# Experiences of Social Support among Volunteer Caregivers of People with AIDS Living in the KwaNgcolosi Community, KwaZulu-Natal

By

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# DECLARATION

I hereby declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged.  It is being submitted for the degree of Masters in Health Promotion in the Faculty of Humanities, Development and Social Science, University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.


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Student name


26 NOVEMBER 2009
Date


SIGNED: _____
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# DEDICATION

I would like to dedicate this study to all my family, my friends and thank them for their invaluable support throughout my journey. I could never have done this without all your love and guidance. Thank you. To my mother, my rock, thank you for just always encouraging me to be the best that you always knew I could be. My precious Ria, thank you for being the most patient and understanding daughter any mother could ask for. Irwin, thank you for being my driving force and constantly motivating me.

# ACKNOWLEDGEMENTS

# ABSTRACT

HIV/AIDS is a significant social problem impacting on families, communities, the public health sector and greater society.

This qualitative study looked at the experiences of social support among volunteer caregivers of people living with AIDS and relationships of trust and solidarity between caregivers and members of the community. KwaZulu-Natal has the highest HIV infection rate in South Africa. This further compounds the burden of care and stigma surrounding caring for people living with HIV/AIDS .This study draws on aspects of social support theory, social capital framework and the theoretical resources of socio-ecological theory more broadly. Methodologically, in-depth interviews were conducted with 10 female volunteer caregivers with a minimum of three months care work experience and Ulin's thematic analysis was utilized to highlight the salient themes around their experiences of social support.

The findings of this study revealed that the burden of care, stigma experienced by the volunteer caregivers and the relationships between the volunteers and community members as well as social networks all played a significant role in the need for the provision of social support to the volunteers. Furthermore, the findings of the study highlighted the social consequences of care work and the need for support in this ambit.

The study concluded that social support for the volunteers is severely lacking for the following reasons; there was a complete breakdown of social cohesion between the volunteers and their community; the relationships between the volunteer and surrounding social networks were under strain and as a result had a negative impact on the accessing of social support. Factors such as social trust, social bonding, social bridging and social linking were lacking between the volunteers and the community therefore accessing social support becomes problematic.

Poverty is a factor that had a ripple effect on the volunteer and resulted in the urgent need for support in the form of tangible and emotional resources.

Volunteerism is an undeniable necessity in the treatment or care of HIV/AIDS patients. The issues around social trust and social networks played a key role in the accessing of social support which ultimately impacted on the efficacy of care provided by the volunteer. The findings highlighted that there was a dire need to mobilize social capital within the KwaNgcolosi community in order to create relationships that would facilitate the social support needed by the volunteer.

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# Acronyms

AIDS      : Acquired Immunodeficiency Syndrome

ARV       : Anti retroviral

CD4       : Cluster Difference 4

HIV       : Human Immunodeficiency Virus

NGO      : Non-governmental Organization

NPO      : Non Profit Organization

PLWHA's : People Living With HIV/AIDS

TB        : Tuberculosis

WHO     : World Health Organisation

# CHAPTER ONE

## 1.1 Introduction and Background

HIV/AIDS is one of the leading causes of death in South Africa (UNAIDS, 2008). As stated in the UNAIDS 2008 global report on HIV/AIDS, by the end of 2007, 30-36 million people worldwide were living with HIV. Sub-Saharan Africa accounted for 67% of this global figure with 370 000 of those infected being children (UNAIDS, 2008). South Africa carries more than half of the world's HIV infection burden (UNAIDS, 2008), and it is estimated that by the year 2010 approximately six million South Africans will be infected with HIV (UNAIDS, 2008).

This is a disease that is devastating humanity and there are a variety of consequences of HIV/AIDS on the individual and broader social levels. On the individual level those infected with HIV/AIDS have to cope with their compromised health. Socially, the ill often rely on the children to take on the role of the household head (Steinberg, Johnson, Schierhout & Ngedwa, 2002). HIV/AIDS has played a major contributing role in South Africa's poverty burden as those who have died from AIDS related diseases leave households unsupported or often run by the children of the house (Steinberg et al., 2002). Those left behind have very little or no means of financially supporting themselves and the orphaned (Steinberg et al., 2002). Once terminally ill, AIDS sufferers are unable to work due to their bodies becoming weakened by the disease as well as the various side – effects of the medicinal cocktail they take has on their bodies (Carr & Cooper, 2000). As an

option, families turn to AIDS grants in order to survive. An additional consequence is an increase in infant death rate and a decrease in life expectancy (Muller, 2003).

It is for such reasons, combined with a substantial shortage of qualified nurses and medical practitioners (Aitken & Kemp, 2003), that the public health sector is under strain. Department of Health policies discuss home-based care as a viable option to hospital care and goes so far as to recommend that public health services discharge patients early to be cared for at home (Akintola, 2005). It is hoped that this will release bed space within hospitals for people with other illnesses and in turn, decrease the cost to public health establishments. In a study by Fox, Fawcett, Kelly & Ntlabati (2002) done in South Africa on integrated community-based and home-based care in South African hospices, home-based care was said to decrease the amount of time spent in hospitals from approximately two weeks to three and a half days when making use of home-based care programmes (Fox, Fawcet, Kelly & Ntlabati, 2002).

Consequently, the government has turned to home-based care by volunteers associated with nongovernmental organizations (NGOs) or family caregivers as a feasible alternative to hospital care (Akintola, 2008a). Home-based care may be described as the provision of health care services by caregivers in the home with the objective of ensuring utmost levels of comfort and dignity of the ill (Campbell & Foulis, 2004). Informal/volunteer caregivers are thus individuals, mostly women, who care informally for the sick without receiving compensation or a formal salary for the service provided by them. De la Porte (2003, p.121) describes volunteer caregivers as "the unsung heroes of the struggle against

HIV/AIDS," and this is demonstrated by the devoted physical, emotional and psychological support given by these carers to their patients.

In order to fully understand the role of care givers, it is important to understand the differences between family care givers and volunteer care givers. Family caregivers are generally family members who take care of their relatives whereas volunteer caregivers are not family members and are normally community members who are recruited by nongovernmental organizations (NGO's) to visit the homes of the people living with HIV/AIDS and provide care on a voluntary basis (Akintola, 2004). Akintola (2004) describes the duties of voluntary caregivers as that of training the families on how to take care of their sick family members. According to Akintola (2008b), some home-based care establishments such as NGOs generally enroll community members and provide them with basic skills in order to assist HIV/AIDS households. The community members who enroll as volunteers are generally not paid a salary but a few receive stipends from international funding agencies or government (Akintola, 2009). They often are not the primary caregivers of the ill and their care work consists mainly of providing basic first aid training, supervision and support to the families of the ill (Steinberg et al. 2002). The role of the volunteer caregiver is also to supervise adherence to medication (UNAIDS 2008; Mulenga & Lungowe 2005). In the case of young orphaned children, caregivers take over the primary or family caregiving role (Akintola, 2008a).

Care organizations in KZN provide different kinds of care and support to the terminally ill such as food parcels, volunteer caregivers, foster care etc. On providing care the volunteer

may identify a child within the household at risk. Social workers belonging to the care organization are then notified and are able to make arrangements for foster care of children at risk of being orphaned due to AIDS (Desmond & Gow, 2001).

More often than not, caregivers are generally issued with care kits by NGO's in order to facilitate their caring duties and prevent the spread of disease as well as patient record keeping and monitoring (Mabude, Beksinska, Ramkisson, Wood and Folsom 2008). (Mabude et al., 2008) carried out a national survey in two provinces in South Africa which focused on the home-based care kits for palliative HIV/AIDS care. In this study it was found that although an adequate care kit should be fully equipped with medicines such as painkillers, antibiotics, antifungals, multivitamins, disposable gloves, cotton wool, bandages and swabs, antiseptics, disinfectant, diarrhea medication, plastic sheets etc., it was rarely the case (Mabude et al., 2008). It was very seldom that caregivers receive fully equip care kits and often were forced to share one kit among a number of other care givers, who in turn, had a number of patients to attend to (Mabude et al., 2008).

Social support as described by Vaux (1998, p.346) is a "transactional process involving network resources, behavior, and appraisals". Cohen & Syme (1985, p.4) define social support as "the resources provided by other persons." The notion of social support is central to caregivers' experiences as the caregiver may very often need to rely on the help of others when necessary. Exploring the experiences of social support would help to highlight volunteer, family, community and political relationships as well as highlighting the significance of volunteer caregivers and the support needed to improve their morale and

performance. This will decrease the burden of their care work. There is a paucity of literature on this topic in the South African context. There have been ample studies around HIV/AIDS and its impact on society. However, past studies have focused on the burden (Akintola, 2004; Mabude et al., 2008), gender (Akintola, 2006, 2009) and the social-economic dilemmas (Steinberg et al., 2002) that care work presents to the volunteer. No documented qualitative study using aspects of the social support theory and social capital framework has been found focusing solely on the social support experiences of the volunteer caregiver in South Africa. D'Cruz's (2002) study is an example of a study that focused on informal support of caregivers. However, this study was done in India and used family caregivers as a sample rather than volunteer caregivers. D'Cruz's study used the social capital theory as the main theoretical framework whereas this study uses aspects of the social support theory, socio-ecological theory and elements of the social capital framework. It is for these reasons that this study will provide valuable insight with regards to the role of social support for caregivers of PLWHA's.

Family and volunteer caregivers have to deal with a plethora of concerns such as depression, feelings of hopelessness and loneliness due to the stigma attached to HIV/AIDS and just mere exhaustion from their copious duties (physical, emotional and mental) as caregivers (Akintola, 2004, 2008a; Chimwaza & Watkins, 2004). Carers, majority being women, often have partners, families and children of their own and as a result of their care work, may have to rely on neighbours, friends, family and community members to care for their families in their absence.

This study may reveal some of the dynamics of these relationships, shedding some light on many issues, e.g. the gendered nature of care giving roles, the role of stigma around HIV/AIDS and highlight the social support issues surrounding volunteers and their HIV/AIDS care work. Even though extensive efforts have been made to educate society on HIV/AIDS, discrimination and stigma related to HIV is still rife among communities affected by HIV making it more difficult for people living with the disease to accept their illness and seek the relevant medical assistance.

It is for these reasons that this study will provide valuable insight not only into the experiences and availability of social support among volunteer caregivers, but also the broader contextual factors in which these experiences emerge.

**1.2 Problem Statement**

Due to the social and economic effects of HIV/AIDS on South Africa, volunteer caregivers have become the most feasible option to providing home-based care for the ill (Akintola, 2005, 2008a). The burden and stigma attached to caring for people living with HIV/AIDS is vast and has an ominous effect on volunteer caregivers in many ways, often leaving volunteers feeling hopeless (Akintola, 2008a). It is for these reasons that this study will look at the experiences of social support amongst volunteer caregivers of people living with HIV/AIDS in the KwaNgcolosi community.

**1.3 Research Questions**

The aim of this study is to explore the experiences of social support, which can be described as help or assistance from family, friends, community members and/or care organizations with the objective of improving the quality of life of the receiver, among volunteer caregivers of PLWHA's. The study will answer the following research questions:

- What is the sources and nature of support for volunteer caregivers?

- Who provides the support to the volunteer caregivers?

- How do volunteer caregivers access the support provided?

- How useful is the support provided?

- What are the unmet support needs of the volunteer caregivers?

## 1.4 Structure of dissertation

**Chapter One:** This chapter will include an introduction into the study as well as the rationale and relevance of the study.

**Chapter Two:** In this chapter, a thorough review of the literature pertaining to the topic will be presented. It is in this chapter that information from prior studies will also be mentioned to highlight the relevance of the research topic. The review of literature will include broad commentary on the theoretical and methodological strengths and limitations of some of the research conducted. The theoretical framework used for this dissertation will be discussed in this chapter. Aspects of social support theory, socio-ecological theory and elements of the social capital framework will be used for the study.

**Chapter Three:** The focus of this chapter is methodological. It will describe the research design, sampling methods and procedures used for data collection.

**Chapter Four:** The findings of the study will be presented qualitatively in this chapter.

**Chapter Five:** In this chapter the researcher will integrate and discuss the findings from chapter four. This chapter will also include recommendations for future research.

# CHAPTER TWO
## LITERATURE REVIEW

### 2.1 Global Perspective of HIV/AIDS

"AIDS is no ordinary epidemic. More than a devastating disease, it is freighted with profound social and cultural meaning. The effect of the epidemic is extended far beyond their medical and economic costs, to shape the very ways we organize our individual and collective lives." (Nelkin, Willis & Parris, 1990, p.1)

According to estimations from 2008, approximately 30-36 million people are living with HIV (UNAIDS, 2008). Humanity, in various forms, is affected by the HIV/AIDS epidemic. Families and communities are being put at risk, children are being orphaned or pushed into parental roles, taking care of ill adults in the home and taking on the responsibility of caring for siblings.

### 2.1.1 Sub-Saharan Africa

Although HIV is a global phenomenon, Africa bears the biggest brunt (UNAIDS, 2008), with sub-Saharan Africa being the most affected region globally (UNAIDS, 2008). It is said that more than 67% of the world's population live with HIV in this region even though sub-Saharan Africa contains approximately only ten percent of the world's population (UNAIDS, 2008). The majority affected by this disease is women and there is a range of personal and social factors that make women more vulnerable to HIV infection.

In sub-Saharan Africa, HIV/AIDS has emerged within a context where socio-cultural factors have shaped the manifestation and consequences of the disease. Cultural and traditional factors have played an important role in making distinctions in gender roles and expectations and, as a result, in the negotiation of safe sex. With regards to African patriarchy and power inequity between men and women, African women are placed in a position of financial and emotional dependence on their partners (Morrell, 2003).

Poverty is a significant social factor linked to HIV/AIDS in sub-Saharan Africa, playing an important role in making women vulnerable to HIV infection. The context in which the care giver works is often one of poverty, their own and their patient. In a study done by Steinberg, Johnson, Schierhout & Ndegwa (2002) on households affected by HIV/AIDS, most of the households surveyed revealed that in most cases the breadwinners of the families had AIDS, were sick, and needed care. As a result the children of the house often suffered with malnutrition due to the fact that often, there was not enough food to feed them (Steinberg et al. 2002). Furthermore, sex may be consented to in exchange for money needed to support families. Also, in addition to poverty, high risk behaviors such as having relationships with older, more experienced and very often married men in exchange for material things such as money, mobile phones or even just the social status linked to having an older, more experienced partner may exacerbate the prevalence of HIV/AIDS (Meekers & Calves, 1997). In a study done by Homan, Searle, Esu-Williams, Aguire, Mafata, Meidany, Osthuizen & Towel (2005) it was found that more than half of the HIV /AIDS affected households were unemployed and a further six percent stated no source of income.

Whiteside's (2002) article on poverty in relation to HIV/AIDS in Africa discusses various levels of poverty as a result of the disease (Whiteside, 2002). He describes household and community levels as being impacted most severely by HIV/AIDS and that the consequences of HIV/AIDS on poverty in households may depend on the community's approach towards helping needy homes and the general accessibility of resources (Whiteside, 2002).

**2.1.2 South African Context**

Whilst Sub-Saharan Africa is affected by HIV in vast proportions, South Africa remains the country with the largest number of HIV infections in the world and accounts for more than 35% of all people living with AIDS (UNAIDS, 2008) with approximately 1000 AIDS-related deaths occurring daily (UNAIDS, 2008). It is estimated that approximately 39% of all people infected with HIV in South Africa reside in Kwa-Zulu Natal (UNAIDS, 2008). The impact of HIV/AIDS in South Africa is apparent as presented in the above mentioned statistics.

