Caring for people with HIV/AIDS

A qualitative study of motivations and experiences of voluntary care workers in South Africa

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ABSTRACT

This study seeks to explore the motivations and experiences of voluntary care workers for people living with HIV/AIDS in semi-rural Kwa-Zulu Natal, South Africa. Social capital offers a framework for investigation, and the main focus is on the positive experiences of volunteering. Twelve Zulu women from groups of volunteers in Clermont and Impola (townships), having at least one year of experience, were recruited. In-depth, semi-structured interviews were carried out, and the responses were thematically analysed. Among motivations for volunteering three themes were evident: 'Community concern, love for people and ubuntu', 'Gain and share knowledge', and 'Work satisfaction'. The volunteers had both negative and positive feelings and experiences related to their work. They talked about hardships and challenges in the work, but also a great deal about rewards, personal growth, and how they would like to continue doing this care work in the future. Exploring how the volunteers perceive and draw up on social capital in relation to their care work revealed that networks are a vital source of social support, trust and solidarity are important, feelings of empowerment were evident, and suggestions for how the government could improve HIV/AIDS care and support in the communities were proposed. A discussion of how we can understand the relation between the motivation, the positive experiences and social capital in this South African context was presented, and finally implications and recommendations for how the volunteers can be better supported were made.

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Umuntu ngumuntu ngabantu – a person is a person through their relationship to others.

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1. INTRODUCTION

1.1 HIV/AIDS CARE IN SOUTH AFRICA

AIDS is the leading cause of death in South Africa (Orner, 2006). The estimated number of people living with HIV/AIDS was 5,7 million people in 2007, which is more than 18 % of the adult population in the country. Only 28% of these are estimated to receive any antiretroviral therapy. The estimated number of deaths due to AIDS was 350 000 adults and children in 2007. KwaZulu-Natal is the province in South Africa with the highest overall HIV prevalence rate, where over 19,2 % of the population is living with HIV/AIDS (UNAIDS/WHO, 2008).

In spite of, or perhaps because of, this ongoing epidemic, the South African government seems to be having difficulties with organizing proper health care and support for the sick people. One particular factor impeding the care in this context has to do with the aftermath of apartheid in South Africa: The institutional change processes have restrained the implementation capacity of the government (Campbell, 2004). Another important factor is the lack of human resources in the formal health care services (Kober & Damme, 2004). The enormous number of people infected with HIV/AIDS has increased the need for care, and over 80% of hospital admissions are related to HIV/AIDS. Antiretroviral (ARV) treatment procedures are labour-intensive, but simultaneously there are huge staff shortages. Health workers are themselves victims of the epidemic: Even they fail to seek aid, they pass away, and the ones who remain have to deal with higher work loads and the fear of getting infected; causing stress and job dissatisfaction. This situation contributes to South Africa's brain drain, with thousands of health workers leaving the country. Many hospitals thereby lack capacity to take care of HIV/AIDS patients, leading the government to promote home-based care (HBC) for these patients (Akintola, 2006). This means that families and communities are taking the main responsibility for the care and support of people living with HIV/AIDS (PLWHA). HBC is defined by The World Health Organisation as «the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death» (cited in Campbell, 2004). The South African government

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has made HBC a national priority health policy. Aside from reducing the burden of HIV/AIDS on the hospitals, the aim of the government in fostering HBC is to reduce the cost of hospital care. This assumption of HBC being cost-effective has been questioned; taking into account all the hidden costs of the people who actually provide the HBC, for no pay (Akintola, 2008b). Ogden, Esim and Grown (2006) have criticized governments globally of generally taking for granted the care work of volunteers, and they call for a more coherent and complete care agenda among policy-makers, valuing unpaid HIV/AIDS care work.

It has been argued that HBC projects have its advantages as long as no cure for AIDS exists: Provided they are efficient and affordable, they can alleviate the load of hospitals, and have health and social benefits for the sick and their families; such as receiving compassionate care and social support from local community members (Chimwaza & Watkins, 2004; Nsutebu, Walley, Mataka, & Simon, 2001; Seipel, Sorenson, & Roberts, 2007). According to Campbell (2004), HBC offers the setting most suitable to dying patients' needs, in the context of developing countries with restricted access to medical treatments. Another reason for HBC being so prevalent in South Africa is the lack of proper knowledge and severe stigma surrounding HIV/AIDS; making families care for their sick ones in secrecy (Akintola, 2008b). HBC can be a useful way of counselling and educating about HIV/AIDS amongst people, in the fight against stigma. It could thus promote acceptance of AIDS patients in the community, as caring for dying people in communities rather than in secluded hospital settings promotes first hand awareness of the dangers of HIV. Local networks of carers could possibly mobilise others to lobby for the interests of PLWHA. Such mobilisation could enable people to influence wider government policies, and generate community solidarity; which then again could strengthen communities' abilities to deal with other challenges (Campbell, 2004).

Caregivers usually consist of family members of the ill person and/or volunteers from community-based organizations (CBO) working with HIV/AIDS. Most of these caregivers are females of all ages, with a general lack of male participation. Studies show that care of the sick accounts for an extensive part of the burden that HIV/AIDS inflicts on communities and families, disproportionately affecting women. This gendered separation of caring roles reflects the pre-existing gendered nature of and societal expectations about household and care work (Akintola, 2006; Campbell, 2004; Chimwaza & Watkins, 2004; Claxton-Oldfield, Jefferies, Fawcett, Wasylkiw, & Claxton-Oldfield, 2004; Ogden et al., 2006). Volunteer

health workers were identified as the most important community resource in a study of community responses to HIV/AIDS in a rural community in KwaZulu-Natal (Campbell, Nair, Maimane, & Sibiya, 2005). These women, nearly all unemployed, facilitated informal HBC, and they were the only group, besides family, that offered direct care and support to PLWHA.

A survey of 771 AIDS affected households in South Africa documented the devastating impact of HIV/AIDS on already poor people (Steinberg, Johnson, Schierhout, & Ndegwa, 2002): The poorest South Africans are the ones most vulnerable to HIV/AIDS, and they are the ones suffering the most severe consequences. These households are also those most underserved by basic public services: Only 43% of the surveyed households had piped water and nearly 25% of the rural households had no sanitation. As many lack electricity as well, these are harsh conditions for both the PLWHA and their caregivers. In his study of volunteers in KwaZulu-Natal, Akintola (2004) argues that care giving for PLWHA is very demanding and stressful. He identified four categories of stress: Physical, psychological/emotional, economic and social stress. He concludes that there is a tendency to focus exclusively on financial and material burden of care giving, neglecting the physical and psychological stress.

There is also a general tendency to focus predominantly on the negative aspects of voluntary care giving for PLWHA. In this study I am in search for a more holistic approach to the subject; giving room for both positive and negative aspects of voluntary care giving for PLWHA. Fredriksen-Goldsen (2007) have asserted that in order to develop interventions that seek to decrease risk and increase the capacities of caregivers it is fundamental to treat care giving as a multidimensional construct including both negative and positive outcomes. Based on my findings I will make some recommendations for how care giving within a South African context can be better supported.

1.2 VOLUNTEERISM

Omoto and Snyder study volunteerism as a source shedding light on pro social action, and they define 'volunteerism' as involving "people choosing to help others in need. Moreover, their acts of helping are ones that have been actively sought out by the volunteers themselves and that are often sustained over extended periods of time and considerable

expenditure of time and effort…it is a form of helping that occurs without any bonds of prior obligation or commitment to the recipients…" (Omoto & Snyder, 2002, p. 847). They developed a conceptual model which seeks to describe volunteerism as a phenomenon that builds bridges between many levels of analysis and that unfolds over time. These levels include individual, interpersonal, organizational and broader societal levels. Considering the broader social contexts and systems in which voluntary activities are embedded, Omoto and Snyder consider community as both context and process for volunteerism. Omoto and Snyder define community beyond the context of the geographically bounded area: "Community is a psychological entity or conceptualization that we believe is likely to have significant consequences for understanding voluntary efforts and broader civic participation" (Omoto and Snyder, 2002, p. 848). In short: Volunteers are embedded in a community context which both influences the volunteer process and can be the target of volunteer efforts. Communities and a psychological sense of community encourage people to volunteer and connect them to service organizations, other causes and other individuals.

1.3 MOTIVATIONS FOR VOLUNTEERING

Why do some people choose to volunteer? What makes it worth the effort? Evidence that volunteers are more satisfied with their life than non-volunteers emerged as Meier and Stutzer (2006) studied the rewards of volunteerism. They reported that generally there are two views concerning the causes of people's happiness: 1) Helping others increases happiness; and 2) people who pursue their narrow self-interest become happy. The authors further discuss the different motives for helping others; in particular intrinsic and extrinsic reasons, which may have an effect on the degree of joy generated by the activity. When volunteers receive an internal award as a direct result of their activity and/or from the outcome of the voluntary work, they do it out of *intrinsic motivation*. People enjoy helping others, so no other material reward is necessary to motivate them. People volunteering instrumentally, do it for *extrinsic reasons*. They see volunteering as an investment and anticipate external benefits or payoffs. Helping others is less important and there are little to none direct positive feelings from helping other people. For most people the benefits of volunteering will most likely be a combination of these rewards (Held & Brann, 2007; Meier & Stutzer, 2006).

Meier and Stutzer presented empirical evidence on the relationship between volunteering and life satisfaction. They studied the issue of causality based on the collapse of the German Democratic Republic (people's opportunities to volunteer were changed by an "exogenous shock"). Previous studies have had problems isolating the most rewarding aspects of volunteering and drawing any conclusions. Meier and Stutzer's study on the other hand, relied on a large data panel set and extended over a 14 years period. The statistics showed a positive relationship between volunteering and life satisfaction. People who never volunteer report the lowest scores of life satisfaction. The study controlled for individual characteristics, individual heterogeneity and other factors influencing life satisfaction. Analysing the relation between life goals and the effect of volunteering on life satisfaction showed: 1) People who put more emphasis on extrinsic goals relative to intrinsic goals are less satisfied with life, 2) volunteers rate intrinsic goals as more important than extrinsic goals, and intrinsically oriented people are more prepared to volunteer, and 3) intrinsically oriented people obtain more benefits from volunteering than extrinsically oriented volunteers. The study concludes that *helping others increases people's individual well-being* (Meier & Stutzer, 2006). This study must also be appraised in the light of being conducted within the western world. The terms well-being, life satisfaction and happiness do not necessarily have the same meaning in the language and culture of a South African context as in our western understanding. Even within our own culture it can be challenging to clarify the terms, as they often are used interchangeably; also with other terms, like quality of life. Peterson (2006) seeks to clarify: 'Quality of life' as an overarching label that includes all of the emotions, experiences, appraisals, expectations and accomplishments that form into the good life. The more specific notion of 'subjective well-being' is often identified as 'life satisfaction', and defined as quite high levels of positive affect, quite low levels of negative affect, and the general judgement that one's life is good. 'Happiness' is often used in more popularized presentations as an everyday synonym for all of the above concepts. Another similar term is 'wellness', often used as a label of the broad state of health. The question still remains whether these concepts have the same meaning universally, or whether they are culturally bound.

The categorisation of intrinsic and extrinsic motivation have been emphasised in the literature on voluntarism, typically labelled as altruism and self-interest. Claxton-Oldfield et al. (2004) challenges this two-category model, and propose four dimensions of motives: Leisure, Personal Gain, Altruism and Civic Responsibility. Within these factors they found

different reasons for volunteering, where as helping to ease the pain of the sick was rated the highest.

Altruism might be equivalent to 'ubuntu' in the South African context. *Ubuntu* is explained as an African ideology or philosophy involving humanity and togetherness between people, meaning "a person is a person through their relationship to others. Ubuntu is recognized as the African philosophy of humanism, linking the individual to the collective through 'brotherhood' or 'sisterhood'. It makes a fundamental contribution to indigenous 'ways of knowing and being'. With differing historical emphasis and (re)contextualization over time and place, it is considered a spiritual way of being in the broader socio-political context of Southern Africa" (Swanson, 2007, p. 55). Both Nelson Mandela and Archbishop Desmond Tutu have been known to promote the meaning of ubuntu. Aside from being a collective way of living, it may be a vital part of individuals' sense of self; their personal and social identity.

Getting involved with HIV/AIDS volunteerism was found to be motivated by two factors in an American study: One as a reaction to the widespread societal views on HIV/AIDS; to be able to spread the word about HIV. The other factor was partly altruistic; it was perceived to be important to help others, and at the same time it provided further meaning for the experience they were going through or had gone through (Carlisle, 2000).

Omoto and Snyder (2002) examined volunteerism in the USA, and identified five primary motivations for AIDS volunteerism: Some volunteer to express personal values or to satisfy felt humanitarian obligations to help others (tended to be endorsed most strongly), some do it out of community concern, some volunteer in search of greater understanding of HIV/AIDS, some have reasons related to personal development (e.g. challenge themselves), and some seek to fulfil esteem enhancement needs (e.g. feel better about themselves). Volunteers also claim that their experiences have powerfully affected and changed them. Experienced volunteers showed increased knowledge about safer sex practices and AIDS-related issues, and less stereotyped beliefs about PLWHA. People get involved in AIDS volunteering with certain needs and expectations (Crook, Weir, Willms, & Egdorf, 2006). Values, experiences with human suffering and community connection were found to be among the reasons for volunteering in a Canadian study. By and large, AIDS volunteerism is enacted by different people to serve different goals, psychological functions, or motivations.

The Values in Action (VIA) Institute in USA, developed the VIA Classification of Character Strengths to measure "good character" (Peterson, 2006). Among the virtues in this classification are the strengths of *humanity*: Positive traits manifest in caring relationships with others, through for example kindness: Doing favours and good deeds (the school of positive psychology argue that doing good deeds will boost happiness and well-being), helping and taking care of other people. These strengths are interpersonal, while another, more social, group of virtues is the strengths of justice: Relevant to the optimal interaction between the individual and the group/community. One example is fairness: Treating everyone the same according to ideas of justice and giving all a fair chance. I believe that these character strengths are relevant when discussing motivations for volunteering, in particular the strengths of humanity, which relate closely to the African idea of ubuntu.

Who are the AIDS volunteers in South Africa? Marincowitz, Jackson and Fehrsen (2004) studied volunteers who remained active over some time in a South African HBC project. They identified factors associated with active volunteers: If the volunteers were female, over 30 years of age, married and self-employed, or had a husband as the breadwinner; it would be more likely that the volunteers stayed active. They found the volunteers to be strongly motivated by their desire to help their own community. Akintola (2004) examined the socio-demographic characteristics, socio-economic status, motivations and caring activities of family and volunteer caregivers in a semi-rural setting in KwaZulu-Natal. He found that only one of 20 volunteer caregivers in his study was a male, and that the care givers generally were poor, with the lack of employment as one reason for joining the volunteer programme.

