# 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.

BY

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# DECLARATION

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

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# Dedication

This dissertation is dedicated to my late brother Mr WB Hlengwa who has always been my inspiration to aim and achieve high academically.

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**Chapter 1**

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# Abstract

The burden of caregiving is alarmingly high in South Africa, where one in every three people admitted in hospitals, is HIV positive. A great number of AIDS patients end up being cared for at home by their families, but mostly by volunteer caregivers. The conditions in which caregivers work under, leave much to be desired, hence work related conditions are a probable cause for high stress levels among volunteer caregivers of people living with HIV/AIDS. This study sought to investigate stress factors of volunteer caregivers of people living with HIV/AIDS and the influence of social capital on high stress levels. Within a South African caregiving setting, social capital influence has not been explored. In a culture where silence and stigmatisation of people living with HIV/AIDS and caregivers is high, this study tries to locate participation of close friends and family, local organizations and government in dealing with caregiving work and support. The study was conducted in 13 semi rural communities in Durban KwaZulu-Natal, South Africa. A survey was used to collect data, and analysis was conducted using quantitative methods. The sample comprised of 127 women from an organization called Community Outreach Centre. The greater (92.2%) of the total sample reported above 50% of stress levels. The findings indicated that caregiving work require urgent support from organizations and government. It was also evident that organizations within communities do not work together nor support each other in dealing with caregiving problems. Contrary to the existing literature, the results also showed that the more social capital elements such as social cohesion and social action at a bridging level increased, the more stressed volunteer caregivers became.

## Definition of Acronyms

1. AIDS – Acquired Immunodeficiency Syndrome
2. CBC – Community Based Organization
3. CC- Community Care
4. DOH – Department Of Health
5. HBC – Home Based Care
6. HIV – Human Immunodeficiency Virus
7. PLWHA – People Living With HIV/AIDS
8. WHO – World Health Organization

# Chapter 1

# Introduction

The HIV/AIDS pandemic has affected everyone. South Africa is the hardest hit country with an estimated 5.2 million infected people, which translates to approximately 11% of the population (UNAIDS, 2008). Despite the decline in the prevalence of HIV among certain age groups over the past three years, South Africa remains the country with the 4th highest HIV prevalence in the world (Shisana et al., 2008; Wikipedia, 2009).

KwaZulu-Natal and Mpumalanga provinces recorded the highest prevalence with KwaZulu-Natal accounting for 23.5% adults of this estimate making it the hardest hit province (Shisana et al 2008; Wikipedia, 2009). The number of AIDS related deaths in South Africa in 2007 alone was 350 000.

The introduction of community home-based care (CHBC) by the Department of Health is a direct response to the high number of HIV/AIDS patients using public health facilities which are embattled with problems such as: insufficient beds, inadequate number of medical, nursing and allied health professionals, lack of treatment and drugs, cost of institutional care as well as crowded and over-stretched hospitals which makes them unable to manage patients with terminal or long term diseases (Department of Health {DOH}, 2001).

Home and Community based care refers to activities and experiences involved in providing help and assistance to relatives, friends or community members who are unable to provide care for themselves, whereas caregiving is the component of one’s commitment to the welfare of another, hence making it a behavioural expression of this commitment (Pearlin, Mullan, Semple, Marilyn & Skuff, 1990; Pearlin & Skuff, 1992).

The shift to the home as a primary place of care for HIV/AIDS patients is a major challenge. The burden associated with CHBC is partly related to the lack of adequate resources for the household to provide proper care (Van Dyk, 2007). These include: (1) lack of adequate training to care for an HIV/AIDS patient, (2) lack of household income due to the high unemployment rate in South Africa, (3) broken down family structures (Akintola, 2006; Van Dyk, 2007). This situation leaves women and children vulnerable to caring alone without the presence and support of a permanent male partner who can help economically and with physical strength in the process of caring for an HIV/AIDS patient (Akintola, 2006; Van Dyk, 2007). Volunteer caregivers with palliative care training therefore become a major source of support to CHBC (Claxton, Catalan & Burgess, 1998).

Depending on different cultures, norms and values as well as affiliation to a specific organization, volunteer caregivers perform different tasks. While some only do home visits to check whether the patient needs medication in order to collect it on their behalf in clinics or hospitals (Ncama, 2005), other organizations provide a buddy who will just sit and provide friendship to patients (Claxton et al., 1998). There are also volunteer caregivers who perform tasks such as cleaning both the house and the patient, cooking for, feeding the patient and even arranging funeral proceedings when the patient has passed on (Akintola, 2006; Maslanka, 1996; Pakenham, Dadds & Terry, 1995; Pearlin, Aneshensel & Leblanc, 1997; Van Dyk, 2007).

Problem Statement:

Caring for a person who is terminally ill is a stressful activity (Akintola, 2006, 2008a; Claxton et al, 1998; Maslanka, 1996; Pakenham et al, 1995; Pearlin et al, 1990; Pearlin et al, 1997; Van Dyk, 2007). Researchers have associated this stress with negative psychological and emotional deterioration (Pakenham et al, 1995). However, previous studies that explored the stress associated with volunteer caregiving for people living with HIV/AIDS use qualitative approach (Akintola, 2008a; Hlophe, 2006; UNAIDS, 2000). While these studies captured the experiences of stress among volunteer caregivers, little is known about the degree to which volunteer caregivers are stressed: there is no quantitative study that has investigated stress among volunteer caregivers. The present study aims to explore the degree of stress as well as the predictors of stress among volunteer caregivers of people living with HIV/AIDS using quantitative measures. The findings of this study could provide home-based care organizations and policy makers with valuable information needed for developing interventions targeted at the most vulnerable caregivers.

This thesis is a part of a larger study presently conducted in KwaZulu-Natal, South Africa. The objective of the larger study is to promote the multilevel elements and mechanisms of social capital that would improve HIV/AIDS care and support in a local community in KwaZulu-Natal. Social capital are those features of social structure such as level of trust, norms of reciprocity and solidarity among members of that structure which thus act as a resource for collective action (Putnam, 1993, 1995). This dissertation will explore stressors associated with caregiving among volunteer caregivers of HIV/AIDS patients and their relationship to social capital and provide insight into how social capital which in other settings has proven to have an influence on stress can be strengthened (Putnam, 1993, 1995).

## Aim

The aim of this study is to explore the stress levels of HIV/AIDS volunteer caregivers in a home-based care organization. Furthermore, the study aims to explore the extent to which social capital is related to stress levels among volunteer caregivers and whether it has influence on stress levels of volunteer caregivers.

## Research Questions

The study will address the following research questions:

- To what degree do caregivers experience stress?
- Which components of stress are more prominent?, Is stress influenced by demographic characteristics of volunteer caregivers?
- Does social capital have any relations to levels of stress, if it does, which components of social capital are most related to stress amongst volunteer caregivers?,
- Do demographics moderate the effect of social capital on stress?

## Chapter Two

## Literature Review

### 2.1. Home-based care defined

to include physical, psychosocial, palliative, and spiritual activities; and with the families and The World Health Organizations (WHO) defines home-based care (HBC) as care given to the patient within his or her own home by either formal or informal caregivers (WHO, 1999).This form of care aims to maximize the patients’ quality of life, health, and functioning through appropriate quality care, that is cost-effective and includes care for a dignified death (WHO, 1999). In 2002, this definition was further modified communities as the key figures to implement these activities (WHO, 2002). HBC can thus be defined as the care given to an individual in his/her own environment (home) by his/her family and supported by skilled welfare officers and communities to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs (Gaborone Declaration on CHBC, 2001 as cited by Mohammad & Gikonyo, 2005). Joy Phumaphi explains HBC well when she says “Home-based care is taking us back to the root of human coexistence. It reminds us that we have the responsibility to care for one another. If we hold hands through this tragedy.....we will be able to retain our humanity and will come out of this epidemic a stronger community” (as quoted by WHO, 2002).

### 2.2. Why home-based care?

Home-based care and volunteer care giving in sub-Saharan Africa is increasing due to the escalating number of people and families who are infected and affected by the HIV/AIDS pandemic. The increasing number of people infected also results in the overburdening of the health systems of most developing countries that are unable to deal with the demands of the epidemic.

The failure of these countries' public health systems to cope with the demands of HIV/AIDS turns households, communities and community health organizations into a main place for primary health care (DOH, 2007; Ncama, 2005; Russel & Schneider, 2000). The inclusion of all relevant stake holders is therefore necessary when discussing home-based care. However, Russel and Schneider (2000) argue that such a large scale of community involvement has, over the years, proven difficult to sustain and incorporate to a more institutionalised system that is working cohesively to produce efficient service to people living with HIV/AIDS (PLWHA). In spite of this challenge, CHBC and HBC remain the most effective way of addressing the care gap created by a lack of capacity in the public health care system. Arguably, it is also the most cost effective and cheap means of providing care for PLWHA. Akintola (2008b) argues that the notion that home-based care is cheap stems from the fact that the very people who are involved in volunteer care work are overlooked by a government system which does not take into account the value of unpaid work carried out by volunteer caregivers. Therefore, he highlights the need to conduct a comprehensive assessment of the total cost of caregiving.

## 2.3. The role of various stakeholders

The South African Department of Health (DOH) outlines the guidelines for HBC, calls for the participation of all stakeholders involved in health care and highlights the roles of each stakeholder (DOH, 2001). These roles are, however, influenced by the model of service used in various communities (DOH, 2001; Ncama, 2005). Russel and Schneider (2000) classifies home-based into five different models: funding programmes, technical assistance and support programmes, advocacy and community mobilization programmes, drop in centres/support group, and comprehensive home-based care programmes. The successful implementation of HBC models depend on all stakeholders playing their respective parts. The DOH (2001) outlines the roles played by each stakeholder in HBC which include: formal systems, non-formal systems, the private sector and clients/patients as outlined below.

*Formal systems*: Stakeholders include doctors, nurses, psychologist and social workers who are expected to identify services, coordinate all planning and evaluate services, do facilitation work, mentorship, leadership and supervision, provide support to volunteer caregivers by creating proper functioning referral systems and follow up (Mohammad & Gokonyo 2005).

*Non-formal systems*: stakeholders include NGOs, CBOs, FBOs, traditional healers and leaders. The guidelines state that their main objective is to identify community needs and priorities including financials needs, deal with operational day to day running of HBC which include community outreach, planning, collaboration, control of available resources, support caregivers and build their capacity, coordinate and deal with referrals of patients to hospitals (Mohammad & Gokonyo 2005).

*Private sector*: These are stakeholders expected to negotiate and encourage medical aid schemes to accommodate and contribute to HBC, intervene by providing financial support where there are identifiable gaps, promote health by running intervention programmes, educational and health promotion programmes and lastly, provide household assistance and emergency care (Mohammad & Gokonyo 2005).

*Clients/patients or consumers*: These stake holders are expected to provide and create a safe working environment for other stakeholders, treat carers with respect and non-discriminatory attitudes, and provide proper communication regarding working arrangements (Mohammad & Gokonyo 2005).

The successful implementation of home-based depends on the performance of these stakeholders. The guidelines for HBC outlined by the South African Department of Health provide a comprehensive way to fight the HIV/AIDS epidemic. However, they are poorly managed because of a lack of strong partnerships between the state and other stakeholders, thus leaving the burden of HBC to families and volunteer caregivers (Hunter, 2007). Nevertheless, consistent commitment from various stakeholders provides sustained organizational support which, in turn, reduces the level of burden on volunteers (Van Dyk, 2007).

## 2.4. Who are volunteer caregivers?

The primary caregivers to PLWHA are family members who reside with the patients. They are usually women (mother, grandmother, daughter or a sister) and are generally referred to as family caregivers (Akintola, 2006; Ncama, 2005). Although the role of men and boys have been poorly documented and inadequately understood, it is generally recognized that women and girls are the principal caregivers in most homes and bear the greatest degree of responsibility for the psychosocial and physical care of family and community members (Ogden, Esim & Grown, 2006).

Volunteer caregivers are unpaid individuals who volunteer their time to help families with their sick relatives. They are usually not family members (Akintola, 2008a). Most volunteer caregivers work for NGOs or community organizations. Volunteer caregivers typically provide support to families. They educate family members on how to provide care for the ill and also provide various kinds of support to families (Akintola, 2008a). Depending on the policy of the care organization and resources available, volunteer caregivers bathe, clothe, feed, talk to and fetch medication for their patients. They also help families access resources needed for effective care of patients.