South Africa is facing poverty, an increase in infant death rate and a decrease in life expectancy due to HIV/AIDS (Muller, 2003). This combined with a substantial shortage of qualified nurses and medical practitioners (Aitken & Kemp, 2003), has placed the public health sector under enormous strain (Shisana, Mandela & Simbayi, 2002; Akintola, 2008b). In 1998 a quantitative survey was done on the prevalence of HIV-related illnesses in the adult wards of a Durban public hospital. In this survey by Colvin, Dawood, Kleinschmidt, Mullick & Lallo (2000) the results stated that the hospital had a capacity of more than half

of all admissions related to HIV. The problem of overcrowded hospitals resulted in government turning to home-based/informal care. Home-based care is carried out by volunteers working through nongovernmental organizations (NGO's) or family caregivers as a feasible alternative to hospital care (Akintola, 2008b). However, such home-based care programmes often receive little support from the government (Steinberg et al. 2002) leaving care organizations to rely mainly on volunteers to provide care for people living with HIV/AIDS.

## 2.2 Home-based Care within the Context of HIV/AIDS

Home-based care needs the resources and skills of both communities and NGOs as well as that of the government as it is an impossible task for a single caregiver to meet the overall challenges of what is required of them. A quantitative study was done by Steinberg et al. (2002) on the impact of HIV/AIDS on households and how these households cope with the epidemic.

In this study Steinberg surveyed 771 households affected by AIDS in South Africa. One of the many findings was that the households worst affected by HIV/AIDS were those who lacked fundamental municipal services such as sanitation, access to running water etc. A lack of such basic services may suggest a need for community support and reciprocity in the form of community members helping families affected by HIV/AIDS with tasks such as fetching clean water etc. Steinberg et al. (2002) also stated that approximately 50% of HIV/AIDS homes made use of volunteer caregivers. Not only does this further add value to

the importance of home-based care, but also paints a bleak picture of the burden of care and the conditions in which caregivers have to work.

### 2.2.1 The Burden of Care

Despite the obvious relevance of voluntary caregiving in the lives of people living with HIV/AIDS (PLWHA's), such home-based care programmes come with many challenges. Given that such programmes often receive little support from the government (Steinberg, Johnson, Schierhout & Ndegwa. 2002), care organizations have to rely mainly on volunteers to provide care for people living with HIV/AIDS. Often caring for more than one person, the physical demands take a toll on volunteers. Care work often involves lifting and moving patients who are often heavier than their female caregivers (Akintola, 2004). Caregivers carry out duties such as disinfecting bed sores, cleaning mouth ulcers, nutritional support (feeding), administration of medicines such as painkillers, ARV's etc, dressing of the patient, aiding and accompanying their patient to and from the toilet and monitoring drug adherence (Akintola, 2006).

In Akintola's (2004) study analyzing the burden of care among caregivers in South Africa and Uganda, he stated that majority of South African caregivers were unemployed. The financial burden of care was a problem for most caregivers in his study as they found themselves in a situation where they often had to provide for their patient's family due to the patient (often the breadwinner) being terminally ill (Akintola, 2004). Daily living expenses increased due to the fact that patient needed particular foods, medicinal costs,

transportation to nearby clinics and care of the children of the patient were a number of financial burdens experienced by the caregivers of Akintola's study.

The burden of caring for someone with HIV/AIDS is complex and sometimes also becomes the responsibility of family members or children of those who are ill. The burden of care weighs unreasonably on women (Akintola, 2004). A reason for this is that women are not only the main care providers in homes, but many have lost their partners or have never been married. This ultimately results in women having to bear the financial costs of caring for self as well as the sick (Akintola, 2004).

Children are also often left with the responsibility of taking care of the home as well as the PLWHAs. In some cases, they leave school in order to do so.

Akintola's 2004 study compared data from assessments done in establishments who offered home-based care to PLWHA's in South Africa and Uganda and data from his (2004) ethnographic study focusing on the nature of home-based care in South Africa., The findings from this study showed that caregiving was very challenging regardless of the training provided to the caregivers. Caregivers who participated in this study also described the burden/function of their care work as constantly changing according to the needs of the patient and the patient's family. Initially providing general assistance, caregivers assumed the role of nurse, counselor, motivator and babysitter (Akintola, 2004).

In an ethnographic study by Akintola (2006) focusing on the gendered nature of home-based care, in South Africa, 21 primary caregivers and 20 volunteer caregivers were

interviewed. The *face* of care generally took on that of women who were poor and without a job and combined their care work with that of breadwinner and head of the households within their homes. Caregivers revealed that they performed varied tasks and disclosed that spiritual support (by praying with their patients) and moral support (through compassion and communication) was often practiced with their patients (Akintola, 2006) but that they also experienced physical and emotional strain due to the burden of care. The strength of the ethnographic nature of this study is that it depends on the personal experiences of the participants (Genzuk, 2003) and in turn adds richness to the study. Very often ethnography allows for the researcher to participate in the study as opposed to the role of observer (Genzuk, 2003). Generally, patients cannot properly control bladder functions or their bowels and need assistance getting to and from the toilet. The burden of this type of duty is further exacerbated by the fact that some of the patients live in conditions that offer poor sanitation and water supply and access to a toilet or running water (Steinberg et al, 2002).

In addition to these duties, caregivers were also responsible for the general hygiene of their patients and very often also assisted with domestic duties such as cleaning of the house as well as transportation and in some cases, cared for the children of the ill while the parents are in their care. Carers also often provided counseling to both patients as well as their families and helped them to better cope with the situation by preparing them for death.

In yet another ethnographic study done by Akintola (2008a) in two semi – rural communities over a 19 month interval on the outskirts of Durban, the various challenges faced by volunteer caregivers and their coping strategies were investigated. Twenty volunteer caregivers and other stakeholders were interviewed. Observations and in-depth

interviews were the data collection tools of choice and described the effects of the burden of care as being emotionally draining and some even entertained thoughts of leaving their care work. They had very little time to cope with their troubles and were unable to access professional support. Care givers who participated in this study stated that they felt pressurized to continue with their work due to the large numbers of people who needed their help. In some cases caregivers are also HIV positive (Akintola, 2008a) or go home to family members who are HIV positive and struggle emotionally between caring for themselves or family members as well as their patients (Akintola, 2004). This can make the care giving experience a difficult and complex one. Caregivers are also left to deal with the stigma attached to HIV/AIDS as well as caring for someone who is HIV positive.

## 2.2.2 Impact of Caregiving on the Health of Caregivers

It is evident that the task of care giving is an exasperating one and in turn, takes its toll on caregivers both emotionally and physically. Over and above their feelings of emotional and psychological distress, due to the nature of their job care givers often experience physical ailments such as body aches and pains. Caregiving is linked with stressors that often results in poor health outcomes for caregivers. Volunteers play a vital role in providing care for PLWHA's but have been shown to experience burdens as a result of their job (Akintola, 2008). The stressors that confront both volunteer and family caregivers not only have a negative impact on their well being, but also on their patients' experiences of the illness (Akintola, 2008b).

Due to the nature of their jobs, volunteers are often exposed to patient bodily fluids and faeces, putting them at risk of diseases such as TB and HIV (Akintola, 2006). In a quantitative study done in California by (Flaskerud & Tabora, 1998), the health problems of family and informal community caregivers of PLWHAs were discussed. The study included 36 female volunteer caregivers who cared for adults with HIV/AIDS. Out of 36 participants 59% rated their health as poor and experienced problems such as respiratory, neuromuscular and depression. Care givers, however, were reluctant to voice their physical discomforts due to feelings of guilt and obligation towards their patients (Flaskerud & Tabora, 1998).

All of the above mentioned stressors make it exceedingly difficult for the caregivers to cope with their day to day activities as they only receive basic training on providing care for PLWHAs without the knowledge of the complexities of care work (Akintola, 2004).

### 2.2.3 HIV/AIDS Related Stigma Attached to Caregivers

The ever present stigma of HIV/AIDS negatively influences preventative or positive behaviours such as HIV testing and the use of condoms (Brown, Macintyre & Trujillo, 2003). Stigma can be as subtle as hearsay to blatant discrimination (Standing, 1992).

> "The epidemic of fear, stigmatization and discrimination has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected. This hinders, in no small way, efforts at stemming the epidemic" (Mbwambo, Kilonzo, Kopoka & Nyblade, 2004, p33)

Although caregivers play an important role in care of HIV/ AIDS sick people, they are faced with discrimination and stigma by their community members due to the nature of their care work (Akintola, 2004; Turner, Pearlin & Mullan, 1998). Stigma can be described by (Goffman, 1959) as an undesired differentness that labels a person as bad or unusual. Goffman goes on to discuss society's way of dealing with stigma as minimizing contact with those who are stigmatized in an attempt to avoid being stigmatized themselves. Goffman (1963) describes stigma as a shaming characteristic that an individual acquires. AIDS stigma is particularly intensified due to the nature and symptoms of the illness as well as the ever present ignorance with regards to the modes of transmission. Boer and Emons (2004) suggest that there may be an association between AIDS stigma and possible fear of or delusions about HIV/AIDS.

Volunteers are linked to HIV/AIDS due to their close contact with their AIDS patients and as a result, are labeled with the same stigma as that of the patient. This, in turn, reduces that individual's standing in the view of society (Cassaux & Reboredo, 1998).  Providing care for family members and people living with HIV/AIDS is particularly stressful for caregivers as they have to endure the stigma attached, not only to people living with HIV/AIDS (PLWHA's) and their family members, but as caregivers they also share the same AIDS related stigma (Cassaux & Reboredo, 1998).

Mwinituo and Mill's (2006) interpretative study done in Ghana focused on the stigma that was associated with Ghanaian cargivers of people living with AIDS. The sample consisted of both male and female family caregivers. The findings of Mwinituo and Mill's (2006) study revealed that the absolute fear of being stigmatized or discriminated against forced

the participating caregivers into secrecy about their care work to a point where they would not disclose the nature of their work or the status of their patient to their extended family members. This resulted in the caregivers being unable to access any support from their extended family (Mwinituo & Mill, 2006). The stigma led to feelings of social isolation and loneliness for both patient and caregiver (Mwinitou & Mill, 2006). Caregivers in this study experienced a lack or lessening of social contact with people previously considered close to them due to fear of the stigmatization on disclosing their caregiving activities (Mwinituo & Mill, 2006).

Interesting to note is that the findings of Mwinitou & Mill's study suggested that the caregivers also experienced stigma from health care workers in the surrounding clinics and the caregivers often felt disrespected by the health care workers due to the nature of their care work (Mwinitou & Mill, 2006).

According to Muller (2003), the occurrence of deaths in a family, due to any reason, can destroy the support systems of a family spiritually, emotionally, financially and socially and this, in turn, may produce a negative health outcome (D' Cruz, 2002). The stigma of death associated with AIDS however, further compounds the stress of death for the family and friends of the deceased.

The issue of AIDS related stigma has been in the forefront of many studies around HIV/AIDS. In an informal settlement in Durban 1998, an AIDS activist named Gugu Dlamini was killed by her community members after she openly disclosed her HIV status (Brown et al. 2003). Although this incident occurred in 1998, AIDS stigma to date still

echoes in its severity and creates devastating barriers not only for disclosing one's HIV status but also for caregivers who need to provide adequate care. (Goffman, 1963) describes a type of stigmatization particularly relevant to this study namely, associative stigma. Associative stigma may be experienced by those who are associated with the stigmatized. It stands to reason then that caregivers may fall prey to this type of stigmatization due to the fact that they are closely associated with people living with HIV/AIDS and are closely affected by the consequences of HIV/AIDS. This, in some cases, may lead to caregivers experiencing feelings of isolation, secrecy and even fear of being stigmatized, further adding to the emotional stress that is experienced by caregivers.

A quantitative study was done in (2003) by Kalichman & Simbayi testing attitudes on AIDS related stigma and voluntary HIV counselling in a township in Cape Town. Five hundred participants completed self administered surveys related to AIDS stigma and voluntary counselling and testing. Results from the study showed that out of the 500 participants 53% had not been tested and a further 12 % would not respond as to whether they had been tested or not due to stigma attached (Klichman & Simbayi, 2003). Further findings showed that those who had not been tested held much more stigma than those who had been tested and seemed to feel that people who had AIDS were "dirty, should feel ashamed, and should feel guilty." These participants also stated that "people with AIDS must have done something wrong to have AIDS" and supported the fact that they would rather not be friends with someone who has AIDS" (Kalichman & Simbayi, 2003, p.444-445).

Caregivers may then find themselves feeling *socially detached* at a time when support from family and friends is needed most. An example of this may be further explained in a quantitative study done by Wight (2006). This study took place in California and focused on family caregivers (mothers) who were caring for their ill sons. It was found that the women concerned protected themselves from most of society except their close family members and friends because they feared being rejected or cast – off by greater society. This reiterates that perceived stigma may influence the caregiver's access to support (Wight et al. 2006). The stigma of HIV/AIDS makes for a complex situation for caregivers who themselves are HIV positive and in comparison with the other caregivers, the psychological pain experienced by those who are HIV positive may be greater due to their own wellbeing and life expectancy (Turner & Pearlin, 1989).

**2.2.4 Stress and Burnout Related to Care giving**

The responsibility of caring is life changing and the impact on the carer may take on various forms (Heron, 1998). As discussed previously, the job of a caregiver is multifaceted and so is the burden of care and the stressors experienced when caring for the ill. It stands to reason that the often stressful effects of long term caring may lead to related burnout experienced by the caregivers. Stress is described by Heron (1998, p.44) as both "a physiological (in the form of and increased heart rate, high blood pressure, etc.) and psychological (manifesting as depression, irritability etc.) state of arousal which occurs when an individual is subject to external or internal pressures," whereas burnout, according to Maslach & Jackson (1986), comprises of three elements: emotional exhaustion, depersonalization and lack of personal accomplishment; all of which may be as a result of

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the prolonged burden associated with care work. An obvious overlap is highlighted when describing both conditions. Both burnout and stress affect a person on physical and psychological manner. One can assume that a prolonged state of stress may lead to burnout. A quantitative study was done in New York, United States by Maslanka (1996) in which he focused on burnout, social support and AIDS volunteers working at the Gay Men's Health Crisis Centre. The aim of this study was to observe the impact that social support from staff and other volunteers of the Gay Men's Health Crisis Centre had on the working ability of volunteers (Maslanka, 1996). The study concluded that the participating volunteers experienced high levels of burnout related to their care work and stressful life-events. Also evident in the study was that volunteers received more support from staff of the organization as opposed to their fellow volunteers (Maslanka, 1996). Although some of these studies were done in the USA, they shed light on the important social factors linked to the role/duties of volunteer caregivers which may be useful in exploring these issues within an African context and highlight the consequences of their care work on both their mental and physical health.

Simpson's (2006) mixed method study focusing on the amounts of psycho-social support provided to primary (family), secondary (volunteer) and tertiary (community based) caregivers discussed burnout as one of the findings. The study consisted of 42 caregivers (male and female) and was set in Stellenbosch. Findings of the study suggested that most of the participating caregivers (88%) were experiencing symptoms of burnout in the form of insomnia, anxiety and a lack of confidence. This indicated a lack of psycho-social support (Simpson, 2006).  Caregiving work may create a perfect setting for burnout as, besides

caring for PLWHA, some carers are employed and after their day jobs, attend to their caring responsibilities. Others just cannot balance both paid and volunteer work as they are almost constantly on call and are sometimes even called out at night to fulfill their caring responsibilities (Heron, 1998).

