becomes imperative to explore what factors need to be mobilised in order to access resources required for effective HBC and the mechanisms for achieving this.

Can home-based care generate social capital?

The World Bank (2000) defines social capital as the norms and networks that enable collective action. It encompasses institutions, relationships and customs that shape the quality and quantity of a society's social interactions. According to Carpiano (2006), social capital emerges out of social networks that provide the basis for the development of socially cohesive communities characterised by strong social organisations, common norms and social trust, which facilitate coordination and cooperation for mutual benefit. There is a fair degree of consensus that African communities possess qualities that help them live together in harmony as a collective. In South Africa, for instance, the concept of *ubuntu* is well known. *Ubuntu* is an African humanist philosophy, which emphasises interconnectedness and mutual dependence of individuals and the need for people to help each other (Akintola 2010a). This seems consistent with the concept of social capital, which refers to the elements in society that serve to make people work together. Before discussing the question of whether social capital can be mobilised in order to access HBC resources, it is important to examine the role of HBC in generating social capital. In doing this, it is apt to begin by discussing the costs and benefits of HBC.

Although there is a fair amount of agreement that HBC has benefits which include savings to the public health system and for patients who are cared for in a familiar environment with kin and relatives, much of the literature on HBC focuses on the negative implications for caregivers (Akintola 2006, 2008a; Orner 2006). Caregivers experience stresses while providing HBC for people living with HIV/AIDS (PLWHA). These include physical stress from the physically demanding nature of care work, which sometimes requires caregivers to walk long distances to patients' homes, lifting patients, transporting patients on their backs to clinics, etc. These result in backache, headaches and body pains (Akintola 2006; HelpAge International 2004; Orner 2006). The physical impact, especially for older caregivers and those who themselves are infected with HIV/AIDS, can be profound. Caregivers who provide care to patients without using gloves or other protective devices could also be at risk of contracting HIV/AIDS through contact with patients' body fluids. Emotional stress comes from the traumatic effects of caring for sick and dying patients and of witnessing the death of patients (Akintola 2006). Emotional stress is exacerbated by caregivers' inability to reverse the progression of disease or to prevent death in the absence of antiretrovirals despite all their efforts at providing care (Akintola 2008a).

Stress also comes mainly from real or perceived stigma. Family members are unable to ask for assistance and support from neighbours and community members because of fear of discrimination. Family caregivers are also reluctant to solicit support from volunteers working with care organisations (Mwinituo 2006). Caregivers are also unable to socialise with friends and community members for the same reason. These result in isolation of the affected family members. Economic stress comes from the negative economic consequences of providing care. These consequences are twofold: financial costs and opportunity costs. Financial consequences derive from the financial and material costs incurred by family members in purchasing resources necessary for effective home care. This includes supplies such as diapers, gloves, linen savers, soaps, detergents, special foods, etc. It also includes transportation costs for patients to hospitals/clinics or transporting the caregiver to the hospital for patient visits. Opportunity costs include the cost of opportunities foregone for care, i.e. costs of alternative activities caregivers relinquish in order to provide care which include paid employment, subsistence production, social activities and time for reading and self-care (Akintola 2010b).

Although it has been previously acknowledged that PLWHA derive a lot of benefits from HBC, the benefits to caregivers have been poorly described. However, recent studies show that caregivers derive rewards from providing care (Akintola 2008a, 2010a). Rewards refer to positive subjective feelings or objective internal and external changes in the caregivers' lives resulting from their caregiving situation (Picot, Debanne, Namazi & Wykle 1997). Rewards include perceived positive feelings or obligations, pleasures, satisfactions, gratifications and positive outcomes from enduring a burden (Picot 1995).

Care-giving generates various kinds of benefits. However, as noted earlier, caregivers do not necessarily receive pecuniary rewards from providing care. A fair amount of the benefits could be said to contribute to elements of social capital such as trust, norms, cohesiveness and solidarity and social networks. Benefits from care-giving extend from the PLWHA to the entire community and society. Caregivers derive emotional benefits from providing care and family caregivers derive emotional satisfaction for being able to provide care to their relatives (Carlisle 2000). These carers develop unusually close bonds with patients that lead to emotional satisfaction. Spiritual benefits can also be derived from providing care as caregivers feel that their deeds will be rewarded by God or a higher being (Akintola 2008b, 2010a). Savings accrue to caregivers as a result of home care. Caregivers, family members and patients are able to save the money they would have spent on hospital care or transport to hospitals (Akintola 2008b). AIDS care-giving can also be a form of investment (Akintola 2008b). The training that caregivers receive could serve as a form of investment in human capital for the caregivers. Family and volunteer caregivers could use the skills acquired in providing care for relatives and other community members. Volunteers could also use these skills and experiences to secure employment as paid care providers. Care-giving could also be an investment in human capital for the patient. The patients who receive care could derive direct benefits of symptom relief and some degree of recovery from illness. But they may even be able to recover fully to resume participation in the labour force and other social activities such as reciprocating the gesture of the carer by providing care and support to others. Therefore, in addition to building human capital, the provision of care could also help generate social capital.

Despite all these benefits, there is a paucity of information on the ability of HBC to generate social capital although a few authors have hinted at this (cf. Akintola 2008b; Russel & Schneider, 2000; UNAIDS 2000). However, the mechanism through which this occurs has not been previously discussed. Nonetheless, social capital has been implicated in the motivations of volunteers. A recent study among volunteers in South Africa (Akintola 2011) showed one of the primary motives for enrolling as volunteers was altruistic concerns for people living with AIDS and for the need of the community. Participants wanted to give of their time and resources to combat the effect of AIDS on their community. This motivation enables people to join networks of people providing care-giving services. It might also help others mobilise for collective action in addressing issues of community care (Akintola 2008b; Batson, Ahmed & Tsang 2002). In poor non-agrarian communities or communities with high unemployment rates, joining existing networks providing care could serve as a way of avoiding idleness (Akintola 2010a; Rödlach 2009) and developing social relationships that help build community solidarity and cohesiveness. Volunteers are also able to develop bridging social capital through networking with other local organisations and government agencies and representatives. Volunteers are able to develop skills in networking and organising in addition to a host of other care-related skills all of which serve to build social capital in communities.

Studies on the rewards of volunteering for volunteers also point to the ability of care to generate social capital among volunteers, PLWHA and the community at large. Volunteer caregivers taking part in a study reported that their ability to make a difference in their patients' lives through the provision of home-based care services engendered community trust (Akintola 2010a). In this case, trust is considered a foundation for community cohesiveness engendered by coming together of the community to support care initiatives. For example, community trust could lead to considerable reduction of the serious problem of stigma and discrimination, the fear of which cause families to hide their ill relatives, thereby preventing access to home care (Akintola 2010a).

Can social capital improve access to HBC resources?

The value of social capital in producing positive health outcomes has been a subject of recent research (Pronyk *et al* 2008). In South Africa, Pronyk *et al* (2008) demonstrated that social capital could serve as a protective factor for HIV prevention. However, the relationship between social capital and HIV/AIDS remain poorly understood. Several writers in this volume examine specific studies aimed at exploring the role of social capital or the lack of it in HBC.

To begin with, studies investigating the relationship between social capital and HBC are in their infancy. Yet, a growing body of evidence suggests that social capital could play a role in mediating stress among caregivers (cf. Chapter 4 in this volume; Smith & Rapkin 1996). Coping, which refers to behavioural and psychological activities employed by people in order to manage stressful events, has been shown to mediate stressful events and well-being (Lazarus & Folkman 1984). Studies among informal AIDS caregivers reveal that the adoption of appropriate coping strategies could lead to a lower burden and positive health outcomes among care-givers (Pakenham 2001; Pakenham, Dadds & Terry 1995). Provision of the appropriate kinds of social support to caregivers has been shown to ameliorate the burden of caregivers (Pakenham 2001; Pakenham *et al* 1995) suggesting that social support can be a coping resource. Indeed, it has been suggested that social support is a care-giving resource (Smith & Rapkin 1996). Thus, one could argue that social support could be drawn on for effective HBC.

Social support is a form of social capital consisting of emotional, instrumental, appraisal and informational components on which individuals can draw in order to fulfil their care-related needs (Carpiano 2006; Cohen, Underwood & Gottlieb 2000). Cohen and colleagues conceptualised social support as comprising various forms. Emotional support may include listening to caregivers, empathy or words of encouragement. Instrumental support could be material support, such as provision of practical assistance like transport, money or a service such as babysitting or helping to lift patients, etc. Appraisal support helps caregivers understand stressful events and interpret it positively. Informational support refers to information given by someone concerning the stressful experience that helps one to cope well.

The impact of social support on the various stress factors has not been explored in the context of HBC, although there are studies in this volume that explored the experiences of support among volunteers. Emotional support is needed to address the emotional stresses confronted by caregivers. Hlengwa's study (reported in Chapter 4 in this volume) among volunteers in South Africa sought to investigate the buffering effects of social capital on stresses experienced by volunteers. The study found both a positive and negative association between elements of social capital and emotional stress suggesting that while social capital can buffer the effects of stress on volunteers, not all social capital is useful. Therefore the nature and quality of social capital is critical. One major finding of Hlengwa's study is that while there is a positive association between trust in governmental structures and levels of emotional stress experienced by volunteers, membership of too many networks or organisations was also related to increased emotional stress.

A body of literature on HBC highlights the instrumental support needs of caregivers. Many caregivers bemoan the inadequate or in some cases lack of materials with which to carry out care work (Akintola 2008a; Campbell *et al* 2008; Orner 2006). The critical shortage of supplies for care work hampers the provision of care. Instrumental support could be mobilised through knowledge of networks that are connected to sources of materials such as private donors or private companies who may be willing to donate materials or government agencies providing material support to HBC organisations. At the same time, informational support may also be important both in identifying the appropriate networks and in partnering with the networks in order to access material resources. Again, research in this area is sorely lacking. In Chapter 6 in this volume, Fynn explores the experiences of social support among volunteers in HBC. She found that, although volunteers understood the importance of support, their access to social support was poor. Her study demonstrated that, although material support was inadequate, volunteers were able to draw on pockets of support from their own families only in a few cases. However, many of the volunteers had a poor knowledge of opportunities for support in other networks in the wider community. Therefore they did not explore opportunities for social support beyond their close family networks. Lessons from this study underscore the need for volunteers to be empowered with skills to request and access support from wider networks in and outside their communities.