## 2.5. Challenges facing home-based care

While the guidelines provided by the DOH (2001) are comprehensive, there are still major challenges with regard to the implementation of HBC programmes. Most answers to these challenges lie in the government playing a direct, comprehensive and participatory coordinating role **(**Mohammad & Gikonyo, 2005**)**.

The challenges include (i) *Human resources*: these are operational issues such as training/capacity building and social/technical expertise that cause strain to the human resource of HBC (Mohammad & Gikonyo, 2005; Ncama, 2005; Russel & Schneider, 2000). (ii) *Lack of proper training and few caregivers*: shortages of volunteer caregivers make it hard to carry out activities and services effectively. (iii) *Referral channels* between HBC, clinics, hospitals and international NGOs are not strong, leaving HBC with the burden of failing to refer their patients when the situations beyond their scope arises (Mohammad & Gikonyo, 2005). *Governments* sometimes fail to channel finances for transportation, working kit and educational materials to HBC organizations (Mohammad & Gikonyo, 2005). A study conducted in Tanzania, also shows that government’s guideline to HBC does not target specific needs of communities and households but is generalised with an assumption that all volunteer caregivers have equal resources to deal with caregiving demands (HelpAge International, 2007). In rural areas, for example, elderly people have to walk several miles to reach the nearest health centre as opposed to urban areas where health centres are within reach (HelpAge International, 2007).

### 2.6. Caregiver stress

Many investigations into the process of AIDS caregiving reveal that the burden of caregiving causes mental and physical health problems for the caregiver (Akintola, 2006; Pakenham et al., 1995; Turner, Catania & Gagnon, 1994). Investigators have suggested that the burden and distress of female caregivers may be greater than that of the male caregivers because of their unequal social and economic role in society (Akintola, 2006). Minorities and people with low income may also experience greater distress and burden (Turner et al., 1994). Socioeconomic and demographic factors associated with physical and mental health problems in caregivers include low income, education and social status, being female, minority ethnic status, age-related life transition (older and younger age of caregiver and younger age of PLWHA); and single marital status (never married and unmarried) (Brown, McDaniel, & Birx, 1995; Sher, 1993; Wardlaw, 1994 as cited by Flaskerud & Tabora, 1998). Pakenham et al. (1995) also add that anger, loneliness, and stigma are some of the health problems associated with caregivers. Most women caregivers report that no one in their surroundings wants to talk about PLWHA. As a result, they feel alone even when they are surrounded by friends and family (Flaskerud & Tabora, 1998).

### 2.7. Factors associated with stress among AIDS care volunteers.

#### 2.7.1. Failure to deal with patients' death

Difficulty in drawing the line between ones work as a caregiver and the HIV/ AIDS patient has been established to be a major debilitating factor and a source for major stress amongst caregivers (Flaskerud & Tabora, 1998). Symptoms of stress and depression, feelings of guilt, anxiety and sadness are often reported by caregivers who feel they are unable to deal with their patients' death (Van Dyk, 2007). The progression of the disease and pain experienced by the patient (which eventually leads to death) causes caregivers to feel obliged to show more concern as a replacement for the limitations of medication (Shisana, Hall, Maluleke, Chauveau & Schwabe, 2004; Shisana et al. 2008). Regarding the intensity of caregiving, volunteer caregivers speak about the need to put their own concern aside in order to care for PLWHA (van Dyk, 2007). They expend more time and emotional energy on their care. Several caregivers reported spending most of their time thinking about or caring for PLWHA. Many others recount not being able to sleep properly while keeping vigil beside a PLWHA, getting up during the night, wandering out of the house or being uncomfortable or in pain (Flaskerud & Tabora, 1998).

Shisana et al. (2004) further asserts that it is sometimes impossible for the caregivers to dissociate themselves from their patients because most volunteer caregivers are also HIV positive or they have family members who are also infected. Therefore, they feel compelled to do more than what their organization stipulates as their responsibility. Despite their working conditions that have minimal support, caregivers hope that when it is their turn to be bed ridden or when they have full blown AIDS, someone will also take care of them (Shisana et al., 2008).

Because volunteer caregivers are members of the same community as their patients, they carry with them the burden of binding confidentiality about the status of their patients, and hence can not disclose the status of their patients to the members of their family regardless of the sometimes irresponsible behaviour of their patients that might endanger their partners or other family members (Van Dyk, 2007). Drawing boundaries therefore becomes a major issue for caregivers because they get caught up in a dilemma of being a responsible friend to the family and preserving caregiver/patient confidentiality.

### 2.7.2. The Overwhelming nature of disease.

The number of people infected with HIV/AIDS is perceived by a considerable number of caregivers to be so overwhelming that they will never be able to provide help to all the people they come across who are HIV positive (Van Dyk, 2007). Patient deaths are not uncommon in the course of professional/ volunteer practice in the health and social service. Being with clients, friends and family members at this crucial life stage, can be a powerful and moving experience. However, as with other similar, these deaths can also induce feelings of regret, anger, sadness, and hopelessness in those who provide care for the patients, because these deaths happen too many a time than anyone can bear (Strom-Gottfried & Mowbray, 2006). At an extreme level, these feelings, if unattended to, can lead to stress which might result in the care givers being highly stressed and subsequently burnout. Anticipatory grief which caregivers experience can lead to a number of negative behaviours for the helping professions and volunteers, such as detachment, avoidance of client, friend or a family member (Strom-Gottfried & Mowbray, 2006). A South African study reveals that nurses describe their feelings about the overwhelming nature of HIV/AIDS as depressive and helpless because patients come to the hospital sick and are discharged while still sick and may pass away, Given these experiences, caregivers may develop a tendency of therefore, they feel like they are mortuary nurses (Van Dyk, 2007). Clearly, it shows that AIDS is not just a disease affecting the infected person but has an array of consequences for people who are providing care for the infected person. avoiding a dying patient, distance themselves from distress or change to another setting/ ward or section of work by being less empathetic and less personally involved (Van Dyk, 2007, p.51). This tendency, however, is accompanied by denial, stigmatization, and access refusal by family of the patients because they assume that volunteers do little or no work at all because patients die anyway (Akintola, 2008a). A caregiver in Van Dyk's (2007, p.51) study expresses this as not seeing the light at the end of the AIDS tunnel:

> "I sometimes wonder why I'm going on. They are all going to die and this is just too big and out of control. It is also disheartening and frustrating seeing a very sick mother wearing a mourning attire (sign of being recently widowed), carrying a sick child and being followed by two primary school kids which evidently becomes clear that these kids will grow up without parents".

It is thus imperative that a study investigating support for volunteers be conducted using quantitative measures that will enhance the knowledge of close social bonds, networks and organization to which these volunteers are affiliated as a form of support structures. This would be done for the sole purpose of providing necessary intervention programmes where needed the most, using available social resources and structures.

### 2.7.3. Lack of organizational support

Caregivers often experience frustration, anger and inadequacy and helplessness due to numerous organizational factors, especially a lack of emotional and practical support, lack of supervision and mentoring, role ambiguity due to role expansion, inadequate training, role discomfort, heavy patient/client load and isolation (Van Dyk, 2007). All of these factors which have been mentioned in one way or another in numerous studies (Akintola, 2006, 2008a; Flaskerud & Tabora 1998; Heaney, 1991; Heaney, Price & Rafferty, 1995; Maslanka, 1996; Ogden et al. 2006; Pakenham et al. 2002; van Dyk, 2007) show that caregivers are double burdened by the fact that there is not enough psychological and material support from the organizations they work for. Furthermore, government agencies are not taking ownership of the development and support of caregivers especially with working material such as nappies, gloves and other protective measures without which caregivers would face the fate of being infected in the course of their work (Akintola, 2008a). In her study, van Dyk (2007) reports that about half of the participants express fear of occupational exposure and infection with HIV and blame their organizations for not providing adequate protective measures for them.

Responding to this dysfunction, Heaney (1991) and Heaney et al. (1995) suggested that increasing the amount of social support available to the members of the organization may facilitate behaviour in three ways. First, organizational support can help caregivers in the organization to modify a stressful situation. This means that when a caregiver is facing a problem, co-workers and supervisors can assist in accomplishing a task, provide guidance and advice, and provide access to information and new contacts. By doing this, a caregiver will not be constrained by the limit of their own ability and personal resources when solving problems and dealing with stressful caregiving situations (Heaney et al., 1995).

Second, the support from within the organization can help caregivers to develop a new perspective on a stressful situation. This means that the caregiver can be equipped by knowing the expectations and demands of the organization and hence be properly alert when demands beyond what is expected of them ensues (Heaney, 1991; Heaney et al., 1995).

Lastly, social support within an organization may decrease emotional frustration associated with problematic working situations related to home care especially for PLWHA. The support within the organization can also provide affirmation and emotional support such as empathy and understanding (Heaney, 1991; Heaney et al., 1995). Most of these organizations, however, are not adequately equipped with resources nor connected to better resourced organizations doing the same volunteer work within the vicinity (Akintola, 2004).

### 2.7.4. Lack of social support

The beneficial effects of social support on health are well documented (Heaney, 1991; Taylor, Seeley & Kajura, 1996). Social support has been found to be associated with longer life, psychological well-being, compliance with health regimes, decreased morbidity, and recovery from serious physical illness and injury (Heaney, 1991). In addition, social support has been shown to buffer against diverse consequences of stress (Taylor et al., 1996). There are two hypotheses that are associated with social support. The first one is the 'direct effect hypothesis. Taylor et al. (1996) explain social support as beneficial in both none stressful as well as stressful situations. The second is the 'Buffering hypothesis' maintains that physical and mental health benefit of social support are evident during the period of high stress and is minimal in less stressful situations. The latter hypothesis acts as reservoir of the sources of coping with high stressful situations and blunts the effects of stress (Taylor et al, 1996). By merely providing avenues for social support, people who are experiencing a stressful life event or life transition, can be protected from harmful effects on their health.

Heaney (1991) asserts that low levels of social support have been firmly established as a risk factor for poor people and women. As a result, the Health Promotion Unit of World Health Organization has made the strengthening of social networks and social support a priority area for intervention, stating that social ties are important determinants of value and behaviour relevant to health and significant resources for coping with stress and maintaining health. According to Taylor, when social support has been assessed qualitatively by measuring the number of friends and organizations that one is a part of, as well as the understanding that one can receive support from these ties and connection, then the buffering effect of social support can be found (House et al., 1988 as cited by Taylor, 1996). Therefore, social support can be conceptualized as a resource that people draw from when coping with stress (Heaney, 1991). Studies of home-based care have established that most caregivers do not receive this type of support from their closed allies. Hence, they find themselves isolated from their communities including their families (Akintola, 2006; Maslanka, 1999; Pakenham et al. 1995; Pearlin et al. 1997; Van Dyk, 2007). Many caregivers explain that the need for constant care prevents them from participating in social activities that might alleviate their loneliness and provide social and emotional support (Flaskerud & Tabora, 1998). Others go as far as saying that mistrust of the intentions of others further acts to isolate these women. Hence, they find their social network shrinking to include only PLWHA (Flaskerud & Tabora, 1998: 30).

### 2.7.5. Role overload and role captivity

When addressing the concepts of role overload and role captivity, one has to acknowledge and build around concepts from the stress proliferation framework articulated by Pearlin and associates (Pearlin et al., 1997). This framework defines primary stressors as difficulties associated with actual task of caregiving such as the problematic conditions that stem directly from the needs of patients and ensuing demands of care. Some primary stressors are objective, reflective, concrete aspects of the situation, such as, the degree to which caregivers routinely assist PLWHA with activities of daily living (ADLs) (Leblanc, London & Aneshensel, 1997, Pearlin et al., 1997). Other primary stressors reside in the subjective experience of caregivers, the degree to which caregivers feel trapped in or held captive by caregiving role (Leblanc et al., 1997). Stress proliferation is defined as the expansion or emergence of stressors within and beyond a situation whose stressfulness was initially more circumscribed (Pearlin et al., 1997). However, stress proliferation among AIDS caregiving is based on the distinction between primary and secondary stressors (Pearlin et al., 1997). This study will focus on the subjective part of primary stressors (see Pearlin et al., 1997).