Even though the harmful effects of stress are evident, carers may find themselves feeling as if they are in a no win situation as, according to Heron (1998, p.45), they "can become accustomed to living this way and find it difficult to let go of all the tasks they feel they need to accomplish" as carers feel a "sense of commitment and duty" to the person they are caring for. Keeping in mind the duties and both emotional and physical roles of care giving as discussed previously, it becomes easy to see how the burden of care may lead to high stress levels as well as burnout as described by Maslach & Jackson (1986). Ross, Greenfield & Bennet's (1999) study investigating the predictors that caused volunteer caregivers to dropout consisted of 76 caregivers of PLWHAs affiliated with a NGO in Texas. Out of the 76 volunteers, 40 dropped out due to stressors such as a degeneration of patient-caregiver relationship, role uncertainty and organizational issues.

The results of the study also revealed much higher levels of depersonalization amongst the drop-out volunteers than that of those who continued (Ross et al. 1999). This study further adds significance to the burden of volunteers care work and the effect it has on their health outcomes. Furthermore, in combination with the benefits of the aspects of social support, it can be suggested that the provision of social support at an early stage may play a mediating role in the occurrence of burnout amongst volunteer caregivers (Ross et al., 1999). Simpson reiterates this statement to a degree as her above mentioned study suggests that the

presence of community resources may lessen the risk of burnout among caregivers (Simpson, 2006).

Burnout and stress related illness may be a major causing factor of volunteer's negative health outcomes as well as place strain on the efficacy of their care work.

**2.2.5 Social Capital and Its Role in the Provision of Social Support**

The social capital framework, according to Blakely & Ivory (2006, p.614)) has been described as being made up of three levels namely; social bonding (relationships of trust and collaboration between networks of a similar nature), social bridging (relationships of respect between people of an unrelated nature) and social linking (involves 'norms of respect' and 'networks of trusting' which connect people of authority).

Putnam (1993) further adds to Blakely & Ivory's description of the three main levels of social capital by describing a further four elements. Putnam's concept of social capital, encompasses aspects of trust (between people), reciprocity, social norms and social networks. These aspects are further explained by Putnam in the following ways; trust between people and groups, facilitates collaboration for mutual benefit (Putnam, 1995). Reciprocity involves an exchange of favours between people and organizations with the expectation of *returning the favour* in the future (Dickhaut & McCabe, 1995). A social norm, as described by Elster (1989) & Putnam (1993) collectively, refers to a set of rules or values with regards to the demeanor/behavior of an individual within a community. Society generally dictates such behavior (Elster, 1989). Social networks are described as a unified

group of people who are connected by similar characteristics e.g religion, gender, race etc. (Harpham, Grant & Thomas, 2002).

Although all seven aspects of the social capital framework pertain to the social dilemmas of HIV/AIDS, I will be focusing on the elements of trust and social networks for the purpose of this study. The nature of this study highlights the link between social capital and social support due to the relationships and networks between community members and volunteers and in turn, the support provided to the volunteers by the community, friends, family and other non-profit organizations. In relation to the study, the above mentioned aspects of social capital theory suggest a dependency between volunteer and other stakeholders with the objective of mutual benefit. It stands to reason then that community cohesion (coming together) and solidarity (unity) become part and parcel of the aspects of trust, reciprocity and social networks. These relationships between the volunteer, the community and other stakeholders play a key role in the provision of social support to the volunteer caregiver. When necessary, volunteers may be able to access support in the form of resources from NGO's, certain kinds of support from their community members and support from the families of the patient.

## 2.3 Theoretical Framework

This study draws on various aspects of social support theory as the main conceptual framework. There are many different views taken by different authors regarding the concept of social support.

Social support is described by (Ross & Mirowsky, 2000) as "various types of support that people receive from others and are generally classified into two to three major categories: emotional, instrumental and informational." Cohen (1992) discusses the term social support as perceived social support under the following definition. Perceived social support, as described by Cohen, is represented as the 'function of social relationships' with the notion that these relationships may provide beneficial resources such as emotional or informational support (Cohen 1992, p.109). The study will draw on aspects of social support theory namely tangible, informational, appraisal and emotional support for the purpose of the study. The social-ecological theory uses the basis that every individual is affected by their surrounding ecological systems and in turn, conditions occurring in the ecological systems may influence the individual's behaviour. For the purpose of this study I chose to combine aspects of both theories to more thoroughly explore the relationships between social support provided or not provided by outside influences to the volunteer and the impact that has on the volunteer. This adds richness to the study.

Taking the above into consideration, aspects of the social support theory are linked to the social-ecological perspective, which focuses predominantly on the effects that the various social-ecological systems have on the individual (namely caregivers) and their experiences and performance.

For instance, Shumaker and Brownell (1984) conceptualize social support as "an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient," (p.13). Cohen & Syme (1985) on the other hand, contradictorily state that the sources provided by others may also have a

negative effect on the receiver. Cohen (1998) suggests that social support affects both mental and physical health through its influence on emotions, cognitions and behaviors. It is then evident from the above mentioned statements that social support involves a 'giving-receiving' relationship between two or more individuals on a physical, mental or emotional capacity for the purpose of promoting well-being and coping skills as well as buffering the effects of stress on the receiver.

Taylor (1999) suggests that social support may take on forms such as appraisal support, tangible assistance, information and emotional support. Taylor then goes on to describe appraisal support as helping an individual to comprehend a stressful experience and adopt the necessary resources and coping skills to deal with the experience. An example of this type of support may be the provision of counseling. Informational support may be provided by relatives or friends and involves the individual being reassured and supported regarding an experience by someone who has experienced the same or similar event (Taylor, 1999). Tangible support refers to support provided through material entities such as financial assistance, services, being taken to the doctor by someone etc. Emotional support may be provided by supportive friends or family members and is carried out by reassuring and individual of his or her value to society (Taylor, 1999).

This suggests that the above supportive deeds involve both the individual and the community and it is this kind of social networking that grants opportunities for the growth of social support (Berkman, Glass, Brisette & Seeman, 2000).

This dissertation will deal with the presence or lack of social support among volunteer caregivers and the ways in which carers experience these types of support. As mentioned previously, social support comprises of the following concepts; appraisal support, tangible assistance, information and emotional support (Taylor, 1999). Cohen, Underwood & Gottlieb (2000) further reinforce Taylor's view on social support by describing appraisal support as shielding an individual against the effects of stress by encouraging the individual to interpret stressful situations less negatively. They go on to suggest that support reduces the effects of stressful events on one's health through supportive actions of others or one's belief that support is available.

Cohen & McKay (1984) further explain this approach in the form of an illustration that depicts the buffering effect that the appraisal perspective has on stress and in turn health outcomes when there is a presence of perceived support. Cohen & Wills (1985) go on to suggest that stress-buffering is only evident when there is a match between the needs elicited by stressful experience and the functions of social support that are recognized to be accessible. Cohen & Wills (1985) reinforce their views by suggesting that particular types of support may be a valuable coping tool with regards to stressors.

 Interestingly, although Coyne & Holroyd (1982) agree with popularity of the above mentioned descriptions of social support, they add that over and above being viewed as a cognitive appraisal or property of a person, social support should also be viewed as a reflection of a set of circumstances of a particular person in a set of particular circumstances. Although this study will take the views of Coyne & Holroyd (1982) into consideration, the views of Cohen & McKay (1984) will take main focus.
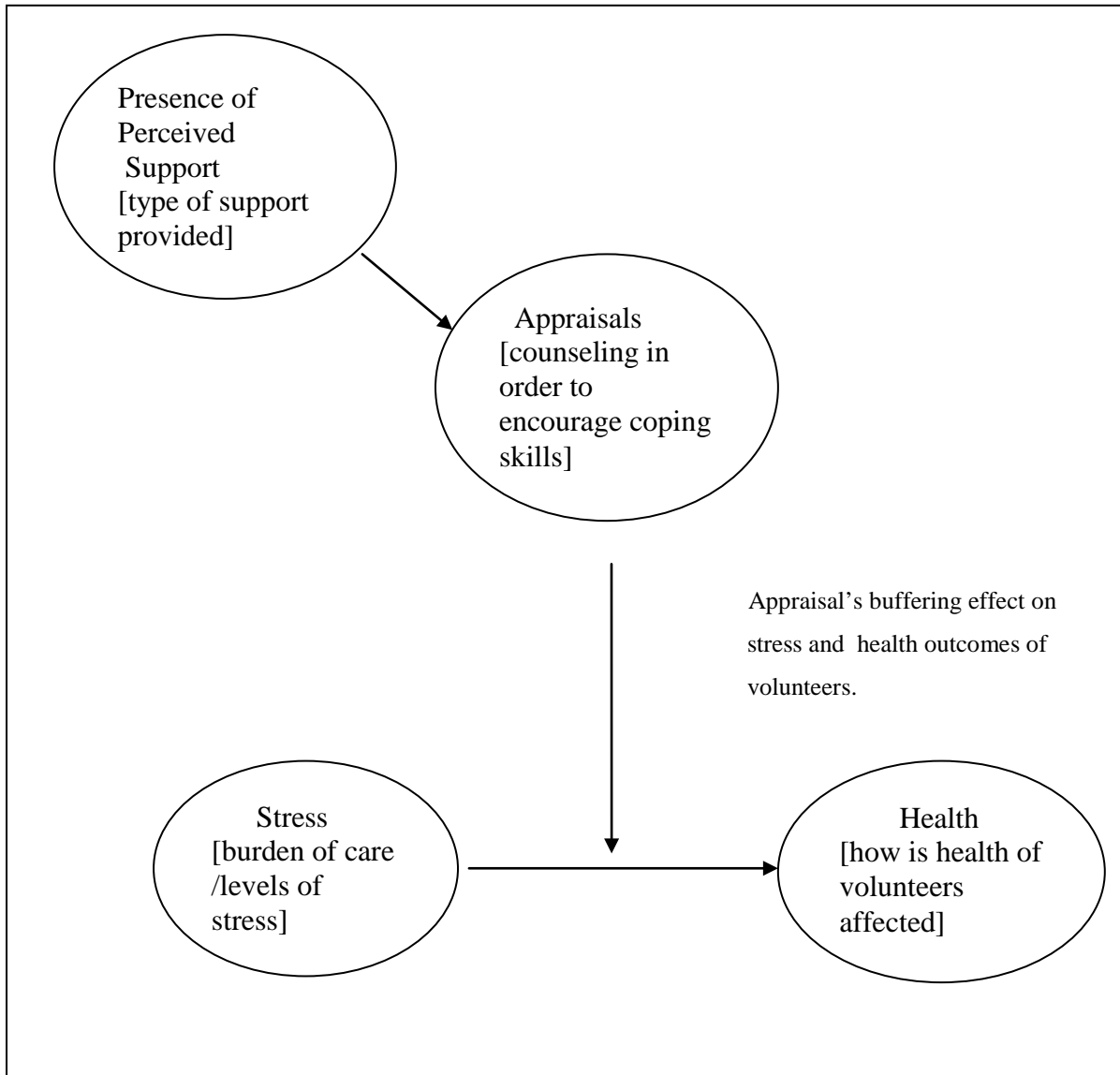
**Figure 1: An schematic representation of Social Support Theory as a buffer against negative health outcomes (Cohen & McKay, 1984).**

Making use of aspects of the social support theory as the conceptual framework of the study allows the researcher to thematically link the experiences of social support with stress and health outcomes of the volunteer caregivers.

**Individual Level**
Caregiver

**Interpersonal Level**
Relationships/support
from family and
friends

**Organizational
Level**
Support /interactions
with NGO's

**Community Level**
Support / stigma from
community members.
Support from NGO's.

**Policy Level**
Government grants
and regulations
regarding caregivers.
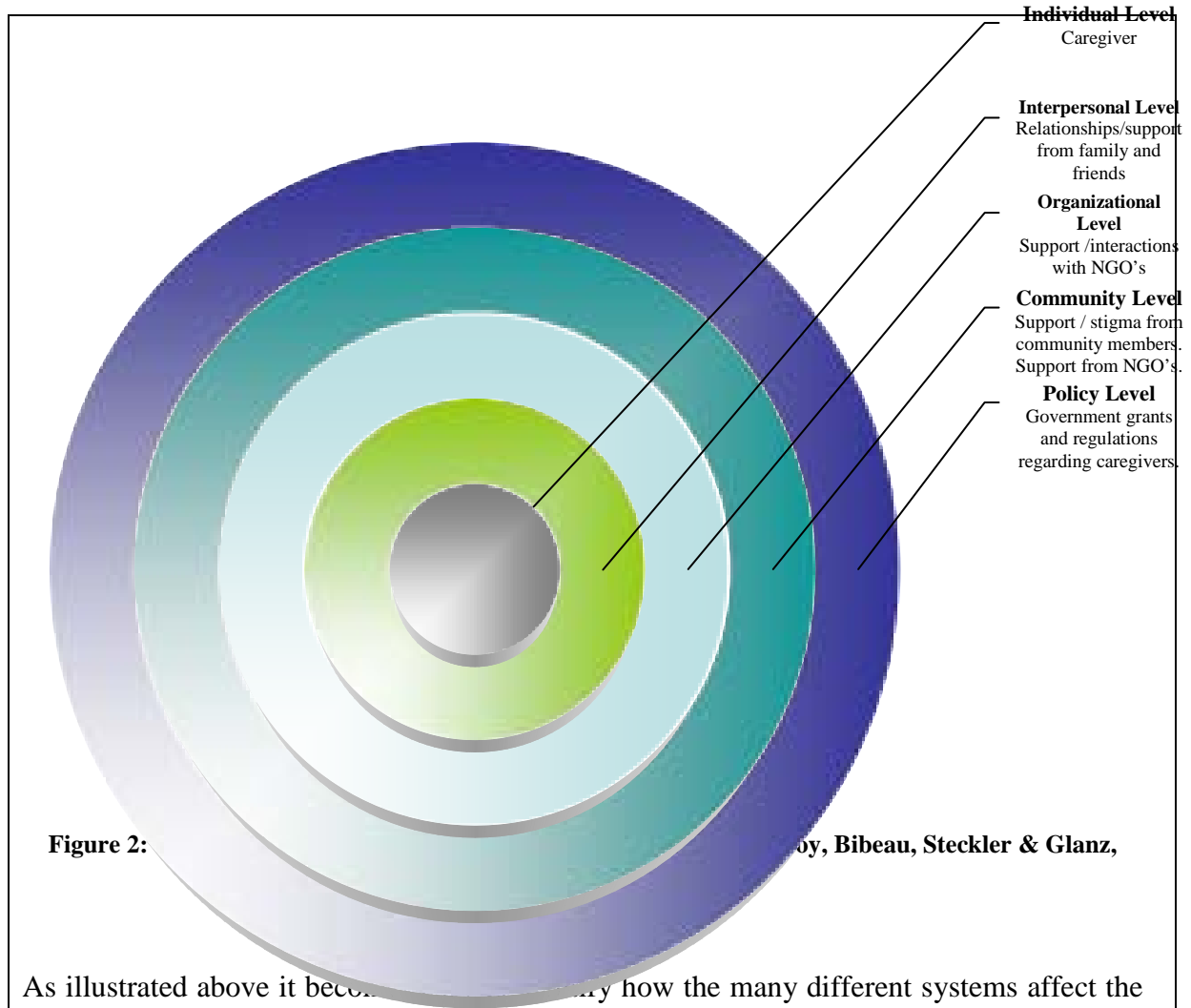
**Figure 2:** ......................................................... **by, Bibeau, Steckler & Glanz,**

As illustrated above it beco............ ....... ...ry how the many different systems affect the

volunteer caregiver and this adaptation depicting the social – ecological perspective further

re-enforces the social support needed at the different levels. The social-ecological model

comprises five elements, namely; the individual level (which is made up of an individual's

knowledge, skills, attitudes etc. pertaining to HIV/AIDS); the interpersonal level ( focuses

on the relationship/interactions between caregiver and patient or between caregiver and

their families and friends); organizational level ( involves both formal and more casual

levels of support/interactions amongst individuals with the same interests such as support

caregiver support groups); community level ( includes interactions/networks between the

organizational level as well as the physical community surrounding the caregiver); and

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lastly, the policy level which focuses mainly on government policies/legislature that would effect, in a positive or negative way, the level of functioning of the caregiver. In the case of the caregiver, such an example would include making AIDS grants more easily accessible to patients, providing more opportunities for knowledge and skills training for caregivers, making sure that all first aid kits remain fully equipped at all times for adequate use etc.