1.4 NEGATIVE ASPECTS OF DOING VOLUNTARY CARE WORK

Existing literature on volunteerism in Africa has focused primarily on the negative aspects. Akintola (2008a) found "defying all odds" to be the overall theme in the way volunteers coped with their challenges. Findings from this South African study included volunteers experiencing denial and stigmatization of patients by their families; this discrimination being a constant stressor for the volunteers. For example some families would lock up the patients, denying they had an ill person there, because of the fear of being stigmatized. Others would insult the volunteers, and suggest that the care given was of no

value. Other stressors included dealing with patients' moodiness, anger and unreasonable demands, the physical condition of patients (bedridden patients in wretched condition), and not being able to alleviate any pain of the patients; a discouraging and emotionally draining experience making it hard to continue (Akintola, 2008a; Campbell et al., 2005; Chimwaza & Watkins, 2004).

Akintola (2006) studied the health burdens that HBC places on women in KwaZulu-Natal, and divided the findings into three categories: Risks, physical and emotional/psychological burdens of care. Among risks related to caring for PLWHA are risks of infection with HIV and tuberculosis (TB), and risks of physical and sexual abuse (Lindsey, Hirschfield, Tlou, & Ncube, 2003). Uys (2002) reported from a study of a home-based AIDS care project in South Africa of cases in which the care givers were not safe when visiting the home of patients: Some of the patients and their families abused alcohol, and others had psychiatric conditions making them psychotic or anxious. The carers found these situations difficult to deal with as their training did not adequately prepare them to handle such problems. Most of the participants in the study of Akintola (2006) reported experiencing some form of physical burden: headaches, body aches, backaches and physical exhaustion were frequent problems. Many care giving tasks are physically very strenuous; for example bathing patients and having to walk long distances. Also, the volunteer caregivers experienced work overload and burnout as a consequence of trying to reach all the sick people in need for care in the area. The study found agreement among the caregivers about the emotional and psychological consequences. Common signs included tearfulness, nightmares, insomnia, worry, anxiety, fear, despair and feelings of hopelessness. The psychological consequences were classified into sub-themes: *Empathy and feelings of guilt*: Constant worry about patients' suffering led to sleepless nights and nightmares. Inability to provide any cure caused guilty feelings. *Fear and distress about the state of patients*: Bathing and cleaning of sores, and patients' expression of pain, highlighted the deteriorating state and imminent death of patients, causing a constant emotional trauma for the volunteers. *Identifying with patients' symptoms and pain*: Seeing the symptoms and suffering of AIDS daily was a constant reminder that others with the disease, including themselves, would go through similar experiences; a source of psychological trauma. *Worry about patients' illnesses and imminent death*: Parents reported feelings of enormous emotional stress while caring for their children or witnessing their death. Infected people worried about who would care for their children after their own death. *Consequences of emotional trauma*: Frequent

experience with death of patients was extremely emotionally disturbing, and haunted the care workers constantly. *Severing emotional bonds*: The special relationships between volunteers and their patients (they often bonded closer than family members) made the death of a patient very traumatic for the volunteers, and typically there were no one to support them. *Carrying the burden of non-disclosure*: Stigma and discrimination made many patients keep their HIV status a secret for their family, and the volunteers had to keep it secret, even after the patients' deaths. Caught in-between patients and their families, the pressure from family members to tell, created a heavy psychological burden on the volunteers, who had to lie about the cause of patients' illness. *Emotional impact of the socio-economic context*: Psychological stress caused by worrying about their own financial situation as well as their patients'. These classifications of the emotional consequences of care convince us of the burden HBC places on women; undermining their health and well-being, and maintaining gender inequalities.

Other studies, both South African and American, support the notion that care giving for PLWHA place considerable emotional demands on the caregivers, negatively impacting their mental and physical health. Caregivers often feel overwhelmed by the care work, on a practical and emotional level, despite receiving helpful support (Chimwaza & Watkins, 2004; Orner, 2006). Challenges include stress; caused by poverty, poor infrastructure and difficulties accessing health services; and the experience of stigma towards both themselves and the patients, heightening their distress levels. Specifically, many report that the reactions of members of their own social networks have caused them to feel embarrassed and uncomfortable because of their AIDS volunteerism (Snyder, Omoto, & Crain, 1999). Equipment problems and carers feeling that their role and status are not respected by the formal health services are other negative aspects (Uys, 2002). A longitudinal study of drop out and burnout in AIDS volunteers in the USA found that stress, in the form of client problem, role ambiguity, emotional overload and organizational factors, significantly predicted drop out amongst volunteers. The emotional rewards of volunteering did not prevent these volunteers from leaving (Ross, Greenfield, & Bennett, 1999).

The results reviewed above give us insight into physically and emotionally demanding workdays of being a volunteer caregiver for PLWHA. Despite all odds many volunteers keep on caring and working – for no retribution, and risking their own health. This points to

some sort of rewards and positive experiences being involved, making the volunteers carry on.

1.5 POSITIVE ASPECTS OF DOING VOLUNTARY CARE WORK

Carlisle (2000) reports on *the search for meaning in HIV and AIDS*, as the way carers find meaning in, and balance the costs and rewards of care giving. This American study focused on the experience of informal/primary care givers. These carers placed great value on getting involved in the broader field of HIV work, not just caring for family members or friends. This helped the carers find meaning in the experience of being affected by HIV. HIV/AIDS had in different ways brought a positive and enduring contribution to the personal lives of the carers; like personal growth, and a reappraisal of their own feelings and the way in which they acknowledged and expressed them. The search for meaning was a positive and essential aspect of caring for PLWHA; they found meaning both in their own lives, in the quality of their relationships with the ill person, and it led them to reflect on and react to stigma in the society. HIV had led to a change in the value system of the caregivers, triggering the growth toward a new and more authentic way of living. This reappraisal of values and restructuring of their lives are seen as positive aspects of being affected by HIV; a phenomenon called "the gift of AIDS" (Carlisle, 2000). Although these results originate from a study conducted in the western world, they may still be relevant in understanding the experiences of carers in other parts of the world. The search for meaning in whatever challenges life brings us is almost certainly a universal issue concerning all humans, no matter the culture.

Reasons for continuing helping may differ from reasons for initiating involvement in that continuing motivations are more related to effects and benefits of the work, versus the more personal reasons, e.g., values, in the initiating stages (Stewart & Weinstein, 1997). One factor Stewart and Weinstein found in their study was connection; connection to their own community, to fellow volunteers and to clients. Another factor for continuing was coping; in the way that involvement helped the volunteers deal with the pandemic's effects on their lives and communities. Also the learning of skills and leadership kept the volunteers going. The rewards of volunteering have been supported in other studies as well. For example did Crook et al. (2006) find in their Canadian study that rewards included improved

skills and abilities, improved health, individual growth and the opportunity to participate in decision-making.

Post (2005) presents a summary of data on altruism and its relation to health, and concludes that there is a strong correlation between the well-being, happiness, health and longevity of people who are emotionally kind and compassionate in their helping activities, as long as they are not overwhelmed. "A generous life is a happier and healthier one" (Post, 2005, p. 73). Eight benefit themes associated with HIV/AIDS care giving were revealed in an Australian study (McCausland & Parkenham, 2003). The most frequently reported benefit was personal growth in character; reported by 41% of the care givers. The other benefits were increase in understanding of others, positive personality change, increase in knowledge of HIV/AIDS, start of a new relationship, strengthening of an existing relationship with care recipient, sense of satisfaction and achievement, and gained perspective (changed values and view of life). The benefits were also found to be positively related to the frequency of using social support.

Marincowitz et al. (2004) studied HBC-volunteers in South Africa, trying to understand what they perceived to be the factors helping them to continue working as volunteers. Their findings somewhat represented general human motivators: Perceptions of personal effectiveness (gained knowledge and confidence), patients getting better and their appreciation of the volunteers' work, support from the project coordinators and other health workers, and a desire to help their own community (internal motivation). Another South African study reported that HBC health workers (paid a minimal wage) felt that they were really making a difference, and they expressed great satisfaction in their work and in helping others (Uys, 2002). During the data collection it was observed that the health workers seemed to be very successful in enhancing the human dignity of the PLWHA.

While research has carefully identified challenges facing home-based carers, a lot still need to be learned about the community and social contexts most likely to support them. AIDS volunteers rarely work in isolation, but are part of networks in different ways; networks made up of family, friends, neighbours or CBOs. These networks along with the community social structures form a foundation of resources and support to draw up on for the volunteers.

1.6   SOCIAL CAPITAL

'Social capital' is a rather widely defined term which lately has grown in popularity within health research. It has been used to describe a number of phenomena concerning social relations at individual and societal levels. Coleman and Bourdieu referred to social capital as the accessible resources that accumulate to people by virtue of their reciprocal relationship and recognition, and that can be used for different productive activities (cited in Macinko & Starfield, 2001). Putnam stated that social capital facilitate natural cooperation, and referred to the concept as "features of social organisation, such as trust, norms and networks, that can improve the efficiency of society by facilitating coordinated actions" (Putnam, 1993, p. 167). Foley & Edwards (1999) conclude that the concept is best understood as resources plus access. They reviewed 45 articles employing social capital, and found that the literature is quite evenly divided between those operationalising the concept in cognitive terms; as norms, values, trust and attitudes, and those who use a more social structural operationalisation; social networks, organizations and linkages. According to Foley and Edwards the structural interpretations of social capital have demonstrated considerable capacity to illuminate the many ways in which social resources are made available to individuals and groups for benefit, which they see as the prime focus and central attraction of social capital.

Through the years many have suggested different definitions of social capital, and still there is a lack of consensus, perhaps reflecting the complexity of social relations. Definitions vary; some emphasize the individual level, whereas others emphasize social groups. The concept has been criticised for being fixed and adapted to cover so many sorts of relationships at so many levels of analysis that it has lost its true value (Macinco & Starfield, 2001). Lack of consistency and clarity leads to limited comparability between studies, and conclusions about social capital's effect on health should be inferred with caution (Berkman & Kawachi, 2000).

It is argued that health and well-being are likely to be better in communities with high levels of social capital; characterized by high levels of people's involvement in local community groupings (Baum, 1999). Campbell (2004) asserts that there is a serious need for developing conceptual frameworks that will organize and unite the numerous valuable insights on HBC. Many point to the central role of 'partnerships' in creating social contexts

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supporting home-based carers, but it has turned out to be very difficult to promote and sustain such partnerships in reality. There is a need to explore the specific types of relationships that could be suitable in promoting partnerships, and to identify the factors influencing the success of these relationships. As the concept of social capital often is referred to in discussions about what constitutes a health-enabling community context, Campbell suggests this concept as a starting point for such a framework. Social capital research examines the role of informal and formal social networks, and norms of cooperation in promoting local community development; that is, how these norms and networks operate both within a local community and in its relationship to outside networks. As such, the concept of social capital provides a useful framework for exploring and contextualising the situation of voluntary HBC workers.

When applying the social capital framework to HIV/AIDS research, Campbell (2004) assumes that within limits of poverty and stigma, people of marginalised communities are able to act together to improve their situation. Building social capital is considered a key challenge for those working with poor people to improve the life circumstances that make them vulnerable to HIV/AIDS, and which hinder them in their efforts to support the PLWHA. Whether this collective action for improving circumstances is successful depends on the quality of the alliances between the poor people and those who have political influence and better access to resources. The goal would be more equal distribution of social capital.

Campbell discusses three levels of social capital relevant to the relationships most likely to support and facilitate HBC: *Bonding social capital* includes relationships of trust, reciprocity and positive common identity in homogenous groups, e.g., groups of women involved with HBC in one community. These networks provide the women with sources of social support and advice from others in similar situations. *Bridging social capital* includes four types of relationships: I) Bridging relationships across different groups in one geographical community, e.g., relationships between groups of carers and church groups, II) relationships between groups in different low-income communities, e.g., networks of solidarity between groups of carers from different areas, III) links between poor and wealthier communities, e.g., links between local carers groups and church groups from wealthier areas, and IV) networks linking the three above mentioned networks at a national level. *Linking social capital* includes linkages between local community inhabitants and

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representatives of economic and political institutions, e.g., alliances between community groups and local businesses may contribute to donations, or local CBOs, larger non-governmental organisations (NGO) and the government cooperating. Ideally social capital linking together marginalised communities and government networks would have the power to ensure that government actors are aware of and respond to the needs of local carers. As many carers' problems result from lack of support, lack of access to material resources and lack of expertise, all three levels are central (Campbell, 2004).

Burr, Choi, Mutchler and Caro (2005) argue that characteristics increasing the opportunities for and likelihood for volunteering include social resources, such as social network characteristics and family relations. We can assume that good quality networks and access to resources will be involved for the volunteers to feel empowered and satisfied in their work.

1.7 AIM OF THE STUDY

There is a lack of studies on positive aspects of HIV/AIDS voluntary care giving in the South African context. I would like to approach the subject primarily focusing on the rewards of being a female voluntary caregiver (outside family relations) for PLWHA, within a specific context of KwaZulu-Natal, South Africa. There is a need to explore the factors which keep volunteers going in this both physically and emotionally challenging work situation, with little or no pay. There is also a need to explore the link between social capital in the community and the experience of volunteering. The circumstances for when and how volunteer care work is a positive and rewarding experience need to be investigated more closely. By studying positive experiences in this context, we may better understand how volunteers can be assisted and supported in the major job they do for the PLWHA. This study will be concluded by discussing how the findings may contribute to a better working environment for the voluntary caregivers.

Research objectives:

1. What motivations do the women in this study have to do voluntary care work?

2. How do the women experience doing voluntary care work, and in what ways does it affect them?

3. How do the volunteers perceive and draw up on social capital in relation to their work?

4. How can we understand the relation between motivation, the positive experiences and social capital, in this particular South African context?

2. METHOD

2.1 A QUALITATIVE APPROACH

As research design I chose to use qualitative method so that I could investigate answers to my research objectives in depth. I conducted in-depth semi-structured interviews in order to get a fuller understanding of the voluntary care workers' experiences. Kvale (1996) explains that for studying people's understandings of the meanings in their lived world and describing their experiences and self-understanding, in-depth interviewing is particularly suited. The interview guide (see appendix) was designed on the basis of doing a literature review, on my own curiosity, and guided by the research objectives.

2.2 STUDY SITE

The study was conducted in Clermont and Impola, which are townships in the eThekwini municipality, KwaZulu-Natal, South Africa. Townships are the areas that were built on the peripheries of South African cities under the Apartheid regime; where the black Africans were forced to live when the city centres became reserved for white people only. Both of my study sites, Clermont in particular, are characterized by poverty, worn out buildings, simple living standards, and over-crowded housing conditions. Many homes lack both electricity and water, and the streets are filled with garbage. There are not many transport options, and the main mode of transport is the local taxis (mini-buses). KwaZulu-Natal is the second most populated province in South Africa, with 10,3 million residents, and it has the highest rate of registered unemployment in the country: 29,1%; in contrast to the national average of 23% (StatsOnline, 2007b). The level of poverty in the province can be illustrated with figures from the Community Survey 2007: The percentage of households using electricity for lighting is 71,5%; nearly 10% below the national average. The percentage of households with access to piped water is 79,4%; yet again nearly 10% below the national average (StatsOnline, 2007a).