### 2.7.6 Coping with Stress

Coping refers to behaviour that protects people from being psychologically harmed by problematic social experiences (Pearlin & Schooler, 1978). It is a behaviour that mediate the impact that societies have on it members. Lazarus & Folkman (1980) state that coping strategies refer to the specific efforts, both behavioral and psychological, that people employ to master, tolerate, reduce, or minimize stressful events. Studies show that many of the difficult problems confronting people are not unusual problems that target certain people but are persistence hardship experienced by those engaged in mainstream activities within major institutions (Pearlin & Schooler, 1978). Two general coping strategies have been distinguished: problem-solving strategies are efforts to do something active to alleviate stressful circumstances, whereas emotion-focused coping strategies involve efforts to regulate the emotional consequences of stressful or potentially stressful events (Folkman & Lazarus, 1984, p. 38). Research indicates that people use both types of strategies to combat most stressful events (Folkman & Lazarus, 1980). The use of one type of strategy over another by people is determined , in part, by personal style (e.g., some people cope more actively than others) and also by the type of stressful event; for example, people typically employ problem-focused coping to deal with potential controllable problems such as work-related problems and family-related problems, whereas stressors perceived as less controllable, such as certain kinds of physical health problems, prompt more emotion-focused coping (Folkman & Lazarus, 1980).

In addition to personal or individual form of coping, there are other mechanisms or resources that can be drawn on for coping at a social, societal or community level. These include social support and social capital. Social Support can be defined as the information leading to a person to believe that he/she is cared for and loved, esteemed and valued, and/or he/she belongs to a network of communication and mutual obligation (Cobb's, 1976). Procidano and Heller( 1983:2) refined this definition by stating that social support is the extent to which an individual believes that his or her needs for support, information and feedback are fulfilled. On the other hand, social capital is the actual exchange (reciprocal) of favours rendered as support by one member to the next of the same social network. Given the role of social capital in mediating the risk of HIV infection (Pronyk et al, 2008), it seems reasonable to suppose that social capital could also be useful in mediating stress among volunteer caregivers. However, no study has explored this hypothesis. An in depth discussion of social capital is presented in the section that follows.

## 2.8. Social capital

### Theoretical foundation, terms and definitions, dimensions and level of social capital

Social capital has been used and applied by a considerable number of social science disciplines including economics, sociology, political science and psychology, to mention but a few (Burt, 1997; Coleman, 1988; Portes; 1998 Putnam, 1995). It is a concept that is fairly new and still in the process of being refined, developed and advanced in order to establish it as one of the influential theories in the social sciences. While there are arguments about how to measure it, there is some consensus on its levels and elements. In this study, social capital will be defined, explained and lastly conceptualized to fit the specific needs of this study which is to establish whether the presence of social capital can be viewed as a buffer that can reduce stress levels of volunteer caregivers.

### 2.8.1. What is social capital?

The emergence of the concept of social capital made popular by Putnam (1995) has made it to be used as a source that can transform societal problems. This concept first introduced in the writings of the French sociologist, Pierre Bourdieu who states that "Social Capital is the aggregate of the actual or potential resource which are linked to the possession of a durable network of more or less institutionalized relationships of mutual acquaintances and recognition or in other words, to membership in a group which provides each of its members with the backing of the collective owned capital, a "credential" which entitles them to credit in the various sense of the word" (as cited by Portes, 1998, p. 3). This seems to suggest that social capital in not individualistic but an aggregate acquired by being in connection with other people and/or by being a member of a group (family, elite group or a social club).

These connections, however, should have durability over a period of time. The benefits of these connections include providing members with credentials and rights to resources that the connections or network has. Resources could either be monetary or non-monetary (cultural) in nature (Bourdieu, 1986). Portes (1998) adds that through social capital, individuals gain access to loans, jobs, investment tips and increase in cultural capital.

Coleman suggests that social capital is defined by its function. By this he means that it is not a single entity but a variety of different entities, with two elements in common: they both involve some aspects of social structure, and they facilitate certain actions of actors-whether persons or corporate actors-within the structure (Coleman, 1988). By concentrating on the functions of social capital, Coleman states that social capital is responsible as an aid in accounting for different outcomes at the level of the individual actors and an aid toward making the micro to macro transitions. However, Coleman does not elaborate on the social structural details through which this occurs (Coleman, 1988:8). Indeed this explanation tries to establish the elements and processes that happen during the interaction of the individual and his networks that result in him/her being in possession of high social capital. In as much there is value that is noticeable in individuals and societies with these connections, there still remains a problem of understanding the actual elements that makes the network connections result in high social capital. This is an improvement on Bourdieu's suggestion or idea because it is trying to locate or establish mechanisms that allow the concept to be measurable.

Coleman (1988) recommends elements such as *Obligations, Expectations and Trustworthiness* as elements that constitute social capital. That is, if member A of the group does something for member B of the same network, then member A expects and trusts that member B is obliged do the same favours for member A when asked to do so (Colman, 1988, p. 9). These exchanges can run for a number of years interchangeably between a considerable number of actors within the society or group without the debt completely cancelling each other out (Coleman, 1988). Portes and Landolt (2000) attribute current interest in the concept of social capital to the limitation of an absolutely economic approach towards the achievement of the basic developmental goals, sustained growth, equity, and democracy. This alternative that is provided by social capital creates a sphere and space for individuals to make economic and non-economic transactions towards growth that are not confined by interest or time specific on returns. It is an ongoing circular motion that works as a support system for individuals who are tied together as part of a family, group or society. Bourdieu (1986) further explains that individuals intentionally build relationships for the benefit that they will bring later, making them reciprocal in nature. For instance, the idea of savings club in South Africa is a well known social networking that brings people together to form friendships and to save money as a group so that at the end of every financial year, they will bulk buy food together which will last each member of a group up to about four months at a time, hence enabling them to save money for financial hardships of the beginning of the year. Money interchanges between these members, creating a barrier of trust and reciprocal behaviour between it members.

Other writers describe social capital as a resource that actors derive from specific structures and then use to pursue their interest; it is created by changes in the relationship among actors (Baker, 1990). According to Schiff (1992, p. 161), “Social Capital is the set of elements of the social structure that affect relations among people and are input or arguments of the production and/or the utility function”. Most interestingly, a very straight forward definition of social capital is provided by Lin (1999) who terms social capital as investments in social relations with expected returns as a result of which individuals engage in interaction and networking in order to produce profit.

Putnam (1995) paints a vivid picture about the disappearance of social capital in the United States of America where he makes a distinction between localized and generalized social capital. Putnam argues that localized social capital develops out of small groups within societies such as soccer teams, girl guides, church organization, choral music groups and these help to foster norms of trust and co-operation that make communities work. He further argues that it is through these private groups that bonds of policy as a whole is forged (Putnam, 1993). Generalized social capital on the other hand, grows out of the patterns of reciprocity, collaboration and community spirit found on the private or localized social capital (Potapchuk, Crocker, William & Schechter, 1997; Putnam, 1993). Putnam (1995) states that "Social Capital is the feature of social life networks, norms, and trust that enable participants to act together more effectively to pursue shared objectives". By adding norms and trust into the definition, Putnam opens a platform and bridges the gap left by his predecessors. His application of the concept is not as dense as Bourdieu's and Coleman's who focus mostly on the immediate family structure. Instead, Putnam broadens his spectrum to entire communal norms and trusts thereof (Portes, 1998).

In more simplified terms Potapchuk et al. (1997, p. 130) states that:

> "In many ways, social capital is the glue that holds a community together. Operating at the interpersonal, organizational, institutional and political levels of community, it includes the neighbour who knows all the children on the block, and can be counted

> on to be there for them in an emergency or during conflicts. It includes a policeman who lives in the neighbourhood and coaches a soccer team in which his daughter plays. It is also includes the neighbourhood association members and the volunteers at the community centre and homeless shelter. They are people who carry forward the values and vision of the community along with the parents, the house of worship and other civic institutions. Furthermore, much like financial capital, social capital increases with use. The more it is invested the more the community has".

In order to understand this concept of social capital, given that it has many faces and applications, I am now going to examine different structures that make up the features of social capital.

### 2.8.2. Dimensions and levels of social capital

For the purpose of this study, I will look into the widely used dimensions of social capital- *Structural and cognitive*- that were highlighted by Putnam but later developed further by Nahapiet and Ghoshal (Adam & Roncevic, 2003; Nahapiet & Ghoshal, 1998; Putnam, 1995).

#### 2.8.2.1. Structural dimension

The structural dimension of social capital refers to the overall pattern of connections between actors- that is, who you reach and how you reach them (Burt, 1992). Basically, this means that the way you are located in a social structure gives you certain privileges and access to advantageous information that can develop you as a person which in turn can help you get favours of job referrals and access to certain resources which people who do not have the same access as you, would not easily acquire (Tsai & Ghoshal, 1998). Put differently, structural dimension refers to the information of informal networks that enable individuals to identify others with the potential resources. Hence, these networks include relationships with strong ties (those with multiple contacts on daily basis) and weak ties (individuals whose contacts occur less frequently), however, the overall structural dimension of social capital reflects the need for individuals to reach out to others within an organization to seek out resources that they have at their own disposal (Lesser & Prusak, 1999). Because of this, Portes (1998) concludes that to possess social capital, a person must be related to others and it is those others not him/her who are the actual sources of his or her advantage.

Lin (1999) also argues that not all networks that individuals have contribute equally to the creation of social capital. In addition, Burt (1997) explains that it is the strategic position that one holds which provides crucial information and support for one to act decisively in decision making, especially, when it comes to managers in big corporate industries. Therefore, social networks become one of the most important aspects of social capital because the flow of information within and between groups facilitates an informed action that an individual can use as a source of support from members of those groups and networks (Coleman, 2005). It is also important to note that the flow of information is much stronger within groups than between groups. This can have both positive and negative attributes at the same time because crucial information and favours can be exhausted within close ties whereas the person who needs it the most might be outside of the immediate group but part of the wider network (Lin, 1999).

Finally, these social networks and relations are expected to reinforce identity and foster recognition for individuals. This assurance and worthiness as a member of a group that shares the same goals and interests not only gives the individual a form of emotional support, but also an entitlement to ones claim of the resources that are shared by the same group, community or network (Lin, 1999). Individuals need strong social networks to generate social capital, whether the results those networks yield are positive or negative (Portes, 1998). The processes of engagement entailed in these groups of networks still have to be understood. That is, the factors that keep these social networks together, making it possible for individual actors to acquire a certain level of social capital need to be investigated. This leads to the second yet important dimension of social capital which is relational in nature.

#### 2.8.2.2. Cognitive social capital

The final dimension, which is cognitive, addresses the need for a common context and language to build social capital. Without a common understanding or vocabulary, it is difficult to construct the connections necessary to create and foster social capital. Building a common context can be done through two mechanisms. The first is the use of common objects and artefacts such as documents, procedure manuals and memos to provide a shared reference point that others can quickly understand. Another technique is the use of stories that convey a sense of shared history and context which is retransmitted and carried on by others in the organization (Lesser & Prusak, 1999). Cognitive dimension is embodied in attributes like a shared code or a shared paradigm that facilitate a common understanding of collective goals and proper ways of acting in a social system. Such common understanding is appropriated by the collective as a resource (Portes & Sensebrenner, 1993 as cited in Tsai & Ghoshal, 1998).

### 2.8.3. Elements of cognitive social capital

Cognitive social capital is characterized by elements of trust, norms and reciprocity shared amongst individuals, group members or community members. These are further explained below.

#### 2.8.3.1. Trust

Fukuyama (1999) defines trust as “the expectation that arise within a community of regular, honest and cooperative behaviour, based on commonly shared norms, on the part of other members of the community. Those norms can be about deep value questions like the nature of God or justice, but they also encompass circular norms like professional standards and codes of behaviour.” Trust entails a willingness to take risks in a social context based on a sense of confidence that others will respond as expected and will act in mutually supportive ways or at least that others do not intend to harm (Onyx & Bullen, 2000). As a trusting relationship develops inside a network, actors build up relations of trustworthiness that may become important information for other actors in the network (Tsai & Ghoshal, 1998).

#### 2.8.3.2. Norms

Putnam (1995) and Colman (1988) both refer explicitly to social norms. Social norms provide a form of informal social control that obviates the necessity for more formal, institutionalized legal sanctions. Social norms are generally unwritten but commonly understood formulas for both determining what patterns of behaviour are expected in a given social context and defining what forms of behaviour are valued or socially approved. Injunctive social norms in particular can have a powerful effect in increasing pro-social behaviour and preventing anti social behaviour (Reno, Caildini & Kallgren, 1993). Both Putnam (1995) and Colman (1998) argue that in neighbourhoods where social capital is high, there is little crime and little need for formal policing. On the other hand, where there is low level of trust and few social norms, people will cooperate in joint action only under a system of formal rules and regulations which have to be negotiated, agreed to, litigated, and enforced, sometimes by coercive means, leading to expensive legal costs (Fukuyama, 1999).