In relation to the social support theory, the social- ecological model highlights the different aspects that affect daily functioning of the caregiver, which in turn, draws attention to the levels at which social support is needed. The social capital framework can be used as an intervention mechanism in conjunction with the social support theory to mobilize support at the same levels as that of the socio-ecological model. For example, at an individual level, social linking and bonding may enable the volunteer to receive adequate training and skills to prepare her for care work. At an interpersonal level, social bonding and bridging may encourage relationships of trust and respect between the volunteer caregiver, patient and respective families. At an organizational level, social bonding and linking may encourage volunteers to openly share experiences with each other in order to gain support from each other. In this case social linking and social networks may also play an imperative role in bridging potential gaps between volunteers and the government in order to facilitate the support process. At the community level social trust and social bridging may play a role in improving the relationships of trust amongst community members and between the community members and the volunteer. The strengthening of such relationships may play a large role in reducing any stigma that may be prevalent and ultimately decrease an aspect of the burden of care work.

Briefly put, the theoretical framework used for this study focuses mainly on social support received as well as the unmet needs of volunteers caring for PLWHA's in relation to their working environments. Furthermore social issues such as community trust and social networks and their effects on the accessing of support by the volunteers are covered when combining aspects of social support theory, socio- ecological theory and elements of the social capital framework. This provides a well rounded view of the volunteer, her experiences of social support as well as the relationships with the stakeholders that may influence how, when and if the support is sourced.

In closing, HIV/AIDS and its implications is an illness that is devastating rural South Africa in many ways. The social implications of caring for someone living with AIDS are vast. Volunteer caregivers play a key role in home-based care but, as discussed in this review of the literature, are constantly exposed to issues such as physical and mental burnout and burden as well as the social wrongs of stigma. This review focused on the prevalence of HIV/AIDS and its uniqueness to Africa as well as the work of volunteer caregivers and past research done on the impact that the virus has on their roles as carers.

# CHAPTER THREE

## RESEARCH METHODS

### 3.1 Setting and context of the study

It is important to note that this study formed part of a larger study focusing on social capital conducted in the KwaNgcolosi area. The sample of this study was derived from that of KwaNgcolosi community. KwaNgcolosi is a peri-urban informal settlement situated in the Inanda area, near the Valley of a thousand hills in the KwaZulu-Natal province of South Africa. The community is located approximately 60 KMs from the city of Durban. All the participants from the study belonged to a local registered nonprofit organization (NPO) called *Uthando Lomama*, a Zulu term which means Mother's Love. *Uthando Lomama* is a NPO that was founded in 2002 by the present volunteer co-ordinator and is in charge of providing materials and training to the volunteer caregivers.

However, it is important to note that during the early stages of development the NPO volunteers were provided with very basic skills in patient care as well and basic skills in counseling. An external health trainer was arranged by the co-ordinator to provide training to the volunteers. Unfortunately, to date, training of this sort does not occur on a regular basis. Although *Uthando Lomama* has approximately 40 members to date only half of the registered volunteers receive a stipend of R500.

**3.2 Design**

A qualitative research method was used for the purpose of this study. Qualitative research, as described by Strauss and Corbin (1990), entails interpretation and constructs findings that are not of statistical derivative suggesting that qualitative research does not make use of numerical statistics in order to interpret the findings of a study but rather qualitative research involves research about lived experiences, feelings, cultural phenomena etc. (Strauss & Corbin, 1990, p.10). According to Ulin (2005), qualitative analysis enables the researcher to connect findings from three components, namely; experience, objective actions or behaviours and context; and to investigate the many relations between them. For example, a caregiver may not just identify her care work simply as a means to help her patient but rather interprets its significance in the light of personal, cultural and social experiences and from what others believe about her care work. Qualitative research allows for this type of reflection, making it the more suitable option whereas quantitative research is more statistical based and may not allow for the expression of the lived experiences of the volunteer. The selected research method will allow for an understanding of the caregivers' experiences of social support from the volunteers' point of view.

**3.3 Sample**

The sample selected for this study consisted of 10 female volunteer caregivers residing in the KwaNgcolosi community. In order to access the sample an initial informal meeting was conducted with the researcher, translator, volunteer co-coordinator and all the volunteer caregivers who belonged to *Uthando Lomama*. The nature of the study was then explained

by the translator to the volunteers in the presence of the researcher. Due to previous experience in the sample setting, the translator also played the role of facilitator throughout the field work process. It was then requested that those volunteers who were interested in taking part in the study confirm in the form of a register with their co-ordinator. The volunteer co-ordinator then arranged interview times with the researcher to facilitate the data collection process. Due to the nature of the study, purposive homogenous sampling was used. Ulin (2005, p.56) describes purposive sampling as a *strategic approach* in which participants are chosen "for their ability to provide rich information." This, in effect, is the perfect sampling technique for a study of this nature as the experiences of social support discussed by the volunteer caregivers selected for the study and interpreted by the researcher will add richness to the content of the study. The participating volunteers of the study were purposefully selected on the basis that they worked with PLWHAs. This meant that the volunteers were those in a good position to provide rich information. Considering the fact that they were providing care for PLWHAs the issue of social support was best asked from the volunteers. Ulin then goes on to describe homogenous sampling as making use of participants that have more or less the same characteristics and goes on to reinforce this by adding that "by limiting the sample selection to individuals who meet the criteria one is better able to focus on a central issue that is relevant to all of them" (Ulin, 2005, p. 57).

The participants were homogenous in terms of race (all participants are of African descent), language (having isiZulu as a first language), gender (the sample comprised of 10 female volunteer caregivers who are currently caring for people with AIDS for a minimum of three months) and responsibility (all participants are volunteer caregivers of PLWHA). They also

had to have volunteered for a minimum of three months care in order to be included in the study. This ensured that they have enough caregiving experience to discuss that will yield rich data. The researcher interviewed 10 female caregivers as females make up the majority of the caregiver community and 10 participants provided rich data during in-depth interviews. A sample of this size provided the researcher with a thick and rich data on the experiences of the volunteers.

## 3.4 Data Collection and Procedure

In-depth individual interviews were conducted with each participant to allow for a more clear   understanding of their experiences. The nature and aims of the study was explained to each participant who was then asked to complete a letter of consent (see appendix A) prior to the interview in order to ensure that they were informed about the study and their role as participants. A semi-structured interview schedule was used to provide direction during the interview (see appendix B).

Questions used to from the interview schedule were used to guide the content of the in-depth interviews. Interview schedule was based on aspects of the social support theory, social capital framework and socio-ecological theoretical frameworks. The interview schedule covered the following themes: the daily care routine, the burden of care, social consequences of care work, social support needed, social support provided, social support lacking, social trust, social networks and social cohesion. A pretest was undertaken with two volunteers as participants. Data from the pretest was collected and analyzed to ensure that the interview schedule elicited the responses needed to answer the research questions

adequately. Data collected from participants in the pre-test were included in the sample of 10.

Each participant was interviewed once and the interview was approximately 40 – 60 minutes. Interviews were conducted by the translator in isiZulu (in the presence of the researcher) as participating caregivers spoke IsiZulu as a first language and have limited fluency in English, which is the researcher's first language. The researcher remained present throughout each interview to ask probing questions via the translator if necessary. The interviews were audio-recorded and transcribed, translated and back-translated to ensure accuracy.

Participants were interviewed at S'thandokuhle crèche in Kwangcolosi and the process was facilitated by the volunteer co-ordinator. All interviews were confidential and respondents remained anonymous.

## 3.5 Data Analysis

The collected data including findings from the pretest were included in the data analysis of the main study. Qualitatively analyses using Ulin, Robinson, Tolley & McNeil (2002) approach to thematic analysis was employed. Thematic analysis is used to identify potential patterns, themes and common elements within the transcriptions (Ulin et al., 2002). All collected data was studied and put into themes according to Ulin's method by the researcher. These themes describe the main essence of the data (Ulin et al., 2002).

Themes emerge from the existing literature around the research question (Ulin et al., 2002). This allows certain validity to the choice of themes, as they are already present in the research area (Ulin et al., 2002). This would allow the researcher to draw out the relevant themes from the data presented. In effect, adding depth to the experiences of the caregivers. As suggested by Ulin et al. (2002), when analyzing thematically, the content must be examined for different themes, patterns and opinions and the data be presented in the form of extracts from individual transcripts. The participants' experiences, thoughts and understanding attached to the research question are the main focus (Ulin et al., 2002).

Themes were sifted from the data and provided patterns which facilitated the commencement of the coding process. According to Ulin (2005) coding may be described as putting all the "text that relate to a common theme together in one place." By doing so this enables the researcher to identify new subthemes and "explore them in greater depth" (Ulin, 2005, p147). On the completion of the coding process the researcher may examine the coded themes more closely for the main subthemes that surface from the data (Ulin, 2005).

All the collected data was coded by the researcher allowing the emergence of subthemes. "A qualitative examination of each subtheme would include attention to specific vocabulary that participants use to discuss the topic" (Ulin, 2005).

Data reduction follows the above mentioned steps. Data reduction is described by Ulin (2005) as the process of refining the coded information as to make evident the most vital

perceptions. This, in turn, sources the most relevant and valuable information needed to answer the research questions.

Lastly, the data is interpreted. "Interpretation is the act of identifying and explaining the data's core meaning. It involves communicating the study's essential ideas to a wider audience, remaining faithful to your participant's perspectives" (Ulin, 2005).

## 3.6 Ethical Consideration

Before commencement of the research process the research proposal was approved and ethical clearance was given by the higher degrees committee (see appendix C). Confidentiality and privacy of the volunteers were maintained throughout the data collection process. This in turn protected volunteer's emotional and physical well-being. Arrangements were made with the counselling centre at the School of Psychology, University of KwaZulu-Natal for referrals of the participants if necessary. However, the need to refer volunteers did not arise.

## 3.7 Limitations of the study

Possible limitations to the study included language barriers. Due to the fact that the researcher was English speaking and all the participants were IsiZulu speakers, a translator was be required to assist when conducting the in depth interviews. All the data had to then be back-translated for the purpose of analysis. This placed additional time constraints on my research project.

# CHAPTER FOUR

## FINDINGS

### 4.1 Introduction

This chapter provides findings on how the volunteers from "*Uthando Lomama*" (Mother's Love) establishment perceive their experiences of social support from their families, NGOs, government, community members etc. Issues around trust and social cohesion between community members come to the forefront in this chapter. All responses from participants are presented in italics. The collected data revealed the following themes and subthemes:

### 4.2 Daily Patient Care Duties

Patient care formed the foundation of the job of the volunteer. Each patient presented with similar care needs which determined the daily routines of the volunteer.

### *4.2.1 Daily Routine*

Routine formed the basis of time management with regards to patient visits. Volunteers had to maintain a daily routine in order to fully accommodate all their patients. It emerged from the findings that on average, the volunteers cared for approximately four patients per day and their care duties were vast, ranging from medicating (adherence monitors), feeding and bathing their patients to domestic duties.

*"I can sometimes take four houses a day. However, it depends on the situation that you will*

*find with the individual patient. If you find a situation that you first have to clean the*

*patient up and wash the bedding because they have messed themselves up, then it*

*sometimes becomes difficult to do four houses a day. Before I start bathing them I would*

*take out their clothes and clean them up, because some of them have messed themselves,*

*bath them, put on body lotion, brush their teeth and then dress them up. After all this I will*

*feed them" Participant 1*

From the above quote it is evident that the routine care duties of the volunteers were very detailed and physically demanding. The volunteers often worked in more than one home at a time and time management was a factor that needed to take priority.

Care work began as early as 8am with volunteers often having to walk a distance of more than 15 minutes between each patient.

*"Every morning I wake up, take a bath, get dressed, drink tea and then leave for work at 8*
*o' clock. It usually takes me about 15 minutes to get to my patients, but it also depends on*
*how far their home is from mine. I go to as many as four homes a day, so I can't really say*
*how many I do a day, it depends on where I'm needed and how much time I have to spend*
*at that particular house." Participant 4*

*"We walk all the way up there all the time and when we come back we are extremely tired*
*and exhausted." Participant 6*

Caregivers found little time for themselves due to the time spent performing their care duties. They described feeling exhausted when their care work was completed and they returned home. This suggests that their care work was taking its toll physically and perhaps emotionally on the caregivers as they would be unable to play the role of mother, wife and home keeper due to the demands of the care work.

## 4.2.2 Finding/accessing *Patients*

The process of finding patients is fraught with difficulties and complications. Once recruited by '*Uthando Lomama*' volunteers accessed their patients in different ways. Predominantly, when looking for patients, volunteers visited homes in their communities, introduced themselves to the occupants and explained the type of work that they do and asked if anyone in that home needed their assistance. Alternatively, volunteers relied on different ways of patient recruitment. One volunteer described the process of recruiting her patients as relying on rumors about possible sick people from other community members who were familiar with her work. She described her frustration when explaining that even though she suspected that the prospective patient may be ill, she could only offer her help once the patient or a family member acknowledged his/her illness and disclosed it to the volunteer.

*"Sometimes we hear rumors from people that there is a sick person in that house…So when you go there and ask about their wellbeing and health, it has to come from them that they actually do have a sick person in their home. If they don't tell you that, you can't say that you heard a rumor that there was a sick person in their home…It must come from the family member?" Participant 2*

A lack of community cohesion and trust is evident as the above quote suggests that rumors about the ill circulate amongst the community members. This re-enforces the influence that stigma may have on the patient's decision to disclose his/her status or accept treatment from the volunteers.

*"So when you go to a house you greet them and then they welcome you and then you introduce yourself to them and explain what you do and why you are there. If they need you they will tell you and accept your services but if they don't then you can force them. That is how we were trained. You can't force yourself on a person. Even though I am trained to look after sick people I can't tell them that 'I see you are coughing or you are like this and so you must be sick.' I have to approach them in a manner that will not insult or offend them, so eventually I will have to get the patient to not only like me, but also to trust me enough to want me to come back and care for them." Participant 10*

One of the challenges for the caregivers as interpreted from the above quotes is the issue of respecting the autonomy of the patient's families. Without the permission of the family members, caregivers face the unfortunate scenario of not being able to provide care for the ill. The implication of such a lack of support from the patient's family members is that the patient may face an undignified death due to a lack of treatment.

Some volunteers described being approached by family members of the patient. These family members appealed to the volunteers for help in the form of materials such as diapers, porridge etc. The volunteers were then able to question the family member as to why they needed those materials. Only once those family members disclosed the fact that

there was an ill person living with them, was the volunteer able to provide care for the patient.

### 4.3 **Patient Relationships With Their Families**

*4.3.1 Family Neglect*

It became evident that almost all of the volunteers had to assume full responsibility for their patients due to the fact that the family members of the patient relinquished responsibility for their ill family member and almost emotionally detached themselves by not referring to the patient by their names or attending to them while the caregiver was away. Caregivers described scenarios where a patient was left for days, having defecated on him/herself, without any assistance or acknowledgement from their family members. Some family members would no longer identify with the patient and often referred to them as a *patient* rather than a family member.

