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Provisions of Home-Based Care for People Suffering From HIV/AIDS in Addis Ababa, Ethiopia

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A Qualitative Study to Explore Provisions of Home-Based Care for People Suffering From HIV/ADIS

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List of Acronyms

CBD	Community Based Volunteers
CBOs	Community based organizations
CHBC	Community home based care
FDRE	Federal Democratic Republic Ethiopia
HBC	Home-Based Care
HAPCO	HIV/AIDS prevention and control office
MOH	Ministry of Health
NGO	Non-Government Organisation National AIDS Control Program
PSFA	People Suffering from AIDS
OSSA	Organization for Social service for AIDS
OVCs	Orphan and Vulnerable Children
UNAIDS	United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
UNISD	United Nations Institute for Social Development
VCT	Voluntary Testing and Counselling
WHO	World Health Organisation
WCC	World Council of Churches

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Abstract

HIV/AIDS is a pandemic infecting and affecting millions of people worldwide. Ethiopia is also severely affected by this disease. Because hospitals cannot cope with patients admitted daily especially with the influx caused by HIV/AIDS patients, the government has introduced home-based care for people suffering from AIDS. Amongst those who practice home-based care are formal and informal (family) care givers. This study is aimed at exploring and describing the experiences of community based volunteers, families involved in home-based care of people suffering from AIDS and patients in Addis Ababa, Ethiopia. The researcher collected a qualitative data with the aim of finding out what it is like to be a care giver involved in home-based care and care receivers in the city. The data was collected by means of semi-structured one-to-one interviews and focus group discussion. A sample of thirty-two research participants was acquired through purposive as well as snowball sampling. The interviews were guided by a number of broad question themes. These data were analysed using Atlas. ti, a computer driven data analyses program by using top down coding. Finally various tools within Atlas.ti (co-occurrence; query; family) were used to analyze the data and related to Tronto's care ethical framework. The study indicates that HBC for people suffering from AIDS does not create quality of care arrangement and supportive environment that facilitates the principles of attentiveness and responsiveness, which means the experiences are not as much positive for phases of taking care of and care giving, as there is some expectations of informal care givers and receivers regarding visiting time and involvement. The large number of people suffering from AIDS surrounding the diseases and the lack of resources play a role in this. Moreover, the care process is not well integrated because of poor communication and division of responsibilities between formal care givers, informal care givers and care receivers.

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Chapter 1

1. Introduction

HIV/AIDS is the major cause of mortality in Africa. Although Africa is home to about 14.5% of the world's population and it is estimated that 67% of all people living with HIV and to 72% of all AIDS deaths in 2009 are located in Africa. In addition, AIDS is now the leading cause of death in sub-Saharan Africa, responsible for one in five deaths (UNAIDS, 2010).

According to UNAIDS (2005) since the start of the epidemic, AIDS has claimed the lives of more than 25 million people, and currently it is estimated that 36.7 to 45.3 million people are living with HIV in the world. Despite efforts aimed at controlling it, AIDS continues to spread in an exponential manner, particularly in Sub-Saharan Africa. More than 95% of the HIV victims live in developing countries, out of this 70% (25million) are living Sub-Saharan Africa (UNAIDS, 2004). AIDS is frightening in this continent.

Ethiopia is an African country characterized by absolute poverty with a GDP of per capita $115 per capital. it faces many political, economic, social welfare, education and health challenges and recurrent drought (Save the Children Alliance, 2001). Besides these problems, Ethiopia is also known for a high prevalence of HIV. HIV, which evolved from two cases in 1986, is spreading alarmingly and in 2004 had infected 1,475,000 (658,000 males and 817,000 females) people in the country (Ministry of Health [MOH], 2004 fact sheet).

Recognizing the magnitude of this problem, leaders from civil society, governments and multinational agencies declared HIV/AIDS as the single most critical security and development issue and required implementing expanded and comprehensive interventions (WHO, 2000). In comprehensive programs, care and support are vital components to mitigate the effects of the pandemic on individuals, families and communities. Such interventions are an important component of the overall response to HIV/AIDS because they increase the impact of prevention strategies and reduce the negative consequences of the epidemic for the prospects of sustainable development.