#### 2.8.3.3. Reciprocity

The common theme in the literature on social capital is reciprocity whereby the individual provides a service to others or acts for the benefit of others at a personal cost but in a general expectation that this kindness will be returned as some undefined time in the future in case of need. In a community where reciprocity is strong, people care about each other’s needs and interest (Onyx & Bullen, 2000).

### 2.8.4. Levels of social capital

Bonding social capital refers to networks formed from perceived, shared identity relations. The reason for being a part of that network or a group is merely because others are considered to be like one hence, justification is made that co-operation and trust are appropriate entities between individuals (Szreter, 2002). The possibilities of social network bonding are, however, influenced by a range of complex issues such as politically negotiated ideas, entrenched beliefs, norms and values, social identities, family ties and traditions and a number of agreed upon concepts and meaning of life (Szreter, 2002).

Bridging social capital, by contrast, refers to networks of association, where the differentiating principles of shared social identity, similar origins or status positions in society, plays no necessary role in determining membership. Participants in the network are typically drawn from a relatively wide range of background. Their main reason for interaction is to engage together in a collective activity, which each of them values and benefits from, which they cannot achieve alone and which is not available through the bonded network they have (Szreter, 2002).

Linking social capital refers to networks and institutionalised relationships between unequal individuals (Szreter, 2002). This refers to links between individuals and higher government institutions regarding their ability to reach consensus on issues that are beneficial to both despite their unequal positions. It also involves proper channels of resources, knowledge and information dissemination between higher authorities, community organizations and the general public.

# Chapter Three

# Methodology and Design

## 3.1. Setting and context

The study was conducted in 13 semi-rural communities (townships) located in the Marianhill area, approximately 30km from the city of Durban in the KwaZulu-Natal province of South Africa. The communities in the Marianhill area are serviced by a hospital owned by the Catholic missionaries. In 1997, the missionary hospital started a community-based organization which provides home-based care services to communities in the Marianhill area. The communities have a high unemployment rate and low literacy levels. The care organization recruits and trains volunteer caregivers from these communities who in turn assist people living with HIV/AIDS and their families in the provision of home-based care services. The organization (i) provides basic nursing care as well as HIV counselling and testing, (ii) educate communities on healthy living, (iii) provides home visiting services (iv) provides food parcels to the most needy, (v) educate families on self-reliance through developing vegetable gardens in Drop-in Centres and schools as well as patients' homes. At the time of the study, there were about 300 volunteer caregivers, 15 coordinators and one project manager working with the organization. Two of the coordinators are retired nurses who are working at the hospital designated to provide nursing care as well as voluntary counselling to patients.

### 3.2. Design

This is a quantitative study that uses the survey method. A survey is a research method involving the use of questionnaires to gather information (data) about people's emotions and behaviour regarding a certain phenomenon that a researcher wants to explore (Myers & Hansen, 2006). A cross-sectional design was used. A cross-sectional design is one in which a statistically significant sample of a population is used to estimate the relationship between an outcome of interest and a population variable as they exist at one particular time (Myers & Hansen, 2006)

### 3.3 Research sample

Participants are volunteer caregivers of HIV/AIDS patients and AIDS orphans working for the community-based organization that offers home-based care services in the Marianhill area. We sought to interview all the 300 volunteers but were unable to reach all of them due to availability and the time for data collection. At the close of fieldwork, we had interviewed a total number of 130 participants comprising of 3 males and 127 females. However, due to the lack of variation for men, they were not included in subsequent analyses.

### 3.4. Measures

A structured questionnaire was used to obtain the following information from the volunteer caregivers of PLWHA. In order to improve response rate and the validity of the instrument, the study was designed to be an interviewer-administered survey. The questionnaire has 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:

*Biographic information* refers to information on age, sex, marital status, academic qualification, grade and level of responsibility, who they care for, how many years they have been in volunteering work, how many years they intend to do the work, how many patients they care for. Respondents are also asked to indicate how many of their patients have passed away. (See Appendix Four for a copy of the questionnaire).

*Stress factors* of volunteer caregivers of HIV/AIDS patients: constructs that are specifically related to stress associated with HIV/AIDS care (also referred to as sub scales) such as ('overwhelming nature of the disease', 'lack of organizational 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 the 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 final 15-item scale had a Chronbach's Alpha reliability of 0.80. (For all the questions of the scale, see Appendix Five).

*Social capital*: Social capital is measured in two dimensions- structural and cognitive social capital. Each dimension is measured on three levels- bonding, bridging and linking levels. Questions asked for each dimension at all three levels are presented in Appendix Six. In some of the questions, respondents are asked to list, whereas in other questions they are expected to respond on a 5-item Lickert-type scale ranging from ‘definitely not’ (1) to ‘to a great extent,’ (5); (1)’Never’ to (5) ‘Very often’; (1)’Very unlikely’ to (5) ‘Very likely’; (1) ‘Very distant’ to (5) ‘Very close’; (1) ‘To a very small extent’ to (5) ‘To a very great extent’; (1) ‘Mostly looking out for themselves’ to (5) ‘Mostly helpful’; and (1) ‘They cannot be trusted’ to (5) ‘They can be trusted’. *Structural social capital*: this construct was adapted from the work of Pronyk et al 2008 on HIV risk in rural South Africa. This construct is measured using 7 items relating to various aspects of structural social capital including organizational density and characteristics, networks and mutual support organizations, exclusion, collective action, and conflict resolution, household members, affiliation with local institutions both formal and informal and is measure in all three levels, see appendix vi. The Cronbach’s alpha for structural social capital is 0.6 (Pronyk et al. 2008).

*Cognitive social capital*: This construct is measured using 13 items relating to various aspects of cognitive social capital including solidarity, trust, reciprocity and cooperation and also measured in all three levels. (For all the questions of the scale see appendix vi). The Cronbach’s alpha for cognitive social capital is 0.55 (Pronyk et al. 2008). However, the composite value of the internal reliability that tries to combine the two types of social capital has Cronbach’s alpha of 0.3. The coding for both structural and cognitive social capital social was adapted from a previous study, see Pronyk et al. (2008).

### 3.5. Procedure

The survey was conducted over a period of three weeks from 2 April, 2009 to 17 April, 2009. The questions were originally drawn in English and the researcher translated the questionnaire from English to isiZulu. The researcher, together with four trained field assistants, collected the data by means of questionnaires. Arrangements were made with coordinators to provide dates and times for meetings with volunteer caregivers. Most of the meetings were held in drop-in centres. Each day, the team would divide and go with the various coordinators to their respective communities. However, due to a poor turnout of volunteer caregivers during the first two meetings, we decided to review the strategy for data collection so as to improve the participation of volunteers in the study. We requested contact details of all caregivers affiliated to the organization from the Project Manager. Before interviews were scheduled, all potential participants in each of the communities were contacted to confirm their availability for the interviews. Some caregivers who were not able to come for the meetings provided us with other dates and times that we could visit them in their own homes for the interviews.

Participants were given consent forms to read and sign before the questionnaire were administered. Others who refused to sign because they were protective of their signature gave verbal consent. All interviews were conducted in isiZulu which is the local language spoken in the area.

### 3.6. Analysis

The questionnaires were checked to ensure that all were properly completed. Thereafter, they were coded, and entered into Statistical Package of Social Science (SPSS 16.0). Next, the captured data was cleaned to ensure that they were captured correctly. The data was analysed by conducting factor analysis, t-tests, correlations, chi-square and linear regression. Details of the analysis performed are presented together with the findings in the following chapter. The t-test was used to determine the most salient stress factor. The relationship between stress and social capital was determined using Spearman’s Correlation coefficient. Finally the linear regression model was run to identify social capital components that are predictors of stress.

## 3.7. Ethical considerations

In compliance with the University of KwaZulu-Natal ethical review committee requirements, permission to conduct the study amongst caregivers was sought and obtained from the gate keepers' executive committee of the community outreach centre. A follow up meeting with all the volunteer caregivers affiliated to the organization was held where the aims, objectives and nature of the study was explained. Questions were allowed in order to clarify all issues.

During data collection, respondents were also given consent forms to read and thereafter sign as a proof of their agreement to participate in the study. However, some of the respondents opted to give verbal informed consent. Participants were assured of confidentiality and that no information would be traced back to them. All the data collected for the study is safely stored in a locked office in the University of KwaZulu-Natal where it would be kept for the duration of five years after which it would be disposed of.

# Chapter 4

# Results

In order to answer the research questions the following tests were conducted: factor loading, correlations, descriptive, t-test, cross tabulations (chi-square) and linear/hierarchical regression. First, the demographic characteristics are presented. Thereafter, the validation of the scales used in the study is discussed. Finally, the analysis is presented in such a ways as to answer the research questions in a chronological order.

## 4.1. Demographic characteristics

The demographic characteristics of volunteer caregivers are as follows.  The total number of participants is 130 consisting of 127 women (97.7%) and 3 men (2.3%). The disproportionate distribution and variance of men and women makes it hard to test any differences between men and women regarding their stress levels and the presence of social capital. Therefore, a comparison of the two groups was not conducted. The mean age of the participants is 35.52 years (SD = 8 and the range of 22-63 years). There was a lack of variation in the following variables: gender, level of education, level of responsibility, and source of income. Therefore high order analyses were not performed using these variables. Demographic characteristics of volunteers are presented in table 1.

**Table 1**. Demographic characteristics of volunteer caregivers

| Items | N | % | Mean | SD |
|---|---|---|---|---|
| Total sample | 130 | 100 | 2 | 0 |
| Men | 3 | 2.3 | | |
| Women | 127 | 97.7 | | |
| Age groups | | | | |
| 20-29 | 25 | 19.2 | 36 | 8 |
| 30-39 | 70 | 53.8 | | |
| 40=< | 35 | 26.9 | | |
| Marital status | | | | |
| Married | 29 | 22.3 | 2 | 1 |
| Not married | 91 | 70 | | |
| Widow/Widower | 5 | 3.8 | | |
| Engaged | 5 | 3.8 | | |
| Level of education | | | | |
| Primary | 6 | 4.6 | 3 | 0 |
| Secondary/high school | 121 | 93.1 | | |
| Higher education | 3 | 2.3 | | |
| Level of responsibility | | | | |
| Coordinator | 5 | 3.8 | 3 | 1 |
| Facilitator | 69 | 53.1 | | |
| Caregiver | 56 | 43.1 | | |
| Type of volunteer work | | | | |
| HIV/AIDS patients | 49 | 37.7 | 2 | 1 |
| Orphans | 18 | 13.8 | | |
| Both | 62 | 47.7 | | |
| Missing | 1 | 0.8 | | |
| Source of income | | | | |
| None | 120 | 92.3 | 0 | 1 |
| Domestic work | 1 | 0.8 | | |
| Street vending | 2 | 1.5 | | |
| Salary (COC) | 4 | 3.1 | | |
| Temporal jobs | 3 | 2.3 | | |
| Years in volunteer work | | | | |
| 1-4yrs | 23 | 17.7 | 7 | 2 |
| 5-8yrs | 69 | 53.1 | | |
| 9yrs=< | 38 | 29.2 | | |
| Number of deceased patients | | | | |
| None | 6 | 4.6 | 4 | 4 |
| 1 person | 16 | 12.3 | | |
| 2-4 people | 65 | 50.0 | | |
| 5=< | 43 | 33.1 | | |
| Years to volunteer | | | | |
| Not sure | 16 | 12.3 | 6 | 6 |
| 1-5yrs | 53 | 40.8 | | |
| 6-10yrs | 13 | 10.0 | | |
| 11yrs=< | 43 | 33.1 | | |

## 4.2. Validation of stress scale

Factor analysis is one way to examine the validity of the scales. The aim is to find out whether items measure certain aspects of stress, and whether some items converge. If items converge to a satisfactory degree (factor loadings higher than .500), it is assumed that they measure at least a great part of the same underlying stress concept. If the items converge with each other, but do not converge with other items, it is assumed that they discriminate well (Pallant, 2007, p. 190). This is done to confirm the previous validation done by Van Dyk (2007) and Pearlin et al. (1997) since the two scales have been combined. Therefore, it is important to determine before further analysis if the stress scale actually measures the hypothesised stress construct. If validity is not checked, it cannot be said that stress has actually been measured. Therefore factor analysis using varimax rotation was conducted on the 15-item stress scale and the following variables are identified: 1) Fear of dealing with patients' death; 2) Overwhelming nature of disease; 3) Lack of Organizational support; 4) Lack of social support; 5) Role overload; and 6) Role captivity. Table 2 provides the factor loadings and alpha for individual variables.