*"Others do help and others don't. They would just say 'here is your person, after all, this is your work'." Participant 6.*

*"Most times they hadn't done anything. For example, if the patient needs a diaper change you will find them with the same diaper that you put on yesterday, even find that they are still sleeping in the same position you left them in yesterday…it does happen though that the person has been so sick that their family is just tired. That is when they start calling them 'your patient'." Participant 4*

The above citation relays a lack of tangible and emotional support from the family members of the patient. The volunteers also voiced a sense of resentment of the patient by the family members due to the fact that, in the eyes of the family, the patient led a reckless

lifestyle and was often warned about the consequences of such. In most cases, when the patient became infected with HIV, his/her family emotionally detached themselves from the situation and adopted an *I told you so* attitude.

*"Well if it's a young person for instance, they would say they have been telling him/her and warning them about the consequences of their lifestyle and behaviour. 'She was disrespectful and didn't pay attention to us, now that she is sick she must call her friends and boyfriends that she went out with to come care for her'." Participant 7*

When asked why they thought that the family members of the patient behaved in this way, some volunteers did not know whilst others suggested that perhaps the family members of the patient assumed that the volunteer was getting a salary and as a result, felt that the volunteer should *do her job.*

*"I sometimes think that they think that we get salaries from doing this work. I would hear them talk sometimes so they believe that since we get paid for it we must do everything ourselves. Otherwise I can't explain or understand how a person cannot look after their loved one at a time like this. Even when they have someone to help them they still don't want to. I just don't understand why people would do that." Participant 9*

4.3.2 *Volunteer's relationship with their patient's families (role confusion)*

The job of the volunteer was often misinterpreted by the families of their patient as that of home keeper. From the findings in the data it emerged that some volunteers felt and were treated as if they were domestic workers. Besides caring for their patient, they performed duties such as cleaning and cooking while able bodied family members either left or did not help in any way. Volunteers found themselves in a position where they had to

constantly remind the patient's family members that their priority was that of the patient and not the domestic chores and often requested help from the family members in vain.

*"One of the family members once said to me 'if this is the way you are going to work here by not coming everyday then I do not think you can work for me'. This was said by a family member who was not sick by the way. I then told her that 'I also cannot come here every day because I have other patients that I am looking after and the patient here is not the only one'." Participant 1*

The above quotation reiterates the general lack of emotional and tangible support from the families of the volunteers' patient and makes clear the presence of role confusion as well as the negative effect such role confusion had on the volunteer's emotional psyche.

However, other participants had more pleasant experiences with regards to their role as caregiver and found that they were more respected and welcomed by some of their patients' family members.

*"You will also find that you will go to the house and the family will be happy to see you because the patient was giving them a hard time and they were asking for me. The moment they see me they would light up in their faces and start calling me their personal nurse and would say to them 'my nurse doesn't do that; my nurse doesn't say that.' The family would come to me secretly and ask me to come earlier because the patient refuses to listen to them." Participant 10*

Generally volunteers' relationships with family members of the patient took on a negative turn as most of the participants felt almost exploited. However, the above quote suggests that in certain instances, families treated the volunteers with dignity and respect. Perhaps

this was due to the strong patient volunteer relationship. The above quote suggests that these family members showed gratitude to the volunteers due to the gratitude shown by their patient. This demonstration of social trust and cohesion was key in providing the volunteer with emotional support in the form of validation.

*4.3.3 Volunteers relationship with patient*
*4.3.3.1 Gender distinctions in care preference*

HIV/AIDS infection is not gender biased and caregivers often cared for both male and female patients. It emerged from the data that there was a distinct difference between the care relationship of female volunteers and male patients. Although appreciative of the treatment provided, male patients displayed embarrassment when faced with their carers in public places. Female patients (including their families), on the other hand, were very appreciative of the help provided by the volunteers.

*"You can tell that they have a problem with that but there is nothing you can do because they need our help anyway. You know when a person is sick all of that doesn't matter, but as soon as they get better they start getting embarrassed when you touch them…Some even get embarrassed when you meet them on the streets and they don't even want to look at you. The women don't have a problem they are just grateful that you have helped them and supported them when they needed it most, even their families." Participant 4*

*4.3.4 Inaccessibility of AIDS grants*

Although AIDS grants are, in theory, made available to AIDS patients, only one participant discussed the fact that she helped her patient to access the grant. The above mentioned participant also expressed her disappointment at the response of the family members of the patient with regards to the AIDS grant and stated that the family members of the patient seemed to only show interest in the patient when the grant was approved and in turn dismissed the volunteer. However, as soon as the money from the grant ran out, the volunteers were requested for.

*"We are the one's that help them to apply for this grant, but once they get it the families push us away and pretend to be supportive of the sick person. However, if it happens by any chance that the grant stops, they come running back to us for help." Participant 2*

The lack of support from the government in terms of the provision of the AIDS grant had a ripple effect on that of volunteer. AIDS grants are issued to those with a certain CD4 count. For as long as the CD4 count remains low (below 200), patients are able to collect an AIDS grant of approximately R1010 per month (Department of Social Development, 2009). Once the patient starts to properly respond to their medication and their CD4 count levels rise, the grant is no longer made available to them as government expects them to then be well enough to go out and seek employment. With no grant and therefore no money for food and other material needs, it becomes easy for the patient's health to become compromised. This vicious process encourages the demoralization of the volunteer who then has to invest in caring for her patient, witnessing her patient become healthier, being shunned by the

family of the patient when the grant is made available and then having to return to her once recovering patient who is again ill.

## 4.4 **Poverty**

The presence of poverty has a ripple effect on volunteer and patient as it was experienced by both and in turn affected both.

### 4.4.1 *Living conditions of the patient*

Poverty played a dire role in the living conditions of both patient and volunteer. Due to the fact that the patient was previously the breadwinner but no longer employed, there was very little or no money for food or to aid with the running of the home. Volunteers discussed the fact that   often their patient's cupboards completely bare. As a result, some volunteers found themselves in a precarious situation where they would sometimes secretly take food from their own homes in order to feed their patient.

*"Sometimes you take from your own groceries at home, ask from your neighbors or use the very R500 that you get to buy the soap to wash the clothes for the month. The thing is patients cannot take medication before they eat, they must have eaten something or even porridge before they can take medication. Sometimes we even give them the porridge for T.B patients because we don't have anything to give them." Participant 1*

When asked if her family and husband knew that she was taking food from their home to feed her patient, participant 2 replied;

*"Oh! I hide it from him. I know he will not agree to that one."*

The above quotes suggest feelings of responsibility felt by the volunteers to their patient. More significantly, it suggests that the volunteers did not find support from organizations as well as their own homes and therefore had to steal food from their homes. This may have had a ripple effect on the relationships of trust between the volunteer and their family members.

## 4.5 **Burden of Care**

The burden of care work affected the volunteer's lives on a physical, emotional and social level.

### 4.5.1 *Consequences of care work on volunteers' family life*

Although fulfilling, care work took its toll on the relationship between the volunteer and her family. Care work usually began early in the morning and often volunteers reached their homes in the evening. This left very little time for them to spend with their children and due to sheer exhaustion, no time to perform any domestic duties. It emerged from the data that volunteers were sometimes contacted late at night by the family members of the patient. They were then asked to attend to the patient and, out of obligation, left their own families to go to their patient.

*"So when you come back the only thing that you want to do is sleep, at times usually at night around nine or ten you find that you get phone calls from the families telling you that your patient had complications and you should come back and have a look at them."*
*Participant 1*

Other volunteers expressed their guilt at the strain that their jobs put on their relationship with their children. They stated that their children found it difficult to understand why they would work unpaid at the expense of their family time.

*"I can't cook anymore at home because I leave at 07h30 and come back at 18h00. I can't even spend time with my children anymore. I have two children and one of them is 5 years old. I don't even have time to sit down with them and give them love, even my husband. They are always shouting at me as to when they are going to spend time with me because I am always not home…I don't feel good at all because they have a point but what can I do, it's my work."* *Participant 2*

It becomes clearly visible that familial relationships and bonds are negatively affected as a consequence of care work.

Because the volunteers were engrossed in their volunteer work there was little time left for any other employment opportunities. It emerged from the data that some of the volunteers would have liked to have become self employed but could not due to time and financial constraints.

*"I should be starting a small business and sell something to get money, but I can't do that…so I do feel like it holds me back financially, maybe if I was selling something I would get some cents from it, but then again I'm still doing my work."* *Particpant 3*

Again, it is suggested that the personal development of the volunteer is compromised due to the burden of care.

4.5.2 *Dangers of the job*

The late night house calls made by the volunteers proved to be dangerous due to the fact that volunteers had to walk long distances, alone and in the dark, to the patients' homes. This resulted in volunteers feeling vulnerable and often carrying weapons in an attempt to protect themselves from possible danger.

*"In our bags we carry everything and we have knobkieries, so we really beat them if they try to do anything. We also carry knives with us for our defense because they lie in the bushes to ambush us. I won't lie but it is dangerous." Participant 2*

The issue of the quality of the materials raised concerns. One volunteer felt as though her health was, in certain instances, being put at risk due to the nature of her job and the poor quality of protective materials that was given to them to use. When asked why she felt that her safety was compromised participant 9 responded as follows:

*"Well as we work in the community we work with people who have AIDS, you can't help but have that fear, yes we use gloves when we care for them, but the gloves we use are not so strong at all. Sometimes when you are using water or bathing a patient you find that there is water inside the gloves and that is not right and it worries me a lot."Participant 9*

Emotional and physical strain due to care work is evident in this chapter. Fear of assault or contracting HIV is cited by the volunteers which in turn highlights a lack of social support

and an urgent need for both tangible support (transport) and emotional support in the form of occupational stress counselling.

## 4.6 **Support Provided**

Although the burden of care weighed heavily on the participants, they did find solace in the modest amounts of tangible and emotional support provided by fellow volunteers and family.

### 4.6.1 *Support provided by co-ordinator*

The volunteer co-ordinator provided support to the volunteers in various forms. She was often seen not only as an authority figure but in some cases, a confidant. However, she was only able to provide limited support due to factors such as insufficient materials, limited experience and lack of training and as a result some volunteers found her help to be of little use to them as the effects and informal counseling provided by her proved to be short-lived.

### *Tangible Support*

It emerged from the findings that volunteers were provided with materials such as diapers, gloves etc. by their coordinator. Although useful, the amount provided proved to be insufficient to care for all the patients and once these supplies ran out, the volunteers were left with nothing. They then had to substitute their gloves for plastic packets and diapers for sheets or towels until the next delivery of materials arrived. Volunteers voiced their

concerns about the quality of the materials provided and spoke of gloves tearing during use. This put them in a vulnerable position.

*"We get working material from our co-ordinator even though it's not sufficient."*
*Participant 5*

*"Our Coordinator is the one who gives us the working material we use, even though it's not enough for us to care for all our patients. It happens that we are short of diapers and toiletries for the patients as we get them only once a year. The stuff is probably for two months, but we are supposed to make use of it for an entire year." Participant 8*

When asked how she handled it when she ran out of materials, the volunteer replied:

*"Sometimes I take the sheets which are also supplied and use them as diapers."*
*Participant 8*

The lack of continuity of tangible support in the form of materials is highlighted in this theme. It is important to note that as suggested by the above quote some form of social support (materials) is provided but it is not enough.

### Emotional

Due to patient confidentiality, volunteers turned to their co-ordinator for guidance when faced with emotionally disturbing experiences. They were then advised by their co-ordinator to try to persevere and to be more understanding of the job that they had undertaken. This kind of support provided a sense of immediate reassurance.

*"We report to our coordinator and she would say that we should persevere and try to understand the pains that come with the job."* Participant 1

*"I come back to our co-ordinator and tell her about all the troubles and emotional problems I am experiencing. She then tries to counsel me and put me back in the right normal position."* Participant 2

Volunteers relied heavily on the co-ordinator to provide emotional and tangible support. This placed excess strain on co-ordinator who lacked proper training to provide the support needed.

4.6.2 *Support provided by the volunteer's family*

Family support played a vital role in encouraging the volunteers. Six of the ten participants acknowledged the support provided by their families and had positive experiences with emotional support provided in the form of encouragement and understanding.

*"My children do. They encourage me to be patient, after all, there aren't any jobs out there and this might lead to something more later."* Participant 6

However, only two out of the six participants found the emotional support given by their families to be useful. This suggests that these volunteers identified and made use of their family members as a source of support. This finding also suggests that the remaining four volunteers did not receive emotional support from their families. This could perhaps be due to the fact that confidentiality dictated what could be discussed with the families of the volunteers and as a result, the remainders of the volunteers were unable to discuss specific

instances that were disturbing for them. Support could then not be provided by the families if they were unaware of the need of support.

With transport playing a significant part in the amount of time that the volunteer was able to spend caring for the patient as well as transporting their patients to the nearest clinic or hospital, one volunteer received support from her husband in the form of transport.

*"The only car I use is my husband's car when the ambulance does not come on time. I ask him to take them to the hospital. My husband takes them even if they don't have the money to hire a car or at least put petrol money. Lately they call my husband's car an ambulance." Participant 2*

4.6.3 *Volunteers support each other*

The interviewed volunteers suggested that by talking with each other they ultimately felt better about their experiences as they were not bound by confidentiality with each other. This suggests that some form of relief from the emotional and psychological burden of is experienced when the volunteers are able to speak about their issues. It also suggests that the volunteers are able to provide each other with emotional support in certain instances.

### *Informational support*

The relationship between caregivers was intensified by the commonalities of their care work. They revealed that talking about or sharing their difficult experiences with each other provided immense support and comfort. Most of the caregivers stated that they tried to

have regular meetings with each other. During these meetings they shared their experiences with each other and provided possible solutions to dealing with stressful encounters.

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

*Participant 10*

The above quote is an example of the information sharing between the volunteers during their meetings. For one of the volunteers though, the conversations and meetings between the caregivers did not prove to be useful due to the fact that the volunteers were not provided with a means to cope or to learn how to deal with their experiences after their meetings.

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

Although volunteer meetings acted as a safe haven, volunteers expressed their need for emotional support in the form of counseling and informational support in the form of training and identified support of this nature as very necessary.

4.6.4 Support provided from the community health care clinic

The relationship between the volunteer and the community health care workers was a strained one. Volunteers described a relationship of tension between the two due to the fact that the patient preferred the care provided to them by the volunteer. Even though the health clinic sometimes provided the volunteers with some working materials it was provided under duress.

*"There are those in the community who don't like us because at the beginning health workers were more prominent in the community and then the community complained that they are not doing their work properly. All they do is take their details and leave them like that; even when they are community programmes they don't notify the community. So when we emerged the community wanted nothing to do with the health workers and they favored us over them. Then there was conflict right there and then because even between the carers and the health care workers there was tension. Now you find in other areas they don't want the health care workers to work there. They demand that we work in their areas because when they get to their patient they just sit and talk and when we get to the patient we work really hard for them." Participant 7*

The above quotation suggests a tense relationship between the volunteer and the health care workers due to the reception of the volunteers from the community/patients. The type of hands on care provided by the volunteers was favored by the community and as a result, the health care workers were turned away by the community. This may have a negative influence on the volunteers receiving adequate social support from the health care workers.

When asked if the volunteers generally received any support from the clinic one volunteer replied:

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

Due to the strained relationship between volunteer and health care worker tangible support
was provided in the form of working materials but the support was only provided on
certain conditions. Volunteers were under the impression that preference was given by the
health care workers to those volunteers who knew a health care worker personally. The
above quotation suggests a breakdown in trust between volunteer and health care worker
and this had a negative impact on how social support was accessed by the volunteer.
Interesting to note, however, is that the health care worker seemed to understand his/her
role in providing the volunteer with support in the form of providing materials but did so
resentfully. The above findings suggest a relative provision of social support to the
volunteer but also highlight a breakdown in the crucial relationship between the volunteer
and health care worker.