As stated earlier, the main players in HBC are the persons living with HIV/AIDS, the caregivers (family or volunteer), the care organisations comprising paid employees and stipended as well as non-stipended volunteers (nurses, counsellors, co-ordinators, etc.), government, community, donors, etc. (WHO 2002). In a well-functioning HBC arrangement, resources should flow among these key players with the net effect that community members will be empowered. One would expect a strong collaboration and partnership between government agencies and AIDS care organisations in which government agencies provide the bulk of the HBC resources to care organisations and directly to AIDS-affected households while the donor community provides supplementary resources. Care organisations will then use these resources to provide home care to patients and support for affected families. Communities themselves should possess local resources such as time for care, babysitting or other forms of assistance for volunteers, transportation and food assistance. Although PLWHA provide some degree of self-care, they usually require some form of care from others.[3] Ideally, family members primarily provide this where they are available and willing to assist. However, in practice, it is almost impossible for family members to provide all of the care needs of PLWHA due to, among others, inadequate or a lack of caring skills and resources and a lack of access to those with requisite skills and resources. These skills and resources are provided to some degree by HBC organisations through the use of volunteers. Volunteers provide the necessary care to PLWHA and support to their families. They also teach family members skills for providing care. The networking among community members assists in community cohesion. From the foregoing discussions, one could argue that communities with high levels of cohesion – especially around issues of AIDS care – would be in a better position to leverage access to resources (Carpiano 2006), such as time for care and respite care, information as well as help for other caregivers. They may also be in a better position to network with other organisations that may have other resources (material, e.g. care kits, training opportunities or financial assistance) or access to those who have resources within and outside the community, such as donors or government structures.

Social cohesion and solidarity, which is fostered by trusting relationships within communities, help to engender the development of social safety nets which confer social immunity on HIV/AIDS-affected families. Social immunity serves to ameliorate the impact of HIV/AIDS on households in the community. In other words, communities adopt coping mechanisms to protect members from the impact of HIV/AIDS. Social immunity entails the sharing of resources among households belonging to the same extended family network or community. Reciprocity is also engendered in that households that receive help from others can reciprocate when others are in need of help. However, while community cohesiveness could create community immunity necessary for AIDS care, this may not be sustainable for a long period. This point is clearly illustrated in a study by Mtika (2001) in Malawi, which found a high level of social immunity with 91% of AIDS-affected households receiving help in the form of food and care during the research period. However, the study also showed that the magnitude of the AIDS problem could undermine the effects of social immunity such that social immunity declines over time due to depletion of resources available to community members which is necessary for sustaining the immunity. Reciprocity is also undermined where AIDS decimates households and communities to such an extent that there is a marked reduction in the number of healthy people in the community who are able to reciprocate the help received (Akintola 2010b).

Despite the value of social capital and its potential role in accessing HBC resources, Mtika's study highlights the importance of external support, particularly in poor communities and those with a high burden of HIV/AIDS. In the absence of external support, the provision of material and financial support to AIDS-affected families (Akintola 2008a, 2010b; Bowsky 2004), could in many ways, serve to undermine community social capital at the bridging and bonding levels, because provision of support serves to make community members sink deeper into poverty. It could also overwhelm community organisations which themselves have access to limited resources. This underscores the importance of interventions that might ameliorate the negative impact of the AIDS epidemic on communities. Such interventions will serve to sustain as well as engender an increase in social capital within communities. At the same time, there is need for the mobilisation of linking social capital that helps communities to gain access to external resources from government as well as private agencies.

Interventions in the form of organised government support that provides access to resources such as skills training, empowerment with skills and support for community farms or gardens, food provision, HBC kits, etc. could help to complement and sustain the role of social capital within communities. Organised access to government resources for HBC can help build social capital at the bonding, bridging and linking levels by keeping the threshold of resources at a certain level for community social capital to build on and sustain. In this regard, social capital that helps to link communities to various forms of organised support will be critical. There is therefore a need to build the capacity of communities to network and form partnerships with external institutions that have resources.

To the extent that HBC, like other forms of care, provides benefits that are enjoyed by society at large in the form of healthy individuals who are able to, among others, reduce the drain on health facilities, participate in the labour market and provide care to others, it is a public good. Like all other public goods, which require state intervention for its production, it makes sense for governments to invest by providing adequate HBC resources in order to increase both the quantity and quality of HBC.

Concluding thoughts

HBC is resource-intensive, requiring enormous resources that could be drawn from various stakeholders. However, we know very little about social capital and its ability to help in accessing community and state resources. In this chapter, the role of social capital in mobilising resources for effective HBC was explored. This contribution shows that, despite the overwhelming discussion of the negative experiences of caregivers and people with AIDS, HBC has many emotional, spiritual, physical as well as socio-economic benefits for patients, family and community. I have also shown that HBC could generate elements of social capital such as trust, networking and social cohesion. The contribution further shows that the presence of social capital in many AIDS-affected communities could help improve access to HBC resources. Social capital could potentially be mobilised to improve access to certain resources such as information, skills training for caregivers and family members, financial as well as material resources from families and neighbours (bonding), among community members (bridging) and with other organisations within and outside the community (linking).

However, the availability of social capital is not a guarantee for continued access to resources. This is because social capital could be depleted if the demands for resources outweigh the amount of social capital as well as resources available. Unfortunately, this is the case for many poor communities with high AIDS prevalence and poor access to government services.

Given that HBC is a public good, governments cannot rely too heavily on communities to produce good-quality care at the needed rate without undermining their own socio-economic well-being. Therefore, there is a need for government to invest in HBC so as to protect social capital present in communities from being depleted thereby sustaining social capital, reducing the burden of AIDS care on communities as well as raising the quantity and quality of care produced.

Notes

1. The wide spread use of technology in the home has led to a dramatic reduction in the amount of time that women spend on domestic work in the developed world. This is not the case particularly among the less well-off in many developing countries.
2. AIDS has unique features, which include the fact that it is an infectious disease that requires specialised care. This is clearly different for care for diseases such as Alzheimer's, mentally ill patients and other chronic illnesses.
3. Patients who are not yet at end stage AIDS are still able to provide some care for themselves including bathing and feeding etc.

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Chapter 13

Taking back practices: Creating reflexive spaces to increase response-ability

Yvonne Sliep & Annette Kezaabu Kasimbazi

Introduction

This chapter reports on a pilot study exploring creative ways for the dissemination of research findings from the study. We often do research in rural areas to deepen our understanding of a multitude of perceptions in various areas of the social sciences. We are less visible in taking our research results back to the communities we have drawn our data from and when we do, it is often via reports that are clearly not written for the audience that generated the data in the first place, illustrating one more way in which we have adopted Western approaches in our practice and research. Keeping written reports as form of dissemination also lessens the likelihood of impact on communities and policies (Finfgeld 2003; Troman 2001:251-273).

Dissemination of the results was already planned in the proposal phase of the project in 2006. It was envisioned that the results would be disseminated eventually to all stakeholders at individual, community and macro level. The inclusion of a dissemination strategy is increasingly considered as an integral part of research where there is an expectation that research results will be returned, after comprehensive analysis, to the original participants in a way that can be understood by the participants. We agree with other researchers who have done similar work that it is a more ethical and morally responsible way of doing research (Cloke 2002; Cutchin 2002; Hay 1998; Smith 2001; Valentine 2003). We also agree with Potocnik (2005), who asserts that disseminating the results in an accessible way is an obligation to everyone involved in the research.

In addition to written reports, we facilitated a drama written by the participants themselves. The interaction deepened understanding and created an opportunity to change attitude and possible behaviour (Dick 2002; Meyer 2000; Waterman, Tillen, Dickson & De Koning 2001) as well as to strengthen social capital. If we want to understand the impact of dissemination this also needs to be built into the research (Finfgeld 2003; Troman 2001) and measured over time (Morse, Swanson & Kuzel 2001). An additional benefit of active dissemination of research is that it pushes our own understanding of the research (Eisner 1997; Rapport, Wainwright & Elwyn 2005).

The dissemination of results from research done through theatre has been demonstrated by others (Gray 2000; Mienczakowski 2003:415-432; Morgan, Rolfe & Mienczakowski 1993; Rolfe, Mienczakowski & Morgan 1995; Saldaña 2003; Sinding, Gray, Fitch & Greenberg 2002). The drama itself can form part of data validation (Mienczakowski, Smith & Morgan 2002:34-52). The chances that understanding will increase which could influence behaviour change is greatly enhanced if a reflexive space is created after the drama (Nutley, Percy-Smith & Solesbury 2003; Sliep & Gilbert 2007).

The kind of dissemination of results that we want to adopt pays attention to both the research results and the way the results are communicated in order to possibly make a difference to the very people among whom the research was conducted (Keen & Todres 2006; Sells, Topor & Davidson 2004; Todres 1998; Willis 2004). Engaging with the data in this way reduces the gap between research and practice (Mullen 2003). Creating accessible alternative ways to disseminate the results, especially when this is done collectively with the participants, forces us as researchers to do one more level of reflection on the results (Campbell *et al* 2003; Paterson, Thorne, Canam & Jillings 2001). Often results of the dissemination lead to shaping interventions that can flow from the research results.

The way in which we are using dissemination is interactive and tailored to the target audience. The participants who were part of the study are the first ones to be given back the results with the opportunity to add or differ on any of the findings. The emerged themes are then written into a script in the form of a workshop. The drama is practised under guidance and is then performed in front of a selected audience. Several options are available after the drama has been acted out. A critical discussion can follow, which is facilitated, or the drama can be repeated through interactive participation of the audience. Paying attention to both the source of the message and the intended audience in addition to the active dialogue increases the possibility of creating both awareness and some form of behaviour change (Percy-Smith, McNeish & Frost 2004). We would like to explain what that means for us in terms of the social capital research project. We agree that this would lead to more successful dissemination of the results and we want to explore this notion deeper.