Although the alphas for 'fear of dealing with patients death' and 'role overload' are low (.554 and .514 respectively) the factor loadings are well within acceptable limits (Pallant, 2007). However, it is best to look at the inter-item correlations which fall within acceptable limits of between .2 and .4 (Briggs & Cheek 1986, p. 115).

Table2: Factor loading on stress factors associated with caregiving

| Scales and Items | Factor loading | Alpha |
|---|---|---|
| **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 organizational 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 lack of leisure time | .820 | |
| **Role captivity** | | .635 |
| Feeling trapped by patients' illness | .856 | |
| I wish I could run away from caregiving work | .856 | |

Stress variables were checked for collinearity using Pearson's r and the results show that they do not correlate too highly with each other. This shows that the subscales are measuring different constructs (Pallant, 2007). Table 3 provides the correlations among the subscales. The results show that none of the variables has a correlation coefficient that is higher than 0.4 indicating that the subscales are not clustered nor are they measuring the same variable. Pallant (2007) argues that correlation of r = .9 signifies existence of multi-collinearity. Therefore, .4 is within an accepted range, (see table 3):

Table3: Correlations between stress variables

| Items<br>N(129) | failure to deal With patient's Death | Overwhelming nature of disease | Lack of organizational support | Lack of social support | Role overload | Role captivity |
|---|---|---|---|---|---|---|
| Failure to deal with Patients' death | . | | | | | |
| Overwhelming nature Of disease | .391** | | | | | |
| Lack of organizational Support | .358** | .385** | | | | |
| Lack of social support | .132 | .398** | .381** | | | |
| Role overload | .313** | .383** | .122 | .231** | | |
| Role captivity | .318** | .372** | .204* | .173* | .365** | . |

**Correlation is significant at the 0.01 level (2-tailed), *Correlation is significant at the 0.05 level (2-tailed)

## 4.3. General stress of caregivers

### Levels of stress in general

Of the total number of volunteers (n=130) who participated in the study, 129 questionnaires were completed and used in analysis. The minimum stress score is 31 while the maximum stress score is 75. The standard deviation is 10 with a mean stress score of 52. Only 10 participants (8%) scored between 40- 50% of the total stress score. The remaining 119 participants (92%) scored above 50% and they are divided like this: there are 26 people who got between 50-60% with 39 people who scored between 61-70%. Again 27 people scored between 71-80% and finally, 27 people scored between 81-100% on the stress level and these are regarded as being at high risk. Fifty percent (50%) of the sample (64 people) fall between the ranges of 60-80% and are between the ages of 30-40 years old. Individual stress constructs were also measured and results are as follows: for 'Failure to deal with patients death' only 18 (10.9%) people scored below 50% and 111 people (89.1%) scoring above, Overwhelming nature of disease 32 people (28.4%) got below 50% and 97 people (71.6%) scoring above 50% mark. For lack of organizational support only 3 people (2.3%) scored below 50% and the rest 126 people (97.7%) felt that there is a major lack of support from the organization, Lack of social support also yielded the same result with only 17 people (13.2%) scoring below 50% and 112 people (86.8%) feeling that they don't get enough support socially. For role overload 77 people (59.7%) felt that the load was not too bad scoring below 50% with only 52 people (40.3%) believing that the load is heavy on them. Lastly, role captivity had 61 people (47.3) who scored below 50% and 68 (52.7%) people scoring above the 50% mark. We expect that volunteer work in this context is stressful, so a moderate stress level could be considered "normal". However, a high stress level could indicate that stress is a heightened risk of burnout and attrition. So it makes sense to split the sample into groups indicating the degree of stress experienced so as to know which volunteers are in critical need of support.

The sample was split into two groups: those who are moderately stressed n = 75 and the highly stressed group n = 54. The split was measured by cutting from those whose answers are from neutral and below and those whose answers are from neutral and above which puts the final cut off point at 53. This same principle was repeated with the subscales. Where the scale has 3 questions, the cut off point is 10 and where there are 2 questions, the cut off point is 7. The total breakdown of all percentages is presented below, (see table 4). This gives an indication and a precise measure for where most volunteers are clustered and also identifies those who are highly stressed and require urgent attention. The mode or mean was not used because these are purely statistical ways of choosing cut point. Mode is good statistically speaking because it divides the sample into two equal groups (which is beneficial for many statistical procedures). However, it might not make conceptual sense. We chose to split based on the answering alternatives (around 3.5). This is because a mean split would perhaps divide the group at the point where participants stated "moderately stressed/unsure". This answer cannot be said to characterize a “highly stressed” person. Whereas an answer of “highly stressed would.

**Table 4.** Stress factors associated with caregiving for HIV/AIDS (General stress).

| Scores | Moderately stressed n (%)<br>30-53 | Mean | SD | Highly stressed n (%)<br>54-75 | Mean | SD |
|---|---|---|---|---|---|---|
| Total stress Levels | 75 (57.7%) | 45 | 6 | 54 (41.5%) | 62 | 6 |

### 4.4. **Which stress components are most salient**?

An independent t-test was conducted to find out which aspects of volunteering is the most stressful. Means of the stress factors were divided (into moderately stressed and highly stressed at a cut off point of 53) for the various subscales. Each of these subscales was then compared with each other. Table 5 provides the output result of an independent t-test.

All differences between means of moderately stressed and highly stressed volunteer caregivers are significant at 0.000 (2-tailed). Overwhelming nature of disease is found to be the most stressful component with the effect size of eta squared at 48.88% followed by failure to deal with patients’ death with an effect size of eta squared at 31.5%. The rest of the components ranged between19-26% effect.

Table5: Independent t-test: A comparison of the subscales of the general stress scale.

| General stress | | N | Mean | Std. Deviation | Eta squared |
|---|---|---|---|---|---|
| Failure to deal with Patients'death | >=53 | 58 | 12.03 | 2.649 | .315 - 31.5% |
| | <53 | 71 | 8.66 | 2.360 | |
| Overwhelming nature Of disease | >=53 | 58 | 12.62 | 2.533 | .4888 - 48.88% |
| | <53 | 71 | 7.92 | 2.310 | |
| Lack of organizational Support | >=53 | 58 | 13.91 | 1.657 | .2222 - 22.22% |
| | <53 | 71 | 11.92 | 2.034 | |
| Lack of social Support | >=53 | 58 | 8.84 | 1.673 | .191 - 19.1% |
| | <53 | 71 | 7.04 | 2.066 | |
| Role overload | >=53 | 58 | 6.28 | 2.505 | .216 – 21.6% |
| | <53 | 71 | 4.03 | 1.603 | |
| Role captivity | >=53 | 58 | 7.23 | 2.505 | .262 – 26.2% |
| | <53 | 71 | 4.62 | 1.988 | |

## 4.5. Demographic influence on stress.

To determine whether demographic characteristics have any influence on the high stress levels of volunteer caregivers, a chi-square was conducted. Results of the chi-square test for independence (with Pearson chi-square) indicate no significant associations between moderately/ high stressed volunteers and demographic characteristics. Results are presented in table 6.

**Table6**: Cross tabulations of demographic characteristics influence on stress

| Variables | Value | df | Aysmp.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 | .06 |
| Years to volunteer | .185 | 3 | .980 |
| Number of deceased patients | .401 | 3 | .940 |

The same procedure was repeated for each of the subscales against demographic influence. Significant influences are found on ‘failure to deal with patients’ death’: years to volunteer **sig 0.044**, ‘overwhelming nature of disease’: years to volunteer **sig 0.054**, role overload: years to volunteer **sig 0.011** and role captivity: age **sig 0.015.**

## 4.6. The relationship between stress and social capital

The relationship between general stress and social capital was explored using regression analysis. The relationship could either be positive, indicating that the presence of social capital increases the levels of stress for volunteers or negative suggesting that the presence of social capital reduces the levels of stress for volunteers. In some instances, no relationship was found. First, the analysis of the relationship between overall stress, measured by the 15-item stress scale, and social capital is presented, next the analysis of the relationship between the subscales of the overall stress scale, and social capital is presented, then the analysis of the relationship between the two split groups (highly stressed and moderately stressed groups) and social capital is presented. Finally the moderating effect of demographic on the relationship between stress and social capital is presented.

### 4.6.1. The relationship between total stress scale and social capital.

In order to answer the question ‘to what extent the different elements of social capital explain the variance in stress levels', a linear regression analysis was carried out. A linear regression can tell us which factors explain most of the variance. Social capital explains 14.6% of the total variance of total stress scores (**R Squared** = 0.146, **sig.** = 0.065.) This implies that the total model is not statistically significant. Although the model as a whole is not significant, some items are significant. Social action at the bridging level (**Beta** = 0.259, **sig**. 0.013) is the strongest variable explaining 5% of the total variance of total stress scores. Trust at the bridging level of **Beta** = 0.242, **sig**. = 0.030 is the second strongest variable explaining 4% of the total variance of total stress scores. This means that when both social action and trust at a bridging level increase, stress among volunteers also increases, (see table 7):

Table7: Regression model measuring the relationship between general stress and social capital.

| Model | Beta | t | sig. |
|---|---|---|---|
| 1(Constant) | 1.981 | 1.981 | .050 |
| Group Bonding | -0.78 | -.0879 | .381 |
| Group bridging | .068 | .0718 | .474 |
| Group linking | -.114 | -1.185 | .239 |
| Social action bonding | -.069 | -.577 | .565 |
| Social action bridging | .259 | 2.520 | .013 |
| General Trust | -.002 | -.022 | .983 |
| Trust Bonding | -.002 | -.017 | .987 |
| Trust bridging | -.242 | 2.191 | .030 |
| Trust Linking | -.165 | -1.455 | .148 |
| Social Cohesion Bonding | .030 | .254 | .800 |
| Social Cohesion Bridging | -.005 | -.055 | .956 |

### 4.6.2. The relationship between individual subscales and social capital.

The relationship between individual subscales and social capital was also explored. A linear regression analysis is again carried out for each of the subscales. No significant association is found between social capital and the stress construct ‘failure to deal with patients’ death’.