## 4.7 **Unmet Support Needs**

4.7.1 Social Support Needed

As discussed in the literature, care work is complex and volunteer caregivers experience a plethora of social injustices such as stigma, lack of working materials, poverty etc. A feeling of neglect or a lack of support was experienced by all participants. They felt that their communities isolated them and government had forgotten about them. This affected their morale in a very negative and demoralizing way. It emerged from the data that the following kinds of social support was needed by the volunteer caregivers of the KwaNgcolosi community.

### *Tangible Support*

4.7.1.1 *Hospice*

Out of ten participants, six voiced their need for a hospice, stating that the presence of a hospice would help tremendously with regards to patient care. Volunteers felt that if all their patients were admitted into a hospice it would cut down on the time spent walking from patient to patient, all working material would be in one place and having the patient in a hospice would take away the negative experience of family neglect. They are also felt that working shift work at a hospice would remove the dangers of having to make unexpected house calls at night.

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

4.7.1.2 *Training*

It became evident from the data that volunteers felt unprepared when dealing with certain situations with their patients. Almost half of the interviewed volunteers stated that they needed some sort of counseling and health care based training to prepare them for their care work as they found themselves in situations where it became necessary for them to practice those skills. Volunteers also found it necessary to have basic counseling training in order to better counsel their patients.

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

*"We need more training. We have been trained before but this work is hard. You know when on of your patients die it gets so hard for me, because I have spent so much time with them and we had a bond between us." Participant 4*

4.7.1.3 *Food*

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

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

*"If we could get a sponsor for food, we could have veggies, bread, soups and all of those things so they will not go a day without food just because their grandchildren don't care."*
*Participant 7.*

4.7.1.4 *Transport*

Volunteers described walking long distances to each patient's house on a daily basis. Although all the volunteers had to travel to their patients on foot, in certain cases of emergency other arrangements had to be made.

*"We always wish that there was a car that could deliver us to all the places we need to go to in the mornings and then pick us up in the afternoon when we have finished working."*
*Participant 6*

Many of the participants described how their fellow community members would not voluntarily transport them and their patient to the nearest clinic when needed. Instead, when asked by the volunteers, community members agreed to provide transport on condition that they were paid for it. Volunteers were also forced to make use of taxis when transporting their patients and many requested that transport be provided to assist with such scenarios.

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

*"We use taxis. That is why I said we needed help with transportation because we have to take taxis with really sick people." Participant 7*

4.7.1.5 *Money*

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

*"If we can get financial support, as in salaries, it would make our lives much better and improve our conditions at home. We do this work because we love doing it. However, we might even end up resenting it because we don't get anything." Participant 2*

*"If we got money we would be highly motivated." Participant 5.*

4.7.1.6 *From researchers*

Volunteers described how they would like researchers to support them in the form of approaching government with the information gathered from the data. They seemed to be under the impression that researchers held the key to providing them with the tangible support they needed.

*"As you are doing research I would like to receive help from you." Participant 3*
*"I think that as you are asking us these questions you can help." Participant 6*

The above quotations strongly highlight the unmet support needs of the volunteer. Unmet needs take on more of a tangible role which suggests that may be seen as a lacking of basic necessities. Interesting to note is that the volunteers saw researchers as the link between

them and government and viewed the research process as a means to provide them with the support they needed.

4.7.1.7 *Government*

It emerged from the findings that the volunteers felt that they needed the most support from local and national government. They felt as though they were dismissed by government and expressed their dismay at how no representatives from the Department of Health interacted with them or visibly acknowledged them and again looked to researchers to bridge the gap between the two.

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

*I think that they are not aware of the work we are doing and the help/support that we need, but I believe that now they will know because we have spoken to you. As you will be writing in your books with this information and our complaints then they will know that we exist and that we serve the community." Participant 7*

This in effect re-enforces the desperate need for support from government.

From the data it emerged that although volunteers tried to arrange meetings through their coordinator with a government representative they were unsuccessful. This added to their frustration. Volunteers stated that although support was provided in the form of some working materials, it was inconsistent and when the supplies were finished they had to wait for long periods of time before they were supplied with more.

*"None of these people give us any help. Not even once do they offer anything to support us with." Participant2*

*"We asked if we could see the person in charge so we could talk but no one came. We just want them to see the community and the conditions we work in and how we come back very tired all the time from the work we do and the distances we walk. We still haven't seen anyone and we never get a straight answer from them." Participant 3*

### 4.7.1.8 *Community*

From the findings it emerged that, according to the volunteers, the community members were particularly unsupportive of the care work done. Volunteers were mocked and their work frowned upon by most community members.

*"We don't receive any help from anybody. Not even the community. No one gives us any help." Participant1*

When asked what the volunteers thought the reason was that they do not receive any support from their community members one of them responded by explaining that the divisions among the community members ran deeper that on a social level.

*"I think it's because they are financially superior and therefore look down on those of us who are financially inferior to them. I believe that those well off don't care about those less fortunate than them." Participant 3*

The findings cited in relation to the lack of support from the community members suggest a negative view of community members. Community members were viewed as uncaring and

snide. Cohesion between community members is also put in a negative light. Participant 3 re-enforces this by suggesting that more financially stable community members maintained a *superior* demeanor compared to those community members who were not.

4.7.1.9 *Community stigma/ridicule*

Caregivers were constantly faced with ridicule from the community members due to the nature of their work. This was disheartening for the caregivers as they could not look to their fellow community members for any kind of support or help. Volunteers explained that the community members laughed at them, ridiculed them and even accused them of being infected with AIDS themselves.

*"We do feel stigmatized especially if it is the people who are not sick saying these things to us. Sometimes when you try to share some of your food or fruit with them, they will say 'no thank you, we don't want it.' This is all because we touch people with AIDS."* Participant 2

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

4.7.1.10 *Volunteer's family*

Although in most cases family members of the volunteers seemed to be supportive of the service they provided to the community, some of the participants found that they could not turn to their families for support. Interviewed volunteers disclosed that they could not talk

to their families about the hardships faced as consequence of their care work due to the fact that the family did not approve of the work done by the volunteers.

*"My family didn't really like what I was doing and I had to forcefully continue working, even here my sisters in-law before they died, they always tried to make me leave my work."*
*Participant 3*

### 4.7.1.11 *Religious groups*

Volunteers found little solace with the local churches. Although they acknowledged that support groups did exist, they also stated that they did not belong to any of the groups. It also emerged from the findings that volunteers did not expect support from their churches and as a result, didn't ask for help. Those who did receive support from the local religious groups got help in the form of family/marriage counseling.

*"There are groups but they don't support me. I have never asked. I have not considered it before." Participant 3*

The above quote raises issues around social capital. Support may have been provided granted that the volunteer asked for it. For some reason the volunteer did not associate this social network as a source of support. Perhaps the volunteer did not trust that support would be provided. Regardless of the possible reasoning behind this issue, it is evident that there is an urgent need to bridge the gap between the volunteer and surrounding social networks.

*"My church helps me when I have problems in my family and home, but not with my work." Participant 4*

Again, in light of the previous quotation, it stands to reason that this volunteer may not have asked for support as she did not recognize her religious group as a resource.

4.7.1.12 Social Cohesion/Social Solidarity

4.7.1.12.1 *Community trust*

As previously discussed volunteers experienced ridicule and discrimination from their community members and as a result did not have a positive view of their community members regarding trust. When asked if the volunteers trusted their community members to provide support such as taking care of their children (if necessary) while they were at work or giving the volunteers or their patient food if necessary, most of the volunteers interviewed said they did not trust the community members due to the ridicule experienced whilst others admitted that they had never asked for any help from their community.

*"I don't trust them at all that there is anything they can support us with." Participant1*

*"It is because they are the ones who laugh at us because of the work we are doing. So how can I trust them? How can they help us then because the only thing they do is laugh at us?" Participant 2.*

On the other hand, four volunteers did trust their community members and seemed to think that the community would provide help or support when needed.

*"I do trust them. I do trust that they can support me." Participant 4*
*"I trust them. I work with them every day." Participant 10*

4.7.1.13 *Insufficient funds*

The lack of funding/ finance had a ripple effect on the daily functioning and morale of the caregiver. Volunteers were provided with a R500 stipend from the government. This amount was meant to be provided on a monthly basis but instead was provided approximately once every three months. The purpose of the stipend was for that the volunteers buy detergent to keep their uniforms clean. However, volunteers had to use this money to survive. Transport and groceries for their families and often for their patient (porridge) were paid for with the stipend and the volunteers expressed their frustration with the irregularity of the provision of the money.

*"Sometimes you take from your own groceries at home, ask from your neighbours or use the very R500 that you get to buy soap to wash the clothes for the month. The thing is, patients cannot take their medication before they eat. They must have eaten something or even porridge before they can take medication. We are supposed to be getting the stipend every month, however, sometimes a month passes by and we enter the second month without getting anything. So it happens that sometimes you get it after three months or so."*
*Participant1*

*"We usually get gloves and aprons that we wear when we are working but we get that from our coordinator even though it's not enough and sometimes it runs out for a long time. At*

*times like that you might have to take your own money and buy things to help the patients and it is very hard because I don't earn a salary for what I do." Participant 6*

4.7.1.14 *Dignified burial of the patient*

The lack of social cohesion amongst community members in the KwaNgcolosi area proved to be very disheartening for the volunteers. Interviewed volunteers described instances where their patients had succumbed to their illness and passed away but were not acknowledged by their community nor were their family members supported by the community. In some cases guardians of the patient did not show any empathy and refused to arrange a proper burial for the deceased. One particular volunteer stated that after her calls for help fell on deaf ears, she had no alternative but to turn to the Minister of Social Development for support with regards to arranging a burial for her patient.

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

Others stated that although in most cases the community was not supportive in the form of helping to arrange a burial for the deceased patient, in some cases, some community members and outsiders did provide once off tangible support in the form groceries.

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*"Recently a girl died from AIDS and some man went over there with donations for the family and they were able to have a decent burial for the girl." Participant 3*

When asked if that was a common occurrence participant 3 replied emphatically that that was not common practice at all. This suggests that perhaps the community members in this case preffered not to get involved with the responsibility of funeral arrangements. Community cohesion seems to be lacking. Other volunteers also stated that they did receive help for the AIDS orphans left behind for a little while and once the person who was providing the help stopped, the orphans were unable to sustain themselves.

*"It's usually a once off thing but there was a white woman who helped us with food parcels. She went around to supermarkets asking them to donate food for the children and we would distribute it weekly. Unfortunately she has left for overseas and we don't know what we will do to help the orphans. So the next thing we did was to try to get them support grants."*
*Participant 7*

4.7.1.15 *AIDS orphans*

It emerged from the findings that the orphans left behind due to the death of a parent were often ignored by the community members and became the volunteer's responsibility as the volunteer has to then find any living family members to take care of the children.

*"I tracked down their father from Intshanga and went there to explain the situation that these kids are now facing and he took his kids. They are with their father now. There are older kids that I have helped to put through school in this community that are orphans and*

*their relatives are making them nannies that stay at home while their own children are*
*going to school." Participant 2*


*"Well the community didn't do anything for them but the volunteer there helped them get*
*their certificates so that they can get their support grants. She goes to their home to check*
*if they are still alright." Participant 8*


The findings in this chapter discussed the daily burden of caring for someone with HIV/AIDS as well as the obstacles faced when  providing care and highlighted the aspects of social support provided, the unmet support needs, the lack of support and the usefulness of the support provided to the volunteers. The lack of acknowledgement of the work of the volunteer and support from that of the government leaves much to be desired and is, in itself, an obstacle to the care of those living with AIDS in South Africa.

# CHAPTER FIVE

## DISCUSSION

### 5.1 **Introduction**

The purpose of this chapter is to provide an analysis and discussion of the findings presented in chapter four as well as to critically discuss the implications of this study. This chapter discusses the issues around social support and the relationships between community cohesion, family solidarity and their roles in providing situations of support for the volunteer caregivers in the KwaNgcolosi area.

### 5.2 **The Burden of Care**

Caregiving places great emotional, mental and physical strain on the volunteers in that they have to care for their patient's every need on a daily basis and sometimes even after hours.

Patient care and the daily routines surrounding patient care formed the core of volunteerism. Patient care was multi-faceted and there was a great need for social support with reference to patient care duties. Volunteers often had to work under dire circumstances with insufficient resources for disinfecting as well as protective materials and described their fears of contracting HIV/AIDS due to working in close contact with their patients whilst using poor quality protective gear. This brought to the forefront the need for tangible support in the form of working materials.

Patient access was an important yet difficult aspect of the care work of the volunteer. Because patients often lived far apart, volunteers spent large amounts of their time walking to care for their patients. This made volunteers fatigued leaving them too tired to provide care to their own families. In some cases the elders in the family or the husbands took care of the children until the volunteers returned home, suggesting that social support was provided from this source. Volunteers discussed their inability to fulfill their duties as mothers and wives and spoke of the guilt that they experienced due to the time consuming nature of their care work. This implies that the consequences of the burden of care have a ripple effect on the psyche of the volunteer as well as the relationships between the volunteer and her family systems. This finding is consistent with that of Akintola (2004). Akintola found that volunteers experienced emotional and physical stress as a result of the demanding care activities. The burden of care also has an effect on the relationships of trust between the volunteer and her family. In order to gain support from the family members, the volunteer would have to trust them to provide her with the support needed as a consequence of the burden of care. In some cases, this was evident. Volunteers were sometimes able to rely on relatives to take care of the children of the volunteer while providing care for her patient. These bonds of trust may have lessened some of the burden faced by the volunteers.

Personal development in the form of employment opportunities were sacrificed by the volunteers due to feelings of responsibility to their patient. This brings to light the need for support in the form of trust (between the volunteers and their families to lessen the burden of care) and bridging the gap between the volunteers and their social networks to provide

relief in the form of a replacement for the volunteers if alternative employment becomes available.

What was interesting to note were the feelings of vulnerability as volunteers spoke of carrying weapons when making late night house calls and others feeling vulnerable when using poor quality protective materials such as gloves that tore or we poorly fitted. This placed them in a precarious position as they felt as though they were at risk of being exposed unnecessarily to the virus. This again highlights the need for tangible support in the form of materials and transport and emotional support in the form of counseling. It also makes evident the lack of social bonding, social trust and a breakdown in social networks between the volunteers and the community members as well as between the volunteers, NGOs and government. Again, the severe breakdown in social cohesion amongst the community members is brought to light.

In order to access social support, social capital needs to be mobilized to bring the community of KwaNcgolosi together. Building on social bonding is necessary as the community members may be able to aid the volunteers in small ways such as providing plastic packets to use, in emergency situations, when the gloves tore or were finished. The improvement of social bridging between the volunteers, government and NGOs with the objective of improving the availability, quality and quantity of the protective materials used by the volunteer is needed. The inclusion of social linking would mobilize the local government and NGOs to provide support in the form of perhaps providing transport to the volunteers to reduce the risk associated with walking alone at night to make house calls as

previously mentioned. By improving social cohesion, through raising awareness on care work and the support needed as well as the community's role in providing support, the community members and the family of the patient may come together to help to care for the patient when the volunteer is not available.

There is an urgent need to improve social networks in order for the volunteers to resource the support needed. The coordinator needs to voice the volunteers' experiences with government officials. Government needs to address the needs of the volunteer by possibly regularly sending a government representative to the monthly volunteer meetings with the objective of reducing the burden of care. Once the above levels of social capital have been addressed it becomes easier to work on the trust issues between the volunteers and the community in order to mend the present strained relationships. Improving trust relationships, particularly between the volunteer and the community members would greatly decrease the burden of care experienced by the volunteer as the volunteer would be able to trust a community member to take adequate care of the patient if the volunteer is not available. Social support would be more readily accessed or resourced once the levels of social capital are addressed in this community. From the findings it is evident that the strained relationships between the above mentioned stakeholders is creating recognizable barrier for social support to be accessed.