In line with the global action, the Federal Government of Ethiopia has developed policies and strategies to reduce HIV pandemic. National Task Force was established in 1985, the National AIDS/STD Control Program (NACP) in 1987 (WCC, 2003); and two medium term prevention and mitigation programs were implemented between 1987 and 1996 (FDRE, 2001). A National AIDS Council was established in 2000, following this the HIV/AIDS Prevention and Control Office (HAPCO) was established. Several relevant policies and regulations were formulated, including HIV testing policies for diagnostic and clinical purposes, professional codes to ensure confidentiality, disclosure policies of HIV testing and resulting provision and comprehensive programs.

The continued spread of HIV/AIDS in developing countries, particularly in sub-Saharan Africa, has caused a steady increase in the number of deaths caused by AIDS or AIDS-related illnesses (WHO, 2002). This has been compounded by the unavailability of antiretroviral medication for the majority of public health institutions. The situation has stretched the capacity of hospitals beyond their limits and has shifted the burden of care to families and communities. Community home-based care (CHBC) has become a central concept in the provision of care . In Ethiopia, the disease has a significant impact on all sectors, particularly the health sector where an increasing percentage of hospital beds are occupied by patients with AIDS related illness (MOH, 2004). According to the World Bank (2005) still extensive investment is required to scale up the AIDS control program.

As suffering caused by the epidemic grew, the need for care for people suffering from AIDS increased. Efforts to respond to this demand have been made by community based and non-governmental organizations. In Africa, CHBC programs were developed, but the provision of care for people suffering with HIV remains low (WHO, 2002). CHBCs are mainly initiated by nongovernmental organizations (NGOs), community-based organizations (CBOs) and concerned individuals (Hearle, 2009)

The first home based care (HBC) programs in Uganda, Zambia and Zimbabwe were developed by hospitals, but it was found that 75 percent of the hospital staff time was spent travelling to the patient's home in the rural areas, which was costly for hospitals (Hunter, 1997). For poor people suffering from AIDS, family members and community volunteers have become the primary source of day-to-day care. It is estimated that between 70 and 90

percent of care in developing nations takes place in the home (Akintola 2008; WHO 2000). According Akintola (2006) HBC plays a vital role in the care of millions of people suffering from AIDS in sub-Saharan Africa where medical services are overwhelmed by the demands of the epidemic. In addition, HBC has grown in significance, as hospital-based care cannot cope with the increasing numbers of patients and is inaccessible and unaffordable to the majority (WHO, 2002). Ideally, HBC provides services that are near to patients and locally responsive to the needs of communities.

The AIDS epidemic in Ethiopia constitutes a burden for the health sectors. For instance, the hospital bed occupancy rates is higher and difficulties of reaching all people suffering from AIDS. The few existing home-based care services, provided by health professionals, families, and volunteers from women and youth groups do not meet the expectations and needs Yeneneh et al. (2002). Beside this, high levels of stigma attached to home-based care, lack of drugs for treatment of opportunistic infections, lack of referral systems, poverty and lack of financial resources and technical support are the major problems related to HBC in the country (MOH, 2004).

Strong extended family ties and community commitment are major components in viable home-based programs that not only include people suffering from AIDS but also orphans and vulnerable children. Neighbour women, volunteers from faith-based organizations and private organizations, groups of people suffering from AIDS, the sub-district and NGOs support through food and materials have been major actors in home-based care in Ethiopia (Yeneneh, 2002).

Many studies in Ethiopia have tried to explore the economic impact of AIDS and the cost of community-based care. However, review of the findings of the existing documented research discloses a number of challenges indicating that more research is needed for the effective and efficient provision of HBC for people suffering from AIDS (UNAIDS,2004). This study is therefore intended to contribute to the existing literature by adopting sociological approach that focuses on identifying the roles of HBC in the arrangement and provision of care in order to create supportive environment for people suffering from AIDS in the Ethiopian context. This research therefore, intends to investigate the quality of care arrangement for people suffering from AIDS, and the challenges they face, to see how

patients' wellbeing and quality of life can be enhanced and how promising interventions and strategies could contribute to this.

