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, academicians, 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.
Response-ability in the era of AIDS

Building social capital in community care and support

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

List of tables ................................................................. i
List of diagrams, photos and figures ............................... i
List of acronyms .............................................................. ii
Contributors ..................................................................... iii
Acknowledgements .......................................................... vii

Introduction

CHAPTER 1: The role of social capital in promoting community-based care and support for people living with HIV/AIDS in KwaZulu-Natal, South Africa ........................................... 1
Wenche Dageid, Yvonne Sliep, Olagoke Akintola & Fanny Duckert

Broader community and system responses

CHAPTER 2: Spaces of response-ability: A mapping of community members’ perceptions of and participation in HIV/AIDS care and support activities ............................ 23
Wenche Dageid

CHAPTER 3: Organisational challenges in creating care and support services for HIV-positive individuals in rural South Africa .......................... 49
Fanny Duckert & Staale Tofte Vaage

Home-based care and volunteering

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 ........................................ 77
Wellington Mthokozisi Hlengwa

CHAPTER 5: Unpaid volunteers and perceived obstacles in ensuring care and support for people living with HIV/AIDS .......................... 95
Annette Kezaabu Kasimbazi & Yvonne Sliep

CHAPTER 6: Experiences of social support among volunteer caregivers of people living with HIV/AIDS ........................................ 111
Sharl Fynn

CHAPTER 7: Those without the choice to care .......................... 129
Fatimah Dada & Yvonne Sliep
Other perspectives on response-ability to HIV/AIDS

CHAPTER 8: Untapped resources for HIV/AIDS care and support .............................................. Nicole D’Almaine De Klerk


CHAPTER 10: Reflections on fieldwork ..................................................................................... Mbekezeli Mkhize & Thulasizwe Kuzwayo

CHAPTER 11: Generative metaphor in community-based action research: Making culturally relevant connections ........................................... Thirusha Naidu

CHAPTER 12: Home-based care and social capital: Exploring the role of social capital in resource creation and access ...................................... Olagoke Akintola

CHAPTER 13: Taking back practices – Creating reflexive spaces to increase response-ability ................................................................. Yvonne Sliep & Annette Kezaabu Kasimbazi

Conclusions and visions

CHAPTER 14: Building social capital in community care and support ........................................ Yvonne Sliep, Wenche Dageid, Olagoke Akintola & Fanny Duckert

Appendix .................................................................................................................................. 287
Index ......................................................................................................................................... 289
List of tables

Table 1.1 A social capital framework for HIV/AIDS-related care and support
Table 2.1 Knowledge of types of groups conducting HIV/AIDS-related activities in the community
Table 2.2 Scores on “To what degree do you expect these different actors to provide services for HIV-positive people in this community?”
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?”
Table 4.1 Factor loadings on stress factors associated with care-giving
Table 4.2 Demographic characteristics of the volunteer caregivers
Table 4.3 The influence of demographic characteristics on stress
Table 4.4 The relationship between general stress and social capital
Table 4.5 The relationship between role overload and social capital
Table 4.6 The relationship between role captivity and social capital
Table 9.1 Mean and standard deviation for total collective self-esteem scale (CSES) and each CSES item