2.3 INFORMANTS AND PROCEDURE

The informants from Impola were recruited through meetings with the Durban branch of the non-governmental organisation Treatment Action Campaign (TAC). TAC advocates for increased access to treatment, care and support services for people living with HIV and campaigns to reduce new HIV infections (TAC, 2009). Being the leading civil society force behind health care services for PLWHA in South Africa, TAC was contacted before I arrived in South Africa. After our first meeting they assisted me in identifying possible informants by snowball sampling. TAC knew of a group of voluntary community health workers in Impola, and when we met with and informed them, they agreed to take part in the study. Five Zulu women were recruited from this group. The other informants were volunteers of a group situated in Clermont. I first met with the Project Co-ordinator of this group, and she was very helpful. The Assistant Co-ordinator set up a list of possible candidates for interviews, and we held an information meeting with them. Seven women were recruited. Even though the ages of all the women ranged between 18 to 48 years, they had similar backgrounds and were at about the same level in socio-economic status: Everyone was relatively poor (the church group received a stipend of 500 Rand monthly, equal NOK 372, and some received children's grants or other grants), living in townships, and many lacked water in their homes. None of them had any paid jobs and their levels of education were relatively low (average: grade 10). Most of the women expressed an active involvement in the Christian religion. At least five of the women were HIV-positive and at least two women were on TB-treatment (not all expressed their health status clearly, and I respected their privacy about this, but there are reasons to believe that more of them were ill). Other health issues mentioned by the women were hypertension, arthritis, the flu, and some of them showed signs of depression. The women had a minimum of one year experience of doing voluntary care work for PLWHA, and the time they spent volunteering varied. Some worked three days a week, some less, and some all week. More detailed information about the women is provided on page 16.

The interviews were conducted in October 2008, at the locations where the HBC groups usually held their meetings. The interviews lasted from 20 to 63 minutes, whereas most of them were closer to 40-45 minutes. The interviews were tape-recorded and transcribed. The Impola-women were comfortable speaking English with me, so I could conduct the interviews myself. The Clermont-women, on the other hand, did not speak

English well, so I was assisted by an isiZulu-speaking interpreter, recruited from the University of KwaZulu-Natal.

Having to depend on an interpreter poses some challenges in conducting a research study. The interpreter I worked with was a University student, so she already had some basic knowledge of science and research principles. This was of great advantage when explaining to her about the study and how to conduct the interviews. She is a bright young woman, and I was very pleased with her assistance. I trusted her work of interpretation, but there will always be some degree of uncertainty about potential misunderstandings and lost information. What I did to counteract these potential risks was to go through the interview guide thoroughly with the interpreter, stressing the importance of asking open questions and letting the women tell their stories in confidence. During the interviews the interpreter stopped after the informant had answered main questions (not for each probe) to give me a translated summary. I did not want to interrupt the interviews too much or for too long, so as to not stop the flow of the conversation. I also wanted the informant to relate mainly to one person, assuming this would facilitate more trust and openness in the interview. Although you loose some control of the interview conversation by using an interpreter, I believe that you may gain more trust by having a person there with the same ethnic and cultural background, and speaking the same language as the informants themselves.

The informants seemed to respond positively to be part of this study. I explained the overall purpose of the study to them before we started the interviews, that I was interested in their stories, and that there were no right or wrong answers. I emphasized the guarantee of confidentiality, and that they could refuse to answer any question without explanation. None of the informants withdrew from the study, and only a few chose to pass a question, just because they did not know what to answer. We ended each interview with a question intended to make them think in a positive way of their achievements. When I was done with my questions, I gave the informants a brief summary of what we had been talking about, and asked them whether they had anything at all they'd like to add to that, or had any questions or comments. Many of the informants told me that it was nice talking about the subjects we talked about; it made them reflect upon their work, and it made them feel good. As a little thank-you gesture for the time and effort spent, the informants received a light lunch/snack, and transport money were provided for those who needed it.

I will now briefly introduce the twelve informants, whom I have given pseudonyms in the form of traditional Zulu female names:

Cebile is 35 years old; living in Clermont, in a building with no water or electricity. She is unemployed, but gets a (small) social grant. Cebile completed grade 10 in school, she is Catholic, not married, and has three children. She is HIV-positive, and she talks openly about it, but still her health is generally fine (she looks healthy). She is a very serious lady, but she talks willingly and enthusiastic.

Fikile is 48, and she also lives in the township, in an average house with water and electricity. She completed a Junior Certificate in school (grade 6), she is unemployed, but her husband has a paid job. Fikile has one adult son, she is a Christian, and her health is generally good (she looks fine), except for hypertension. She talks willingly and openly.

Funani is 44: She is renting a home equipped with water and electricity, in Clermont. She has completed grade 12 in school, is unemployed, and single. She had a daughter, but she passed away. Funani is a Roman-Catholic, and her health is generally fine (she looks healthy), except for some menopause problems. She has been with the HBC group since January 2007.

Gatsha is 30, but looks older. She lives in Impola, in a fully equipped house, together with her husband and their twins. She has no paid job, but her husband does. Gatsha completed grade 10 in school and has attended various courses later on, she is an active Christian, and her health is ok (she looks well).

Gugu is only 18 years old, but she has already been volunteering since she was 15. She lives in Impola, in a building with electricity, but no water. She has not managed to get any work since she got out of school (completed high school, grade 12), she is single and have no children. When I ask her about her health she says it is fair. Gugu is a pretty looking young woman, dressed in nice clothes; she is well articulated and dedicated. She speaks English very well.

Jabulie is 24; a pretty young woman, dressed nicely. She is very serious, and looks as if she is not feeling well; she is sitting leaned forward, rocking back and forth. She is HIV-positive, and has been on ARV treatment since 2006. Jabulie is a single parent of one child; living with her siblings and their children in a two-room house in Impola. She completed grade 8 in school, is unemployed, but has a grant income of about 2000 R monthly (NOK 1475,-). She has been with the HBC group since 2006.

Kaya *is 30, but looks older: A pretty looking woman in nice clothes, living in Impola. She is relaxed and smiles a lot. She completed grade 9 in school, is unemployed, but gets grants for her children. Kaya is Christian, not married, and she says her health is fine. She started to volunteer in 2006.*

Lindiwe *is 18, and lives with her little family in a small house in Impola. The house has electricity, but no water. Lindiwe is still in grade 12, about to complete high school. She has been volunteering on her spare time since 2006. She is single, has no children, and she has no health problems. She looks healthy and is a sweet young lady, dressed in nice clothes.*

Mbali *is 33, but looks older. She is dressed nicely and her hair is neatly done in braids. She is relaxed and smiling. Mbali lives with her mother in Clermont; in a big house with water and electricity. She completed grade 6 in school, is unemployed, and not married. She is an actively involved Christian.*

Nandi *is 36, but looks older. She talks willingly, is dedicated and gesticulates a lot with her hands. She is relaxed, but serious. She looks healthy; she is not HIV-positive, but is currently on TB-treatment. She got infected when working with a patient with TB, and she fears also getting infected with HIV, because of lack of protective equipment. Nandi is a Christian, she completed grade 12 in school, she is unemployed, and a single mom of a teenage girl.*

Nolwazi *is 32, but looks much older. She is extremely thin, but when I ask her about her health she just says she gets a cold from time to time, and that she is on TB-treatment. Nolwazi lives in Clermont, together with her 9-year old child and her partner (not married), in a house with water and electricity. She completed grade 11 in school, is unemployed, but her partner has a paid job.*

Sizani *is 42: She is calm, relaxed, and nicely dressed. She talks willingly and with enthusiasm. She lives in Clermont; in a rented room with water, but no electricity. She is a single mom of two kids, and she makes a little income by mending and sewing clothes. Sizani is HIV-positive and on ARV treatment. She is a Christian, and her highest level of education is grade 12 (high school).*

2.4   ETHICAL CONSIDERATIONS

Clearance was sought and approved from the Norwegian research ethics committee (REK) and the Norwegian Social Science Data Services (NSD). Oral and written informed consent was obtained from the informants before participation. I explicitly informed the women that participation is completely voluntary, and that they were free to leave the interview at any time, without having to give any explanation. Confidentiality and

anonymity was guaranteed, and all information was handled and stored in a safe way. There are no names directly connected to the data material, which is locked up, password-protected and only I have access to the files. The data will stay safely stored for the next three years, and will then be maculated. A short report of the main findings and recommendations will be produced for TAC and the other groups involved.

There might be some potential pitfalls with me coming from a completely different culture and background into this semi-rural South African context. Being a white Norwegian student it is almost certain that I bring with me different understandings and different cultural norms. One thing I have to consider is that the women may have adjusted their stories (twist or hold back information) for me, and that I as a person and as a researcher to some degree might influence the stories. I tried to counteract this as much as possible by adhering to Kvale's (1996) principles of interviewing qualities: Having good knowledge about the subject and communication; be organized, clear, friendly, sensitive, open and critical; and be able to interpret and remember informants' statements.

Striving towards reporting a valid account of the research findings, I assure that I have done my very best to be true to the narratives of the twelve interviewed women.

2.5   THE ANALYSING PROCESS

For the purposes of this study I chose thematic analysis, since it has been portrayed as a foundational method for qualitative analysis, offering an accessible form of analysis for students with limited experience (Braun & Clarke, 2006). Thematic analysis is flexible and quite independent of theory and epistemology; benefits which appealed to me. I wanted to provide a rich description of my whole data set to convey the predominant themes. The themes within the data were identified in a deductive, 'top down' way, driven by my analytical interest in the field, and coded for my specific research questions. I still tried to keep an open mind, and look out for interesting themes and patterns outside my research questions. Further, I decided to identify the themes at a semantic, explicit level; not looking much beyond what the participants said, since I did not have enough data to contextualise properly at a latent level. As for epistemology I was guided by an essentialist/realist approach: Theorizing motivations, experience and meaning in a straightforward way, on basis of assuming a simple, largely unidirectional relationship between meaning and

experience, and language (cited in Braun & Clarke, 2006). See appendix for an excerpt of the coding process and the final thematic map.

I worked through my data set following the step-by-step guide to thematic analysis, provided by Braun and Clarke (2006). First I transcribed the data; I did the English ones myself, and my interpreter transcribed the interviews done in isiZulu, after I explained the procedure to her. The utterances in the interviews were transcribed in a matter that was true to their original nature. Afterwards I double checked the English transcripts against the original audio recordings for accuracy. Then I had to familiarize myself with all my data. I read the data in an active way, looking for meanings and patterns, and marked ideas of interest for coding. During phase two I produced initial codes from the data; features of the data I found interesting. I did this work manually; I wrote notes below each data extract, numbered my codes and copied them to a separate document. At the end of this phase I had over 300 codes. In the third phase I started searching for themes. I sorted the different codes into potential themes, and collated all the relevant coded data extracts within the identified themes. To manage this task I used visual representations for help: I printed out my list of codes, used scissors and cut them apart. Then I organized the different codes into different piles of candidate themes and sub-themes, and made a thematic map of these themes. Phase four was about reviewing themes; refining my candidate themes. I kept Patton's dual criteria for judging categories in mind; focusing on internal homogeneity and external heterogeneity (Patton, 1990). This process led me to rearrange some of my themes and sub-themes, and thereby also to alter the thematic map. Defining and naming themes was the task for phase five. I defined and further refined the themes and analysed the data within them. This meant going back to collated data extracts for each theme, and organize them into a coherent and internally consistent account, with accompanying narrative; identifying what was of interest and why. For each theme I conducted and wrote an analysis.

The process of analysing and producing this report has been long, challenging and at times frustrating, but also informative and interesting. When reporting on data extracts and conveying quotations I have reproduced them in their original form, not altering the language, only adding some punctuation to ease the understanding. Since English was not the mother tongue of any of my informants there may be some grammatical errors in the extracts.

3.   FINDINGS AND DISCUSSION

I will now present the main findings of the study, in accordance to my research objectives. The findings will be discussed and collated with other literature along with the presentation. Subsequently I will conclude with an overall discussion of the findings, and end with implications and recommendations.

3.1 MOTIVATIONS

Exploring the motivations the women had for doing voluntary care work for PLWHA, I found three themes that stood out as important:

1. *Community concern, love for people & ubuntu*

2. *Gain and share knowledge*

3. *Work satisfaction*

3.1.1 Community concern, love for people & ubuntu

The most pervasive motivation, which all the women mentioned, was the desire to help people in need. E.g., Sizani expressed that she loves to take care of sick people. I interpret this as an expression of the love they have for people, at least their fellow community members, in line with volunteers' sense of community (Omoto & Snyder, 2002). Love for people and helping people in need proved to be essential reasons for most of the women to continue with the voluntary care work over time. 'To help others' have been found to be crucial motivations in other studies of AIDS volunteerism as well (Carlisle, 2000; Omoto & Snyder, 2002).

> *"Ok, the one thing that makes me continue being a volunteer is that people are getting the help they need and deserve…Ever since I started working I told myself that I am doing it for the people…"*   Nandi

Another central motivation that all the women agreed up on was ubuntu; possibly reflecting what would be labelled as altruism in other contexts. Sizani uttered that she does not think one can love and care for a sick person without ubuntu. She noted that in some

homes the family would not even touch their ill family member, so to be able to do this job you must have love and ubuntu. Gatsha agreed:

"…if you work with the people, you have to have ubuntu…So if you are health worker you have to. Without that it's not easy. Cause sometimes you get inside the house, you see it's dirty and even the patients, maybe he brought everything on the bed, you have to go there and clean up the bed, cause you got ubuntu. And you are volunteer. There's no one forcing you. Understand that? And then you do that thing with your love, with your heart."   *Gatsha*

The desire to help the community (community concern) turned out to be yet another pervasive part of the women's motivation. This was mentioned by six of the women. The desire to help the community was also found in the study of Marincowitz et al. (2004). This relates to ubuntu, in the sense that togetherness between people and community concern goes hand in hand. Gugu and Nandi also mentioned a desire for taking action and making a difference, having a goal of contributing to changes in the community, and for people to be happier.

"This place has a lot of sick people and I just wanted to help out…There were people who were sick in the community and were not even working…They fear what the community is going to say about their status, so they sit there and deteriorate alone. I saw that I could make a difference and change their minds and help them get better, they need to know about this disease so that they can do something about it before it is too late."   *Nandi*

These three reasons for getting involved with the voluntary care work are all connected. As for community concern Nandi and Sizani think about the fact that there are so many sick people in the community, and as Sizani put it:

"I saw the way people were getting ill and I also realized how the hospitals no longer admit them if they are too sick. So other would be sick and alone their houses, they have no one to take care of them."   *Sizani*

Her decision to go out and help these people corresponds with both the desire to help people and ubuntu. Omoto and Snyder (2002) have identified primary motivations for AIDS volunteerism (in USA), and they coincide with my findings: What they found to be endorsed most strongly; satisfying felt humanitarian obligations to help others, can be juxtaposed with the most pervasive motivation expressed in my study.

The ability to feel empathy towards other people was also mentioned by some of the women as a reason for continuing their work over time, and this was also compared to having ubuntu.

> *"…if you want to help me you have to be in my shoes, imagine yourself as me, even if I need help about anything, if you want to help me you have to change yourself first and become me, otherwise you won't be able to help me at all (…) whenever I do anything for a person I always put myself in their shoes, as if it is happening to me, know that it could happen to me, I should accept it. It could happen to my child, I should accept it, when I get sick I would love to be given love too as I do, sleep in clean linen and have food to eat, even when I can't eat any more, I'd love to be bathed and sleep in clean linen."*   *Fikile*

As part of the motivation for getting involved with HIV/AIDS voluntary care work, some of the women mentioned having family members who were either ill with, or had died from AIDS. This caused them to open their eyes for the disease, wanting to learn more about it and wanting to help other people going through the same. This suggests that the women in this study have a lot of compassion and love for other people.