Family members of the patient exacerbated the physical burden of care by refusing to help the volunteers when caring for their patient. In some cases family members spoke to and treated the volunteers as if they were domestic workers and often expected them to perform house cleaning and other domestic duties. Some families of patients seemed to be

somewhat confused by the role of the volunteer and treated the volunteers as if they needed to split their duties between the patient and housework. To a degree this is consistent with Akintola's (2008b) study dealing with the challenges of volunteer caregivers in South Africa. In his study he describes poor treatment from the family members in the form of insulting the volunteer. However, there is little literature about issues such as role confusion of this nature. These findings suggest a lack of support tangible support from the family members of the patient and also imply that the family members of the patients displayed ignorance at the duties of the volunteer. The lack of support with regards to the burden of care may ultimately lead to a negative health outcome as suggested by the social support theory as there is no buffer for the stress (burden) experienced by the volunteer. There is an urgent need for intervention in the form of mobilizing social networks in order to facilitate social support from the government in the form of visible information on the role of the volunteer and the nature of the care duties of the volunteer. This would dispel such role confusion as well as lessen the burden of care for the volunteer. Social bonding and building trust between the volunteer and community members would also become necessary to decrease the negative effects that the burden of care has on the volunteer health.

## 5.3 The Stigma of AIDS

AIDS stigma played a negative role in the accessing of patients. In some cases volunteers had to rely on rumours circulating through the community about the potential patient's illness. Volunteers would then approach the patient and informally discuss their role in the community with the patient and his/her family.

Help could only be offered when the potential patient accepted it from the volunteer. This is consistent with Akintola's (2008a) study dealing with how volunteers cope with the challenges of their care work in. In Akintola's study family members of the potential patient would sometimes deny that there was a sick person living there due to fear of stigmatization. The negative connotation linked to a rumour or gossip may place further strain on the relationship between the volunteer, patient and the community. The implications of this are that a further lack of trust may develop which would encourage nondisclosure. This would ultimately fuel further rumours and place more strain on an already tense relationship between the volunteer and the community.

Issues of social cohesion and social bridging become highlighted at this point as the community members may have fuel the feelings of isolation and loneliness experienced by the volunteers due the stigmatizing way in which they treated the volunteers. This is consistent with Mwinitou's (2006) study on the stigma experienced by Ghanaian caregivers of PLWHAs in Ghana. In light of the stigma experienced by the volunteers there is a need to bridge the relationship between the volunteer and community in the form of educating community members on HIV/AIDS as well as the nature of the care work of the volunteer. This social bridging will in turn encourage the community to come together to provide support for the ill if necessary in the form of helping to transport the patient or helping to provide food to the patient if the need arises.

In view of Kalichman and Simbayi's (2003) quantitative study concerning attitudes on AIDS related stigma and voluntary HIV counselling, stigma affected both patient and

volunteer in different aspects. Patients experienced observable stigma from their own families in some cases as well as their community members. Community members preferred not to associate with them and offered no support whilst some family members blamed the patients for bring the illness on themselves stating that the patient's disobedience to their elders and fast paced lifestyles resulted in their illness. As a consequence, some patient's families refused to acknowledge or care for them. Kalichman and Simbayi's study set in a township in Cape Town further revealed that participants in their study who had taken a HIV test and had a negative result viewed those who were infected as dirty and should be ashamed of themselves. In support of Kalichman & Simbayi's literature, my study revealed that volunteers experienced harsh ridicule and stigma from their community members and sometimes their own family members (regardless of testing) due to the nature of their work. Mwinitou (2006) re-enforces these experiences in that the family caregivers in the study experienced such harsh stigma form the community and health care workers that they refused to disclose the nature of their care work to their extended families and found it easier to completely distance themselves from their friends and family as to avoid any stigma. As a result of this secrecy, the caregivers in this study could not draw on support in any form (Mwinitou, 2006).

Volunteers resentfully described being named *the garbage trucks* by their community members who justified this derogatory name by explaining *that they spent their days cleaning up sick people's mess.* Again, social cohesion among the KwaNgcolosi community is portrayed in a very poor light. The ridicule experienced by the volunteers further adds to the stigma and may have the same devastating effects of isolation, loneliness and depression on the volunteer. More importantly these incidents may play a

major role in volunteers not accessing support from the community for fear of ridicule. Intervention in the form of educating the community on HIV/AIDS transmission and the work of the caregiver may be a solution to the breakdown of social cohesion within the community and in turn improve the community cohesion that is desperately lacking. In other instances, volunteers experienced stigma from their families. The family members of some volunteers would not be touched until the volunteers had washed their hands in bleach and completely disinfected them. To a degree, this finding is consistent with Mwinitou's (2006) study on stigma experienced by caregivers in Ghana. The caregivers in Mwinitou's study were family caregivers and were so afraid of the stigma and discrimination that they would receive from their own families that they did not disclose the nature of their care work.

Wight's (2006) study concerning family caregivers (mothers) found that AIDS stigma forced the caregivers to isolate themselves from society due to the fear of being discriminated against. In agreement, the volunteers in my study avoided seeking help/support from their communities due to the fear of more ridicule and stigma which suggests poor relationships of cohesion and trust with the community members. Instead, they turned to fellow volunteers during their monthly meetings for emotional and informational support. This finding extends knowledge in that it shows that the volunteers also experience the stigma that family caregivers experience regardless of the fact that they may not be infected and are not related to the infected. They experience this stigma simply because they provide care. It is interesting to note that the volunteers experience such

stigma from their own families in some cases. The ridicule experienced by the volunteers suggests a critical lack of emotional support from the community.

Although useful at the time, the effects of the support shared amongst the volunteers may not have be long lasting due to the fact that volunteers had to wait a month between meetings before they are able to discuss issues and often were unable to attend meetings regularly due to patient obligations. Because the other volunteers were experiencing a similar burden it may have compounded their problems as they may not have had the opportunity to be debriefed by somebody who not experiencing that particular problem. This, in turn, may add more of a burden to the volunteers experiencing similar burdens. A possible solution to this may be to educate the families of the patient and volunteer as well as the community members about HIV/AIDS in order to perhaps decrease AIDS stigma. Social bridging and linking between the volunteers, family of the patient, community members and government would be necessary to facilitate the support needed to reduce stigma and the effects of that stigma on the volunteer.

## 5.4 **Patient Neglect**

It emerged from the findings in the previous chapter that in most cases, volunteers highlighted very negative family dynamics between the patient and their families. Neglect was a theme that emerged amongst almost all of the participants. Volunteers described scenarios of complete disregard for the patient to a point where the families no longer referred to their ill relatives by their names but rather as *the patient*. Patients were ignored and in some cases left for days unchanged, not bathed and if they had defecated on

themselves the family members would not touch them until the next visit from the volunteer. These findings are consistent with Akintola's (2008a) study in which stigma formed a major challenge for the caregiver. The caregivers in Akintola's study described the treatment of the patient from their families as stressful for the caregiver to be exposed to (Akintola, 2008a). In some cases, family members locked the patient and fed them on separate crockery through a hole in the door so as not to associate with the patient (Akintola, 2008a). The neglect, and to an extent abuse shown by some family members filtered through to the provision and accessibility of the AIDS grant provided to the patient. Volunteers spoke of being shut out of the relationship with their patient by the family members once they had received their grant. Family members of the patient made use of the grant for their own purposes and once the money was depleted, sought help once again from the volunteers. This is consistent with Akintola's (2008b) study in that the volunteer helps to access the AIDS grant for the patient. However, I have found no literature discussing the family of the patient's abuse of the AIDS grant. This finding suggests a severe breakdown in social trust between the patient, family of the patient and the volunteer. An intervention in the form of promoting social bonding and trust between the above mentioned, would greatly improve the relationships between the patient, family of the patient and volunteer. By doing so, the family members may adopt and appreciation for the AIDS grant in improving the quality of life of the patient and in turn, would not make the volunteer feel exploited.

This highlighted the lack of support provided by most family members of the patient to both relative (patient) and volunteer and may have possibly heightened volunteer feelings of despair and fatigue, further suggesting a breakdown in social cohesion. The families of

the patients consciously did not make any efforts to work together to improve the well being of the patient but rather shirked their responsibilities to a point of exploitation of the patient. Social bonding is urgently needed to improve the relationship between the volunteer and the family of the patient. Family members need to accept their role as the primary caregivers of the patient by accepting basic training from the volunteer as suggested by the literature (Akintola, 2008b). By doing so, this will decrease the burden of care for the volunteer. Social bonding between the families and the patient is necessary due to the fact that the family members had become emotionally detached from the patient. Social bonding can be facilitated by educating the families about HIV/AIDS and transmission. This will improve the quality and quantity of care and also improve the quality of life of both patient and volunteer.

## 5.5 **Poverty**

The living conditions of both patient and caregiver were demoralizing. The consequences of such poverty included deception on the volunteers' part. In most instances volunteers who themselves were experiencing poor living conditions and were unpaid had to take food from their own cupboards in order to feed their patient. In order to do so volunteers hid their actions from their families and more specifically their partners as they were aware of the implications. Such actions were likely to jeopardize the trust between the volunteer and her family as well as diminish the possible support provided to the volunteers by their families. Consistent with Akintola's (2008b) study, patients were often the breadwinners of their families and as a result of their illness were unable to work. Money was no longer being brought into the homes, groceries became a luxury and daily commodities were no

longer available. Such poverty supports Steinberg et al, 2002 study on the effect of HIV/AIDS on households in South Africa. This suggests that not only were their patients starving but these living conditions were hampering their recovery and placing strain on the volunteer's family relationships. This further suggests that other sources of support such as social networks are not being resourced. By mobilizing social networks (government) and social linking, AIDS grants may become more easily accessible in order for patients to survive and will also lesson the burden of care with regards to the volunteers deceiving their families in order to take food to the patient.

## 5.6 **Social Support Provided**

Although the burden of care weighed heavily on the volunteers they found reassurance in that some support was provided.

Some working materials were provided to the volunteers by their coordinator and although this proved helpful, volunteers noted that the provided materials got finished quickly. Once depleted, the materials were not replaced leaving the volunteers to them make alternative arrangements with whatever materials they could find for example using plastic packets as a substitution for gloves. This placed a large amount of stress and feelings of vulnerability on the volunteers. This finding supports the findings of Mabude et al. (2008) study which focused on assessing home-based care kits and home-based care programmes. The quantitative data was collected in South Africa and the objective of the study was to improve the production of home-based care kits. What the study found was that there was a great demand for the kits, however, home-based care kit content and availability was poor.

The implications of such a finding is that the lack of working materials placed extra starin on the volunteers and created the need for tangible support.

The relationship between patient and volunteer was highly respected by the volunteer in that patient confidentiality was maintained. This strengthened the bonds of trust between the two but placed enormous strain on the volunteer. Due to confidentiality constraints the volunteer unable to share her experiences and gain the support needed for that. As an alternative the volunteers turned to their coordinator for counseling. Their coordinator tried to provide support in the form of informal counseling but due to her lack of training in that field was unable to provide them with the adequate skills needed to cope with the stressful experiences faced. It is suggested that the coordinator be provided with tangible support in the form of skills and training to adequately counsel the volunteers when necessary. It is essential that social networks such as the government, need to recognize the role of the coordinator and provide her with training. This would result in the empowerment of the coordinator and ultimately her being able to provide the emotional support that is needed by the volunteer.

In some cases volunteers obtained useful support from their own family members and discussed positive experiences around the support provided and in some cases referred to the support from their families as '*encouraging*' and '*being the reason for them continuing with their care work*'. In these cases it stands to reason that perhaps the relationships of trust between the volunteer and her family members were sound enough for the volunteer to share certain experiences in order to gain support. This also suggest that in cases such as

these perhaps the family members of the volunteer acknowledged the importance of care work and as a result provided support and motivation when necessary.

An interesting relationship of *support being provided* was that between the volunteer and the healthcare workers. Although some sort of support was provided in the form of materials, it became evident that those volunteers who knew certain health care workers personally were given preference when it came to the provision of the working materials that they needed. Those volunteers who did not know any health care worker on a personal basis were refused access to any working materials. The health care workers behavior may possibly be due resentment of the close knit relationship shared between the volunteer and patient as opposed to the strained relationship between the patient and the health care worker. To an extent these findings are consistent with Mwinitou's (2006) literature in that the volunteers experienced stigma and discrimination from the health care workers. This suggest a further breakdown of social cohesion between the two and intervention in the form of improving social bonding and bridging is suggested in order to bring the volunteer and health care worker together for the health care worker to acknowledge the role of the volunteer and to provide the necessary support to the volunteer.

## 5.7 **Social Support Needed**

The support needs of the volunteers were immense due to the nature of their care work. The main forms of social support needed were tangible and appraisal/emotional support. The tangible support needed included that of financial support in the form of a salary; working materials in the form of protective gear, disinfectants, wound dressings;

transportation to and from their patient's and the provision of first aid, patient care and counselling training. Apppraisal and emotional support needed overlapped each other somewhat and took on form of counselling provided to the volunteer. From the findings volunteers often expressed the need to talk to somebody about their issues but were unable to. Regular counselling of this nature would be necessary form of support. These findings are somewhat consistent with some of the the findings of Akintola (2004). However Akintola's 2004 ethnographic study in Uganda and South Africa focused on the burden of care of both family and volunteers caregivers and one of the objectives of that study was to describe the nature and amount of support available to the caregivers. This study is solely based on the experiences and nature of social support provided or lacking with regards to volunteer caregivers. Furthermore, this study makes use of elements of the social capital framework to identify possible trust issues and reasons for a lack of support from social networks.

The social support needed may have been accessed from various resources. However, important to note is that there was an issue of not asking for support from social networks/organizations among some of the volunteers. Volunteers did not seem to be able to identify with organizations such as religious groups as a source of support and rather associated with these organizations at face value i.e. they saw churches as solely for praying and other religious practices. Perhaps the reason for this was a lack of social trust and social cohesion between volunteers and social networks which resulted in a lack of support provided. The volunteers may not have trusted that the organizations would be able to provide support and as a result, they did not ask. In order to resource support form

organizations, the volunteers and organizations need to come together in a open forum to discuss the needs of the volunteer.

This finding brings into light the urgent need for social bridging between volunteers and organizations in order to facilitate social support. Relationships between social networks and volunteers need to be at a position where volunteers are able to identify these organizations as resources or sources of support.

## 5.8 **Recommendations**

This study identified the main barriers to providing adequate care to HIV/AIDS ill patients among volunteers. These barriers included a lack of tangible, emotional, appraisal and informational support. Moreover, a severe breakdown in social cohesion amongst community members, social trust and social networks emerged from the findings. Based on the above, the following recommendations are proposed.

### 5.8.1 **Stakeholders**
In line with the finding that the volunteers experience a lack of support, there is need for mechanisms to be put in place to provide social support to these volunteers as follows:

#### 5.8.1.1 **Tangible**
- *Materials on a regular basis*
  - It is recommended that ample working materials be provided for use by the volunteers on a regular basis.

- *Transport*

- It is necessary for transport to be provided to volunteers perhaps in the form of a mini bus or shuttle to transport them from patient to patient. This will decrease time wasted in commute on foot between patients and will allow more time for care work.

- *Hospice*
  - It is recommended that a working space be provided for the volunteers. This will enable volunteers to work in shifts, provide patients with 24 hour care, all working materials and patients will be in one venue and will also create closer links and working relationships between local clinics and volunteers.

- *Salary*
  - The issue of non- payment was a major source of stress for the volunteer. It is recommended that a payment option be revised by government in order to provide the volunteers with some sort of remuneration for their care work.

5.8.1.2 **Appraisal and Emotional support**

- *Counselling*
  - It is essential that counseling be provided for volunteers due to the traumatizing events experienced by them.