In the selection of what we are going to work with we have to realise that we cannot convey everything and certainly not as precisely as the data revealed to us in the analysis (Eisner 1997). This is even more the case when we use the participants to give back the data through stories and drama performance. The participants use what speaks to them most strongly and then construct a story or script on what could have happened in real life, a story that the audience would be able to recognise and identify with. In this form of dissemination, the storyline usually represents some of the findings but not all of it. More of the data could however emerge in the critical dialogue that follows the drama. This kind of drama is also referred to as ethnodrama. In ethnodrama, the purpose is to stay true to what the participants (interviewees) and informants contributed in terms of their lived experiences (Mienczakowski *et al* 2002). The facilitators need to recognise that the experience may marginalise other groups that were interviewed in the case study, for instance in our project, the community workers and clinic were the antagonists in the story of the volunteer home-based carers (HBCs). In presenting the data, back cognisance must be taken of possible tensions that may arise between the groups that could have an effect on the everyday working reality. The researchers may withdraw from the project, but the groups within the community stay behind and have to continue working alongside each other.

We argue that close attention needs to be paid to the power practices within which the work takes place and in this case also the dissemination of the results. In our own professional work in communities (Sliep 1998:141-158) and in training community practitioners in the fields of psychology and health promotion (Sliep 2008; Sliep & Gilbert 2006; Sliep, Weingarten & Gilbert 2004), we have also found the ideas of self-reflexivity useful. Understanding the way we position ourselves and the way our positions and actions reflect dominant discourses and practices should be a prerequisite for working with cultural diversity in situations of economic, gender and political inequalities.

Putting the participants in charge of the drama leads to a feeling of greater control over their lives. This may be a 'messier' and less linear way of conducting the drama (Rossiter, Kontos, Colantonio, Gilbert, Gray & Keightley 2008) but results in a collectively created piece that is negotiated and with which everyone can identify (Gray & Sinding 2002).

For us as researchers, the main purpose of the study was to understand how social capital within the area of study works. Disseminating the results by actively increasing participation, which was found as one of the strongest mechanisms in the study (cf. Chapter 2 in this volume), would also increase social capital. It has further been argued that communities with high levels of social capital have been found to be more effectively able to implement health interventions like HIV/AIDS prevention, treatment, voluntary counselling and testing (VCT), care and support for those infected and affected by HIV/AIDS (Kelly & Van Donk 2009:135-153). Enhancing participation while disseminating the research results could further stimulate social capital in that setting.

The methodology used

It was decided by the researchers that the kind of performance that would be used to disseminate the research results would be through Narrative theatre based on narrative theatre. Narrative theatre is a strategy that makes use of actual life stories that are enacted to increase understanding and to map effects of particular behaviours. Without taking the focus away from the individual, it enhances social conscience that stimulates collective efficacy and action. The participation of the collective is also likely to maximise the possibility of sustained behaviour change. Innovative strategies like narrative theatre make use of local knowledge to get an understanding of the problem, raise awareness around the impact of the problem, explore alternatives to develop preferred outcomes and assess whether any change has taken place. The strategy is strength-based and non-judgmental, which strongly encourages a shift from dependency on external agencies, to rely on the capacity of the local context and communities. It encourages building on people's abilities, and linking people through coalitions and networks. In addition, it builds capacity by increasing social networks and cohesion, while moving towards collective action with a sense of hope (Sliep 2005, 2006:89-100). This is crucial not only for those directly affected, but also for the community workers who are continuously confronted with overwhelming problems associated with HIV/AIDS.

Narrative theatre as a research strategy builds on participatory action research in qualitative methods, such as Clandinin and Connelly's (2000) narrative inquiry, and alternative or arts-based ways of knowing and representing research (Eisner 1997; Finley 2003). In narrative theatre, participants' performances depict and examine their 'performances' in real life, providing insight into their lived experiences and their cultural world. The player is both involved and detached, alternating from one to the other observing the self in action, comparing the two worlds to arrive at some understanding or meaning (Courtney 1988). As such, it offers an alternative performative way of knowing, a unique and powerful way of accessing knowledge, drawing out responses that are spontaneous, intuitive, unspoken, experiential, personified or sentimental, rather than simply cognitive (Courtney 1988). Through the discovering and uncovering of knowledge in narrative theatre, community members gain an understanding of their situation, confidence and ability to make changes for the better. This validates and confirms the importance of indigenous wisdom and increases community participation, community mobilization and empowerment (Servaes 1995:73-91).

The narrative theatre strategy recognises that an individual is not independent of his/her environment and is therefore affected by social, cultural, economic and environmental problems. Hence, narrative theatre is directed at both the individual and the social environment, with specific interest in strengthening social fabric through a process of critical consciousness and self-reflection. The narrative strategy is therefore strategic for increasing awareness and sensitivity of social capital in the context of HIV/AIDS because it works with groups by presenting problem stories alongside elicited strength-based stories for collective problem solving. These efforts are even more successful with reciprocal collaboration where community members listen to each other's point of view so as to contribute to the collective action.

Narrative theatre fits well with participatory action research. Participatory action research is a recognised form of research that focuses on the effects of the researcher's direct actions of practice within a participatory community with the goal of improving the performance quality of the community or an area of concern. Action research involves utilising a systematic cyclical method of planning, taking action, observing, evaluating (including self-evaluation) and critical reflecting prior to planning the next cycle (McNiff 2002; O'Brien 2001). It is a collaborative method to test new ideas and implement action for change. It involves direct participation in a dynamic research process, while monitoring and evaluating the effects of the researcher's actions with the aim of improving practice (Checkland & Holwell 1998; Dick 2002; Hult & Lennung 1980). At its core, action research is a way to increase understanding of how change in one's actions or practices can mutually benefit a community of practitioners (Carr & Kremmis 1986; Masters 1995; McNiff 2002; Reason & Bradbury 2001). A reflexive space must be created after the drama had been enacted to facilitate the practice of narrative theatre. Preferably this should happen straight after the drama, but it can also take place over several sessions.

It can be anticipated that the form of relationships between the groups and stakeholders, which are already interlinked in complex ways, may undergo some change. Not only do different stakeholders represent different institutions and voices; they also establish new relationships in their engagement with other stakeholders, which ripple back into the local community and into the broader society. The assumptions and intentions of different stakeholders reflect specific historical, cultural and political positions and these are often tacit and not personally acknowledged. It needs to be understood that any action in this context is temporally and spatially defined. It is therefore helpful to be mindful of where, with whom and in what place, in the history of events, action takes place (Gilbert & Sliep 2009). The effects of the changes would have to be explored and become part of an on-going process, which continues to influence social capital. All of these factors have to be taken into consideration when making decisions on what part of the research results are given to which audience.

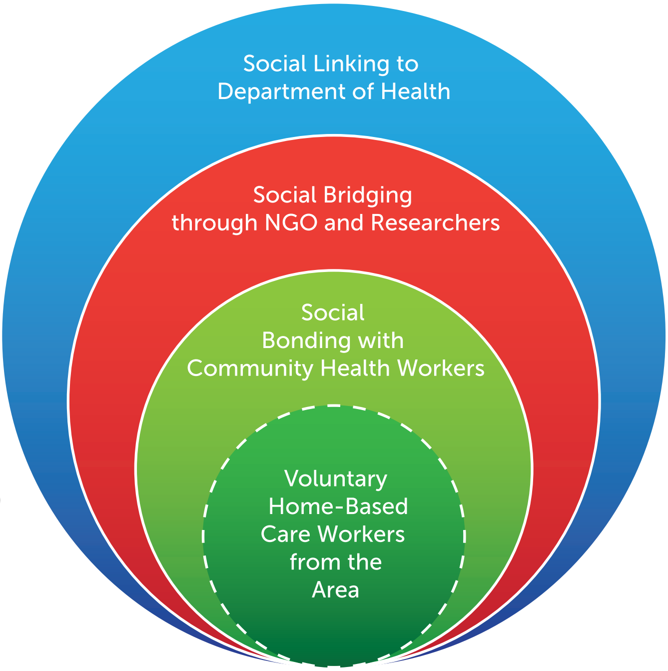
It is known that the more levels involved interactively through dissemination of the research results the greater the impact could be (cf. Diagram 14.1: Mechanisms and response-able possibilities in enhancing social capital to strengthen care and support in HIV/AIDS). These could include participants in the study and in the wider community from which the participants are drawn, but also students, practitioners, policymakers, researchers, academics, service users and general citizens (Keen & Todres 2006).

One of the reasons for wanting to understand social capital through the various levels is the hope that it will be possible to enhance agency in terms of HIV/AIDS care and support. Social capital is considered an important asset because it provides access to other assets, and it is access that is the most critical resource of all. There is a broad agreement that social capital is present in the networks, norms and social trust inherent in associations whose members work together in concerted collaborative action (Scholz, Berardo & Kile 2008; Woolcock & Narayan 2000). More specifically, social capital is the store of good will and obligations generated by social relations. Looked at in this way, networks, reciprocity, norms, and social trust are all evidence of social relations in which social capital is generated. Thus, as Woolcock and Narayan (2000) point out, the adage "It is not what you know, but who you know" refers to the potential support that arises from social relationships that have been created through collaborative activity, or have been inherited through family or organisational membership. Social capital is thought to be an inactive asset, and individuals can increase or deplete it depending on where they stand in the reciprocal exchange of social support and obligation.

Woolcock and Narayan (2000) provide a useful distinction between bonding and bridging social capital. Bonding social capital is evident in the close-knit relations of friends and families who can be depended on for basic survival in times of distress. It is bonding social capital, for example, that will be drawn upon by a family with a person bed-ridden with HIV/AIDS to seek for support from neighbours or other members of the extended family or the community or by a woman whose husband is sick and unable to take care of himself and his family who may then appeal to the community for a contribution of useful resources. By contrast, bridging social capital provides leverage in relationships beyond the confines of one's own affinity group, or even beyond the local community. For example, a local female volunteer group might use their network with a local clinic to refer a sick person to that clinic for treatment, or receive free fruit and vegetables from local farmers to distribute to the ill in their community. Whether social capital is used for bonding or bridging purposes, the total value of social capital to collective action is now widely recognised. Associations provide the connections and the experience of collaborative effort for the individual and collective good, which improves the overall well-being of the community members. The synergy in these partnerships occurs because communities with stocks of social capital are able to demand greater responsiveness from local institutions. At the same time, local institutions are likely to view that stock of social capital in a particular community as a reason to invest in that community.