> *"I started in 2003. Why? Because my brother was sick on that time. And we did not know what caused, but later we found that he's HIV-positive. And then, from then...my mom decided to take him away from house cause he's HIV-positive. I suffered a lot cause I like my brother and he gave me support...I decided to take care for him. I searched and joined TAC in 2003, and then I learned more information about TAC. They teach us everything about HIV, and I realised 'Oh, my brother, my brother, he's HIV-positive'...So when I started to be a member of TAC I learned more things..."*   *Gatsha*

Perhaps it is in a way like Carlisle (2000) reported: That 'the search for meaning in HIV and AIDS' is the way carers find meaning in the care giving experience, and balance the costs and rewards of care giving. Carlisle's study found that carers placed great value on getting involved in the broader field of HIV work, not just caring for family members or friends. This helped the carers find meaning in the experience of being affected by HIV. According to Carlisle the search for meaning is a positive and vital aspect of being a caregiver for PLWHA.

Their own HIV-diagnosis did also play a part for at least a couple of the women. They were thinking ahead, about getting sicker themselves, and wanting to have someone taking care of them then. This might be a part of their motivation which on one hand reflects their ubuntu ideology, in the form of reciprocity to their fellow community members. On the other

hand it can also reflect a more extrinsic form of motivation, by hoping to gain future rewards in the form of care for themselves when they get sick.

> *"I just loved to work with PLWHA, because I know that one day I'm gonna be sick. Like I said, I'm also HIV-positive, and I would like someone to take care of me...when I cannot take care of myself."*   *Jabulie*

Although only a few of the women explicitly mentioned this as a source of motivation, it is plausible that there were others who felt the same, as there were more of them who had HIV.

Fikile was motivated by a particularly interesting reason: She had observed other volunteers in their (lack of) care work and was not impressed; she could do better!

> *"I was a voluntary supervisor at KZN Health, I was supervising the volunteers there, it was bad. I saw the way they were doing their work and it was not right: They came in, in the morning and sign and then they would go back to their homes. At that time there was a person who was sick right across my house, and so was their son and daughter who had a child and she eventually passed away. No one went there, even once, they didn't go...I was touched by all of this (...) I was an unpaid supervisor, and every time I told them what they were doing was wrong, they would tell me that they know their jobs and no one is going to tell them how to do it, they had been there for a very long time, you see...I evaluated the situation and decided to stop the work I was doing as a supervisor, I wasn't getting paid anyway, so I decided to quit that job and came here to work as a voluntary worker."*   *Fikile*

Fikile had a strong feeling of this being all wrong: Not only did she want to do better, but she may also have felt that the other volunteers actually undermined the job as a voluntary care worker for PLWHA, by disrespecting the ill people and disregarding the importance of this work. In this way Fikile's motivation also relates to community concern.

One reason for continuing the work over time was the fact that people they helped actually got better, and that they expressed their gratitude. This is in line with the South African study of Marincowitz et al. (2004): They found that the volunteers were motivated by patients getting better and their appreciation of the volunteers' work (positive feedback).

> *"One of the reasons why I'm still doing it is when I see my patients recovering and getting better...In July I had a patient, whom I took to hospital, she didn't want me to leave, she asked me to bathe her, because the nurses handle her badly and her body was sore."*   *Fikile*

Some of the women also expressed signs of internalising their helping behaviour; continuing their work partly as a result of the activity becoming an integral part of self.

> *"…it's in my blood now…"*   *Cebile*

Nandi explained that with no money involved you do this work with your heart, happily. A typical example of intrinsic motivation (Meier & Stutzer, 2006).

3.1.2 Gain and share knowledge

In their USA study of AIDS volunteerism Omoto and Snyder (2002) found that some people volunteer in search of greater understanding of HIV/AIDS. To learn more about HIV and AIDS and to pass this information on to other people turned out to be an important motivation for many of the women in this study as well. They saw the situation in their communities: Many people were not educated and not fully informed about the disease, and the women wanted to change this for the better. Some of the women explicitly stated that they love to learn in general, and that the devastating effects of HIV were something that triggered a particular need for more information.

> *"So we were happy because we now knew, so we could go tell them that no if it's like this…and not to say that some one is cursed you see, it's because of this and this. And so we explain it has happened in our families too. (…) And we are here to let them know about this virus so they won't live through life not knowing how to take better care of themselves to live longer."*   *Cebile*

Being fully informed and having the correct knowledge about HIV/AIDS, and not at least also having the courage and spirit to go out and communicate this to other people is crucial for fighting ignorance, stigma and staying motivated to help those who are affected. To share your knowledge with others will most likely make you feel like you are doing something important, which yet again may well affect your feelings of self-worth in a positive way. An increase in knowledge and understanding of HIV/AIDS, health services and health, and a sense of satisfaction, purpose and achievement were reported as benefits of care giving in a previous Australian study (McCausland & Parkenham, 2003).

3.1.3 Work satisfaction

> *"I started having the love to do this job...I was very happy, because this was my opportunity to do what I wanted and loved to do (...) The reasons I am still doing this, is that I love my work...I am passionate about it...I always strive to be professional in my work. I love it and I don't want to leave it..."*   *Funani*

Most of the women in my study said that they love their work and that they enjoy doing it, and surely this will keep them motivated to continue. The feeling of pride was only explicitly mentioned by Gatsha, in contrast to the study of Carlisle (2000), where there often was a sense of pride among the caregivers. The women in my study reported having the same feelings about doing the care work after some time had passed as they had in the beginning. They still liked it, loved it and felt happy about doing it. Some of them did however report slight changes in the way they felt about the work:

> *"...it's getting better. Like now we know how to handle the people's pressure, the stress and everything (...) It's different because I learned things that I didn't know about people...and it made me grow a lot in knowledge, to help other people."*
>   *Lindiwe*

Uys (2002) reported findings comparable to those found in my study. She found that community care givers in South Africa expressed great satisfaction in their work and in helping others; feeling like they were really making a difference. Although being among the majority of the women who said that they love their work, a couple of them were prepared to move on and work as a professional nurse if they would get the opportunity to do so. To be a nurse represented their dream for a better future, but also motivated them in a more extrinsic type of way, by thinking ahead of potential future rewards:

> *"...since I was born and I went to school, I always wished to be a nurse, but it didn't happen. I loved working with sick people, I also wanted to work in the hospital, because I love helping sick people (...) I always tell myself that as I am a volunteer now, one day I will be a professional, so I have to work hard everyday, because as I am this low today, in the near future I might find myself this high through my hard work (...) For as long as I can, or become a nurse..."*   *Funani*

In sum: In this study the women's motivations for doing voluntary care work included a sense of community concern; seeing all the ill people and wanting to contribute to changes for the better. They further expressed their love for people, in the collective spirit of ubuntu; factors important for all the women for doing voluntary care work. Seeing their patients

getting better and appreciating their work motivated the women to continue, and some of them seem to have internalised their helping behaviour; it's in their heart now. For most of the women it was personal; they were HIV-positive themselves and/or they had family members who had suffered and died of AIDS. To gain and share knowledge was also a reason which stood out. Finally, work satisfaction represented one part of the motivation for continued involvement in voluntary care work: Most of the women said that they love their work and are happy doing it, and a couple of them also had aspirations to become a nurse.

3.2 EXPERIENCES

This theme concerns how the women experience doing voluntary care work, how that work affects them and how it makes them think about the future. My focus is as mentioned previously mainly on the positive experiences, as these may contribute to explaining why the women continue with voluntary care work. However, there are also negative experiences that need to be taken into account. The 'experiences' theme was divided into three sub-themes based upon the women's accounts:

1. *Hardships in the work*

2. *Rewards and personal growth*

3. *Future plans*

3.2.1 Hardships in the work

> *"When I first visited people in their houses it was bad. There was a lot of sadness there that we had to deal with. At times I got there and a person would be dying, others did die while I was there, others didn't have food and could not afford it and they had children to feed too. I found myself having to give them from my food, I had to give them a little of my money so that they could get by."*   *Nandi*

The women told me that they had to deal with much sadness: The extreme poverty, people who were famished, suffering and dying from AIDS, and generally bad conditions in the communities. They sometimes had to give away some of the little food and money they possessed, so that the sick and their children could have something to eat. This is of course a big part of being a volunteer in areas like these, and what's remarkable is the fact that these

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women still go on and do their work for no pay, in the face of the hardships they see and experience every day.

> *"I saw some things that touched my heart and it hurt so much I fell ill, to know that*
> *there are people in the community who go without food for days on end."*   *Fikile*

The findings of my study support those of Akintola's (2006) study of the health burdens that HBC places on women in South Africa. Among the psychological consequences of care giving found there were the worry about patients' illnesses and imminent death, the consequences of emotional trauma (frequent experience with death of patients was extremely emotionally disturbing) and the emotional impact of the socio-economic context (psychological stress caused by worrying about their own financial situation as well as their patients'). Common signs included tearfulness, worry, anxiety, fear, and feelings of despair.

A few of the women in my study mentioned the heartbreaking pain of seeing ill persons being rejected and abandoned by their own families; sadly a quite usual problem in these contexts.

> *"...because in some homes the families don't even want to touch their sick family*
> *members...sometimes I find that a patient will only bath when I am there, otherwise*
> *they leave them like that no matter what."*   *Sizani*

Gatsha explained that in the beginning she was scared of being judged and stigmatized. She said that if you teach people about HIV, they will think that you also are HIV-positive. Feelings of stigma and discomfort following AIDS volunteerism are unfortunately common.

Mbali told me that the volunteers usually are well received in the community, but they also face difficulties; not everyone wants them in their houses (because of stigma), still the volunteers try to help. Quite a few of the other women did also tell about relationships with patients that were not always that good. They sometimes have to use their skills to calm down rude patients who are feeling angry and bitter because of their illness.

"Well, in some cases it's not that good, cause sometimes we get older people who really can't understand. Take me for an example: I'm young, I'm very young. So when I go to an older person, they will be like 'argh (sound)...you don't know what you're talking about, and you can't feel the pain that I'm feeling right now'. But we actually do, cause age doesn't matter, it really doesn't."   *Gugu*

These findings are supported by findings from other studies. Marincowitz et al. (2004) and Akintola (2008a) found that stressors of volunteer caregivers included emotional overload, and patient problems, which also was evident in my study. In some rare situations it got so bad that the woman would end up feeling threatened, scared and hurt.

"...he kept on asking questions until I was scared that he was going to kill me, you see. Sometimes you try to talk to a person to get them to tell you something to the point where you just know that you have done it all, there is nothing more you can do...you have to use the skills that you have been taught as a health worker to find ways to approach him. That really hurt me because I was trying to help him, but I almost got hurt in the process..."   *Funani*

I wanted to know how their experiences as voluntary care workers had affected the women's well-being in terms of health, happiness and life satisfaction; as it is reason to believe that helping others and doing good deeds make you feel better about yourself. Although many of the women answered positively, a few of them explained how the care work can constitute a health hazard, e.g., lack of work kits make them susceptible to infections. Risks of infection with HIV and tuberculosis is well documented (Akintola, 2006; Lindsey et al., 2003).

"...my well being hasn't been badly affected at all, but my health has. There are times where I get to patients and they have TB which has not been treated, because the patient doesn't know that they have it yet. Yes so as I said that I was on TB treatment, that is where I got it from, and there are a lot of other things that we get from there. Most of the time we work without a kit so we have to use plastics when we are washing the patients which is not safe at all."   *Nandi*

Fikile told me that her well-being was negatively affected, in terms of feeling sad and upset about the bad situation. AIDS leave behind enormous amounts of orphans in South Africa, and Fikile feels that the government should take more responsibility and do more to support these children and supervise their adoptive parents. Fikile discloses that the way things have degenerated makes her feel like people by and large do not care much about each other.

"It has affected me greatly. I see orphans and the way the government is not doing the expected job, and I say to myself if I was the government this is what I would be focusing on...if a child loses their parents and is adopted, the social workers don't supervise the new parents to see whether the child is getting the right care or not. They end up on the street and doing crime, yet they get grants, you see that, it just makes me upset (...) It has showed that people don't care about each other. It has made me realize that I could be sick and no one would take care of me, I would die in my house alone and no one would know."   *Fikile*

It can seem as though these women have coped and in a way become habituated to seeing all the hardships around them. As Nandi stated: *"Now it is not that hard anymore..."*

3.2.2   Rewards and personal growth

This theme reports on the positive feelings, personal changes and growth the women have experienced in connection to their involvement in voluntary care work.

"I was happy to do this job, because as I had said that I was very happy to have been trained to work in the community, that I could help the people that I wanted to help."   *Funani*

I asked the women how they felt when they first started doing the care work. Most of them had merely positive feelings. They felt happy and enthusiastic about doing what they wanted to do, and as one of them pointed out: Even though there were challenges she felt motivated and passionate about contributing to changes.

"I could say I am learning, I am growing, by doing this work as the years have gone by. I think now I can even work in hospital, I'll be able to do this and that. I can see the light now. (…) I have grown, even now if I encounter a problem I know what to do; I am not dependent on other people anymore. Another would be that I fight hard, I look after myself so much that I don't find myself bedridden, because that could be the end of me, I have seen it."   *Sizani*

Experiencing personal growth as a benefit of AIDS volunteerism has previously been reported (Carlisle, 2000; Crook et al., 2006; McCausland & Parkenham, 2003). Almost all the women in this study did also feel that the experiences they had gone through being a volunteer had helped them grow in many different ways. Many talked about growing mentally, becoming more mature and more independent.

Most of the women told me about changes in their lives and within themselves as a result of having more information and gaining new knowledge about HIV and AIDS. For example they were helped by learning valuable information on treatments and healthy diets.

> *"…when I was growing up I was afraid of sick people. I had no empathy to the extent that I would laugh at them, until my sister died. So after I worked here I have learned to have sympathy and help out instead of standing back and laughing, because I have seen it, it has become more personal now"*   *Nandi*

From this account we can infer that volunteering apparently has made Nandi go through a process of personal change, in the form of developing an ability to feel empathy for others.

Being powerfully affected and changed by the volunteer experiences have been found in other studies of volunteerism as well. Experienced volunteers have shown increased knowledge about safer sex practices and AIDS-related issues, and less stereotyped beliefs about PLWHA (Uys, 2002). This gained knowledge constitute perceptions of personal effectiveness; motivators found to help volunteers continue their work (Marincowitz et al., 2004; Omoto & Snyder, 2002). A few of the women explicitly expressed feeling more confident and skilled in their jobs: *"…and I think now I am better in my job than before."*   *Nandi*

The women in this study reported that they had learned how to handle and communicate with different people. They stressed the importance of confidentiality; skills of a true professional.