- *Informational workshops (including follow ups)*
  - It is recommended that regular workshops on patient care be provided to the volunteers and conducted and facilitated by nurses from the surrounding clinics.
  - More formalized information (pamphlets) and involve patients as to avoid/ prevent

exploitation.

### 5.8.1.3 Social Networks and Trust

- There is a critical need to improve the relationships of trust and reciprocity amongst the community members and between the volunteers and respective organizations.

- There is an urgent need to mobilize social capital in the KwaNgcolosi community. Before attempts at accessing social support can be made, the immediate focus needs to be on the improvement of relationships of social trust, social cohesion and social networks.

- Interventions need to be facilitated between the above mentioned parties in order to bridge the gap between them. Volunteers need to be made aware of the supportive roles that social networks such as religious groups and health care clinics may have in providing the volunteers with the support they may need.

### 5.9 Areas For Further Research

1. It is recommended that further research be done focusing on national policy and on the training and payment of volunteer caregivers.

2. Further studies are needed to investigate the possible reasons behind the strained relationships between volunteer care workers and social networks as a barrier to the

provision of adequate  care.


3. There is a need for further studies to be done on the role of the family of the volunteer as

a resource of support.

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**APPENDICES**

Appendix A: Letter of Consent

Appendix B: Interview Schedule

Appendix C: Ethical Clearance

Appendix D: Summary of Support Needed by Volunteer Caregivers

APPENDIX A



UNIVERSITY OF
KWAZULU-NATAL

# Informed Consent Form

**Title: Experiences Of Social Support Among Volunteer Caregivers Of People With AIDS in the KwaNgcolosi Community**

**Dear Participant**

You are being asked to participate in a study concerned with the experiences of social support among volunteer caregivers of people with AIDS. The aim of the study is to ascertain if social support is provided to caregivers. The researcher would also like to learn more about the type of support given as well as the accessibility of the support. Participation by you would include a one hour, confidential interview with the researcher.

**With Regards To Confidentiality**

Although the interview will be recorded, it will remain anonymous and confidential. Your name and signature on this form is an acknowledgement and confirmation of your participation, consent and understanding. Although the data will remain anonymous, the results of this study will be used for academic purposes and we thank you for your participation.

_____

Sharl Fynn (Researcher)
Masters in Health Promotion
School of Psychology
Howard College

For the purpose of the study, please tick the appropriate block.

|  | Yes | No |
|---|---|---|
| 1. I agree to participate in this study. | ☐ | ☐ |
| 2. I have been able to ask questions pertaining to the study. | ☐ | ☐ |
| 3. I am satisfied with the information and explanation given to me regarding the study. | ☐ | ☐ |
| 4. I understand that my child is a volunteer and is free to withdraw from the study at will. | ☐ | ☐ |

**Consent**

I……………………………………………………………………(name and surname of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project. I understand that I may withdraw from the project at any time, should I so desire.

_____          _____

SIGNATURE OF PARTICIPANT                    DATE

APPENDIX B

# Semi-Structured Interview Schedule

1. Could you please tell me about your daily tasks/issues as a volunteer?

   - Is there anyone you can rely on to help you with your daily routine duties e.g. providing you with transport, helping you to take care of your patient?

2. Could you please tell me about your other activities and how your caregiving role has affected these activities? (explore routine duties e.g. child care, house chores, social and religious life, informal or formal/temporary work)

   - How do you care for your patient and your family/personal wellbeing at the same time?
   - Does your care work impact negatively or positively on your family and spiritual life?
   - Are you able to formally work over and above your care work?

3. What kind of support do you need regarding each of your 1 tasks and 2 other activities affected or foregone as a consequence of care work? (explore tangible, emotional, informational, appraisal forms of support for each of the tasks mentioned above).

   - Does your family understand or make you feel good about your caregiving ?
   - Do you perform your tasks alone?
   - Do you have someone who you can talk to about the kind of support that you need?

4. What is the nature/ kind / type of support that you, as a volunteer receive and from whom? (explore tangible, emotional, informational, appraisal support for each of the tasks mentioned above in question 1 and 2.

   - How do you perform your tasks/duties every day?
   - Do you have help from your community members e.g. providing transport, looking after your patient while you are away performing task?

5. How useful are these forms of support to you? (explore the usefulness of each form of support for each form of care task carried out)

   - How helpful is a member of your community coming to visit your patient to you?
   - How helpful is the more physical support like lifting of your patient, cleaning wounds, bathing of your patient to you?
   - How useful is the more emotional based support e.g. getting re-assurance from people like community members or your family to you?
   - How useful is support provided in the form of counseling for you?
   - How useful is getting information from a peer who can relate to your job to you?

6. Trust: How much can people in this community be trusted to provide support? (explore all forms of support for the various care-related tasks). Have there been any incidents that have encouraged or discouraged you? Explain or describe these incidents.
   - How much do you trust people in this community to take care of your patient while you are away?
   - How much do you trust members of your community to take care of your family while you are busy with your care work?
   - How much do you trust community members with your confidence? Can you talk to them about your caring work?

7. How helpful are the following in providing support to you and to family caregivers and the patients? National government, provisional government, local government, traditional leaders, health system, public services, NGO's, the church.
   - What experiences have you had with;
     national government, provisional government, local government, traditional leaders, health system, public services, NGO's and the church that have made your care work encouraging or discouraging?

8. Social Cohesion: To what extent do you think that people in the community would come together to help families affected by HIV/AIDS. For example, to cope with orphans of AIDS, provide support for funerals, transport, donating food, toiletries, money etc? (probe for all the situations that require support)
   - How likely do you think it would be for people to provide support in the form of taking care of /providing shelter for the orphans of AIDS?
   - Do you think that community members would be supportive in the form of providing counseling for the affected families?

9. What groups do you belong to? How important are they to you? To what extent can you rely/depend on them for support in your care work and/or in providing support in other work affected by care work?

   - Are these groups reliable and available if you need support?

10. Could you please tell me about the support that you would like but are not receiving?

    - Where do you think support is lacking with regards to your care work?

11. Who would you like to provide you with support?

    - Is there anyone who you can rely on?

    - Is your community generally of a supportive nature?

12. What do you think is preventing these people from providing you with the support you need?

- What do you think are the obstacles preventing you from getting the support that you need?

**APPENDIX C**

**Ethical Clearance Form**

APPENDIX D

## SUMMARY OF THE TYPE OF SUPPORT NEEDED BY VOLUNTEER CAREGIVERS

| Daily tasks of caregivers | Type of support needed by caregivers related to task | Type of social support mentioned in conceptual framework | Perceived Support Lacking | Social Cohesion (togetherness of families) | Groups and Community Network | Social Solidarity (integration shown by a group or society) | Who Would You Like Support to Come From | Who Should Support Come From | Repercussions of Care Work on Volunteer's Family | How is Volunteering Creating a Need for Support For the Volunteer |
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| **Lifting of patient** | - help when lifting.<br><br>-better knowledge of proper techniques of lifting as to avoid injury to herself. | -**tangible** support (lifting aids e.g. harness).<br>-**informational** Support (information provided by health professionals regarding better lifting practices to protect the caregivers physical health). | **Government** (government not giving DOH enough funding therefore we see a ripple effect with a lack of resources in Clinics etc.)<br><br>- **Lack of human resources** (not enough nurses / health workers to visit volunteers or to maintain skills<br><br>training workshops with them. | - family members can be shown by the volunteers how to lift the patient and do so when help is needed. | -trusted community members who are aware of the patient's routine may visit when their help is needed to lift the patient. | -community church workers can provide aid in the form of physical help or perhaps sewing/making harnesses as part of the women's club projects. | community members.<br><br>-family members. | -health department should ensure that volunteer kits are fully equip and made available to the volunteers. Regular visits by professional health workers should be made in order to source out what is lacking.<br><br>- health department should hold regular update workshops with volunteers in order to provide/ refresh the necessary skills needed. | - | - |
| **Cleaning** | - correct | -tangible | - family | -family | communities | -community | - clinic's. | -local clinic's | | |

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| **wounds** | protective wear e.g. gloves.<br>- correct disinfectant / application. | support (caregiver kits). | - clinics | members living with the patient should be shown how to properly clean a wound in order to help the volunteer as well as perform this task when the volunteer is not available. | can provide support in the form of lending the volunteer disinfectant/plaster if she runs out and they have some available. | churches/NGO's can make attempts to provide the relevant disinfectants through donations. | -hospitals | and hospitals need to ensure that the volunteers are provided with gloves, bandages, disinfectants etc. and also need to make volunteers aware of other alternative in order to create skills e.g. using slat water if there is no disinfectant and using plastics bandages to protect their hands if there are no gloves available. | - | - |
| **Bed bathing** | - proper materials (disposable sponges etc).<br><br>-disposable plastic sheeting. | -**tangible support**.<br>-**appraisal support** (being exposed to bed sores etc may require counseling of the caregiver in order to help her to better cope with the process). | - clinic (supplies)<br><br>- family (help)<br><br>- trusted friends.<br><br>- NGO's (counselors) | -family members can take turns to help with this process by helping to turn the patient while the volunteer is bathing him, emptying out the dirty water while the patient is being clothed by the volunteer. | | -church groups/NGO's may be available to provide counseling if needed by the caregiver. | -family members.<br>-local clinics. | -health sector must ensure that ample disposables are made available to the volunteer for activities such as bed bathing. | - | - |
| **Toileting** | - gloves.<br>- anti – bacterial | -**tangible support**.<br>-**appraisal** | - family (physical help) | -the patient may feel more comfortable | -neighbors of the patient may support | - NGO's can donate things like toilet paper | - family and community | NGO's , the health sector, AIDS grants. | - | - |

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| | surface cleaner. | **support** (to aid with better coping skills with regards to the process experienced). -**emotional support** (positive re-enforcement from family and the community may be needed in order to remind the caregiver of her value to society). -**informational support** (views and experiences of others in order to facilitate a smoother process). | - government (AIDS grants) - community members (emotional support) | having a family member help him/her in the toilet. Support from family may be provided in this way. -volunteers may also need support form family members of the patient in the form of helping the volunteer to walk the patient to and from the toilet. | in the form of helping to replace things that are needed but are finished e.g. If the house runs out of toilet paper or disinfectant for the toilet. | or detergents to these families. | | | | |
| **Praying with patients** | -prayer book. | -**tangible support** in the form of prayer books. -**emotional support**. | - NGO's (counselors) - church -friends (community) | - family members could designate a time to spend in prayer with the patient while the volunteer takes care of other things. | -community member could have special prayer evenings with the patient. Spend half an hour praying for and with the patient. | -local churches could donate bibles or generic prayer books. -priests could deliver the host in the home of the patient. -the priest could provide emotional/spiritual support in the form of confession for the volunteer. | -family of the patient and local church. | - church , without imposing that particular religion. | - | - |
| **Counseling** | -counseling skills / | **informational support** (skills | - clinics | -family may show support in | - trusted community | -NGO's and local clinics may | -trusted community | - Counselors provided by | - | - |

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| knowledge. | building in order to provide counseling). -**emotional support** (in order to reinforce the caregivers value to society). | - NGO's (councilors) - friends | the form of positive re-enforcement of the volunteer. | members may provide counseling in the form of informal advise to the volunteer. | have professional counselors available for volunteers as well as provide skills training in order to equip the volunteer for counseling both patient and her family members. | members to provide emotional support. | No's and clinics. | | |
| **Taking care of the patient's family e.g. children** | -groceries to prepare Meals. -electricity or candles to assist with the children's schoolwork. | -**tangible** (AIDS grant to purchase groceries in order to feed the patients family as well as pay the necessary Bills). | - friends - government (grants) - community members | -family members to help with the preparation of meals to facilitate a speedy process. | -trusted community members can prepare certain meals while the volunteer helps the patient's children with their homework. | -babysitting service can be offered by church groups. | -family members. -community members. | -family members. | -this lessons the time spent with the volunteers own children. | -result in needing community members to help by taking care of volunteers kids. |
| **Household chores** | -cleaning agents including brooms, cloths etc. | -**tangible support** (Aids Grant to make such Items attainable). | - family of patient. | -family members can show support by maintaining the cleanliness of the house. | - can show support by donating or lending brooms etc. | - NGO's can donate cleaning agents , brooms etc. | - family members. | -family/ community members. | - | - |
| **Grocery shopping** | -transport to get to and from the market. | -**tangible support** (in the form of transport. Special bus service etc.) | - community members. - friend (to provide transport or just extra hands). | -can accompany the volunteer to help with groceries. | -community members with cars can provide lifts to the supermarket. | -church buses or taxi's can provide a shuttle service. | community members. | -health department should have transport available for trips to the supermarket, and home affairs to collect AIDS grants etc. | -volunteer may not be able to get groceries in a timorously manner for her family. | -basic household and family responsibilities now shift to members of the community. |
| **Paying of** | -transport to | -**tangible** | - friends | -family | -community | -members of | community | -Health sector. | -bills may run | -same as above. |

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| **financial bills etc.** | facilitate this process. | **support** (transport). | -government | members can take responsibility for certain bills. | members can look after the patient while the volunteer pays the bills. | church groups can take care of the patient while the volunteer pays the bills. | members. | | into arrears due to time spent taking care of the patients bills. | |
| **Arranging/ planning of patient funerals** | -money (for the cost of the funeral. Coffin, burial plot etc.) -transport for family members of the patient. -food for the people attending the funeral. | -**tangible support** (money, donations in the form of food, transport, coffin etc.). -**emotional support** (positive re-enforcement from community members) -**appraisal support** (provision of counseling for family members of patient as well as volunteer.) | -community members | -family members can assist the volunteer in sourcing donations form community members. -community members as well as family members of the volunteer may provide positive reinforcement to both the family members of the deceased as well as the volunteer respectively. -NGO's, health clinics may provide counseling to both volunteer and family of the deceased. | -community members may take care of the smaller kid's needs during this time. -community members may offer support in the form of transport. | -NGO's to donate consumables such as food. --churches to donate a plot of land for burial. | -community members -family members | -government (make the process of collecting AIDS grants a more user friendly one). -health clinics (counselors). -health department (social workers to attend to AIDS orphans). | -volunteer may experience depression due to the death of her patient. May in turn act out on family. | -volunteer's experiences would require counseling for both the volunteer and her family. |
| **Volunteer family issues:** organizing someone whom you trust to take care of your kids while you are caring for | -trusted community members or family members to support in this way. | -support in terms that the volunteer has someone who she can always **RELY** on. -**emotional support** (positive reinforcement | -friends -community members. | -family members of the volunteer or older brothers or sisters may care for the younger children in the family in terms of homework, cooking, walking | -trusted community members may provide support by taking turns to supervise the children of the volunteer. -community | -NGO's, churches etc may offer support in the form of an after care facility for the children of the volunteer where a meal is provided as well. | -family members. -community members. | - family -community -NGO's | -having to trust somebody else to take care of/ take on mother role of her kids. | - amount of time spent caring for her patient and time spent away from her own family could leave the volunteer feeling guilty as well as the family of the volunteer feeling rejected, |

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| your patient. Supervision, preparing meals, helping with homework etc. | | of the volunteer as well as her family members; reinforcement of mothers love for her kids. | | to/fetching from school. | members may assist in the form of taking the children to school. | | | | | Counseling. |
| **Arranging transport /help to fetch children from school if necessary.** | -community/ family members to accompany / provide transport for the children of the volunteer. | tangible support -transport<br><br>**SOCIAL COHESION SUPPORT** -community members / family to walk children to school. | -community members | -family/ community members to aid with accompanying the children to school. | -community to take turns taking kids to school. | -NGO's may provide transport to the kids in a localized are/ community. | -family<br><br>-community | -NGO's<br><br>-family<br><br>-community | - having to trust somebody else with her child's safety. | -putting trust in community members to take care of the children. |