Social capital explains 12% of the total variance of ‘overwhelming nature of disease’ (R Squared = 0.120, sig. = 0.171). This suggests that the total model is not statistically significant. However, ‘social action at a bridging level’ has a significant contribution with **Beta** = 0.260, **sig**. 0.014. This accounts for 4.8% of the total variance of ‘overwhelming nature of disease’. These results indicate that an increase in social action leads to an increase in the construct ‘overwhelming nature of disease’ (see table 8):

Table8: Regression model measuring the relationship between overwhelming nature of disease and social capital.

| Model | Beta | t | sig. |
|---|---|---|---|
| 1(Constant) |  | 3.421 | .001 |
| Group Bonding | -0.53 | -.590 | .557 |
| Group bridging | .005 | .057 | .955 |
| Group linking | -.112 | -1.150 | .253 |
| Social action bonding | -.012 | -.142 | .887 |
| Social action bridging | .260 | 2.489 | .014 |
| General Trust | -.043 | -.456 | .649 |
| Trust Bonding | -.016 | -.172 | .864 |
| Trust bridging | .134 | 1.196 | .234 |
| Trust Linking | -.070 | -.603 | .547 |
| Social Cohesion Bonding | -.010 | -.083 | .934 |
| Social Cohesion Bridging | -.139 | -1.449 | .150 |

Social capital explains 11.6% of the total variance of ‘lack of organizational support’ (R Squared = 0.116, sig. = 0.193). This indicates that the total model is not statistically significant. ‘Trust at a bridging level’ which is **Beta** = 0.325, **sig**. 0.0050, explaining 6.5% of the total variance of ‘lack of organizational support’ is significant. Again, beta value here indicates that an increase in trust at a bridging level leads to an increase in the construct ‘lack of organizational support’ (see table 9):

Table9: Regression model measuring the relationship between lack of organizational support and social capital.

| Model | Beta | t | sig. |
|---|---|---|---|
| 1(Constant) |  | 5.686 | .000 |
| Group Bonding | .008 | .088 | .930 |
| Group bridging | .057 | .595 | .553 |
| Group linking | -.162 | -1.653 | .101 |
| Social action bonding | .008 | .064 | .949 |
| Social action bridging | .037 | .354 | .724 |
| General Trust | .046 | -.488 | .626 |
| Trust Bonding | -.036 | -.377 | .707 |
| Trust bridging | .325 | 2.893 | .005 |
| Trust Linking | -.048 | -.418 | .677 |
| Social Cohesion Bonding | .044 | .370 | .712 |
| Social Cohesion Bridging | .074 | .764 | .446 |

Social capital explains 13.3% of the total variance of ‘lack of social support’ (R Squared = 0.133, sig. = 0.106). Individual variables within the model show significant results. Social cohesion at a bonding level is the strongest with **Beta** = -0.279, **sig**. 0.021 explaining 4.2% of the total variance of ‘lack of social support’. The second strongest variable is trust at a linking level with **Beta** = -0.264, **sig**. = 0.023 explaining 4.04%, (see table 10):

Table10: Regression model measuring the relationship between lack of social support and social capital.

| Model | Beta | t | sig. |
|---|---|---|---|
| 1(Constant) | | 5.036 | .000 |
| Group Bonding | -.024 | -.268 | .789 |
| Group bridging | .097 | 1.013 | .313 |
| Group linking | -.120 | -1.235 | .219 |
| Social action bonding | -.236 | 1.951 | .054 |
| Social action bridging | .228 | 2.201 | .030 |
| General Trust | .026 | -.277 | .782 |
| Trust Bonding | -.084 | -.893 | .374 |
| Trust bridging | -.216 | 1.939 | .055 |
| Trust Linking | -.264 | -2.310 | .023 |
| Social Cohesion Bonding | -.279 | -2.350 | .021 |
| Social Cohesion Bridging | .043 | .448 | .655 |

Social capital explains 17.1% of the total variance of ‘role overload’ (**R Squared** = 0.171, **sig.** = 0.022). The model, however, is also not statistically significant with some individual variables within the model being significant. ‘Trust at a linking level’ is the strongest with **Beta** = -0.313, **sig**. 0.006 explaining 6% of the total variance of ‘role overload’. The second strongest variable is ‘social action at a bridging level’ with **Beta** = 0.227, **sig**. = 0.021 explaining 4% of ‘role overload’, (see table 11):

Table 11: Regression model measuring the relationship between role overload and social capital.

| Model | Beta | t | sig. |
|---|---|---|---|
| 1(Constant) |  | .514 | .609 |
| Group Bonding | .028 | .322 | .748 |
| Group bridging | .051 | .549 | .584 |
| Group linking | .029 | .303 | .762 |
| Social action bonding | -.093 | -.785 | .434 |
| Social action bridging | .227 | 2.235 | .027 |
| General Trust | -.049 | -.539 | .591 |
| Trust Bonding | .155 | 1.682 | .095 |
| Trust bridging | .142 | 1.305 | .194 |
| Trust Linking | -.313 | -2.794 | .006 |
| Social Cohesion Bonding | .211 | 1.821 | .071 |
| Social Cohesion Bridging | -.022 | .233 | .817 |

In the final model, social capital explains 17.2% of the total variance of ‘role captivity’ (**R Squared** = 0.172, **sig.** = 0.021). Individual variables that are significant included ‘social action at a bridging level’ which is the strongest with **Beta** = 0.261, **sig**. 0.011 explaining 4.8% of the total variance of ‘role captivity’. The second strongest variable is ‘trust at a bridging level’ with **Beta** = 0.248, **sig**. = 0.025 explaining 3.8% of the total variance. The third strongest variable is ‘trust at a linking level’ with **Beta** = 0.216, **sig**. = 0.056 explaining 3% of ‘role captivity’, (see table 12):

Table12: Regression model measuring the relationship between role captivity and social capital.

| Model | Beta | t | sig. |
|---|---|---|---|
| 1(Constant) |  | .342 | .733 |
| Group Bonding | -.158 | -1.823 | .071 |
| Group bridging | .114 | 1.223 | .224 |
| Group linking | -.008 | -.083 | .934 |
| Social action bonding | .075 | .634 | .527 |
| Social action bridging | .261 | 2.582 | .011 |
| General Trust | .003 | .029 | .977 |
| Trust Bonding | .017 | .186 | .853 |
| Trust bridging | .248 | 2.276 | .025 |
| Trust Linking | -.216 | -1.929 | .056 |
| Social Cohesion Bonding | .025 | .213 | .831 |
| Social Cohesion Bridging | .119 | 1.278 | .204 |

### 4.6.3. The relationship between general stress and social capital using the split between moderately and highly stressed volunteers.

As mentioned earlier, most of the volunteers have high levels of stress; therefore, volunteers were split into two groups of moderately and highly stressed volunteers. The following analysis is based on the split groups.

The relationship between 1) total stress and social capital, and 2) subscales of the stress scale and social capital was also explored by splitting the total stress scale and the subscales of the stress scale into two (moderately and highly stressed). A linear regression was thereafter conducted. None of the two models is statistically significant. However, 'social action at a bridging level' for the highly stressed group i.e. p>53 is significant with **Beta** = 0.461, **sig** = 0.002. Social action deals with community participation regarding the AIDS pandemic. These results signify that as volunteers participate in and interact more with the community, the more their stress levels will be. Lack of cooperation, different ideologies regarding HIV/AIDS and stigmatization could be the cause of this finding.

Regarding the relationship between subscales and 'social capital' using the same procedure for the split groups, only the model of social capital and role captivity for the moderately stressed group (p<=7) is significant at 0.042. Within the model, groups at a bridging level is significant with **Beta** =0,258, **sig** = 0.024 and 'social cohesion at a bridging level' with **Beta** = 0.264, **sig** = 0.027. While the model is not significant (p>7), 'social action at bridging level' is significant **Beta** = 0.428, **sig** = 0.045.

### 4.6.4. Moderating effects of demographics on social capital and stress

Hierarchical multiple regression was used to assess the ability of one control measure ‘social capital’ to predict the levels of stress, after controlling for the influence of demographic characteristics including age group, marital group, type of volunteer work, years in volunteer work, number of deceased patients, and years to volunteer. Demographics were entered at step 1, explaining 2% of the variance in total stress scores. After the entry of social capital variables at step 2, the total variance explained by the model as a whole is 16.2%, F (17, 102) = 1.159, p< 0.311. The control measure explains an additional 14.2% of the variance in total stress, after controlling for demographic characteristics. R squared changed = 0.142, F change (11, 102) = 1.574, p< 0.118. In the final model, only two control measures are statistical significant, with ‘social action at a bridging level’ recording a higher beta= 0.238, sig = 0.018 and ‘trust at bridging level’ with beta = 0.238. sig = 0.047. However, the total model is not statistically significant.

The same procedure was repeated for the subscales to measure differences between the moderately stressed and highly stressed volunteer caregivers on the moderating factor of demographics on social capital and total stress. Social capital explains 6.3% of the total variance of the total stress scores for ‘moderately stressed’ volunteer caregivers (p <= 53) **R Squared** = 0.063, **sig**. = 0.961. This indicates that the total model is not statistically significant. None of the individual items has a significant contribution.

Social capital explains 19.1% of the total variance of the total stress scale of volunteer caregivers who fall under the category highly stressed (p>53) **R Squared** = 0.191, **sig**. = 0.008. The total model is statistically significant. ‘Social cohesion at a bridging level’ has

**beta** = 0.311, **sig**. = 0.002 and 'trust at bridging level' has **beta** = 0.280, **sig**. = 0.01, with items making significant contribution to the total model (see table 13):

Table13: Regression model measuring the relationship between stress subscale (highly stressed >53) and social capital

| Model | Beta | t | sig. |
|---|---|---|---|
| 1(Constant) | | 4.550 | .000 |
| Group Bonding | -.087 | -1.014 | .313 |
| Group bridging | .115 | 1.246 | .215 |
| Group linking | -.123 | -1.316 | .191 |
| Social action bonding | .002 | -.021 | .983 |
| Social action bridging | .311 | 3.139 | .002 |
| General Trust | -.012 | -.139 | .892 |
| Trust Bonding | -.004 | -.048 | .962 |
| Trust bridging | .280 | 2.602 | .010 |
| Trust Linking | -.209 | -1.894 | .061 |
| Social Cohesion Bonding | .022 | .189 | .850 |
| Social Cohesion Bridging | .029 | .316 | .753 |

Still following the same procedure, 'failure to deal with patients' death', 'overwhelming nature of disease', 'lack of organizational support', 'role overload' and 'role captivity' for highly stressed group are all not statistically significant on both moderately and highly stressed volunteer caregivers.

It is expected that demographics would not have an influence on the relationship between stress and social capital since in previous analysis. Demographics did not have any influence on levels of stress or levels of social capital. Thus, when controlling for demographics, a linear regression was again conducted on the subscale 'lack of social support'. Social capital explains 18.2% of the total variance of 'lack of social support' among moderately stressed volunteer caregivers (p <= 7) **R Squared** = 0.182, **sig**. = 0.824. The total model is not statistically significant. However, 'social cohesion at a bonding level' is significant with **beta** = -0.570, **sig**. = 0.037, (see table 14):

Table14: Regression model measuring the relationship between lack of social support (stressed <= 7) and social capital.

| Model | Beta | t | sig. |
|---|---|---|---|
| 1(Constant) | | 2.972 | .006 |
| Group Bonding | -.081 | -.386 | .702 |
| Group bridging | -.060 | -.308 | .760 |
| Group linking | .038 | .162 | .873 |
| Social action bonding | .383 | 1.513 | .141 |
| Social action bridging | .099 | .491 | .627 |
| General Trust | .033 | .173 | .864 |
| Trust Bonding | -.004 | -.021 | .983 |
| Trust bridging | .155 | .719 | .478 |
| Trust Linking | -149 | -.682 | .501 |
| Social Cohesion Bonding | -.570 | -2.186 | .037 |
| Social Cohesion Bridging | -.154 | -.756 | .455 |

The same procedure maintained for the subscale ‘lack of social support’ of highly stressed i.e p > 7 explained by the model which includes ‘social capital’ variables records **R Squared** = 0.129, 12.9% with **sig**. = 0.459. This indicates that the total model is not statistically significant. ‘social cohesion at a bridging level’, however, is significant with **beta** = 0.298, **sig**. = 0.026, (see table 15):

Table15: Regression model measuring the relationship between lack of social support (Highly stressed >7) and social capital.

| Model | Beta | t | sig. |
|---|---|---|---|
| 1(Constant) | | 10.574 | .000 |
| Group Bonding | -.036 | -.324 | .747 |
| Group bridging | -.082 | -.669 | .505 |
| Group linking | -.133 | -1.120 | .266 |
| Social action bonding | .120 | .768 | .445 |
| Social action bridging | .298 | 2.276 | .026 |
| General Trust | -.007 | -.056 | .956 |
| Trust Bonding | -.027 | -.230 | .819 |
| Trust bridging | -.024 | -.161 | .873 |
| Trust Linking | -.154 | -1.009 | .316 |
| Social Cohesion Bonding | -.021 | -1.137 | .891 |
| Social Cohesion Bridging | .118 | .972 | .334 |

Lastly, a linear regression was again conducted. Social capital explains 23% of the total variance of 'role captivity' of moderately stressed volunteer caregivers (p <=7) **R Squared** = 0.230, **sig**. = 0.042. The model is statistically significant with 'groups at a bridging level' significant with **beta** = 0.258, **sig**. = 0.024, (see table 16):

Table16: Regression model measuring the relationship between Role Captivity (stressed <=7) and social capital.

| Model | Beta | t | sig. |
|---|---|---|---|
| 1(Constant) | | -.022 | .983 |
| Group Bonding | -.125 | -1.162 | .249 |
| Group bridging | .258 | 2.309 | .024 |
| Group linking | .148 | 1.279 | .205 |
| Social action bonding | -.154 | -1.092 | .278 |
| Social action bridging | .125 | .982 | .329 |
| General Trust | .010 | .086 | .932 |
| Trust Bonding | .099 | .058 | .394 |
| Trust bridging | .119 | .886 | .379 |
| Trust Linking | -.022 | -.143 | .887 |
| Social Cohesion Bonding | -.053 | -.391 | .697 |
| Social Cohesion Bridging | .264 | 2.255 | .027 |

## Chapter five

## Discussion

This study seeks to measure stress levels of volunteer caregivers of PLWHAs. It goes beyond measuring the total stress experienced by volunteers and identifies which of the stress constructs (subscales) are more salient than others. The study also measures the degree to which stress is influenced by demographic characteristics. It also explores the relationship between variables of social capital and their relations to the various stress constructs. Finally, the study aims to identify whether demographic characteristics would moderate the effect of social capital variables on stress. This is because it is assumed that the presence of social capital within individuals and community at large can serve as a buffer in reducing high stress levels for volunteer caregivers.