Case study

The case study discussed here is a description of how the results were disseminated during a pilot study with the volunteer HBC workers. The first part of the case study will focus on volunteer HBC workers. The original results discussed are covered in this volume in Chapter 5 by Annette Kezaabu Kasimbazi. It emerged from the study, which explored perceptions of thirteen volunteer community workers, that the social capital levels of bonding and bridging and the elements of trust, norms, reciprocity and social networks, act as resources for collective action. The study showed that denial, mistrust, stigma and discrimination were some of the hindering factors of social trust, which in effect weakened social bonding and bridging. Social norms were also perceived to be on the wane and social networks amongst community members were reported to be existent though feeble. Reciprocity, though inadequate, existed amongst a few community members who borrowed from one another and this played an important role in care and support of those affected by HIV/AIDS. The study also highlighted that tension at a community level existed between the paid community health workers (CHWs) and the voluntary HBCs who only received expense coverage for the physical hard work that they do. In Chapter 2, Wenche Dageid discusses how social bonding can lead to its own problems. The tension between two groups living in the same community and serving the same community was something that directly affected all members as well as the households they worked with. Figure 13.1 illustrates dissemination of results in relation to the volunteer HBC group:



(Yvonne Sliep)

Figure 13.1 Mediating tension between healthcare workers and care providers through dissemination of results

In this case, the researchers and the local NGO, Narrative Foundation (NF), played a mediating role between the two groups by bringing them together for the results, being mindful of tensions that may emerge. The following steps were covered:

Group discussion to share the results

All the HBC providers that had been interviewed for the study were called together. The researcher had made a summary of the results of the research in a language and manner that was appropriate to the group. The following is an example of results that were shared:

> *Volunteers suggested that people affected by and/or infected with HIV/AIDS had lost trust in their neighbours and as a result there was mistrust, shame, stigma, discrimination and denial on the part of people living with HIV/AIDS. According to the volunteer community workers, lack of trust on the side of the sick person and the family is usually generated by internal*

> *stigma and feelings of guilt and may also be perpetuated by the new norms of fear, denial, stigma and discrimination that are associated with HIV/AIDS. This lack of trust in the community members by those infected with HIV/AIDS and their families has led to the breakdown of social cohesion in most communities. In a few isolated cases however, family members leave their patients with a few trusted neighbours. In general, those infected and affected by HIV/AIDS do not get the much needed care and support from the community members. At the emotional level, patients and volunteer community workers feel isolated in a community where stigma makes people reluctant to disclose their HIV status, often even to their carers. This means that both patients and carers battle on with no emotional support. Most HIV/AIDS patients do not want their families to know that they are HIV positive. The fear of rejection by family members was reported as one of the biggest challenges in volunteering. The volunteers noted that it not only leads to self-stigmatisation of the HIV-positive person but also leads family members to chase away volunteers as nosy people who should have no business with their sick person.*

Additional feedback from the volunteer HBC workers

The next step was to get additional feedback from those participating in the research. They wanted particular things emphasised:

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

The researcher asked about the relationship with the community health workers:

> [A prolonged argh] *Our relationship is very strained because the HBC initiative is a relatively new thing so when they got to know that we had started, they felt we were going to replace them. It was so bad so that they really, really hate us. Even the people in community health workers who were my friends do not speak to me anymore. At one point our supervisor and the* [name of a large NGO outside of the community] *supervisor came together to try and reconcile us and explain that our duties are independent of each other's duties, but it was not possible*

> *that day for them to understand. Some are beginning to see that we do different things from them but up to now some of them still hate us.*

Scriptwriting on themes

After a discussion was held with the researcher the group was invited to participate in a workshop to generate a script and drama that would convey the results to other groups in the community. The translator, who was used as interpreter for the fieldwork, had been trained in participatory scriptwriting and narrative theatre. She organised and facilitated three sessions of three hours each.

The first session was used to deconstruct the meaning of the results according to the participants. The discussion held earlier with the researcher was discussed at length and participants were given another opportunity to add anything they thought was important and which had not come out in the results. Once the participants had reached an agreement on what they thought was important in the study, they were given the opportunity to make decisions in terms of what was going to be given back to the wider community. It was made clear that the participants could decide what the most important feedback was that they wanted to focus on and who the audience was that they wanted to invite.

Because the HBCs fall under the CHWs they did not want their discontent with the CHWs to be part of the feedback. They did however choose to have them invited to the forum where the results were going to be dramatised. It is a tension that had to be acknowledged as it has very real consequences in the lives of the participants. At the conclusion of the first session, the following list of problems as perceived by the participants was generated:

- The family is not very welcoming [to the HBC], especially during the initial visits because they think you are going to start talking about them.
- Poverty/hunger because of unemployment. Parents die and leave the children with grandparents. The children may end up being street kids, thieves, drug addicts and drunkards.
- Lack of sexual awareness in teenagers caused by our culture of hiding things from children.
- Sick people live by themselves.
- Children engage in risky behaviour.
- The sick people do not have food.
- Sick people do not have access to grants.
- They take alcohol with their medication.

- The community does not accept this sickness.
- There is secrecy around HIV/AIDS – so people end up not having access to grants. They end up lonely because no one is allowed to visit them.
- Old people look after children. They don't have an idea how to go about organising.
- Families do not accept the sickness or people who come offering to help.

From the list, the participants felt most strongly about poverty, alcohol abuse and the lack of love and support for sick people in the community. While discussing these topics a lot of discussion was also generated regarding people not being helped when they explicitly ask for help. The theme that the participants wanted to elaborate on was called 'lack of love'. The causes for 'lack of love' were perceived as:

- Feeling of betrayal – the sick did not contribute when they were still healthy.
- Sick people are nagging, rude and expect a lot from their carers.
- People have their own lives to live, personal businesses.
- Stigma and discrimination from the community makes them not to ask for help from the community because they will have a permanent label.
- Lack of information about care and support and fear of getting infected makes people wary of the sick.

The consequences of this 'lack of love' were described as:

- Some people die of neglect, others commit suicide.
- Stress levels go up for both the household caretakers and the sick.
- Increase in denial and lack of disclosure for fear of how they will be treated.

This script shows the subtle way in which this happens:

Scene 4

[Ma N's house. A health worker arrives.]

H/WORKER	*Knock, knock, knock!*
Ma N	*Come in my child. It is so hot today!*
H/WORKER	*Mother, my work is taking care of people who are ill. I heard at church that the man of this house in not in good health. I was wondering if I'd be allowed to help him.*

Ma N	*Looks like you are going to help my child. Do you see that grass house in the garden? You'll find the man of this house in there.*
H/WORKER	*Mother, I am not allowed to go in by myself when there is a family member present. Can you come with me?*
Ma N	*Everything of his is in that house. I see no need for me to come with you. Just feel free and go.*

[The health worker goes outside. She re-enters soon after.]

H/WORKER	*Mother, may I please have some sugar and water? Father has been having a runny stomach and I have to give him some glucose. He is dehydrated and very weak.*
Ma N	*My child, what is available in the house is only enough for my children. That one did not bring any sugar or salt when he came back from Umlazi* [looking the other way].

Nobody in the script is being rude, but help is not forthcoming. The relations referred to as 'mother' and 'daughter' are not blood relations, but reflects the cultural ways of addressing each other with respect.

Other parts of the scenes enacted had longer monologues and depicted feelings more explicitly:

HBC Z	*When I entered the house, there was a smell that was not so nice, but I ignored it. I went to B.'s bedroom. When I got there I was welcomed by the same stink I smelt when I entered the kitchen. There were bottles of booze all over the bedroom. B. was staring at me as if he wanted to say something but couldn't speak. When I greeted him, he just stared at me. The smell! Which meant that no one bothered to give him a bath. Even the clothes he was wearing and the sheets he slept on – it was all filthy. I could see that the child of my mother was really sick. He used to be so neat! But booze! AIDS has turned the child-of-my-mother into a vegetable. I tried waking mom and dad, but they were too drunk – snoring loudly. I warmed up some water and washed him. I could see it was really bad, so I called the ambulance and it took him to hospital. When we got to hospital, they put him on a drip and gave him painkillers, but they said I must take him back home because they had no way of helping him. My friend, I am scared of AIDS – it has finished*

> *my brother! When I came back here, I left him just like that. What worries me most is this booze that mom and dad keep feeding to him. But there is nothing I can do about that.*

Generating the drama

In the last session, more detailed attention was given to the character roles and the detail of the dialogue they wanted to use. The dialogue was not memorised but came from an understanding of what they wanted the drama to convey. There was an opportunity to rehearse before the drama was shown to the general audience a week later. A number of body and movement exercises were done to orientate the participants in taking an acting role in drama. Different stories were then told around similar themes. The stories were woven together by the facilitator to generate one story that could be acted out by the group. The participants were very animated during the process. The facilitator remarked that the workshop had been very intensive and actually needed more time to allow space to process what was happening between the workshop days.

Deciding on the audience that the drama would be performed to

The volunteer HBC workers specifically wanted the CHWs to see their drama. They hoped that if the CHWs saw their work that it would influence their understanding of the difficulties they face every day. Up to this stage, there had been little contact between the HBCs and the CHWs. Other members of the wider community were also invited and the research team also attended the meeting (and video recorded the session).

Performance of scripts

The performance was done by the HBC workers themselves who used few props. The space they chose to perform in was the building within the community called the First Aid Station. The participants cleared one side of the area for the performance and set up seating arrangements on the other side for the audience. The performances took approximately twenty minutes and then the floor was opened for dialogue.