1.1.   Problem Description

Care of people suffering from AIDS is putting tremendous stress on the health services in developing countries, raising issues of equity for patients with HIV and other illnesses. Yet much can be done to improve the efficiency and the humanity of care provided, even within the severe constraints of resource that exists Ncama (2005). Home-based care and volunteer care giving in sub-Saharan Africa are increasing due to the escalating number of people and families who are affected by the pandemic. The increasing number of people infected also results in the overburdening of the health systems of most developing countries that are unable to deal with the demands of the epidemic Ncama (2005).

As the number of people who require care at home increases, so should community home-based care (CHBC) services respond to the increasing demand. There needs to be justification for the continued existence of the services and empirical evidence is necessary to determine the impact of these services on comprehensive care for people suffering from AIDS with in Ethiopian context (MOH, 2004).

Currently, home based care (HBC) programs for people suffering from AIDS are implemented in different African countries. Within the home, care is usually given by family members and/or by "volunteer" caregivers recruited from the community (Akintola, 2006). This work largely done by women, especially poor women (and children) in developing countries, which limits their possibilities of social engagement, can lead social exclusion, and the depletion of human capabilities. In addition, caregivers often experience isolation, social stigma, psychological distress, and lack basic education about both care giving and HIV/AIDS (Nkosi et al. 2006; Lindsey et al. 2003)

The government of Ethiopia attempts to achieve a number of targets under the six Ethiopian Millennium Development Goals including combat HIV/AIDS, malaria and other diseases (UNISD, 2007). This led to the development of intervention programs like HIV campaigns and family planning education in schools, social media, and healthcare units. Likewise, HBC programs are initiated and operated in a few areas of the country by following it as strategy

from other Africa countries. However, the practice has been diverse, not following any standards in terms of quality of care, even though the Ministry of Health (MOH) has developed a national guideline on 'CHBC for People suffering from AIDS in 1996, to help and organize the service (FDRE, 2001).

To develop effective responses, research is needed to understand AIDS at a terminal stage, HBC programs and their strategies. Currently, there are not sufficient studies conducted on the role of HBC on quality of care arrangement in the country. The rationale behind this research is based on the gap between making care and support available at the community and home levels in order to inform further developments and research for building an effective and sustainable HBC program in the study region as well as the country.

To find answers to the research questions, the theoretical frame work of Tronto (1993) is applied. It provides a comprehensive overview of the phases of care and requirements of good care. The study will also incorporate a micro-ecological approach to care (Niehof, 2004).

In order to create healthy social, psychological and physical environments, home based care givers are instrumental in enhancing health, functioning and quality of life of people suffering from AIDS by providing home based care services. Therefore, the aim of this research to explore the roles of HBC in the arrangement and provision of care for people suffering from AIDS, using the framework of (Tronto 1993) to identify quality of care in the context of HBC for people suffering from AIDS in Addis Ababa, Ethiopia.

1.2. Research questions

To achieve the goal of this research, the following research questions were developed. The main research question is:

What is the role of HBC in the arrangement and provision of care for people suffering from AIDS in Addis Ababa, Ethiopia?

The main research question can be split in the following sub questions:

1. What are the roles of the different actors in the arrangement and provision of care?

2. What are the major challenges faced by home based care givers (informal and formal) and care receivers in care provision?

3. To what extent is the care process integrated?

4. What resources are required in providing quality of care for people suffering from AIDS?

5. How do the factors 1 to 4 influence the quality of care?

Chapter 2

2. Literature Review

To establish a link between what this research seek to explore and what has already been done in this field of study and to prove why the approach adopted in this study is a feasible solution to the research problem, this chapter discusses the concepts that guided the research and develops a theoretical framework that shows the relationship between concepts and their operationalization. A literature review was done on a number of themes pertinent to the research topic.