> *"…still you must not tell them that you have been told by someone else about them, you have to use the skills that you have been taught as a health worker to find ways to approach him (…) I have to humble myself and not let it get to me, and speak to them in a way that will make her feel like she can be comfortable with me...maybe she has a family problem and now she wants to take it out on me, I must not show her that I see that. I have to tolerate her no matter what, until she realizes that I am here for her and not against her (…) I have to be able to handle that kind of a situation, you see, so from those things I became more skilled in handling them without being too emotional..."*   *Funani*

> *"I take it as my job. I have to do it; I have to be professional in everything I do, so I cannot let hardships get in the way."*   *Nolwazi*

An increased understanding of others, and improved skills and abilities have also been found in other studies as rewards involved in volunteering (Crook et al., 2006; Gert

Marincowitz et al., 2004; McCausland & Parkenham, 2003). McCausland and Parkenham (2003) found that 97% of the caregivers they asked open-ended questions, reported benefits. Some of these benefits were categorised as 'start of a new relationship' (with patient) and 'strengthening of an existing relationship with care recipient'. Benefits like those were not explicitly mentioned by the women in this study.

As a consequence of learning how to take proper care of sick people in a safe way, the women also learned how to take better care of themselves. Some of them did think about their own future as a HIV-positive person; that they would be the ones bedridden some day, and in need of care at that time.

> *"Well, it acknowledges me, in the way that I must eat, or I must keep myself, in all those situations. It makes me aware of all those little things that people don't consider, that are important. Like exercise! In this area we don't have playgrounds, you don't have those facilities. But a walk every now and then can make you a better person, also can boost your self confidence, cause when you look good, you feel good."*
> *Gugu*

Cebile was also concerned about taking care of her self and maintaining a positive self image. She compared her situation to that of others', and realised that she could be worse off:

> *"They have helped me grow in so many ways. You see, I have no one; all of my sisters have passed away, I am the only one left with all their children, so I think as much as I may feel life is hard for me there is always someone out there who has it worse than I do."*
> *Cebile*

Finally, some of the women expressed that they had gotten new perspectives on their own life situation as a consequence of their experiences working as voluntary care givers; in line with findings from previous studies (Carlisle, 2000; McCausland & Parkenham, 2003).

Regarding effects on well-being; many of the women answered that they had not experienced any problems as far as their feeling of well-being, and that their health had not been negatively affected, due to well training and taking certain precautions. Gatsha told me with a smile on her face that she feels happy, because she is doing what she wants to do. These findings contrast others, more negative findings, as discussed in the introduction part. Then again it has been suggested that African volunteers often keep quiet about their problems for various reasons (Akintola, 2004).

(Smiling) "I wouldn't say that it has affected me badly, because I still can do the things that I did before and I can do whatever I need to do now. I can go to work to look after the sick and still be able to attend to my own life too, I can do both well without any problems (...) sometimes you get to a house and it is so dirty and filthy that you can't even go in you can hardly breath, but you still have to go in, in that condition, but I can say that God being so great I am still healthy..."   *Funani*

3.2.3 Future plans

This theme concerns the women's thoughts about their future as voluntary care workers, whether they see themselves as staying or leaving. All the women answered in a positive way.

"I will keep on doing it, because when if I ever do find another job, I will still continue doing it, by passion, not for permanently [full time] you know, yeah, I'd do it part time."   *Jabulie*

Apparently none of the women had any plans of quitting their work any time soon. Most of them actually expressed thoughts of planning to stay for a very long time ahead. Some even said they would stay until there is no more work left to do. Others would also like to continue their work for as long as possible, but they were hoping for a paid job as well. If they would get one, they pictured themselves still continuing with the voluntary care work, on the side.

South Africa is a country where a great deal of the population is quite religious. A couple of the women in my study did mention God as a guiding force for their future volunteer plans:

"And at the end of the day God is the one who plans my life, so if He has planned for me to be a nurse I'll be a nurse and if He wants me to be a care giver forever that's what I will do. (Laughs) Or anything else that has to do with helping out HIV/AIDS patients I'll gladly do it."   *Cebile*

An American study of college students found that the best predictor of intention to repeat volunteer service was intrinsic motivation to volunteer, and this was associated with expressing a personal relationship to God (Ozorak, 2003). The link between religious activity and volunteerism has been demonstrated in many studies and in many countries. Active church members are more likely to volunteer than non-religious, and the religious context of society has been shown to increase levels of volunteerism as well (Ruiter &

Graaf, 2006). This is also reflected in my informants' accounts of the importance of religion in their lives.

In sum: Different feelings (both positive and negative) about doing the work, personal growth and future plans make up the experiences these women have and have had while doing voluntary care work for PLWHA. Most of the women felt happy about doing the care work when they first started out, whereas many also felt hurt by all the sad situations they had to deal with as voluntary care workers. They also had to deal with patients who were angry, non-cooperative and not appreciating the efforts of the women to help; to the point of being threatened on their lives. The women felt that the experiences they had gone through being a volunteer had helped them grow in many ways: They were changed because of new knowledge, they learned important skills for taking proper care of both patients and themselves, and some got new perspectives on their own lives. Their health and well-being had been affected in different ways, but most of the women reported being ok, not having any problems. However, a few of them were negatively affected, e.g., being infected with TB. As for the women's thoughts about the future nearly all agreed on wanting to continue their voluntary care work for as long as possible, whereas a few of them would go on until a paid job would come along, but would still continue seeing patients on their time off.

3.3 SOCIAL CAPITAL AND SUPPORT FROM DIFFERENT LEVELS

The third theme entails information about elements of social capital. In accordance to my third research question this theme can possibly explain how the volunteers perceive and draw up on social capital in relation to their care work. I found five sub-themes:

1. *Networks as a vital source of social support*

2. *Trust and solidarity – important values for the volunteers*

3. *Feeling empowered to make positive changes*

4. *The significance of community participation in HIV/AIDS related activities*

5. *Government support and suggestions for improvement*

3.3.1 Networks as a vital source of social support

Networks are considered important elements of social capital. As mentioned; social capital research examines both informal and formal networks, at three different levels (Campbell, 2004). I wanted to explore the networks of the voluntary care workers. Being part of good networks is valuable in situations when you need help with anything, from getting assistance when you are sick to borrowing money, and importantly to provide overall social support. From the way the women talked about their co-volunteers, we can infer that this relationship made up a valuable network for them. All the women, with no exception, spoke of their relationships with the co-volunteers in positive terms. They used words as fine, good, great, togetherness, connected, helping and taking care of each other.

> *"We are connected; we are connected as health care workers and as volunteers from the same group. (…) I would say it is good, because when I have a problem with something I know that I can call them and sit them down and we work it out and try to find a solution."*   *Nandi*

> *"It's warm, it's comfortable, it's a place where you feel comfortable. Cause everybody is open…You're able to communicate in a very open way, so you like, feel at home with them. It's very warm and comfortable."*   *Gugu*

Also when I explicitly asked the women about the social support they got, quite a few of the women pointed towards their group of co-volunteers. Support from other health workers was one motivating factor helping the volunteers to continue with their work. Marincowitz et al. (2004) reported similar findings in another South African study. This relationship is a typical example of bonding social capital; likely to support and facilitate HBC (Campbell, 2004).

> *"In our organisation there's counselling…everybody needs counselling now and then. And it helps you to get a person to talk to when you're not feeling good, or when you feel down. It really helps, they take care of us, cause after that you do feel better. I've learned that after talk you do feel better."*   *Gugu*

Relationships with their patients constituted another important network for many of the women. Funani felt that her presence had to make the patients smile, so she often talked to them about fun topics, and not merely serious ones, trying to maintain a positive mood. Patients can become friends, and many of the women spoke of their relationships with patients as good, characterized by mutual trust.

"I normally trust my patients. When they have recovered, when they are better they are capable of helping you when you need help. Even when a member of your family dies they are there to help. (...) They feel like family. I feel like I am at home when I am with them, they have become my family, to the extent that I tell them about my life story..."   *Fikile*

The relationship with the patient could also function as a kind of surrogate for the patient's lacking relationship with their own family:

"At times I would go to the house and everyone else is outside and I would ask where they are and they will give me a bad attitude and say they are in the bedroom. And they would start referring to them as my person as if they are not part of their family, you see. And you find that there is no good relationship between the patient and their relatives. So it's my job to go in and sit with them and talk."   *Cebile*

Friends are of course an important part of the women's networks. Many of them have a few close friends to rely on, and some even have numerous close friends to rely on. The women reported spending much time with friends. Sizani reported spending all her spare time with her friends, while for most of the women, the frequency of meeting friends was not that high.

"Maybe three times a week. As often as you can. It's the best to show a person that you care and that you're there..."   *Gugu*

Neighbours are also important parts of the women's networks; they are always close by, they help out whenever needed and they provide social support as well:

"Yes, yes I can depend on my neighbours. For example I can ask my neighbour to help me turn over a sick person in bed when I'm alone in the house. Or when I need someone to look after the children I know I can ask my neighbour to help me out with that...most of my friends work, so I usually see my neighbours more than my friends, yes."   *Cebile*

As mentioned earlier, family relations and other social network characteristics are examples of social resources which can increase volunteering (Burr, Choi, Mutchler, & Caro, 2005). Family turned out to be an important part of the networks for the women in this study as well, as a source of social support, and someone to rely on if they needed help with anything. These are networks at the bonding level of social capital: Vital relationships of trust, reciprocity and positive common identity within homogenous groups (Campbell, 2004).

When we talked about social support Jabulie and Nandi felt that they did not get any of that at all because of the endless stigma surrounding HIV/AIDS. Volunteers who help marginalized members of society, as the PLWHA, are known to experience negative reactions from their social networks due to the company they wilfully keep (Snyder et al., 1999).

> *"I wouldn't say I do…Especially from my neighbours, unfortunately they still discriminate towards people with HIV, and so I also end up being discriminated against because I work with them."* Nandi

All but one of the women were members of the one organisation where they based their voluntary care activities, and none other. Investigating social capital at the bridging level (Campbell, 2004) I asked the women whether their organisation interacts with other organisations in the community. Most of the women reported that their organisation interacted with other ones, and some of them added that the different community groups do work together in a positive way.

> *"…the way I see the work being done…and the level of success, I would say they do interact. (…) I think they work together…maybe in this organization they need something from the other organization, they would ask for help and if it is the other organization they too come here for help. (…) It is because, most of the time here we work with people who have HIV/AIDS, and Mthande deals with the elderly, maybe we find an old patient, since we don't work with old people, we ask to refer them to Mthande, because they work with old people."* Funani

Cebile and Fikile felt otherwise, their impression was that any interaction would happen between the volunteers themselves, but not between the groups.

> *"No, it is the individual volunteers; the groups themselves cannot work together, their working policies are not the same. KZN specializes in advising and counselling only and leave, whereas our group focuses on helping the patient in their homes, as you would like to be helped. (…) I don't see them working together; each one wants their own group to prosper."* Fikile

3.3.2 Trust and solidarity – important values for the volunteers

> *"If you can't trust me, if I can't trust you, there's nothing there. You know, the best foundation is trust, it's honesty. So if we can trust one another, we can go a long way. That's what I believe."* Gugu

According to Putnam (1993) trust and norms are characteristics of social organisation which may contribute to more coordinated actions in society. Many of the women in this study expressed having a great deal of trust in their fellow community members. Among the reasons they reported for trusting were feelings of confidentiality between persons, loyalty, togetherness, collaboration and simply having a good relationship. Some of the other women on the other hand, said that they do trust their fellow community members, but not a lot, or not all of them; they trust their colleagues more. Fikile explained that there are people in the community whom she is not close enough with to say that she really trusts them.

If they were to get sick, most of the women said that they would trust their neighbours to come and help them; because the neighbours see how the volunteers continuously help others.

> "I can ask my neighbour for help, because if they is sick I go there to help them, yeah. They no need to ask, I go by my self. Yeah."   Kaya

The women agreed that trust and solidarity is very important for them in their line of work. They have sworn on patient confidentiality, but they may face challenging situations for which they would need to discuss their experiences with others; then they can rely on each other within the group. To have this kind of support service available has proved valuable for volunteers as one way to deal with stress (Held & Brann, 2007). Some of the women felt that trust and solidarity was particularly important for their work environment, while others pointed to the vast number of ill people in the community and the need to work together in order to help as many as possible.

> "Trust in this kind of work is the important thing, because when you work as a group you have to love each other and trust one another, so that whenever you encounter any problems as volunteers, maybe I have a problem with my patient, I know that we trust each other so it is easy for her to help me, but if you don't trust one another and don't show compassion, they will not help you. It creates a better environment to work in for all of us."   Funani

With the need to ground responses to HIV/AIDS within local community networks, and the importance of strengthening local networks that support effective care, solidarity among community members is crucial as an element of network building (Campbell et al., 2005). When it comes to solidarity among community members in this study, the women were divided in their views. Some felt that most of the people in the community are trying to

be helpful; they know that the time will come for them to need help themselves. Others felt that people are not so helpful, and rather just looking out for them selves, not knowing much about HIV/AIDS, and focusing on what would be in it for them. A few of them felt that people in the community both like to be helped and to see others get help:

> *"Most of the time people like to be helped, but when someone else has a problem it becomes hard, but I can't do what other people are doing, because I will end up like them."*   *Fikile*

3.3.3 Feeling empowered to make positive changes

> *"I always tell myself that, I alone can make a difference in the community. One day I ask myself what I could establish that could help the people, to develop them. I always think about that, and wonder what I can do to help the community, so it can be better one day."*   *Funani*

The feelings of empowerment among the women turned out to be surprisingly strong. Every one of them felt that they had the influence to make their community a better place to live in.

> *"I would say that I do have the influence, as I see the change already since I have started working as a volunteer...Some even want to join the organization, because they too want to change lives."*   *Cebile*

Factors behind the feelings of empowerment included sharing of knowledge, team work, patients looking and feeling better, and people appreciating all the good these women are doing. Gugu stressed the importance of working together in order to make a difference. She believed that the right people with the right attitudes could change the community.

> *"Yes. Yes, if you're working as a team, cause if you are in a team, there's a part I know how to play...But there is a part that I don't know how to play that part, that you. So if you are a group, we can work together. We can make a big difference even in our communities, as long as we work as a team, as a group. Yes."*   *Gatsha*

As for having the power and ability to make important decisions that change the course of their own lives all the women believed that they did have that. Cebile felt that as long as she could pay her rent and provide well for her children she was in power of her own life.

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"As long as I am alive, I always tell myself that as long as I am alive and walking on this earth there is nothing that will defeat me, or that I couldn't do for myself. At all times I tell myself that whatever I want to do I will succeed, no matter what, as long as I do it myself and not rely on anyone else. I don't want to rely on anyone else, I tell myself that I will make it by my own power."   *Funani*

These high levels of self-empowerment feelings may well have protected the women from overwhelmingly caregiver distress, and perhaps even increased their feelings of well-being (Fredriksen-Goldsen, 2007).

3.3.4 The significance of community participation in HIV/AIDS related activities

As mentioned in the introduction, high levels of social capital are related to high levels of people's involvement in local community groupings (Campbell, 2004). In line with this I wanted to explore the women's thoughts and feelings about the local HIV/AIDS organisations; how important they considered them to be, how satisfied the women were with their efforts, and the levels of community participation in HIV/AIDS related activities. I also wanted to enquire about the levels of collective action and social cohesion in the community.