Critical dialogue

The audience appreciated the various drama sections that took much longer to perform than when it had been prepared during the workshops. The researcher asked the audience if they recognised similar situations in the community. The following were some of the responses that were given:

- *Yes, it happens a lot when you get to a house to help they tell you there's your person and they leave you there, they expect you to do everything.*
- *It does happen. Like me I'm HIV positive, people see me and think they can say what they want. You go to the clinic and the nurses ask you why do you keep getting pregnant you have AIDS. It doesn't mean you can't have babies. Some people don't even want to help you with your babies because they are scared of getting AIDS. I wish God can do something different so that some organisations can help us to do things different.*
- *Another thing that also doesn't sit well with me is that people assume that HBCs only work with people that are sick with AIDS. I would like to say that people with HIV are not sick, they just have HIV.*

The fact that someone who is HIV positive stood up and disclosed her status created a space for support and dialogue. It directly addressed one of the biggest obstacles named in a number of studies completed in the research project, namely the prevailing stigma.

One of the CHWs stood up at the end of the session and remarked the following:

- *I just want to thank the volunteers; they are doing a great job because they take a lot of abuse. I see there's a lack of love from the mothers of the sick children, it looks like they really have had it and that hurts because as mothers we need to learn to love and the story that made me see that was the one of Ma N, the grandmother.*

It was a very important remark as it offered space for the volunteer HBC workers and the CHWs to work together again with less tension.

Workshop following the feedback session

As pointed out, the dissemination exercise is most useful if it is followed up by a workshop addressing any of the issues that may have emerged from the critical reflections. In this case, the workshop was held after the disseminating session. The topic that the HBCs wanted to work with most was the issue of vulnerable children, which was both a burning issue for them and also a safe one to work on alongside the CHWs as partners. The additional space created the opportunity to create an in-depth dialogue around the issues. The session was conducted through the narrative theatre strategy described earlier in this chapter.

Some of the other critical questions asked included:

- Why is this happening?
- Why do families behave in this way?

- Does culture influence behaviour?
- How do mothers survive under these situations?
- Who makes the decisions about this?

Reflections of the facilitator after the session included:

- *What really worked well was to assist the participants to look at their own knowledge and how their self-esteem grows as they discover their own strengths. As one of the participants said: "We know what to do, we think we don't but we do."*
- *As always, I was yet again amazed by the deep understanding that people have once they are reminded that they have all the answers amongst them because of all their lived experience and knowledge and how responsible they go about with their own exploration of their knowledge.*

Reflections after the sessions

A member of the NGO who was involved as a partner in the data collection and follow-up session wrote this in her field notes two months later:

- There has been a major positive shift since the initial interviews by Annette and the dramas created by the HBCs and NF. The animosity between the HBCs and CHWs has been resolved. Although, a lot of behind-the-scenes work was done by NF and the main shift was initiated by the supervisors of the two groups. The CHWs realised that it was a big shift and were proud to announce the achievement to me. It seems that this relationship is getting stronger by the day.

Second example of the case study was with the traditional healers in the area

The example will be kept short and will focus on different aspects. In this illustration, it is emphasised that the results illustrated that there is little networking happening at a social bridging level. Even in the dissemination of the results, the activity happened mainly at a social bonding and social linking level. The challenge for us as researchers and practitioners is how networking at all the various levels of social capital can be optimised. How the dissemination evolved through the lens of the social capital framework, is depicted in Figure 13.2, which was mentioned earlier in the introduction. The context is illustrated visually through the photos that have been inserted in each phase.

(Yvonne Sliep)

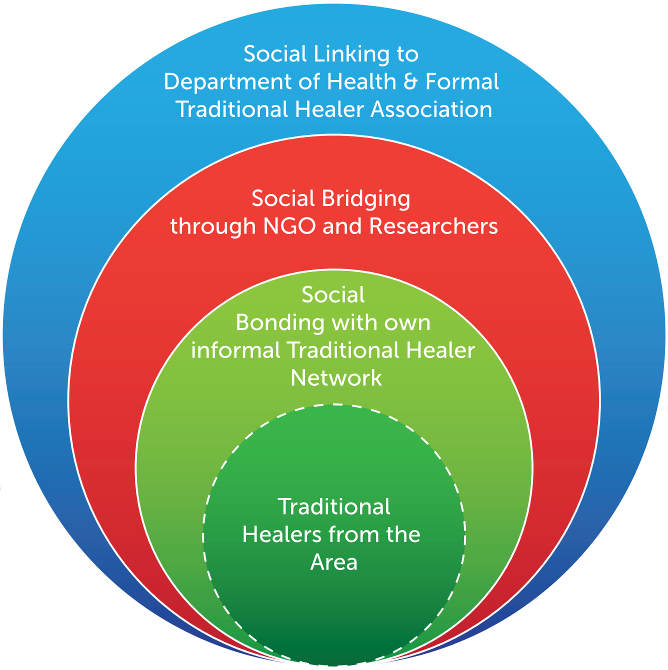


Figure 13.2 Creating a space for the voice for the traditional healers

Phase 1

The traditional healers were called together by the partner NGO NF and the research team to convey the results of the social capital survey described in Chapter 2. These results showed that among all relevant providers of services to HIV-positive people, community members expected most from traditional healers. The discussion took place in a setting which the Traditional Healers chose themselves (cf. Photos 13.1 and 13.2). The traditional healers had not met as a group for a while and regarded the session as an opportunity to organise themselves again. This is an example of social bonding through the dissemination process.

Phase 2

A workshop was held with the traditional healers where they not only responded to the results, but also added to the existing information. Creative exercises were conducted to create a space where the traditional healers were speaking from their own strength, as there is a tendency to work towards socially desirable answers that are usually informed by what the formal health sector expects the healers to do in relation to HIV/AIDS.

Photo 13.1 Divining hut of a local sangoma

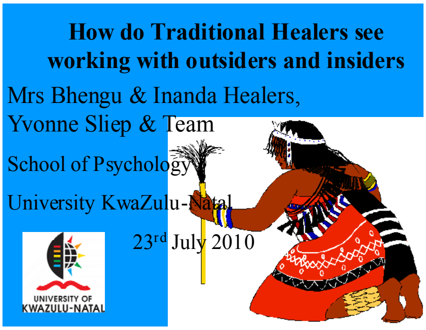
The traditional healers were then given an opportunity to participate in an international conference as a group where they could directly share their views instead of it being done for them. The conference was mainly for social scientists working with indigenous knowledge systems, but the Department of Health and the National Traditional Healers Association were also present. To prepare for the session, another workshop was held that was directed by the healers and supported by the NGO and the research team. This is an example of social bridging as the conference would give the healers the opportunity to connect with other important stakeholders.

Photo 13.2 Traditional healers in a meeting inside the divining hut

Phase 3

The healers attended the conference as a group (cf. Photo 13.3). Instead of giving a formal presentation, the healers formed a circle on the stage and conducted a conversation with each other taking turns to address the points they had prepared for the presentation. The conversation took place in isiZulu and was translated for the audience. It reduced the intimidation that a conference setting could have created. Unfortunately, due to the fact that previous sessions took longer than anticipated, the presentation was interrupted and stopped. We thought the traditional healers would regard this as a lack of respect and would emphasise their feelings of not having a voice in official forums. This aspect was especially noticeable since the healers were sangomas, also known as diviners, and they were women. Diviners stand in service of their ancestors and cannot make the same demands that *nyangas* or herbalists, who tend to be men, can. Diviners are also not allowed to demand payment for their service whereas herbalists tend to have set fees.

During the reflection after the session, where we took a very apologetic position as researchers for what had happened, we were given unexpected feedback. The healers had felt acknowledged by merely being given a space in a university setting where people wanted to learn from them. For the healers, the real value was not what they had shared, but the connections they had made. During the breaks, they were approached by members of the Department of Health who acknowledged the good work they were doing as well as by the Formal Association of Traditional Healers who gave the group a personal invite to their next official session. The healers did not need the researchers or NGO to do anything specific, but becoming visible and heard seemed to make all the difference.



How do Traditional Healers see working with outsiders and insiders

Mrs Bhengu & Inanda Healers,
Yvonne Sliep & Team

School of Psychology

University KwaZulu-Natal

23rd July 2010

Photo 13.3 Attending the conference in traditional healer clothes

Discussion

This chapter explored how data results in the study could be disseminated through critical post-modern performance methods (Denzin 1997). Taking the authority away from the researchers into the hands of the research participants, one also gives away control that can be slippery. One way to keep control is by giving the data back through drama pieces where the researcher can stop the play at any given moment and make clarifications for the audience. Applied theatre (Stuttaford, Bryanston, Gillian Hundt, Connor, Thorogood & Tollman 2006) specifically works on such interactive methods. It remains the responsibility of the researcher and/or the facilitator to ensure attention is given to all the different members of the audience so to prevent domination by few. It is also the responsibility of the researcher to take note of what has not been included, taking into account the overall context and research. In the case study, the HBCs were very clear that the tensions that existed between themselves and CHWs formed a big part of their everyday experience. Yet they chose not to bring any of this into the applied performances. Retrospectively the relations did however improve by inviting the CHWs to witness the telling of how they experienced the burden of their work. An impact study would have to be done to assess how sustainable the changes were.

If there are multiple tellings of the same data, it can be expected that the narrated stories will change over time depending on what had happened in previous performances and as more information and opinion of others become available (Mienczakowski 2003). A distinct advantage of the per-formance is the embodiment that gives a rich contextual understanding and a presence that is hard to represent in the written text. In this way, when members of the audience become actively involved they experience the roles of other people rather than only being passive observers (Tyler 1987). The audience becomes more directly available to the participants through the critical dialogue. This mechanism of participation can lead directly to a strengthening of social capital, which depends heavily on accessibility. It would therefore be essential to ensure that the various levels that want to be reached are present at the performance. Although the clinic staff and a representative of the local municipality had been invited to the performance, they could not attend due to other commitments. It would only be at a social linking level that structural changes like stipends and conditions of service could be influenced and again representatives at this level were not present at the meeting. It can also be assumed that at a social linking level, policy re-commendation and scientific reporting would be essential to contribute to change.

From studying the literature and looking at the results of the pilot study, a decision has been made to include theatre practitioners and academics from other university departments in the bigger roll-out of the results. The participants themselves will still be performing the dramas, but postgraduate students and professionals will guide the script and the pre-paration. There are multiple groups that have been involved in the study who can be involved as target audiences.