2.1. The HIV/AIDS Pandemic: An overview

HIV/AIDS is the major cause of mortality in Africa. Although Africa is home to about 14.5% of the world's population and it is estimated to be home to 67% of all people living with HIV and to 72% of all AIDS deaths in 2009. In addition, AIDS is now the leading cause of death in sub-Saharan Africa, responsible for one in five deaths (UNAIDS, 2010).

HIV is the most serious infectious disease in the world, and is an enormous challenge to global public health (WHO, 2009). Particularly at risk are: sex workers, men who have sex with men, injecting drug users as well as migrant populations (WHO, 2009). In addition, it affects females disproportionately, with women accounting for about 60% of all HIV infections in sub-Saharan Africa (UNAIDS & WHO, 2009).

The high infection and death rates due to HIV are indicative of people's lack of access to effective intervention programmes, and to treatment and care services, all of which are necessary to form a comprehensive system for managing the disease (WHO, 2009). The progression of HIV places a significant burden on public health systems to provide care to PLWH because need of patients can often not be met by health professionals due to a lack of resources as well as the large number of people suffering from AIDS who require assistance.

Additionally, people in developing countries often cannot afford to pay for the transport to get to hospitals to collect Anti-Retroviral medication (WHO, 2007).

The HIV epidemic has produced challenges in caring for and supporting people suffering from AIDS. Hospitals have been overwhelmed, especially in countries with high prevalence where hospital care cannot be feasibly provided to all patients (Uys & Cameron, 2003). Hospital care has been replaced with home care by formal and informal caregivers, who may be nurses, social workers, household members, neighbours, or friends. Home care is provided mainly by women, who are generally more vulnerable to the consequences of HIV both in terms of morbidity and mortality, whether they themselves have HIV or are living with and caring for family members who are infected (Duffy, 2005; World Health Organization [WHO], 2003). Comprehensive, cost-effective home care is possible but demanding in the social context of many African countries (Uys & Cameron, 2003).

2.2. Care

The word *care* is commonly used to specify the attention, support, and protection given by one person to another, it can be paid or unpaid ((UNRISD, 2007). Individuals with intense care needs include young children, the frail elderly and people with various illnesses and disabilities. Paid carers include nannies, childminders, nurses and care workers in homes for the elderly and other institutional settings. They can work in a variety of institutions (public, market, and not-for-profit).

Direct care of persons (bathing them, feeding them, accompanying them to the doctor, taking them for walks, talking to them and so on) is often seen as separate from the other necessary activities that provide the preconditions for personal care giving such as preparing meals, shopping and cleaning sheets and clothes. Tronto (1993 P: 103) give a very comprehensive definition of care that is applicable in the context of AIDS. According to her care as maintenance and as restoring (or healing), and not only of ourselves but also of our environment, including our social environment, which means, an activity that includes everything we do to maintain, continue and repair our 'world' so that we can live in it as well as possible In addition, Du Preez and Niehof (2008) powerfully articulated care as 'labour of love', which links cares as emotion with care as an activity.

According to Feliassa (2010), there are formal and informal care givers. Formal care givers include nurses, medical professionals, behavioural health specialist and social workers; Informal caregivers, who are household members, neighbours, or friends. In this study both formal care givers specifically social workers and informal care givers will be included.

The theory of care applied in this study is largely based on Tronto (1993). Tronto's care ethical framework were used to deepen the understanding of good care for people suffering from AIDS to shed more light on the positive experiences as well as the challenges during the provision of care and the role of different actors in care provision. Tronto's care ethics stems from the idea that all human beings are vulnerable at certain moments in their lives. People are thus mutually dependent and take care of each other. Care is a fundamental human activity. According to her, care is a continuous and interactive process. Caring does not stop when needs have been identified and fulfilled, as needs change over time and as care-receivers may not always be responsive to care.