All the women agreed that the local HIV/AIDS organisations were important in the community: If not for them, the sick people would not get the help and care that they need. As far as for the satisfaction with the job these organisations are doing, most of the women felt satisfied with the organisations' efforts. The local HIV/AIDS organisations are important for various reasons. One group can not help everyone, so the other HIV/AIDS organisations are important to reach as many as possible. Other reasons why the organisations are helpful is that they help the volunteers to be able to help the sick people, they provide food for the poor people in many instances, and people are depending on these organisations for help since there are things that the clinic does not do.

"They are very important, because they are very helpful to, only those who have trained staff, they help by creating awareness in the community, they also sponsor the sick with food parcels. At times you find that a person is sick. You already know that they are sick and they need to take their treatment, but they don't have food to eat. So they also give them counselling and also by establishing support groups for them, those kind of things, they also do follow ups in that regard."   *Nandi*

Concerning whether most of the PLWHA receive the assistance they need from these organisations, some of the women said that the sick persons do receive the needed assistance. However, others explained that many do, but still there are many HIV-positive persons who do not want to disclose their status. They hide themselves, and thereby do not get any help.

> *"I'm not really sure on what to say on that. I can say that there are a lot of people who get helped, however there are still plenty of them who have not come out, therefore making it hard for them to get the help that they need. You see here you get help when you have registered as a patient and you receive a card afterwards. But then again you find that there are people who are bedridden and are unable to come here for themselves and need their families' help, of which some don't really get."*
>
> *Cebile*

Community participation in HIV/AIDS related activities seemed to be generally quite high. According to many of the women, people do participate. Funani was of the impression that the declining HIV-rates in the community were partly a result of people participating and showing their dedication to the cause. Then again Gatsha and Gugu felt that the level of community participation in HIV/AIDS related activities sometimes was good, and other times not, because of stigma. Jabulie and Mbali felt that the level of community participation was actually very low, once more as a consequence of stigma.

> *"At present I would say that people still need to be given more information. They are still stigmatized when they participate in HIV campaigns. Some come and most don't, they are scared of being laughed at."*   *Mbali*

Many studies have reported stigma as a problem which both the PLWHA and their caregivers continuously face (Campbell et al., 2005; Lindsey et al., 2003; PathfinderInternational, 2006).

A large study of the gendered impacts of HBC in KwaZulu-Natal found a general absence of male participation, and an acceptance of these culturally bound gendered roles among many women. The women believed that men were just not suited to give care; that they were fearful and would not be able to cope (Akintola, 2006). It was suggested also in my study that women are more active, while many men are rather ignorant and scared:

"...Men are scared of what other people are going to say...men are ignorant and they don't want to go to places where they could get knowledge about HIV and they still know that HIV is only transmitted sexually only, because when you get to them and you can see that they are really sick, you accompany them, you plead with them to go to the clinic. They get there and they test positive, when that happens they blame the women, accusing her of sleeping around. They don't regard the fact that where they drink, they fight and they stab and cut each other with bottles and might have gotten the virus from there, you see, so when you sit down with them and tell them that is possible they just don't want to understand...they need to be taught about HIV; we have to go where they are, where they spend their time together as men...When you call the community they don't want to come; only the women do, so they need to be targeted at the places they spend their time in, and create awareness there."   *Nandi*

The community is able to work together willingly, according to the women's responses. The community members are predominantly united in social cohesion, building social capital (Macinko & Starfield, 2001). The community holds meetings on a regular basis, discuss problems and find solutions. For example if there are problems of burglaries, the community members get together and discuss how they can prevent that from happening again.

"A lot of times the community would get together as women and do bead work together and plant vegetables as a community (…) I think they, the community that we live in now, does things from their heart; no one has to force them to do anything. Especially with regard to the economy of this country, they like to do things that will help them financially."   *Funani*

As for collective action in the case of any problems, many of the women told me that the councillors try to help out: For example in one place the councillors helped out with the water problem by installing community taps alongside the road, and the councillor can be of assistance for families who cannot afford to bury their deceased. But then some of them also added that in many cases the councillors are not of much help after all; making the people unhappy and feeling as though no one cares about them and how they live their lives.

"...there was a lady that I was taking care of and she passed away. When she died, she had no one else that was staying with her but her child who was fourteen, so when she died she hadn't told her daughter who her father was and where he was from. So the child was left behind and alone with this problem and we didn't even know how she was to be buried. So when I went to ask her neighbours how this should be handled, they said there was nothing that they could do. Even now the child is there and her mother hasn't been buried as yet. Even the councillor is not coming out with a concrete plan of action, you get there he tells you a lot of stories and you come back again the next time he tells you something different, so that child is still there..."   *Nandi*

3.3.5 Government support and suggestions for improvement

This theme is about how the women perceive government support for HIV/AIDS organisations, and suggestions they have for improving the work conditions for themselves and the local organisations. As discussed by Campbell (2004), building social capital is dependent up on the quality of the alliance the grass root people have with the more resourced people in power. Thus, support from the government was central for the women in this study.

> *"No, the government is not supporting the organizations, especially the NGOs; I don't know the reason why they don't support these organizations, because the work done by these organizations is very great and important."*   *Nandi*

How the women perceived the quality of the government support varied. Some said that it is not well, not enough, while others said it is ok, but that the government still can do better. Three of the women, however, found the government support to be quite sufficient. Some ARV treatments being free, and distribution of food parcels was mentioned as reasons for being quite satisfied. The very limited government involvement in HBC programmes has been documented throughout Africa (Nsutebu et al., 2001).

Concerning suggestions for how things could get better for the HIV/AIDS organisations, the volunteers and the rest of the people, the women did not have too many demands. There was some agreement that a local hospice for the many ill people was a necessity in the community, since many could not afford the travelling expenses for going to the distant hospitals.

> *"…by supplying food and building hospices in the community, because when people get really sick the hospitals are very far and people die because of that, there is no close place for them to go to, you see, so if the government could take care of that maybe things would be better. And for them to also support those people who work as volunteers, because you would find that a person would start of enthusiastically and eventually lose heart of the job because they are not getting paid."*   *Nandi*

I find it interesting that only one person mentioned a wish to get paid for the volunteer work. Considering the situation of the volunteers; with no paid jobs, minimal incomes and children to care for, one would think that they would utter a wish for some financial support for the hard work they do for the people and the community. Few studies have mentioned anything about whether the volunteers hope to get paid for their work, but Akintola (2004)

reports of volunteers disclosing that they needed money to at least cover some of their expenses. The stipends some volunteers receive are not enough to cover basic needs. The volunteers in Akintola's study were bitter, and believed that the lack of food undermined the HBC.

"...there is more that they need to do, there are a lot of things that we still need. People need to at least eat porridge in the morning for, them to take their treatment, just porridge. Even that seems to be hard for the government; he cannot even give us gloves."   *Fikile*

Other suggestions for improvement included providing food for the sick people and equipment for the volunteers; a working kit with gloves being an essential need.

"One of the things I would appreciate is a name tag, which will identify us as volunteers, we don't have it. In other places like in the township, it doesn't really matter what we are wearing, even if we don't wear a uniform...we don't have them, we need something that will identify us to the community that we are volunteers...another thing is for us to have working material, a kit for every volunteer."   *Sizani*

Equipment problems and carers feeling that their role and status are not respected by the formal health services are challenges mentioned in other HBC-studies as well (Uys, 2002).

In sum: The results suggest that most of the women enjoy good networks, predominantly at the bonding level of social capital: Their group of co-volunteers, friends, neighbours, family members and even patients were people on which the women could rely on for help and social support. All of the women, except one, were members of only one organisation, and most of them reported that their organisation cooperated well with other organisations in the area. Trust and solidarity was reported by all the women to be important for them in their work. Many of the women expressed having a great deal of trust in their fellow community members. As for solidarity among community members, the women were divided in their views: Some felt that most of the people in the community are trying to be helpful, while others felt that people generally are not very helpful. Feelings of empowerment among the women were very strong. Everyone felt that they had the power to change both their own lives and the community for the better. All the women agreed on the importance of the local HIV/AIDS organisations, and were satisfied with the work they do. Community participation in HIV/AIDS related activities seem to be generally quite high.

Women generally participate more actively than men. In general the community is able to work together willingly. As far as for the feeling of togetherness in the community, the women disagreed in their views. Regarding government support some of the women said that it is not enough, while others said it was ok, but that the government could do better. Suggestions for how working conditions could be better included the government setting up local hospices, providing food for the sick and providing a work kit of necessary equipment for the volunteers.

4. OVERALL DISCUSSION

In this section I will examine the relation between motivation, the positive experiences and social capital in the particular context of doing voluntary care work for PLWHA in a disadvantaged semi-rural area of KwaZulu-Natal, South Africa.

The serious HIV/AIDS situation in South Africa, with the government promoting HBC for those who are ill, requires people on the grass root level to take responsibility and to take care of each other. Several studies show that women are far more active in providing basic care for the ill than men; reflecting the traditional gender roles. As the devastating impact of HIV/AIDS hits the hardest among the poorest and already struggling South Africans, the conditions for providing care are harsh, and the community members performing these services are typically poor themselves. So why do they use their time and efforts, and even some of the little money they have, to care for people who are dying of AIDS?

Most of the women in this study did it out of their love and compassion for people in need, and their desire for helping their community and contributing to changes. Many motivations for doing voluntary care work were revealed; findings in support of many previous studies of AIDS volunteerism, both in Africa and in other parts of the world (Carlisle, 2000; Claxton-Oldfield et al., 2004; Crook et al., 2006; Gert Marincowitz et al., 2004; McCausland & Parkenham, 2003; Omoto & Snyder, 2002; Uys, 2002).

As mentioned in the introduction, Stewart and Weinstein (1997) claim that reasons for continuing helping can differ from reasons for initiating involvement. In relation to that claim I did not find any clear indications of different motivations in my data set. I did however find reasons for volunteering comparable to the findings of Stewart and Weinstein, even though we have not labelled them the same: Connection to their own community, to fellow volunteers and to clients; coping in the way that involvement helped the volunteers deal with the pandemic's effects on their lives/communities; and learning of skills.

There are both negative and positive aspects of being a voluntary caregiver, and all these different experiences do affect the lives of the volunteers in various ways. The women experience much hardship in their role as voluntary care workers, but the findings of this study reveal many rewarding experiences of volunteering as well. Most of the women felt

happy and enthusiastic about doing what they wanted to do, despite the challenges. The most salient theme was that the experiences they had gone through as a volunteer had helped them grow as a person in many different ways, and that their health had not been negatively affected, due to well training and taking certain precautions. For these women it is safe to say that despite the hardships HIV/AIDS had paradoxically brought a positive and enduring contribution to their personal lives, comparable to the findings of Carlisle (2000). 'Pride' was only mentioned by one woman in the study, and I find it a bit odd that none of the others mentioned this specific feeling. We can assume that pride is something most of, if not all, the women would feel about their work, as reflected in their feelings of empowerment. Why not any more women explicitly mentioned pride might be because it simply slipped their minds, perhaps it is just not a salient theme for them - they do not think about it, or perhaps this is an example of cultural differences.

I found it hard to separate between intrinsic and extrinsic motivations (Meier & Stutzer, 2006) of the women's accounts in many instances, since many reasons mentioned could be interpreted as both intrinsically and extrinsically motivated. For example are the benefits of praise and recognition hard to categorise; where would we put those? In one way they could be categorised as intrinsic; received as an internal award directly from the volunteer activity, and conversely these benefits could just as well be seen as external. Although it was clear that there were more internal awards than external benefits involved in the reasons for volunteering, we can assume that for many of the women the benefits of volunteering was a combination of the two types of rewards. This is due to some of them mentioning clearly extrinsic reasons along with intrinsic ones. Typical examples of extrinsic reasons include expecting future care being HIV-positive themselves, or aspiring to be a nurse some day. This supports what Meier and Stutzer claimed to be the case for most people volunteering.

The results of several studies (Meier & Stutzer, 2006; Post, 2005) suggest that volunteers are more satisfied with their lives, and that helping others can increase happiness and life satisfaction. I do not have enough data to conclude if this is the case for the women in this study, but all the positive experiences of volunteering which they conveyed suggest that there may be some support for the claim that intrinsically oriented people are more prepared to volunteer, that they obtain more benefits from volunteering than extrinsically oriented volunteers, and that helping others do increase feelings of well-being (Meier &

Stutzer, 2006). Could this possibly be related to the *good character* of the women in my study? Although the character strengths of the women were not measured, it is safe to say that they clearly displayed strengths of humanity; as positive traits manifested in their caring relationships with other people (Peterson, 2006). It is possible that their kindness, represented by their acts of doing good deeds and taking care of others, contributed to boosting their subjective feelings of happiness and well-being.

Under which circumstances can volunteerism be too much? Post (2005) found that volunteerism was associated with happiness, enhanced well-being and a reduction in depressive symptoms, and that *moderate* amount of volunteerism was associated with lower risk of death. In regards to altruistic social behaviours' effect on health, giving help was more significantly associated with better mental health than was receiving, as long as the feelings of others' demands did not become too overwhelming. A recent Australian study on volunteering among older adults found nonlinear associations between hours spent volunteering and well-being. These associations were characterized by inverted U shapes, with non volunteers and those volunteering at high levels producing lower well-being scores relative to those volunteering at moderate levels (Windsor, Anstey, & Rodgers, 2008). The women in my study spent a various amount of time volunteering, depending on how ill their patients were, but there is no doubt that they spent quite a lot of their time helping people. On one hand their voluntary efforts may contribute to their feelings of happiness, and on the other hand they could be at risk for declining levels of well-being if the voluntary work got too overwhelming. Omoto et al. have revealed in their studies that the relationships between volunteers and the PLWHA typically fall short of the high expectations that the volunteers often have for the quality of these relationships (cited in Omoto & Snyder, 2002). Problematic relationships with patients could possibly set limits for volunteering in turns of contributing to burnout among the volunteers. The quality of the relationships with patients for the women in my study varied, and in many cases it was not very good. In those instances it is important for the volunteers to be prepared through adequate training and to know how to handle potentially uncomfortable situations. Receiving social support from good quality networks can also play a role in counteracting the negative experiences.

Apparently none of the women in my study had any plans of quitting their work any time soon. The response made most often was intentions of staying for a very long time ahead. Others agreed that they would like to continue their work for as long as possible, but

they were also hoping for a paid job, and they pictured themselves still continuing with the volunteering, on the side. These women had all been volunteers for at least one year, but we can find that in some areas around 50% quit within the first year (G Marincowitz et al., 2004; Uys, 2002). This could possibly be an indication of the women in my study as extraordinarily motivated in their work. If so the findings could be somewhat biased in the sense that perhaps the least motivated women had already quit. It can also be feasible to bear in mind that behavioural intention and actual behaviour do not necessarily coincide (Taylor, 2006).

Elements of social capital revolving around trust and solidarity were important for the women. Many of them expressed having a great deal of trust in their fellow community members, and they agreed that trust and solidarity is very important for them in their line of work. The feelings of empowerment among the women were very strong. All of them felt that they had the influence to make their community a better place to live in, as well as having the power and ability to make important decisions that could change the course of their own lives.