As expected, the level of stress among volunteer caregivers is extremely high with over 92.24% of participants reporting stress levels beyond a 50% mark. Most respondents are within the range of 60-80% with few outliers on either end. This is a clear indication that volunteer caregivers of this organization are stressed. This resulted to the analysis being split into two groups of stressed and highly stressed at an average point 52 which was also a cut up point as explained in the result section. The split was primary done so that a comparison would be done to see whether there were significant differences between the two groups in terms of demographic characteristics of which there were none. However, a number of studies have supported clinical observations that high levels of stress experienced by caregivers especially those of patients with dementing disorders lead to negative outcomes including, fatigue, burnout, extreme burden, social isolation, depression and health problems (Haley, Levine & Brown, 1987). However, for HIV/AIDS caregivers, these stress outcomes are also influenced by the nature and progression of the disease (Pakenham et al., 1995). Pearlin et al., (1997) have also attributed high stress levels among volunteer caregivers to the fact that they are exposed to unprecedented death of young people and that most caregivers are also HIV positive themselves. It is important to note that studies were conducted in Western countries.

Previous studies among volunteers have focussed on the experiences of stress by documenting volunteers' perceptions (Akintola, 2008a; UNAIDS, 2000). This present study makes use of quantitative measures to provide insight into stress levels of volunteer caregivers in a South African context. It also tries to establish whether social capital in this context can moderate stress levels. Furthermore, it distinguishes those who are highly stressed from those who are moderately stressed. An overwhelming number (42%) of volunteers report being highly stressed. This is 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 is oppressive work load, over-involvement with people with HIV/AIDS and their families, and personal identification with the suffering of people with AIDS . The high stress levels thus indicate that caregivers in this organization need special attention and support in their caregiving work by acknowledging that caregiving work is hard and stressful. These high stress levels, if left unattended, may result in volunteer caregivers reaching burnout stages (UNAIDS, 2000).

In addition to understanding the stress levels of caregiving work, this study also focuses on the most salient variables of stress factors.  Overwhelming nature of disease is found to account for most of the stress among volunteer caregivers, contributing 49% of the total variance of the total stress. The absence of cure of the disease and feelings of hopelessness experienced by caregivers and the poor access to antiretroviral treatment for PLWHAs seem to be a major contributor to high stress levels among volunteer caregivers (UNAIDS, 2000).

Van Dyk's (2007) study on professional caregivers shows that nurses reported that they joined nursing to help and cure sick people but the hopelessness of HIV/AIDS has turned their work to that of mortuary attendants instead of being caregivers. Also, in the same study, teachers seem to be the most affected by the nature of the disease because of having to deal with orphans caused by HIV/AIDS who live in abject poverty (UNAIDS, 2000). A similar trend is also reflected in the study conducted on buddy groups in England (Claxton et al., 1998). These feelings of defeat and despair expressed by volunteer caregivers could be attributed to different factors. Some of the volunteers are actually HIV positive. Therefore, the pain, distress and the progression of the disease as they witness them on daily basis resembles what they will have to go through, hence creates fear for the future (Akintola, 2006; UNAIDS, 2000). This in itself requires more depth of coping mechanisms from volunteer caregivers.

Furthermore, volunteer caregivers in this study work in the communities where they live. .Therefore, the pain of witnessing people they know, family members and peers, going through excruciating pain which is exacerbated by extreme poverty, might be too much to bear. These could result in high stress levels. These findings are also consistent with a previous study that indicate that patients' stage of sickness is positively correlated with caregivers' stress levels and coping adjustment (Pearlin et al., 1997).

The second stress most salient factor is ‘failure to deal with patients’ death’ which accounts for 32% of the total variance of total stress. Volunteer caregivers seem to find it difficult to deal with issues of bereavement, death and dying among patients resulting in high stress levels. When patients die, the responsibility for removal of the corpse, funeral arrangements and everything pertaining to the burial proceedings, sometimes fall on volunteer caregivers (Van Dyk, 2007). In addition, they often have to comfort and help by counselling the bereaved family members (Van Dyk, 2007).

Surprisingly, despite the high stress levels reported by volunteer caregivers, 41.1% reported that they will be willing to work as volunteer caregivers for more than five years. This is consistent with a previous study among volunteer caregivers (Uys, 2001). The author reports that despite the fact that caregivers have high stress levels, they still felt that they are making a difference in the lives of other people who need help and are satisfied with their work. Akintola (2010) 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 community, hope for future employment and for training leading to professional work, avoiding idleness and for personal growth.

On the question of whether stress is influenced by demographic characteristics, results show that none of the characteristics (as outlined in appendix four) has any significant influence on volunteer caregivers’ stress levels. The fact that there is no significant association between years of experience in volunteer work and stress levels is not consistent with literature which suggests that the number of years in volunteer work gives enough experience to handle stressful situations (Claxton et al, 1998). Hence, inexperienced and experienced caregivers would react and handle stress differently. It is also well documented that young caregivers (age) experience higher stress levels than their older counterparts (Claxton et al., 1998). However, the findings are consistent studies by Van Dyk (2007) who found that demographic characteristics are not a predicting factor of stress among professional caregivers. Everyone working in an HIV/AIDS care related field is experiencing stress (UNAIDS, 2000; Ogden et al., 2006). However, literature suggests that age, experience, level of education and economic status are major predictors of high stress level (Claxton et al., 1998; Pearlin et al., 1990). It is noteworthy that this is a homogeneous sample dominated by women (that is it lacks variability) Hence, it is difficult to draw comparisons between different demographic characteristics of volunteer caregivers.

The results reveal that the increase in collaboration and working agreements between different groups and organizations within the society causes an increase in stress levels. Social action and trust appear to be strong features of social capital. It is possible that volunteers who are active in trying to collaborate with other stakeholders in the AIDS care field become more stressed in the process. It is also possible that there is competition, rift and struggle for proper coordination, knowledge sharing and collaboration among AIDS care and support organizations in the study communities as has been documented in a rural community in KwaZuluNatal (Kasimbazi, 2009).

At the same time, having a low level of ‘trust at the linking level’ is related to high levels of stress. Low levels of trust may arise from previous failure to get results when trying social action. Thus, there is probably a lack of support system from the top e.g government, clinics. The DOH (2007) reported that while volunteers work together with other health care workers 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 sense of urgency when dealing with ambulances and referrals to hospitals (Kasimbazi, 2009). All these could contribute to increasing stress levels among volunteer caregivers.

‘Overwhelming nature of disease’ is found to be the most salient stress variable of the overall stress scale. The positive relationship, thus, shows that the more volunteer caregivers are involved with other organizations and people who are working in the HIV/AIDS field the more distressed they become. Several reasons can be attributed to this. Clinics and hospitals lack enough human resources to deal with the escalating numbers of HIV/AIDS patients. Secondly, the introduction of HBC is a direct result of having health systems that are over stretched by the influx of AIDS patients (DOH, 2001). Therefore, the direct involvement of volunteer caregivers in CBOs, HBC, who lack necessary resources to support volunteer caregivers because they are also failing to cope with the pandemic, thus leave caregivers overwhelmed by the disease.

Van Dyk (2007) reports that most health care professionals and caregivers feel stigmatised and looked down upon by their friends because they are working with PLWHA. Other volunteer caregivers indicate that their friends are advising them to quit working with PLWHAs because it is risky and disgusting. Utterances like these could increase the already existing stress of volunteer caregivers. Literature also shows that volunteer caregivers, sometimes, have problem dealing with confidentiality (Akintola, 2008a). Individuals could put a caregiver under strain to disclose a friend’s HIV status (Van Dyk, 2007) perhaps due a lack of understanding of the nature of caregiving work.

Results also show that when social action increases for volunteer caregivers, stress also increases. ‘Social action at a bridging level’ deals with the caregiver’s participation, involvement and interaction with other organizations in the community as a means of social support. It is possible that a lack of success in trying to acquire enough support from other community-based organizations that might have adequate resources induces high stress levels for these volunteer caregivers.

While ‘trust at a bridging level’ is diminishing, results show that volunteer caregivers still trust that the government can better their working situation. ‘trust at a linking level’ predicts a negative relationship; implying that volunteer caregivers trust that if government agencies can play an active and visible role in engaging community and family participation in caregiving, stress levels can decrease. In Uganda, government intervention strategies for reducing HIV/AIDS prevalence and HBC support involves the entire nation in peer education, counselling, home visit and support (UNAIDS, 2008). This strategy saw the prevalence declining and recorded minimal stress levels on volunteer caregivers (UNAIDS, 2008). ‘Social cohesion at bonding level’ also predicts that closeness to family members is a form of social support that can moderate high stress levels. Therefore, it is expected that strong family ties and bonds will serve as a supporting system where volunteer caregivers can expect to find relief and tranquillity from stressful work of caregiving.

The overall model of ‘role overload’ and ‘social capital’ is significant with the increase in ‘social action at a bridging level’ predicting high levels of stress. Issues surrounding groups working in HIV/AIDS field and problems associated with them 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 lack of family and leisure time for volunteer caregivers.

However, volunteer caregivers in this sample trust that government participation and involvement with all it resources can reduce the amount of work that they handle. Russel and Schneider (2000) argued that the DOH guidelines of HBC are regarded as well conceptualized. However, it is one of the worst implemented, leaving the burden of caregiving to volunteer caregivers. Results show that volunteer caregivers still believe 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 mobilization at this level should be considered a high priority.

With regard to the question of whether there is a significant difference between the ‘moderately stressed’ and ‘highly stressed’ volunteers and their relationship to social capital, the only model that is significant is ‘role captivity’ for stressed volunteers with a sig. = 0.042 with groups at a bridging level of r = .258. The increase in the number of networks (groups at a bridging level) is associated with high stress levels for the moderately stressed volunteers. This, again, is contrary to what has been found in the literature (Burt, 1997; Portes, 1998; Tsai & Ghoshal, 1998). In other contexts such as among factory employees, the number of groups and associations that an individual is part of, has been found to be a measure of the presence of social capital for that particular individual which produces a variety of benefits that can also include moderating high stress levels (Burt, 1997; Portes, 1998; Tsai & Ghoshal, 1998).

There is no significant relationship between ‘lack of social support’ and ‘social capital’ for both stressed and highly stressed groups. However, ‘social action at a bridging level’ is the stress inducing factor for the highly stressed with r = .298 which does not appear to be the problem with the stressed group. Issues pertaining to ‘social action at a bridging level’ have been discussed above.

Lastly, ‘social cohesion at a bonding level’ appears to be a major stress moderating factor for the stressed group with r = -.570. This implies that the stressed group rely more on intimacy with their family members as a source of support which, on the contrary, is not the case with the highly stressed group.

When demographic characteristics were put into the model to measure whether the relationship of stress and social capital will change, no significant changes were found. This seems to suggest that the conditions that volunteer caregivers work under are the cause of high stress levels for this target group rather than the volunteers’ demographic characteristics. The homogeneity of this sample could also be the cause. The majority of these samples are unemployed and single women with low levels of education. Lack of variation limits demographics from higher levels of analysis.

# Chapter Six

## Conclusion and Recommendations

This study has sought to identify the levels of stress of volunteer caregivers and to explore the relationship between stress and social capital.. Findings reveal that the volunteer caregivers are highly stressed. There are only eight volunteer caregivers who scored below 50% on the total stress scale with 92% of volunteer caregivers scoring above 50% mark of the total stress scale. In trying to identify the sources of stress, it was found that demographic characteristics do not have any influence on these high stress levels. However, volunteer caregivers reported being highly overwhelmed by the nature of the disease. Based on the findings, it is concluded that stress levels are attributable to the nature of AIDS caregiving work. This supports previous findings from qualitative studies on stress among volunteers (Akintola, 2008a; UNAIDS, 2000). The fact that there is no cure to 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 the difficulties faced by their patients and the hopelessness of the immediate solution (Akintola, 2004).