Care is inter- subjective as the needs can only be identified through observation and communication with the care receiver. Tronto (1993) distinguishes four phases in the process of care: (1) caring about, recognising the necessity of care and identifying needs; (2) taking care of, assuming some responsibility for the identified needs and determining how to respond to it; (3) care giving, directly meeting care needs and (4) care receiving, the subject of the care responding to the care that the person receives. According to her each of these phases in the caring process requires certain virtues. The first virtue is 'attentiveness' to the particular needs of this specific person. The second virtue is 'responsibility'. One can only take care of someone if one feels responsible to improve the well-being of this person (as opposed to being functionally responsible given one's role. The third virtue is 'competence'. Without specific expertise one cannot provide good care. The fourth virtue is 'responsiveness'. The care receiver should be open to care. The final virtue is integrity of care, which means good care requires that the four phases of the care process must fit together in to a whole. According to her care as a practice involves more than simply good intentions, it requires a deep and thoughtful knowledge of the situation, and all actors, situations and competences. According to Du Preez (2010) separating four phases of care is

difficult especially with a condition of AIDS, because each phase are overlap as AIDS is not a specific disease that will takes a predictable course.

Table 1. The frame work of care Tronto (1993)

Phase	Requirements
1. *Caring about*- the recognition that care is necessary, identification of care	*Attentiveness* – not be self-centred and looking the other way or turning a blind eye or deaf ear (not saying "I didn't know", while you could have known)
2. *Taking care of*- feeling responsible and doing something about it	*Responsibility* – taking responsibility, not just seeing and leaving it to others
3. *Care-giving-*– directly meeting the needs for care by physical work in face-to-face contact	*Competence* – care-giving should be done in the right way, quality of care-giving is at stake here.
4. *Care-receiving*- acknowledgement and feedback by the person receiving care	*Responsiveness* – allows for assessing the adequacy of care as perceived by the care-receiver
All phases	*Integrity* – the phases should be linked into a well-integrated care process

2.3. Community-and Home based care

Community Home Based Care(CHBC) is programme to provide comprehensive care services at home and at community level in order to meet the physical, psychological, social and spiritual needs of terminally ill clients including people suffering from AIDS and their families (WHO, 2004). According to WHO (2002), the first step in providing effective CHBC is to assess the patient's environment and make sure that the basic needs of the patient and his/her family are being met. This includes ensuring that families have adequate shelter, food, safe water, proper sanitation and clothing.

Home based care is the provision of health service by formal (volunteers') and informal care givers by immediate family and friends, as well as by home based care organisations in home in order to maintain the ill person's maximum health, comfort and functioning of individuals (Akintola,2008). However, the main focus of this study is specifically on home based care for people suffering from AIDS.

HBC helps mitigate the burden of AIDS on the health care system and AIDS-affected families and communities. Home-based care organizations have stepped in to mitigate the burden of care on families. These comprise a variety of organizations from community-based organizations, faith-based organizations, non-governmental and non-profit organizations. Home-based care has been recommended by many international and donor organizations, governments as well as researchers as having many benefits. An argument used is that it allows patients to receive care in a familiar environment and thus improves the experience of dying and death (Uys, 2003; Akintola, 2008). It has also been shown to help in reducing stigma and discrimination as well as facilitate acceptance and disclosure of HIV status (Uys, 2003).

According to Akintola (2008) home-based care organizations depend almost entirely on unpaid volunteers who comprise a large proportion of their staff. They play a central role in the provision of care to people living with HIV/AIDS and therefore in mitigating the burden of AIDS on families. These volunteers are typically members of AIDS-affected communities who are recruited and trained by care organizations to assist and provide informal hands-on training for AIDS-affected families in carrying out care responsibilities in their communities.

Accordingly in Africa volunteering has many of the characteristics of a full-time or part-time paid job in healthcare except that workers are not salaried and most of those who volunteer are women since it has to do with caring. This coupled with the fact that volunteers spend an inordinate amount of time providing care with many walking on foot to their patients' homes (Campbell et al, 2005). In general a potential benefit of home based care is that sick people are surrounded by people they love and are familiar with, so they can also receive more flexible and nurturing care. They will also not be exposed to hospital-based infectious diseases. As people suffering from AIDS and terminal illness generally spend their final moments at home, improving the quality of their care at home also removes the cost and

distress of travelling to and from the hospital when they are weakest (Opiyo et al., 2008). Furthermore, in being cared for at home, a person suffering from AIDS may be able to do some work or look after family members for short periods of time while the primary earners work. The time the family would otherwise use for travelling to and from hospital can instead be spent on house work and looking after other family members. Moreover, expenditure on transport and hospital costs is reduced (Campbell & Foulis, 2004).