List of diagrams, photos and figures

Diagram 1.1 Social capital framework within the research project
Photo 1.1 The community in which the study took place
Figure 2.1 Satisfaction with groups working on HIV/AIDS-related issues in the community in %
Figure 2.2 Respondents’ view about who should address community problems in %
Figure 9.1 Marital status and resilience groups
Figure 9.2 Education and resilience groups
Figure 9.3 Household monthly income and resilience groups
Figure 11.1 A simple action research model
Figure 13.1 Mediating tension between healthcare workers and care providers through dissemination of results
Figure 13.2 Creating a space for the voice for the traditional healers
Photo 13.1 Divining hut of a local sangoma
Photo 13.2 Traditional healers in a meeting inside the divining hut
Photo 13.3 Attending the conference in traditional healer clothes
Diagram 14.1 Mechanisms and response-able possibilities in enhancing social capital to strengthen care and support in HIV/AIDS
List of acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ARV/ARVs</td>
<td>Antiretroviral(s)</td>
</tr>
<tr>
<td>CBC</td>
<td>Community-based care</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-based organisation</td>
</tr>
<tr>
<td>CD4</td>
<td>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</td>
</tr>
<tr>
<td>CHW</td>
<td>Community health worker</td>
</tr>
<tr>
<td>CSES</td>
<td>The collective self-esteem scale</td>
</tr>
<tr>
<td>FBO</td>
<td>Faith-based organisation</td>
</tr>
<tr>
<td>HBC</td>
<td>Home-based care, home-based carer</td>
</tr>
<tr>
<td>HBCV</td>
<td>Home-based care volunteer</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>Human immunodeficiency virus/acquired immune deficiency syndrome</td>
</tr>
<tr>
<td>IFRC</td>
<td>International Federation of Red Cross and Red Crescent Societies</td>
</tr>
<tr>
<td>MSF</td>
<td>Médecins Sans Frontières (Doctors Without Borders)</td>
</tr>
<tr>
<td>NF</td>
<td>Narrative Foundation</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental organisation</td>
</tr>
<tr>
<td>NPO</td>
<td>Non-profit organisation</td>
</tr>
<tr>
<td>NSP</td>
<td>National Strategic Plan</td>
</tr>
<tr>
<td>PhD</td>
<td>Philosophiae doctor, a postgraduate academic degree</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People living with HIV and AIDS</td>
</tr>
<tr>
<td>RSA</td>
<td>The Resilience Scale for Adults</td>
</tr>
<tr>
<td>SOCAT</td>
<td>The Social Capital Assessment Tool</td>
</tr>
<tr>
<td>STI</td>
<td>Sexually transmitted infections</td>
</tr>
<tr>
<td>TAC</td>
<td>Treatment Action Campaign</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>The Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary counselling and testing</td>
</tr>
<tr>
<td>WEMWBS</td>
<td>The Warwick-Edinburgh Mental Well-being Scale</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
<tr>
<td>ZAR</td>
<td>South African Rand</td>
</tr>
</tbody>
</table>
Olagoke Akintola is a public health promotion specialist and Senior Lecturer at the School of Psychology, University of KwaZulu-Natal, Durban, South Africa. His research interests are in the intersections of health and development using a gender lens. His current research focuses on community participation in health and development programmes and implications for public policy.

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**Staale Vaage** obtained his Masters degree in Health and Social Psychology from the University of Oslo (UiO). He has a Bachelor’s degree in General Psychology from the University of Bergen, Norway. His masters was on the subject of how treatment, care and support are organised in a small semi-rural community in South Africa, where he also did a four-month field study.
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We also want to acknowledge our work places: School of Psychology, University of KwaZulu-Natal (UKZN), and Department of Psychology, University of Oslo (UiO), for assistance throughout the project period. In particular, we want to acknowledge the project assistants Ayanda Kholeka Unathi Rasmeni, Lydia Hangulu, Santie Strong and Sithabile Mbambo. We also like to thank the accountants at the Howard College campus of the University of KwaZuluNatal Mr Rajan Munesar, Ms Nirvana Singh and Ms Bavashni Naidoo for providing technical support that facilitated the project operations. Professor Steve Collings (Head of School of Psychology, Howard
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In 2006, we received seed funding for North South academic cooperation from the UiO, which enabled us to work together on a project proposal that secured funding for our research. The research was financially supported by the Norwegian and South African governments through the SOUTHAFRICA program (2007-2010) administered by the Research Council of Norway and the National Research Foundation, South Africa.

Last but not least we want to thank our families and friends for supporting us all the way, giving us hope and courage and being our greatest sources of social capital.

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

**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 ac-
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, interpersonal 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

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.

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
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 investigations. 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 postgraduate 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 contributing 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-building 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 amongst 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 organi-
sations, 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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