Conclusion

We have to acknowledge that the participants will use the platform in a way that they may find most appropriate and relevant to their lives, which is not necessarily what the researchers consider most important. By putting together another layer of understanding that happens through the critical dialogue, a more tailored intervention could be developed. We have therefore consciously chosen performances that are informed by the research process but do not adhere strictly to the data as script (Gray & Sinding 2002; Rossiter *et al* 2008; Saldaña 2005). Disseminating research results through applied theatre can engage and entertain audiences, but is especially valuable in the ability to transfer complex information in a nuanced manner (Paget 1993). It brings the reality of the findings to the reality of the people. Part of the process needs to measure the impact of the dissemination (Morse *et al* 2001). The project cannot report on that as yet, but it has been written into a second phase of the project to be completed for a doctoral study. Particular attention needs to be given to the various power relationships and how these are played out in different ways. The enacted drama sections became a microcosm of the overall power relations in the community.

From this it becomes clear that active dissemination of research results through applied theatre cannot take the place of scholarly reports, but it adds a rich layer especially at a social bonding and social bridging level. What the exercise has demonstrated is an ability to stay closer to the research population; thus closing the gap between research and practice.

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Chapter 14: Conclusions and visions

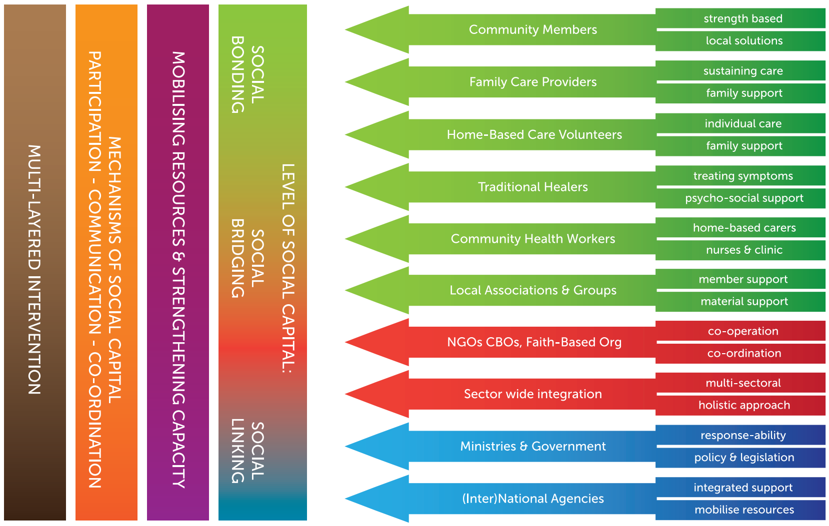
Building social capital in community care and support

Yvonne Sliep, Wenche Dageid, Olagoke Akintola & Fanny Duckert

Is social capital useful as a framework for studying care and support for PLWHA?

Social capital has become a dominant discourse in the literature of both development and public health. It is argued that communities characterised by high levels of social capital enjoy good health. While this rhetoric seems appealing, attributes measured by social capital are only a small part of the complex multi-layered processes of relevance in understanding patterns of health and well-being (Boare & Meyer-Weitz 2003; Hawe & Shiell 2000; Sliep 2008; Sliep & Meyer-Weitz 2003), and the constructs around social capital still need to be developed more fully. Despite the limitations of social capital as a construct to encapsulate and measure the complexities of social phenomena and its relation to health inequalities (Mackenbach 1995; Shy 1997), social capital has proven to be a useful framework when applied critically, especially in a geographically defined space where resources are poor, as was the case in the project described in this volume.

Our study has drawn on various elements in the social capital framework across the three levels of social capital in order to obtain insight into care and support for people living with HIV/AIDS in a specific, rural community. It has also drawn on data from other communities within the greater Durban metropolitan area for additional insight. In the introductory chapter, we presented an overview (cf. Diagram 1.1 in Chapter 1) indicating which actors and networks would be involved at the three levels of social capital pertaining to HIV/AIDS care and support. This figure has been expanded in the current chapter (cf. Diagram 14.1) to illustrate additional insights and provide a visual summary of the project. The horizontal bars represent the actors and networks involved, and the vertical bars represent the layers and mechanisms of social capital.


Support around HIV/AIDS in rural communities – a social capital perspective

(Yvonne Sliep)

Diagram 14.1 Mechanisms and response-able possibilities in enhancing social capital to strengthen care and support in HIV/AIDS[1]

It must be emphasised that social capital, as depicted in Diagram 14.1 and discussed in the following sections, is situated within a socio-economic framework with structural needs and conditions that have to be addressed in order for social capital to be mobilised effectively. The groups described in the green horizontal bars are the groups found in the community at a social bonding level; the groups in the red horizontal bars could be based either within the community or within the surrounding municipal areas. The social linking level, which is depicted in the blue horizontal bars, functions at a national level. In the research, we explored how the different groups experienced the functioning of the social linking level. In the overall study, the challenge for social capital in HIV/AIDS care and support was directly influenced by the lack of resources accruing to individuals, networks and groups, which was the result of an insufficient pool of resources to draw from in the first place. The socio-economic status of community members, structural opportunities and community infrastructure were inadequate for the purpose of building strong social capital. The social capital of the community was evidently shaped and constrained by the broader context of social, political, historical and economical forces of South Africa (Coovadia, Jewkes, Barron, Sanders & McIntyre 2009).

Structural social capital: groups and networks at bonding, bridging and linking levels

The results of our study revealed that there was some degree of social capital related to HIV/AIDS care and support in the community. In quantitative terms, the community survey reported in Chapter 2 showed that social capital was moderate, with 50% of the community members reporting that they knew of local organisations.

Across all groups, most of the activities carried out were at the bonding level with few of the groups networking along bridging lines. While some groups made efforts to tap into networks across bonding, bridging and linking levels, most did not actively explore this option. Additionally, with a few exceptions, organisations did not seem to know how to link up with authorities or larger organisations outside the community to access resources for care and support. The pattern of more bonding than bridging groups is typical for poor areas, as the needs of the community is likely to centre around immediate survival needs (Ferlander 2007). Studies have shown that local social capital results in more widespread and efficient delivery of services (Grootaert & Van Bastelaar 2001). This, however, requires a diversity of groups that can function and have access to resources at the different levels, that is to operate vertically across bonding, bridging and linking levels. The level of linking social capital in the community of our study was low and therefore too weak to facilitate care and support for people living with HIV/AIDS on a wide scale. This had devastating consequences for people who were on the antiretroviral (ARV) programme, as treatment was not always accessible or available (cf. Chapter 3). The cooperation between the community and government, a major avenue for addressing this challenge, was poor or altogether non-existent.

Many group activities were taking place, but they seemed to be confined to certain individuals who were involved in more than one group in the community. Tight bonds within a group could prove excluding to outsiders (cf. Chapter 9). Coupled with tension over meagre resources, tight bonds could lead to limited participation of community members despite the existence of numerous groups at a community level. Tight ties at a bonding level could also prove problematic, as illustrated in Chapters 6 and 10, where some got access to a disproportional number of resources due to their link to authorities. As Woolcock and Narayan (2000) point out, “It is not what you know, but who you know.” In the worst of cases, there could be a danger of corruption and non-transparency, which in turn could have detrimental effects on community development. Social capital may in certain instances act as a barrier to social inclusion and social mobility; dividing rather than uniting communities (Portes 1998). The kinds of groupings and associations which can generate social capital always also carry the potential to exclude others.

Lin (2002) treats social capital as an ability to mobilise and access re-sources through network ties, with the primary unit of analysis being the social relation. This was further demonstrated in Chapter 13, where the dissemination of results increased network ties. However, our study has shown that not all groupings add to the social capital in relation to HIV/AIDS. For instance, the community survey revealed that people's satisfaction with organisations and the cooperation between them at best was modest. There was also tension, competition for resources, overlap of service provision, and lack of cooperation and coordination between different groups, in particular between the volunteer care workers and the community health workers, as evidenced in several chapters in the volume. This is in contrast to the finding by Birdsall and Kelly (2005) that the most successful and sustainable initiatives are those that had established partnerships and referral relationships with other local programmes.

Through our study, it was demonstrated that the burden of care and support for people living with HIV/AIDS (PLWHA) in the community was severe, and that it fell disproportionately on the women in the community, particularly on informal and volunteer care workers. This finding is supported by other studies done in South Africa (Akintola 2008; Steinberg, Johnson, Schierhout & Ndegwa 2002). This resulted in a high degree of stress on a few individuals. Sources of stress for the carers included lack of salaries, lack of training, negative community attitudes, poor collaboration between the different organisations due to a lack of a mechanism for coordination of the efforts, and a lack of material resources to provide proper care. There was also an expressed need for a hospice.

The presence of social support can reduce the effects of stress (Cohen, Underwood & Gottlieb 2000). In our research project, carers reported low levels and few sources of support. The lack of support from government was in particular lamented. There was also evidence that families and volunteers did not request support from individuals and groups who could potentially provide support, such as other family members and faith-based organisations (FBOs) (Chapters 6 and 7), possibly because families and volunteers felt that help would not be forthcoming, or because they had not thought of these individuals or groups as potential sources of support. Findings pointed towards the importance of good quality relationships between people, as opposed to the quantity of relationships. Even one good relationship could be enough in terms of resilience and social support (Morland, Butler & Leskin 2008:39-61).

Recommendations

- There is a need to promote more diversity in networks, resources and view points, which could prove a foundation for new solutions to conflicts and challenges facing the community. Diversity of groups could be encouraged by a focus on training, access to and distribution of resources, interventions targeted at those who presently do not participate, and assistance from outside agents, in particular government. According to our findings, there might be an untapped potential for care work among youth and men.
- Cooperation and communication between groups at a community level need to be strengthened. This could be a task for local or provincial authorities and government. Organisations could be trained in administration, or a coordinating unit consisting of trained individuals could be created. There are indications that the creation of structural social capital in the form of supra-communal organisations linking community-based groups around issues of shared interests can have positive results (Bebbington & Carroll 2000).
- To alleviate the burden for volunteer carers, government should increase the proportion of allocation to home-based care (HBC) and ensure equitable distribution of resources for care and support such as bandages, over-the-counter medicines, cleaning agents, provision of bigger kits of gloves, diapers, and antiseptics to care organisations and communities. Government should also put in place a mechanism for the proper coordination of care and support programmes and services and the distribution of care and support resources, so as to reduce competition among organisations and concomitant poor access to resources and waste of resources.
- As part of the general framework for care and support, there is the need for the Department of Health to adapt standardised training curricula such as the WHO/IFRC training package in order to improve knowledge and skills of volunteers and informal caregivers. In this regard, there is a need to expand the criteria on training to be more inclusive of training programmes run by other organisations. The Department of Health should help harmonise various training curricula and programmes and facilitate registration of these programmes with the local skills training bodies.
- Interventions should also focus on the need for psychosocial support for volunteers working as home-based carers (HBCs), as well as the

mobilisation of other groups such as taxi drivers, gardening groups, *stokvels* and church groups in order to provide the various kinds of tangible, emotional and informational support needed by caregivers.