Informal caregivers (family) play a major role in providing home care for people suffering from AIDS. Informal caregivers are people who provide care outside the formal healthcare setting and are not employed or receiving payment for their services (Akintola, 2006). They comprise family members who provide care for siblings, parents, spouses and other family members with HIV/AIDS (Akintola, 2006).

Volunteer caregivers are not usually members of the patient's family, but are people recruited from AIDS affected communities by AIDS care organizations. They are trained to assist family members in providing care for the people suffering from aids, but do not receive any remuneration (Steinitz 2003, Akintola 2006). Volunteer caregivers typically provide support to families, educate family members on how to provide care for the ill and also provide various kinds of support to families (Akintola, 2008). Depending on the policy of the care organization and resources available, volunteer caregivers bathe, clothe, feed, talk to and fetch medication for their patients. They also help families access resources needed for effective care of patients. Patient education carried out by volunteer caregivers covers the provision of information about HIV/AIDS/TB transmission and prevention, nutrition and positive living and alcohol abuse. The training that volunteers receive also enables them to provide basic nursing assistance to the people suffering from AIDS (Akintola, 2006).

Formal and informal care giving has become an increasingly important aspect of the delivery of health and social services for people suffering from AIDS. Care giving imposes a burden that may compromise the caregiver's health (Opiyo et al., 2008), and therefore, the experiences of formal (volunteers) and informal caregivers of people suffering from AIDS must be considered. In the study on the impact of AIDS on children in Zimbabwe, Forster and Williamson (2000) observed that people suffering from AIDS who have children increase the burden on the formal and informal caregivers. In most cases, AIDS orphans experience

disruptions in their schooling, poor health, poor nutrition, migration, and psychological problems. In most instances, the care providers are grandparents who equally need care. This increases their burden (Opiyoet al, 2008). As a result, the burden of care falls not only individuals but also on households and communities (Barnett & Whiteside, 2002; Niehof, 2004). Hence efforts are initiated to develop formal support structures for those offering home based care.

2.3.1. Home-based Care: Ethiopian context

The accelerated increase of AIDS cases in Ethiopia, the inadequacy of the health services system, hospital bed occupancy rates of 50% and higher for AIDS patients only and difficulties of reaching all organizations and informal groups taking care of AIDS patients point to the urgency for national coordination to foster patient care and psychosocial support in the home (Yeneneh, 2001). The few existing home-based care services, provided by a wide range of health professionals, family members and volunteers from women and youth groups do not meet expectations and needs, although the situation is improving. Innovative approaches to care and support for AIDS patients and their families within extended family structures and social networks have been proven to be useful in other African countries (MOH, 2002).

In a collaborative study WHO (2004) summarized information on 8 of 20 projects in different communities in Ethiopia and reported that caregivers including physicians, nurses, neighbours' (mostly females), health assistants, CHAs, TBAs, volunteers from women's' and youth groups and family members, benefited more than the 1,300 AIDS cases. Although these activities were well received by patients and resulted in decreased social stigma in the project areas, they fell short of meeting basic needs, including food, material requirements and treatment of infections.

The Ministry of Health developed guidelines for community- and home-based care in 1996 and the introduction of community- and home based care (CHBC) has also been given due recognition in the HIV/AIDS Policy. Encouraging psychosocial, economic and medical support for people suffering from AIDS and affected members through using the patient's familial and social networks are among the strategies specified in the HIV/AIDS Policy (MOH, 2004).

Lack of resources and the personal, socially sensitive nature of the support and care giving process in an environment of persisting stigma, discrimination and fear put an emphasis on family and volunteer support and care.