When stress is measured against social capital, the expectation is that the relationship between the two variables would be negative, indicating that the presence of social capital would moderate high stress levels of volunteer caregivers. However, most of the significant social capital variables are positively correlated with either the general stress factor or the subscale; indicating that increase in the social capital variables induce high stress levels for volunteer caregivers. The most significant variables are ‘social cohesion at a bridging level’, ‘groups 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 organizations working in the field of HIV/AIDS in these communities, hence the strife between the groups and organizations (Kasimbazi, 2009).

Lastly, as it has been highlighted in the literature, the government has failed to implement proper coordination of resources to support HBC. However, volunteer caregivers have shown that they trust that if government agencies were to play an active and a positive role in coordinating HBC, their stress levels would be reduced. Therefore, government's participation through the distribution of resources to home-based care organizations as well as programmes that are directed at improving partnerships ad collaboration with community organizations, could improve care organizations' access to resources.

**Recommendation**

1. Policy makers should provide home-based care organizations with comprehensive technical assistance that will help them build the capacity of volunteer caregivers to deal with stress.
2. Government agencies responsible for distribution of resources and budget allocation for home-based care programmes as well as donors should increase their financial support for home-based care organizations to provide psychosocial and support for volunteers.
3. Government should provide leadership and facilitate co-ordination and networking among home-based care organizations.
4. Both the government and home-based care organization should develop and disseminate standards and guidelines of providing care. There is also need for monitoring and evaluation

systems targeted at the wellbeing of volunteer caregivers that will provide respite for volunteers allowing them to have time for themselves and their families.

5. Government agencies and home-based care organizations should conduct workshops to educate communities about the important role, impact and the nature of services provided by volunteer caregivers to the communities. This could reduce the stressors from the community.

## Limitations

1. The sample was not randomly selected because of the lack of access to volunteer caregivers, hence a convenient sample was used.
2. The study was conducted on a single organization; stress levels of volunteer caregivers affiliated to other care organizations may be different.
3. The homogeneity of the sample made it difficult to conduct other analyses and comparisons.
4. The volunteer caregivers who participated in this study are unpaid. Stress levels of paid volunteers may be different.

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# Appendix I

UNIVERSITY OF
KWAZULU-NATAL

## Consent Form

I _________________ have read the information about this study and understand the explanations of it given to me verbally. I have had my questions concerning the study answered and understand what will be required of me if I take part in this study.

Signature_____________________ Date_____________

(or mark)

**Zulu Version**

Incwadi Yemvume

Mina, ___________________Sengifundile mayelana nokuqukethwe inhlolovo noma ngiyaqonda izincazelo zenhlolovo njengoba ngazisiwe futhi ngachazelwa ngazo ngomlomo. Isiphenduliwe imibuzo yami ngalenhlolovo, ngakho ngiyaqonda ukuthii yini ebhekeke kimina uma ngiba yingxenye yalenhlolovu.

# Appendix II

UNIVERSITY OF
KWAZULU-NATAL

**Letter for permission to conduct a study**

To Whom It May Concern

Dear Programme Manager

I am writing this letter asking for a permission to enter you area in KwaNgcolosi and conduct a study with the organizations that are based in this area. I am doing Masters in Health Promotion at the University of KwaZulu-Natal and my study is about **Stress levels of volunteers of HIV/AIDS patients and Social Capital** . I am bound by the university's ethical rules and procedures of conducting a research study, hence the volunteers will be protected and will not be exploited by me. The information they will give will be secured by the university.

South Africa is faced with the epidemic of HIV/AIDS, hence the hospitals are challenged with the problems of over crowding, and therefore many people are being returned home. The responsibility of caring for the sick is thus left with either the family or volunteers to care for them. This responsibility comes with a lot of stress and burnout for volunteers, however, there is not enough support for these volunteers regarding the coping strategies they employ. This study will try to bridge this gap and possible lobby to policy makers to provide necessary support for the volunteers.

Your cooperation and permission for us to conduct this study in your area will be highly appreciated.

Yours Sincerely

Name……………………….

Contact no: (031) 2624147/ 078 184 9204

# Appendix III

UNIVERSITY OF
KWAZULU-NATAL

**Letter for permission to conduct a study**

To Whom It May Concern

I am writing this letter asking for a permission to conduct a study with the volunteers in your organization in KwaNgcolosi. I am doing Masters in Health Promotion at the University of KwaZulu-Natal and my study is about **Stress, Burnout, and Coping strategies of volunteers of HIV/AIDS patients**. I am bound by the university's ethical rules and procedures of conducting a research study, hence the volunteers will be protected and will not be exploited by me. The information they will give will be secured by the university.

South Africa is faced with the epidemic of HIV/AIDS, hence the hospitals are challenged with the problems of over crowding, and therefore many people are being returned home. The responsibility of caring for the sick is thus left with either the family or volunteers to care for them. This responsibility comes with a lot of stress and burnout for volunteers, however, there is not enough support for these volunteers regarding the coping strategies they employ. This study will try to bridge this gap and possible lobby to policy makers to provide necessary support for the volunteers.

Your cooperation and permission for us to conduct this study with your organization will be highly appreciated.

Yours Sincerely

Name……………………….

Contact no: (031) 2624147/ 078 184 9204

# Appendix IV

## DEMOGRAPHIC QUESTIONNAIRE

1. Age:……………………….

2. Gender Male 1 Female 2

3. Marital status:

| | |
|---|---|
| Married | 1 |
| Single | 2 |
| Widow/widower | 3 |
| Divorced | 4 |
| Separated | 5 |
| Engaged to be married | 6 |
| Cohabiting | 7 |
| Other (specify)……………………. | 8 |

…………………………………….

4. Level of highest education (grade/degree completed): …………

| | |
|---|---|
| Not educated | 1 |
| Primary | 2 |
| Secondary/ high school | 3 |
| Tertiary | 4 |

5. What is your grade or level of responsibility?

| | |
|---|---|
| Co-ordinator | 1 |
| Facilitator | 2 |
| Volunteer | 3 |
| Other (specify) | 4 |

6. Who do you care for?

| | |
|---|---|
| HIV/AIDS patients | 1 |
| Orphans | 2 |
| Both | 3 |

7. How long have you been a volunteer caregiver? (in years)…………

8. How long are you intending to be a volunteer caregiver? (in months/years)………

9. How many patients, clients/orphans are you caring for? ................

10. How many have passed away? ……………..

11. Do you have any other work that gives you income?

# Appendix V

## Stress factors of volunteer caregivers of HIV/AIDS patients

### Failure to deal with patients'death

1. My patients'/ clients or orphans bereavement, death and dying issues, sometimes becomes too much for me.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

2. It is very stressful for me to deal with distressed relatives/loved ones of my patients/ clients or orphans.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

3. I am overwhelmed by grief when I do volunteer work with patients/clients or orphans with HIV/AIDS.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

### Overwhelming Nature of disease

4. The absence of the cure of AIDS makes me feel that the situation is hopeless.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

5. I feel disappointed and disheartened as if I can no longer see the light at the end of AIDS tunnel.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

6. My volunteer work load often makes it difficult for me to cope.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

## Lack of organizational support

7. There are insufficient support systems for caregivers and counsellors from the government and private agencies.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

8. It feels as if I work in the dark because there is no supervision to guide counsellors and caregivers.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

9. I feel that there are just too many people with HIV/AIDS or orphans whom I am never going to be able to help.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

## Lack of social support

10. My family or friends do not really understand what I am going through in volunteer work with my patients/ clients or orphans who are HIV/AIDS.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

11. I don’t get enough support from my family or friends in this volunteer work.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

## Role Overload

12. I am never able to finish what needs to be done in a day’s work.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

13. Because of this volunteer work I do not have time for myself.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

## Role Captivity

14. I sometime feel trapped by my patients’/ clients’ or orphans illness.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

15. At times I wish I could run away from this care giving situation.

| | | |
|---|---|---|
| Strongly disagree | 1 | |
| Disagree | 2 | ☐ |
| Neutral | 3 | |
| Agree | 4 | |
| Strongly agree | 5 | |

# Appendix VI

## Social Capital measurements

## Section A

### 1. Structural social capital

#### Groups/Networks:

**Bonding –** About how many friends do you have these days?

**Bridging –** How many groups in your community that are important to you are you a part of?

**Linking** - How many groups outside of your community are you a part of, NGO's, political groups, international groups etc?

#### Social Action:

**Bonding –** How many times in the past month have you got together with friends to have food or drinks, either in their home or your home?

**Bridging –** A. Most HIV/AIDS organizations/groups are doing a good job in providing HIV/AIDS related services.

(1. Strong disagree 2. Disagree somewhat 3. Neutral 4. Agree somewhat 5.agree strongly)

B. Most HIV positive people receive the assistance they need from HIV/AIDS organizations and groups.

(1. Strong disagree 2. Disagree somewhat 3. Neutral 4. Agree somewhat 5.agree strongly)

**Linking –** The level of community participation in HIV/AIDS related activities is high.

(1.Strong disagree 2. Disagree somewhat 3. Neutral 4. Agree somewhat 5. Agree strongly)

## Section B

## 2. Cognitive social capital

### Trust

**General trust -** A. Within this community, would you say that people can be trusted or that people cannot be trusted?

(1. They cannot be trusted, 2. Some can be trusted, 3. Unsure, 4. Some can be trusted, 5. They can be trusted)

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

(1. Mostly looking out for themselves, 2. not very helpful, 3. neither helpful nor unhelpful, 4. somewhat helpful, 5. mostly helpful)

**Bonding -** A. If you suddenly had to go away for a day or two, could you trust on your neighbours to look after something that is important to you, e.g. your children, your house etc?

(1. Definitely not, 2. Probably not, 3. Unsure, 4. Probably, 5. definitely)

B. Do you trust your family and close ones to act in your best interest?

(1. Definitely not, 2. Probably not, 3. Unsure, 4. To somewhat extent, 5. To a great extent)

C. 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? Please rate them on a 1 to 5 scale, where 1 means you trust them minimally and 5 mean you trust them a lot-(A:Family, neighbours and friends)?

(1. To a very small extent, 2. To a small extent, 3. Average, 4. To a great extent, 5. To a very great extent)

**Bridging -** A. 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? Please rate them on a 1 to 5 scale, where 1 means you trust them minimally and 5 mean you trust them a lot (B: Home-based carers, C: Clinic staff: counsellors, nurses, E: Traditional healers, F: Community leaders, G: Volunteers and workers in CBOs)?

(1. To a very small extent, 2. To a small extent, 3. Average, 4. To a great extent, 5. To a very great extent)

**Linking –** A. How much do you trust, or how much confidence do you have in the following groups?

| |
|---|
| National government |
| Provincial government |
| Local government |
| Traditional leadership |
| The Health system |
| The Public services |
| NGO’s/COC |

(1. To a very small extent, 2. To a small extent, 3. Average, 4. To a great extent, 5. To a very great extent)

B. To what extent do you trust local government and local leaders to take into account concerns voiced by you and people like you when they make decisions that affect this community?

(1. Not at all, 2.probably not, 3. Unsure,4. To some extent,5. To a great extent)

C. 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? Please rate them on a 1 to 5 scale, where 1 means you trust them minimally and 5 mean you trust them a lot.

| |
|---|
| D. Hospital staff: nurses, doctors, social workers |
| H. Staff and volunteers in NGOs |
| I. Local government officials |
| J. Provincial government officials |
| K. National government officials |

(1. To a very small extent, 2. To a small extent, 3. Average, 4. To a great extent, 5. To a very great extent)

## Social cohesion and Reciprocity

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

(1. Very distant, 2. Somewhat distant, 3. Neither distant nor close, 4. Somewhat close, 5. Very close)

**Bridging-** A. If a community project does not directly benefit you but has benefits for many others in the community, would you contribute time or money to the project?

(1. Definitely not, 2. Probably not, 3. Unsure, 4. To somewhat extent, 5. To a great extent)

B. How likely is it that people in the community would get together to help a family that have lost a family member to AIDS and that cannot afford a funeral as well as helping the orphans in the area?

(1. Very unlikely, 2. somewhat unlikely, 3. neutral, 4. somewhat likely, 5. very likely)

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

(1. Never, 2. Once, 3. Few times, 4. Many time, 5. Very often)