- A hospice to provide end-of-life care for patients with AIDS should be established. Already, there exists an opportunity to build a palliative care unit within the existing health facility within the community, which would be better than building a separate hospice. This would prevent the stigmatisation that might come with the building of a hospice, given the high levels of stigma and discrimination in the community.
- This should be complemented by the provision of mobile clinics that can be accessed by bedridden patients, thereby providing opportunity for saving money, time and energy spent on walking or transport cost.

Cognitive social capital: norms, values and attitudes

A consistent finding throughout our research project was that social norms, in particular social cohesion, were declining and at best perceived to be moderate. Social cohesion is necessary to unite community members to work around issues of communal importance. Social cohesion may, however, also be problematic. Too much social cohesion and unity may constrict the emergence of new, different ideas and groups and thus restrict availability and access to a diverse pool of resources. As discussed in Chapter 12, community cohesiveness may also not be sustainable for a long period due to lack of resources.

Stigma was a considerable hindrance for HIV/AIDS care and support in the community. Stigma is a complex social process that is shaped by meanings and explanations for sickness, ideas concerning disease transmission and sexual behaviour, and fears associated with illness, disease and sex (Bond, Chase & Aggleton 2002). In this project, we found that HIV/AIDS was associated with death and promiscuity (cf. Chapters 5 and 8), which shaped people's attitudes towards PLWHA as well as towards those who worked with PLWHA. Volunteer and informal care workers did not request support from individuals who could potentially provide support, due to fear of stigma. Stigma was also suggested as an explanation of why a community hospice would face challenges: people would associate the building and its inhabitants with undesirable attributes. Already, the clinic practiced use of a separate door for those coming for HIV testing. This may have encouraged differential treatment towards those visiting the clinic for reasons associated with HIV/AIDS. The door that was meant for privacy (a positive connotation) would instead signify stigma (a negative connotation).

In our research project, the metaphor of love came out strongly as a positive value that HIV/AIDS care should be built upon. However, the generative metaphor of *umqondo kamama* ('the mind of a mother', cf. Chapter 11) also served restricting purposes by suggesting that care work was for women, and suggesting that men were excluded. There are in fact very few male volunteer care workers in South African communities (Akintola 2006). Social norms surrounding care and support for PLWHA seem to be largely influenced by current prevailing gender norms (Campbell, Nair, Maimane & Sibiya 2008; Wight, Beals, Miller-Martinez, Murphy & Aneshensel 2007). Perhaps the care rhetoric has been so focused towards the physical and medical care that other forms of support such as socialising, practical help and other forms of assistance, mentioned as potential avenues for care and support by men in particular (Chapter 8), have been ignored. Prevailing gender norms result in more women and girls providing all the care and create social barriers to men and boys becoming caregivers, which again increases the care burden for women and girls.

Hope, optimism and religious commitment were related to well-being in HIV/AIDS care and support, reported by both PLWHA and their carers. FBOs were rated by community members as the most important and most frequently used groups. However, qualitative accounts pointed towards FBOs being seen as carriers of religious practice, instead of as sources of specific HIV/AIDS support. There seemed to be an untapped potential in the community in terms of awareness of the extensive amount of HIV/AIDS-related work being carried out by FBOs in South Africa and the way these groups may be utilised better in support work. While previously being connected to stigmatising attitudes and lack of a supportive environment, many of the FBOs today take on a caring role for those infected and affected by HIV/AIDS (Birdsall 2005; Magezi 2007).

There are indications that community members may lack a sense of individual and collective self-efficacy and self-esteem. In Chapter 2, it was speculated whether the low individual community participation could in part stem from a lack of empowerment. In corroboration with this, it was found in Chapter 13, (which gave back results found in Chapters 2 and 5) that a strength-based participatory approach of dissemination indeed did imply that participants re-discovered their abilities and self-esteem. Members of self-help groups reported in Chapter 9 also felt themselves valuable members of their groups, thus experiencing a strong, positive social identity. Self-efficacy and self-esteem are important factors for collective action (Bandura 2000). Non-participation may prove detrimental to health, since being part of networks has been associated with more social support, self-esteem, identity and perceptions of control for an individual (Cattell 2001).

In the light of the lack of participation among general community members, one would expect the expectations and trust towards other HIV/AIDS service providers to be higher. As evidenced in this volume, such trust and expectations were at best modest. This could point towards a sense of apathy, powerlessness, and despondency at a community level. Support for this assumption comes from the surprising result that the volunteer care workers were rated by the general community as the least important in the provision of HIV/AIDS services. Volunteer care workers were however seen as a vital and trusted resource among those who knew of their services and needed it. This finding could address the sense of hopelessness and stigma around HIV/AIDS. In Chapter 4, hopelessness among volunteer care workers, resulting from the overwhelming nature of HIV/AIDS and the lack of a cure, was the most significant finding. Another possibility is that the majority of community members who responded to the survey (Chapter 2) knew the volunteer care workers better than any other group in relation to HIV/ADS care, yet found the work done by these groups to be inadequate in the face of the growing HIV epidemic

Recommendations:

- In order to increase the groups' potential for taking on a bridging function, there should be a continued focus on fighting stigma at all levels. This is needed in order to promote acceptance and disclosure, as well as to facilitate testing, and to get access to treatment, care and support in the community (cf. Chapter 3).
- Given the low level of social capital in the community, there is an urgent need to evoke the philosophy of *ubuntu*, community solidarity and moral and reciprocal support. Through *ubuntu,* the communities could be mobilised for the provision of care and support. Institutions such as schools and religious organisations have the potential to serve as channels for achieving the promotion of *ubuntu* through meetings, youth programmes, plays and songs and all accessible media. This would encourage community solidarity, as well as moral and reciprocal support. Positive social norms should be promoted to engender people's interest in care and support.
- Metaphors are important in shaping identity, therefore a deeper understanding of metaphors and how they inform practices and self-perceptions of those working in HIV/AIDS care could help inform programmes and policies on informal HIV/AIDS care.

- Self-help groups for people living with HIV/AIDS are a particular form of bonding group that provide various forms of support. As argued in Chapter 9, to make such support groups more capable to respond to the needs of those living with HIV/AIDS, there is a need for services that provide for the psychosocial needs of members. Programmes that build resilience and well-being must be put in place for the participants for the empowerment needed to make their voices heard and to have an impact at the linking level.
- Consideration of norms and values (in particular stigma) in the community should be taken into account when creating HIV/AIDS care services, such as hospices. There is a need to work simultaneously in forming the services in such a way that stigma is not exacerbated, while at the same time working to reduce stigma through awareness. Attention should also be paid to the social norms and values that underpin the work of the different groups in the community and their inclusive or exclusive connotations.

Social capital and capacity-building

The degree of collective action and social cohesion in a community is thought to influence peoples' well-being and health outcomes, via their ability to extract resources and to respond to issues concerning them as individuals and as a group (Kawachi, Subramanian & Kim 2008). A prerequisite for extracting resources is availability of and access to information through appropriate channels.

In the community where our study took place, radio, newspapers and friends, family and neighbours were the main channels through which community members in general gathered HIV/AIDS-related information (cf. Chapter 2). This is an indication of the channels through which campaigns targeted at communities such as ours should be directed, as also evidenced in a study about support group outreach in the Limpopo province of South Africa (Dageid & Duckert 2007). The community members in our study were fairly homogeneous in terms of background and socio-economic status (cf. Chapter 1). Individuals and groups at the same structural level will, according to Burt (1997), have access to the same information. They will therefore only be able to provide and access information that is already available. As such, there is a need for individuals and groups within and from outside the community who are on structurally different levels than the community members. These individuals and groups may be able to provide new, beneficial information to community members on how to care for and support one who is ill with HIV/AIDS.

The lack of information gathering from the formal health system and from community-based organisations (CBOs), non-governmental organisations (NGOs) and FBOs speaks of an untapped potential in terms of disseminating information about HIV/AIDS care and support to the general public. Such information is needed to change negative community perceptions and stigma related to HIV/AIDS. As found by Bond *et al* (2002), we also noted that misinformation was one of the driving forces behind HIV/AIDS-related stigma.

There was an expressed need by individuals and groups to be independent and to act for and by themselves, yet the level of community participation was low. This could signal a need for empowerment. At a community level, empowerment is related to a sense of belonging and collective self-efficacy (Bandura 2000). This includes sharing a strong social identity, a sense of solidarity of trust and mutual help between community members, and perceived community control and power (McMillan & Chavis 1986; Woolcock & Narayan 2000; Zimmerman 2000). In order to mobilise people towards personal and social empowerment critical consciousness must be raised (Freire 1970). People must think first and then act in an informed and empowered way about their lives and the issues that affect them. That is why working with changing or strengthening community values and norms should go hand in hand with work that could promote strong horizontal and vertical networks and groups. However, empowerment using a bottom-up perspective is not enough to significantly improve HIV/AIDS care and support in communities. The issues of power and control over resources and distribution of these are pertinent.