MOH has been revising these guidelines with the objective of using them as a reference for the provision of CHBC at all levels and its expansion in a manner that permits basic approaches to be kept within the limits of standard care and support while maintaining flexibility to suit local conditions. It endeavours to bring care and support to people suffering from AIDS and also addresses the needs of the families affected. Among the areas of the CHBC program in the new guidelines are: family and community mobilization, establishing an effective way promoting the health and functioning of people suffering from AIDS in Ethiopia (Yeneneh, 2002; Maes et.al, 2010).

In the face of a late-maturing HIV/AIDS epidemic (National Intelligence Council 2002), volunteerism in community health care has grown substantially over the past decade in Addis Ababa. However, the experiences of volunteer caregivers and CHWs in general in Ethiopia have received very little attention.

2.3.2. Challenges of home based care givers

According to Campbell & Foulis, (2004), HBC programs, have faced several challenges, that is, poverty can act as a barrier to the provision of quality HBC and that many patients are referred home without adequate assessment of their domestic environments. Poverty contributes to poor nutrition and shelter, causing caregivers to have to struggle to accommodate patients in a home lacking basic necessities. Similarly poverty has an impact on accessing ART as it is expensive for a person who lives with HIV and is poor. Even if the person has access to these medicines, their efficacy may be compromised by livelihood outcomes, especially poor nutrition, because almost all anti-retroviral drugs need to be taken at regular intervals and on a full stomach. So these drugs may pose a problem for the poor with inadequate nutrition or irregular access to food (Masanjala, 2007).

The burden of care usually falls on women, including the elderly and young girls in the family. In a study completed by Akintola (2006), it was found that women carrying the

burden of caring for people suffering from AIDS in South Africa were suffering from exhaustion, malnourishment, and psychological distress. Akintola also points out that two-thirds of primary caregivers in households surveyed in southern Africa were female; one-fourth of them were over the age of sixty. Caregivers (family and volunteer caregivers) sometime are required to perform multiple roles and conflicting roles that require nursing skills and meeting their own home and work obligations. This can lead to physical exhaustion (Campbell & Foulis, 2004). Accordingly, many families pass through severe economic stress when the breadwinner suddenly falls ill, making it difficult to meet family needs. In such situations, NGO's sometimes are compelled to assist the family of the client financially. The loss of income can make it difficult for caregivers to meet their personal needs. Furthermore, the number of people infected with HIV/AIDS is perceived by a considerable number of caregivers to be so overwhelming that they will never be able to provide help to all the people who need it (Uys, 2003).

The stigma surrounding HIV/AIDS can be a challenge to caregivers. The attitude of the community in rejecting HIV positive individuals because of the disease and its mode of transmission affects caregivers' incentives to provide care. Furthermore, parents of HIV-positive children additionally face the challenges of organising care for their children, worrying about the needs of those who are sick and those who are healthy, trying to help their children cope with the disease and facing possible stigmatisation from the community (Stegling& Jacques, 2004). The literature suggests that home-based care is associated with an increase in physical, emotional, social, and economic costs both for caregivers and other family and community members (Nkosi et al. 2006; Orner, 2006).

2.4. Micro- Macro Linkages

In order to provide quality of care to those who are suffering from AIDS several institutions are involved in care provision, which are multiple stakeholders including the formal healthcare system (i.e. healthcare professionals), family members, caregivers from the non-formal sectors (i.e. NGOs), as well as caregivers from the informal sectors (for example community volunteers and church members) who all need to work together, Accordingly, there may be collaboration of various caregivers may therefore be involved in supporting

people suffering from AIDS throughout their illness: family members, friends, NGO caregivers as well as health care professionals all play important roles in caring for people suffering from AIDS (Akintola ,2004; Niehof, 2004).

According to Russel and Schneider (2000) the successful implementation of home-based care depends on the performance of different stakeholders, including doctors, nurses, psychologist and social workers, who are expected to identify services, coordinate all planning and evaluate services, do facilitation work, mentorship, leadership and supervision, provide support to volunteer caregivers by creating proper functioning referral systems and follow up. Accordingly, NGOs, CBOs, and leaders have to identify community needs and priorities including financials needs, deal with operational day to day running of HBC which include community outreach, planning, collaboration, control of available resources, support caregivers and build their capacity, coordination and dealing with referrals of patients to hospitals (Rajaraman et.al, 2008).