Protective factors predicted to be associated with decreased caregiver distress and increased well-being include empowerment and social support (Fredriksen-Goldsen, 2007). Fredriksen-Goldsen found that despite the difficulties in their lives, more than 70% of AIDS caregivers in the USA were moderately to highly satisfied with their lives. Factors that contributed significantly to well-being included greater caregiver health, higher levels of caregiver optimism and self-empowerment and lower levels of discrimination. This implies that the women in my study actually could be protected from overwhelming caregiver distress by their sense of self-empowerment. Perhaps their well-being could be increased even more if we could manage to combat some of the stigma and discrimination surrounding HIV/AIDS.

Debates about politics, and governmental actions and efforts are comprehensive among most people in South Africa. South Africa is the richest country of Africa, but still HBC programmes are only minimally funded, and can mainly provide basic nursing care with very little medication (Akintola, 2004). Uganda, on the other hand, manages to provide comprehensive medical care and subsidize costs for patients through its HBC projects. How the women in this study perceived the quality of the government support varied. Some said

that it is not well, not enough, while others said it is ok, but that the government still can do better. As for suggestions for improved conditions they mentioned having a local hospice in the community, having food provided for the sick people and a working kit for the volunteers. Only one person mentioned a wish to get paid for the work she did. Considering the situation of the volunteers in this context one would think that they would utter a wish for some financial support for the hard work they do. Is there no need for payment? As caregivers lose opportunities to earn income when they volunteer this probably could not be it (Akintola, 2008b). Does it somehow go against any principles in the "volunteer world"? Perhaps the Zulu culture of givers being regarded as stronger than receivers play a role? Volunteers are valued as physically and emotionally strong due to their work in certain socio-cultural contexts of KwaZulu-Natal (Akintola, 2004). There is also a possibility that the women might have avoided to tell me as a white and relatively rich foreigner about this need. Then again it could have been just as likely for that situation to actually facilitate *more* talk of payment, in the hopes of potentially attaining my assistance.

All the women agreed that the local HIV/AIDS organisations were important in the community, and most of the women felt satisfied with the organisations' efforts. Community participation in HIV/AIDS related activities seemed to be generally quite high. The community is able to work together willingly, according to the women's responses. These are important factors for building social capital in the community and facilitating care for PLWHA (Campbell, 2004; Campbell et al., 2005).

The results of this study could be said to support Omoto and Snyder's (2002) model of volunteerism; a phenomenon building bridges between individual, interpersonal, organizational and broader societal levels. Even though Omoto and Snyder have developed their theories on the basis of research done on HIV/AIDS volunteer programs in the USA, their conceptual model could prove valid in the South African context as well. Omoto and Snyder claim that the community (with its standards, norms, resources and institutions) provides a backdrop for individuals and organisations to take on volunteer activities, and is changed by the volunteers responding to the needs of the community. Connections to and concerns about communities can motivate and sustain the activities. Heightening and broadening a sense of community may be likely to have beneficial effects on feelings of personal efficacy and social support for PLWHA and volunteers. A greater sense of community is likely to increase confidence that social support is available, and provide more

and different resources to draw on. A sense of community could then contribute to individual and collective action, and facilitate other civic participation, including helping and being helped. The increased resources, confidence and esteem provided by a sense of community could also breed feelings of empowerment. In this way a psychological sense of community may lead individuals to act to change or participate in their communities. Evidence suggest that people's sense of community and their social networks may be important factors in deciding to become volunteers (Omoto & Snyder, 2002). This theory of community as a context for volunteerism has a lot in common with the framework of social capital which I proposed. Factors such as knowledge/personal efficacy (norms/resources), social support, community concern, individual and collective action and empowerment are all important elements of social capital. Many of the women I talked to mentioned community concern as important motivation for volunteering, and it is likely that their connection to the community (love for the people) also sustained their activities. Most of the women further told me that they do receive much social support; from co-volunteers, friends, neighbours and family. This could stem from a greater sense of community these women might have. It could be argued that their strong feelings of empowerment also are a result of this sense of community. These connections have lead me to assume that there is a relationship between motivations for doing voluntary care work, the positive experiences (growth) the women have doing it, and social capital – possibly through the women's sense of community. Exactly what this relationship is and with what kind of psychological mechanisms it works I cannot say. It is possible that ubuntu plays a central role in these relationships; sustaining volunteerism and the positive experiences through social cohesion among people. I believe this study has contributed to shed light on which social contexts and relationships support volunteers in their key roles as community resources in the fight against HIV/AIDS.

4.1 IMPLICATIONS AND RECOMMENDATIONS

The findings of this study offer some ideas of how voluntary care workers for PLWHA can be better assisted and supported, and what future research should look closer into.

Exploring the motivations and experiences of the volunteers in this study has revealed many positive aspects of care giving. It is important to understand these along with the

negative ones, so that the conditions most likely to support the caregivers can be tended to and reinforced. Community concern, ubuntu, knowledge dissemination, networks, trust, solidarity, empowerment, community participation and government support are factors as such.

Carers need aid with the pressing challenges of meeting all needs of their patients, they need help lobbying for the recognition of the needs of both themselves and their patients, and there is a need to develop local community health networks which support carers and patients, and also might strengthen communities to cope with other health challenges (Campbell, 2004).

The volunteers in this study had some suggestions for how their working conditions could be improved tremendously, with some assistance from the government: A local hospice, necessary equipment for the volunteers and food for the ill and poverty struck people. This would naturally make the ill people feel better by benefiting more from the ARVs, and make the working environment for the volunteers much safer. I would assume that these things also would make it easier for the volunteers to stay motivated in their work.

The volunteers in this study appear to have the most resources at the bonding level of social capital, and lacking at the bridging and linking levels. They are in need of a larger voice facing the government. Perhaps the government need to take more responsibility for facilitating and contributing to bridging and linking social capital in the communities; so as to build cooperative and fruitful relationships with and among the groups at grass root levels.

An idea for future research would be to further explore the relationship between motivation for volunteering, the positive experiences, social capital and sense of community. If we were able to understand these relationships and the underlying mechanisms, then perhaps we would know how to support the AIDS volunteers in their working conditions in an efficient and realistic way. The South African context for the mechanisms of amount of volunteering and positive or negative outcomes also needs to be further explored, for preventing future burnout.

4.2 LIMITATIONS OF THE STUDY

There are a few limitations to this study that need to be considered. First of all, the findings of this study are not meant to be generalised, but applies to the women in this particular context. Hopefully their stories can contribute to shedding light on a relatively under-researched area of positive experiences of AIDS volunteerism in relation to social capital, in South Africa. The next potential limitation considers the validity, or truthfulness, of the study: Did the women tell the whole story? This study could not capture all the underlying processes; for doing that I would have to follow the women over a longer period of time, and observe them in action. To not be able to go back into the field for any follow-up questioning constitutes another potential limitation of the study.

The dissimilar cultural background which I bring with me into this study could possibly be a source of limitation; perhaps making me miss potentially important issues, and have an effect on the women's accounts. One issue I have to consider is whether the women truly are as satisfied as they claim to be, or if they could in some way be influenced by me as a stranger and a white person. This, along with certain language barriers could have led to problems of communication. Although there might have been a few small misunderstandings along the way, I do not believe that it has affected the overall meaning of the findings. Using the assistance of an interpreter poses its own challenges, as already briefly discussed in the introduction part. We rely on language, and translation by an interpreter can lead to lost attributes of communication (Raval & Smith, 2003). Another pitfall could be the interpreter seeing her role as being advocate for the informant; editing responses in translation, so as to cast the informant in a more favourable light.

Finally we have to consider the possibility of my informants being selected in a way, since these volunteers had stayed in the HBC group for over a year, in contrast to the 50% of volunteers who have been found to leave within the first year. If the women in this study are the ones who are the strongest and most motivated volunteers, it could possibly bias the findings and implications.

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6. APPENDIX

6.1 Interview guide

Semistructured interview:

Has a sequence of themes to be covered, as well as suggested questions in order to follow up the answers given and the stories told by the subjects (Kvale, 1996).

<u>Remember open questioning</u>: How? What? Can you describe…? Why? Tell me some more…

Openness of purpose? Yes.

Briefing:

Define the situation (present information) for the subject, tell about the purpose of the interview, tape recorder, etc. and ask if the subject have any questions. Make sure it is understood and completely voluntary. Remember to get the informed consent letter signed!

Background information:

How old are you?

Where do you live? Can you describe your home? (Size, Electricity, water, equipment…)

What is the level of the highest education you have completed?

Are you presently in paid work? What kind? Monthly income?

Are you married/single/widowed/co-habitating? (What does your partner do?)

Do you have children? How many? Age?

What are your religious views? How actively involved are you?

How would you describe your overall state of health?

1. Motivations for volunteering

<u>Why did you first volunteer for care work for PLWHA?</u>

(Ex.: Wanted to help the community, do good deeds, hoping for a stepping stone into paid work, wanted to learn more…)

- How were you recruited? When? How did you go about? Who did you talk to?

- How did you feel about doing the volunteer care work in the beginning?

- How much time do you spend volunteering?

- What kind of care work do you do? (Ex.: Tend to basic needs, pain-management, emotional/spiritual support, educate...)

2. Reasons for continued involvement

A) <u>What are your reasons for continuing your involvement in volunteer care work?</u>

(Ex.: Satisfied with the work, connection, coping, learning new skills...)

- How do you feel about doing the volunteer care work now?

- How does the care work affect your well-being and your health?

(Ex.: Feel happier, feel better about oneself, feel like a better person…)

- What kind of social support do you receive in your work?

- How is your relationship with the other persons in the organisation?

- How is your relationship with your patients?

- For how long do you think you will you keep doing the voluntary care work?

3. Making use of social capital/ubuntu in the voluntary care work

A) <u>Which groups/organizations/**networks** are you a member of, and how actively do you participate in each?</u>

- Which group is most important to you? Why?

- To what extent do this group interact with other groups (inside/outside community)? How do they work together?

- How many persons do you know you can call on for help? (Close friends) (Ex.: If you suddenly had to go away for a day or two, could you count on your neighbours to look after your children?) (Ex.: If you suddenly needed to borrow a small amount of money (enough to pay the expenses for your household for a week), are there people beyond your close relatives to whom you could turn and who would be willing and able to provide this money?)

- How often do you talk with and visit friends and neighbours?

B) <u>To what degree do you **trust** your fellow community/group members?</u>

- Why / why not?

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

- How likely is it that you would ask your neighbours for help if you were sick?

- If your neighbour did something for you, how likely would you be to return the favor

- How do the levels of trust and **solidarity** (= a unity of purpose and togetherness) affect your volunteer activities?

C) <u>In what ways do people in your community **cooperate** and **act collectively** (together)?</u>

- To what extent are people willing to participate in the community? (Ex.: If there was a problem with safe water supply in this community, how likely is it that people will work together to solve this problem?)

- How does the level of collective action in the community affect you?

D) <u>How strong is the feeling of togetherness or closeness in your community?</u> (**social cohesion**)

- Is the community generally peaceful or characterized by acts of violence?

- In general, how **secure** do you feel when you are alone at home?

E) <u>How much influence do you think you have in making this community a better place to live?</u> (**Empowerment and social action**)

(Ex.: Do you feel that you have the power/ability to make important decisions that change the course of your life?)

F) <u>How important are the local HIV/AIDS organizations in the community, in regard to providing HIV/AIDS services?</u> (Care and support)

- How satisfied are you with the job they are doing? (Ex.: Do most PLWHA receive the assistance they need from these groups?)

- Is the government providing adequate support for HIV/AIDS community groups?

- How high is the level of community participation in HIV/AIDS related activities?

- How influential do you think the norm of *ubuntu* is in motivating people to join activities of voluntary care and support for PLWHA in this community?

4. Ending question

A) <u>How have you grown as a person after having these experiences?</u>

Debriefing:

Mention some of the main points from the interview. <u>Any further comments or questions by subject?</u>

6.2 Extract of analysing process, phase 4

Social capital and support from different levels: Empowerment

125. Empowerment: Strong feelings of having influence to change community for better (i2, i4, i10x2, i12)

"I think I have a lot…" (i2)

"I always tell myself that, I alone can make a difference in the community/one day I ask myself what I could establish that could help the people, to develop them/ I always think about that, and wonder what I can do to help the community, so it can be better one day." (i4)

"I believe that I have a lot of influence…" (i10)

"Much influence." (i12)

94. Empowerment: Dependent upon money to have the power to change the community (i3, i5)

"If I were to have money, I would change the community; I would start development projects and no on would a criminal." (i3)

"If I had the resources I could…" (i5)

56. Empowerment factors: Share knowledge (i1, i3, i11, i12)

"…Because people know that they can to me and I give them the little knowledge that I have, you see…" (i1)

"…we counsel them and tell them that a person doesn't die before their time." (i3)

"I can go door to door, tell them about life, how can carry on in life, then they / I think they will see that it's very important to have us in community, as a group…" (i12)

159. Empowerment factors: Team work (i8x2, i10x3)

*"…*As long as we're working as a group, yes you can, yes." "Yes. Yes, if you're working as a team / cause if you are in a team, there's a part there's a part I know how to play …. But there is a part that I don't know how / I don't know how to play that part / that you. So if you are a group, we can work together. We can make a big difference even in our communites, as long as we work as a team, as a group. Yes." (i8)

"…we have to work together in every way. Cause a person alone can / can't change the world, but if go together and we work together, a huge difference can be done. Ja..." "…with the right people / with people with the right attitude towards life, I think we can, you know, we can change this community if we want. I believe." (i10)