Structural and socio-economic inequalities at a country-wide level must be addressed by those in government. In discussing the role of social capital in community development, Wakefield and Poland (2005) suggest that a discussion of social capital should run parallel to conceptions of economic and political structures, and includes an emphasis on the redistribution of resources. They argue that social connections are contingent with, and structured by, access to material resources, and suggest that a narrow focus on social cohesion and relations does not factor in broader influences on social relations. They suggest a construction of social capital that highlights a critical consciousness of social justice. As discussed in Chapter 12, care can be considered a ‘public good’ and adequate resources for care and support services should therefore be put in place by government and other funding institutions. This is particularly the case for volunteer care work, which constitutes the backbone of community care efforts, yet it remains in essence unpaid work. Akintola (2008) and Campbell, Nair, Maimane and Sibiya (2007:361) have highlighted how mobilisation of grassroots community participation is not necessarily a cheap or easy way of delivering HIV/AIDS care and support services in deprived communities. If local services are not well resourced, or are run by external agencies with little real local input in decision-making, the notions of empowerment and community participation could be nothing but a romanticised idea.

Clearly, more resources, skills upgrading, and better coordination and cooperation among community-based groups and among the informal and formal care and support structures would help build and expand community capacity. This requires building of bonding social capital inside the community, and also adding relations and external resources in the form of bridging and linking social capital. Efforts by those who are more powerful and who can provide resources for HIV/AIDS care and support, namely government and municipalities, local authorities, large NGOs and international donors, will help the networks and groups to function better, open up for more and better cooperation, and also increase individual members' socio-economic status and space to respond to their own and others' life situations (Abdool Karim, Churchyard, Abdool Karim & Lawn 2009; Coovadia *et al* 2009). At the same time, a strong bridging sector through which the bodies at a linking level may distribute, is essential. This will depend on who the group is and how they are functioning at a particular point in time; thus, the assessment of where the most efficient networking can happen was demonstrated by the case study with the traditional healers in Chapter 13.

Recommendations

- For an effective response, greater involvement from government is imperative. Government must provide clear leadership and a conducive environment that will facilitate the growth of social capital in HIV/AIDS-affected communities. This entails provision of appropriate resources necessary for supporting community efforts at providing care and support.
- The key to an effective response is the active participation and networking of the various stakeholders ranging from individual community members to government policy makers. Clear communication, coordination, accountability and transparency are crucial factors for the success of such larger networks.
- The study also identified a need for exploring untapped potentials for care and support. This should be done in order to tap into the interests and strengths of individuals, cognisant of the fact that not all individuals will be able to provide hands-on home-based care (HBC). Given that the influence of socio-demographic characteristics on interests and

strengths relating to care and support, characteristics such as age, gender and socio-economic variables should be taken into consideration when mobilising individuals for care and support (cf. Montgomery, Hoosegood, Busza & Timaeus 2006).

- Following the ‘public good’ argument, care and support should be considered a good that will benefit society at large. There is the need for governments to promote care and support by investing in the structural architecture for care and support. An important first step is the recognition of access to care and support for PLWHA as an extension of the universal access to care and as a basic human right, not a privilege or competing priority, for poor communities.
- Social networks should be targeted to improve the flow of information and awareness regarding care and support in the community. For instance, volunteers could be encouraged to approach other groups (bridging) to disseminate information aimed at discouraging denial and rejection among those that are infected and affected by HIV/AIDS. Individuals and groups presently not active in HIV/AIDS care and support should be targeted, preferably through the sources of information most often mentioned in the community. For example, media campaigns could be developed that target men as carers.
- Given unemployment and poverty in this community and the amount of work done by volunteers, government should consider making job creation an integral part of its HIV/AIDS-care policy (Akintola 2006). This will entail developing a cadre to accommodate home-based carers as formal healthcare workers in the primary healthcare system, which will enable grassroots women and communities to be employed and ensure sustainability of care programmes.
- In line with the above, there is the need for increased communication between those involved in community healthcare work and governmental healthcare plans. This could be a way to increase the flow of resources and information between the various vertical structures in the healthcare system and bridge the gap between marginalised communities and the government that has been found in many studies.
- Empowering nurses and healthcare personnel at the clinic through training to initiate ARV treatment in the community would solve many of the problems connected to the lack of human resources and of professional staff in the village. Volunteers should be trained to participate in ARV treatment and adherence as has been done with success in other contexts (Apondi *et al* 2007; Hlophe 2006).

- To assist in local capacity building, poor communities should be trained and funded to conduct their own needs assessments and to evaluate and monitor existing HIV/AIDS-related care and support services. This can be done using participatory strategies such as narrative theatre that is strength-based, non-judgmental and all-inclusive, which will enable the strengthening of social fabric necessary for social action. The government, together with large NGOs or international donors, should set aside training and capacity-building funds for such strategies.

Research design, field work and social impact

The fieldwork for our research project employed a variety of research designs and data collection methods to collect rich data. In accessing various groups, it was important to use a snowballing approach. Several of the organisations, which were not known to average members of the community, were therefore identified through referral from other organisations that were active. The overall project employed ethnography and participatory action research, which stressed the need to involve the community as on-going partners when doing research that has the aim of benefiting community members.

In disseminating the results of our study to the study communities, we have chosen culturally appropriate methods that are a departure from the usual scientific methods of dissemination. We employed performances that were informed by the research process, but that did not adhere strictly to the data as script. This has the ability to transfer complex information in a nuanced manner (Paget 1993), bringing the reality of the findings to the reality of the people. This process helped us stay close to our research population and helped us close the gap between research and practice (Gilbert & Sliep 2009; Sliep 2006:89-100; cf. Chapter 13).

The research team has extensive research experience from African settings, in South Africa in particular. We used our personal and professional backgrounds to attain a contextual, broad understanding and to reflect on our practice in the field. Understanding the way we position ourselves and the way our positions and actions reflect dominant discourses and practices were prerequisites when working with cultural diversity in situations of economic, gender and political inequalities.

It is of course also important to note that our research directly benefitted the community members and groups, and involved students and assistants from different backgrounds including the disadvantaged, and thus constituted a capacity-building endeavour in itself.

Recommendations

- For future research in similar projects, it is recommended that emphasis be placed on ethnography and participatory action research where the people who are the focus of the research study remain on-going partners throughout the research and intervention process. Through more active involvement in the engagement with results more realistic actions are shaped that are owned by the communities we work in. In the end, the overall purpose of our research was to inform our understanding and interventions that build capacity at various levels for a healthier society.
- Disseminating the results through interactive forums such as narrative theatre where access to marginalised voices is increased, directly contributes to the participation of one of the strongest mechanisms of social capital. Narrative theatre also has potential of disseminating complex information in simple ways for community members to understand.
- At the organisational level, there is a need for in-depth studies to understand variables in organisations that influence effective functioning and which have greater social capital value, compared to those that cause organisations to dwindle or function ineffectively (Gregson, Terceira, Mushati, Nyamukapa & Campbell 2004).
- Further studies should address bridging social capital at a community level. For empowerment to take place resources must be available, and people must have knowledge, self-efficacy and opportunity to access resources. Information concerning the availability of services, as well as opportunities to access these, could probably best be channelled through bridging groups working in the community.

Notes

1. Adapted from work done in Burundi (Sliep 2008).

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Appendix

A list of theses completed as part of the social capital project[1]

Theses completed at the University of KwaZulu-Natal:

Dada F. 2010. A social capital perspective regarding available support: Informal HIV/AIDS carers in [*name of community*], KwaZulu-Natal.

D'Almaine N. 2010. Exploring perceptions of informal care and support by community members not currently involved for those with HIV/Aids in [*name of community*], KwaZulu-Natal, South Africa.

Fynn S. 2010. Experiences of social support among volunteer caregivers of people living with HIV/AIDS.

Hlengwa WM. 2010. An investigation of the role played by social capital working as a buffer to reduce stress levels among volunteer caregivers of HIV/AIDS patients in KwaZulu-Natal.

Kasimbazi AK. 2009. Exploring how care and support around HIV/Aids is perceived by volunteer community workers at [*name of community*], KwaZulu-Natal.

Myeni L. 2010. Exploring the difference between trust and respect in a rural Zulu community according to field workers conducting research in [*name of community*]. (Honours thesis.)

Theses completed at the University of Oslo:

Arnesen A. 2009. Resilience, social capital, and well-being: A cross-sectional study in a context of adversity.

Nesje K. 2009. Social identity, group membership and trust.

Sæberg T. 2009. Caring for people with HIV/AIDS: A qualitative study of motivations and experiences of voluntary care workers in South Africa.

Vaage S. 2010. Treatment, care and support for HIV-positive people in rural South Africa: A qualitative study of the link between formal and informal health care.

Endnotes:

1. The name of the community in which the studies took place has been withheld due to ethical reasons. All theses are masters theses, unless otherwise specified.

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Social capital has become a focus of interest in health research, and serves as a useful framework to understand aspects of care and support for those living with HIV/AIDS. *Response-ability in the era of AIDS: Building social capital in community care and support* explores the social norms, mechanisms and practices related to HIV/AIDS care and support in a semi-rural community in KwaZulu-Natal, South Africa and makes specific recommendations for improvement of the current care and support situation.

The chapters in the book provide different yet complimentary ways of understanding and responding to HIV/AIDS care and support in a local setting. The first section of the book introduces social capital as a framework for study of HIV/AIDS care and support. In the second section, broader community and system responses are discussed, paying particular attention to participation, cooperation and coordination between community organisations, and challenges connected to this. Home-based care and volunteering are the themes of section three. While being a corner stone of HIV/AIDS care and support efforts, support for the volunteers are often lacking. Through in-depth exploration, important messages concerning the current situation and potential ways of strengthening the volunteer work are given. Section four contains novel perspectives on HIV/AIDS care and support, and tells of how one can empower and give results back to the community using narrative theatre as a tool.

The aim of this book is to disseminate the results of our research, and to further inform, inspire and create a platform for debate between practitioners, academics, researchers, trainers and facilitators interested in addressing community needs in terms of HIV/AIDS and support. The whole research process was approached in the context of capacity building and the book formed part of developing the voice of postgraduate students. The book is mainly written for a graduate and professional public, but will be interesting and useful for practitioners as well. We hope that the lessons we have learnt during this time will also inspire others working in the field.

Wenche Dageid (PhD), *Yvonne Sliep* (PhD), *Olagoke Akintola* (PhD), and *Fanny Duckert* (DrPhilos) are the research team behind the research project reported in this book. They all are experts in the field and are accomplished teachers, supervisors and researchers.

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SCHOLAR

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