126. Empowerment: Strong feelings of having the power to change own life for the better (i4, i10)

"As long as I am alive/I always tell myself that as long as I am alive and walking on this earth there is nothing that I will defeat me, or that I couldn't do for myself/at all times I tell myself that whatever I want to do I will succeed, no matter what, as long as I do it myself and not rely on anyone else/I don't want to rely on anyone else, I tell myself that I will make it by my own power." (i4)
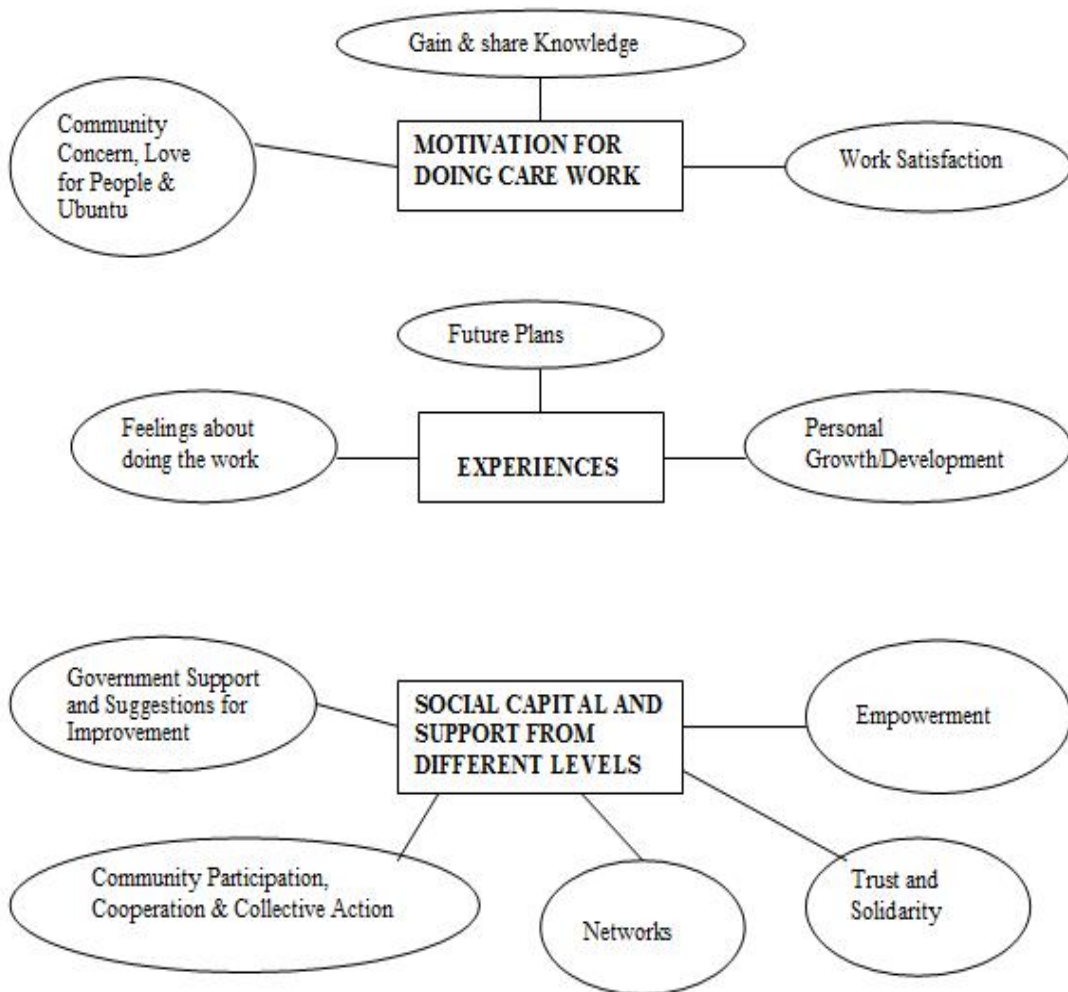
"Definetly. Yes." (i10)

60. Empowerment: Feelings of having the power to change own life for the better (i1x2, i2, i3, i5, i8, i10, i11, i12)

"…but I can say that I since I can still provide well for my children, therefore I do have the power on my own to change my own life. Even at the place I live in I have to pay rent. To also say that if my children still go to bed at night and are not hungry, I believe that I'm doing a great job." (i1)

"Yes I can/I am/I don't wait for a man to do things for me…" **LAUGHS** "I do things for myself." (i3)

"Yes. Yes." *Laughs* (i8)

"…So we can change our lives, we can change our situations. Cause it is up to us to change our lives. Yes." (i10)

6.3 Request for participation in the research project

Positive experiences of voluntary care-work for people living with HIV/AIDS in KwaZulu-Natal, South Africa

Background and purpose

This is a request for your participation in a research project which deals with examining the positive experiences of volunteer care work for people living with HIV/AIDS, in relation to social capital. Relevant participants for this study are adult (18 years or more) women living in and around the area of KwaNcgolosi. We will recruit volunteers who have been involved in HIV/AIDS related care and support activities and organizations for at least 2 years. The study is conducted by the University of Oslo, Norway, in cooperation with the University of KwaZulu-Natal.

Procedure

Information will be collected through individual semi-structured research interviews and focus groups. You only participate and answer the questions if you are willing to do so. You have the right to withdraw from the research any time you want to.

Possible advantages and disadvantages

A possible disadvantage for you is that some questions or procedures might make you feel uncomfortable. Some procedures can be time-consuming. The information you give can however contribute to new knowledge on how social networks, trust and norms, and collective action operate in relation to HIV/AIDS care and support in your community. Based on this information, recommendations and programmes can be made to strengthen social capital and improve HIV/AIDS related care and support in your community. Specifically the context of volunteer care work.

What will happen to the information you give in this study?

The information given by you will be registered and used only in accordance with the purpose of this study. A code, connected to a list of names, will be used to identify the information you give. This means that the information you provide is treated with confidentiality.

Only authorized personnel that are part of this research project will have access to the list of names that could be traced back to you.

It will not be possible to identify you through the results of the study when these are published.

Voluntary participation

Participation in this study is voluntarily**.** You may at any time and without stating a reason withdraw from the study. If you wish to participate in the study, please sign the informed consent on the last page of this document. If you at this stage agree to participate, you may still withdraw your consent at any point of the study. If you at a later stage wish to withdraw, or have any questions regarding the study, please contact Therese Sæberg at thersae@student.sv.uio.no, or Wenche Dageid on telephone +47 22845184 or 072 760 2448, address Department of Psychology, University of Oslo, Forskningsveien 3, P. O. Box 1094, NO-0317 Oslo, Norway, or email wencheda@psykologi.uio.no

Additional information about the study can be found in **Section A**

Additional information about protection of personal data and economy can be found in **Section B**

Statement of informed consent follows after section B.

Section A. Thorough explanation of the study

Criteria for participation

Informants must be local women (minimum 18 years old) residing in eThekwini or KwaNcgolosi and the surrounding community. Participants must have a minimum of 2 years experience as a volunteer care worker for people living with HIV/AIDS. Only women will be recruited as men are almost non-existent within this form of volunteer care work. The women will be recruited through community based organizations providing HIV/AIDS services, by contacting the volunteer coordinator, and setting up an informational meeting.

Background information about the study

This study aims at examining the role of social capital in promoting community based care and support for people living with HIV/AIDS in KwaZulu-Natal, South Africa. Social capital has been thought of as a web of cooperative relationships between people that facilitates resolution of collective problems, promote sustainable development and increase well-being. Social capital can be viewed along several dimensions: The scope or unit of observation (*micro-meso-macro*); the forms or manifestations (*structural*: roles, networks, other structures supported by rules, procedures, and precedents (*cognitive*: shared norms, values, trust, attitudes, and beliefs); and the channels through which it affects development/well-being (information sharing, collective action, decision-making).

Specific research objectives

Identify how elements of social capital in relation to care and support for people living with HIV/AIDS in the community manifest themselves and are inter-related through exploration and evaluation of:

    a. Women's motivations for doing voluntary care work

    b. The reasons for continued involvement in voluntary care work over time

    c. Volunteers' perceptions of social capital in the area, and how they draw up on social capital in relation to their work.

    d. The relation between the positive experiences of volunteer care work and social capital, in this particular South African context.

Procedure and instruments

The study takes place during 2008-2009, and following methods and instruments will be used: In-depth interviews, focus groups and field notes. The instruments will be adapted to the local context and translated into isiZulu, and Zulu-speaking university students will assist in the translating.

Advantages and disadvantages

The study will inform the community about the levels and mechanisms of social capital that operate in HIV/AIDS related care and support, and how to improve these. Groupings and organizations could be assisted in improving their functioning, and new knowledge can be obtained at individual and group levels. Participatory methods are likely to have benefits for the participants. Disadvantages include time-consuming procedures and possible discomfort in answering questions.

Section B – Protection of personal data, and economy

Protection of personal data

The information that will be registered about you will be treated with confidentiality by the research team at all stages of data collection, analysis, and during report writing. The research team is responsible for making sure that all participants are informed of the nature and purpose of the research and have autonomy to choose whether to participate in the research

The right to access personal information and maculate information about you

If you agree to participate in this study, you have the right to access registered information about you. You also have the right to correct eventual mistakes in the information we have registered about you. If you withdraw from the study, you can demand that all information about you should be maculated, unless the information has already been analysed or used in academic publications.

The study is financed by the Norwegian Research Council and the National Research Foundation South Arica.

Information about the results of the study

Participants have the right to know the results of the study. The project emphasises continuous dissemination and discussion of findings. A final report will be distributed after the completion of the project, in the form of a Master Thesis in Psychology. The findings may also be further published.

CONSENT TO PARTICIPATE IN THE STUDY

I am willing to participate in the study

_____

(Signed by respondent, date)

I confirm that I have conveyed correct information about the study

I will observe the anonymity and confidentiality of the respondent

_____

(Signed by the interviewer/researcher, date)

6.4   Statement of approval from NSD and REK

NSD

Wenche Dageid
Psykologisk institutt
Universitetet i Oslo
Postboks 1094 Blindern
0317 OSLO

Vår dato: 12.06.2008   Vår ref: 18806 / 2 / JE   Deres dato: Deres ref:

TILRÅDING AV BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 07.03.2008. All nødvendig informasjon om prosjektet forelå i sin helhet 10.06.2008. Meldingen gjelder prosjektet:

18806	*The Role of Social Capital in Promoting Community Based Care and Support for People Living With HIV/AIDS in KwaZulu-Natal, South Africa*
Behandlingsansvarlig	*Universitetet i Oslo, ved institusjonens øverste leder*
Daglig ansvarlig	*Wenche Dageid*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven/-helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.
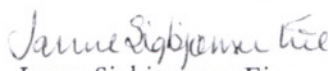
Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk_stud/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/prosjektoversikt.jsp.

Personvernombudet vil ved prosjektets avslutning, 31.12.2015, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Bjørn Henrichsen   Janne Sigbjørnsen Eie

Kontaktperson: Janne Sigbjørnsen Eie tlf: 55 58 31 52
Vedlegg: Prosjektvurdering

Avdelingskontorer / District Offices:
OSLO: NSD. Universitetet i Oslo, Postboks 1055 Blindern, 0316 Oslo. Tel: +47-22 85 52 11. nsd@uio.no
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Personvernombudet for forskning

Prosjektvurdering - Kommentar

Personvernombudet forstår det slik at prosjektet er et samarbeid mellom University of Kwa-Zulu Natal i Sør Afrika og Universitetet i Oslo hvor sistnevnte er behandlingsansvarlig institusjon. Ombudet forutsetter at denne behandling/ansvarsfordeling formelt er avklart mellom institusjonene og anbefaler at det utarbeides en avtale som bl.a. omfatter ansvarfordeling, ansvarsstruktur, hvem som initierer prosjektet, bruk av data og eventuelt eierskap.

Utvalget består av voksne kvinner og menn i KwaZulu-Natal, Sør-Afrika.

Data samles inn gjennom blant annet spørreskjema, dybdeintervju, fokusgrupper, deltakende observasjon, notater, tegninger og narrativt teater. Alle instrumenter vil bli adaptert til den lokale konteksten og oversatt til isiZulu.

Det registreres sensitive opplysninger om helseforhold og medlemskap i fagforeninger, jf. personopplysningsloven § 2 punkt 8 c) og e).

Det gis skriftlig informasjon og innhentes skriftlig samtykke fra alle deltakerne. Informasjonsskrivet som forelå 10.06.2008 finnes tilfredsstillende forutsatt at dato for prosjektslutt oppdateres til 31.12.2015 og teksten "unless the information has already been analysed or used in academic publications" slettes i avsnittet "The right to access personal information and maculate information about you". Dette unntaket i trekkmulighet gjelder kun for biologisk materiale og kan dermed ikke benyttes i det foreliggende prosjektet.

Behandlingen kan hjemles i personopplysningsloven §§ 8 første ledd og 9 a), samtykke.

Prosjektleder opplyser at det skal ikke foretas datainnsamling om husholdet likevel. Det skal dermed ikke etterspørres informasjon om tredjepersoner. Det tas likevel høyde for at informasjon om tredjepersoner etter all sannsynlighet kan dukke opp gjennom datainnsamlingen, særlig i narrativer og intervjuer. Ombudet legger til grunn at opplysningene vil være av begrenset omfang og av betydning for prosjektets formål. Personvernombudet finner at behandlingen kan hjemles i personopplysningsloven §§ 8 d) og 9 h). Med bakgrunn i at opplysningene om eventuelle tredjepersoner avgis tilfeldig og gjerne uten direkte personidentifiserende opplysninger, er det ombudets vurdering at prosjektleder kan unntas for sin informasjonsplikt overfor tredjepersonene, jf. personopplysningsloven § 20 annet ledd b).

I tillegg til prosjektleder Wenche Dageid og forskerteamet vil også masterstudenter, forskerassistenter og en PhD-student ha tilgang til materialet.

Prosjektet skal avsluttes 31.12.2015 og datamaterialet skal da anonymiseres og lydopptak slettes. Anonymisering innebærer at direkte og indirekte personidentifiserende opplysninger slettes eller omkodes (grovkategoriseres), navneliste/koblingsnøkkel slettes.

Prosjektet er meldt til Regional komité for medisinsk og helsefaglig forskningsetikk som har vurdert prosjektet som ikke fremleggelsespliktig.

UNIVERSITETET I OSLO

DET MEDISINSKE FAKULTET

Post doctoral researcher Wenche Dageid
Department of Psychology
Universitetet i Oslo
Postboks 1094 Blindern
0317 Oslo

Dato: 07.11.2008
Deres ref.:
Vår ref.: S-08634d, 2008/18203

**Positive experiences of voluntary care-work for people living with HIV/AIDS in
KwaZulu-Natal, South Africa. (Master-oppgåve under det allerede godkjendte
prosjektet "The role of social capital in promoting community based care and support
for people living with HIV/AIDS in KwaZulu-Natal, South Africa".)**

The committee discussed the application on 23.10.2008. The project has been evaluated in
accordance with the law of 30 June 2006 on the treatment of ethics and integrity in
research, the Ministry of Education and Research's regulation of 8 June 2007 and
guidelines of 27 June 2007 for the regional committees for medical and health ethics.

Evaluation of research ethics:
The Norwegian *Terms of Reference for the Regional Committees for Medical and Health
Research Ethics,* 3, states that

*All biomedical research projects involving trials on humans, which are not of such a nature
that they can be deemed to be part of an ordinary, established treatment procedure, shall
be submitted to the committees. This applies both to therapeutic and non-therapeutic
research on patients and healthy subjects. Biomedical research projects involving trials on
humans shall also be understood to include research on identifiable or anonymous human
material and identifiable or anonymous data.*

The scope of this project does not constitute the requirements for research as stated in the
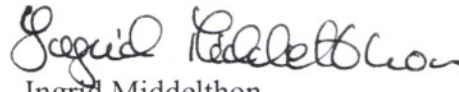Terms of Reference.

Decision:
The project falls outside the mandate of the Committee.

The decision was unanimous

The decision of the committee may be appealed (See Section 28 of the Public Administration Act) to the National Committee for Research Ethics in Norway. The appeal should be sent to the Regional Committee for Research Ethics in Norway, South-East D (see Section 32 of the Public Administration Act). The deadline for appeals is three weeks from the date on which you receive this letter. (see Section 29 of the Public Administration Act)

Yours sincerely

Stein A. Evensen (sign.)
Professor dr.med.
Chairman

Ingrid Middelthon
Secretary

Kopi: Norges Forskningsråd, v/Jan Håkonsen, P.b. 2700 St. Hanshaugen, 0131 Oslo
Psykologisk institutt, v/Kristin Nordseth, P.b. 1094 Blindern, 0317 Oslo
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