However this study specifically focuses on care provision offered by formal and informal care givers (family members and care givers from NGOs) in the provision of care and support at the household level.

2.5.   Home Based Care and Social Capital

HBC is defined as any form of care given to sick people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. HBC draws on two strengths that exist throughout the world: households and communities (WHO, 2004; Niehof, 2004). Households are the central focus of care and form the basis of the HBC team. Communities are places where people live and a source of support and care to individuals and families in need. The goal of HBC is to provide hope through high-quality and appropriate care that helps family caregivers and sick family members to maintain their independence and achieve the best possible quality of life.

In order to effectively provide home-based care, certain social networks are needed. According to Ferlander (2007) different forms of social capital or social networks influence health and wellbeing of an individual. Social capital and health analysis at both the individual and societal levels shows that social capital and health are associated (Rose et al., 2000).

Social capital has been empirically linked to both mortality and self-rated health status (Brainerd & Cutler, 2005). Although there are numerous empirical studies of the association between social capital and health, not many have investigated the mechanisms underlying the relationship between the two. Social influence and various forms of social support have often been described as the potential mechanisms, affecting health through behavioural and psychological pathways, such as healthy behaviours, stress reduction, promotion of personal control and a sense of belonging (Berkman & Glass, 2000; Ferlander, 2007).

Ferlander (2007) argues that there are different forms of social capital. In relation to health, social capital has mainly been considered as being constituted of bonding social capital (informal, strong social ties, such as connections with family and close friends). In general, informal family connections may be good for one's health because they can provide sources of emotional and direct instrumental care giving, such as having someone to talk about personal problems. These forms of support mechanisms may affect health positively through stress reduction by providing a sense of belonging (Berkman & Glass, 2000; Ferlander, 2007). The second one is linking social capital (vertical, strong or weak ties with people in different hierarchal positions). Accordingly, Du Preez (2010) also states that social capital is not only important for care receivers but also for care givers in all phases of care in order to access resources to provide quality of care. Based on the above discussion, a working definition has been formulated for this study. For this study social capital is defined as the social relations and resources that are needed in the provision of care. This takes into consideration not only the meaning of social capital, but also the perspective of care receivers and the relation between different forms of social capital and the different phases of care.

2.5.1. Measuring Social Capital

Social capital is concerned with social relations and the resources that can benefit people irrespective of whether they are part of organised networks. This study therefore, adopts measures associated with social relations including number of friends and organizations that one is a part of, as well as the understanding that one can receive support from these ties and connection and level of involvement in the network, those associated with social support, and cohesion (Berkman & Glass, 2000; Ferlander, 2007). Social cohesion involves building shared values and developing a sense of togetherness, based on a sense of trust,

hope and reciprocity among members of a society (Van Kemenade 2002). Indicators of social cohesion are the activities or resources which people draw and behaviours that strengthen social unity and minimise social distance among individuals and members of a group. According to different studies, home-based care has established because of most care receivers do not receive this type of support from their closed allies. Hence, they find themselves isolated from their communities including their families (Akintola, 2006; Van Kemenade, 2002). In this study the measures of social capital and its theoretical relevance is explained below.

According to Ferlander (2007) social relations and interactions are important for the improvement of people's health and wellbeing. Thus, consideration should be given to interaction – the nature of interaction, the frequency of interaction. Respondents are often asked how often they engage in certain activities, the number of activities they are involved in and the kind of activities concerned. In addition, it is also useful to ask who is interacting with whom; there are networks involving close friends and family members, networks involving distant friends, etc., and interactions involving state officials or people with more resources (Ferlander,2007). These studies draw upon Ferlander's arguments regarding the importance of strong and weak ties in order to provide quality of care. Consideration should be given to the network types and resources embedded in them. This measure is important for the present study because of the relevance in knowing the extent to which all forms of social capital are important in a well-integrated care process and provide quality of care for people suffering from AIDS.

Table 2. The relation between phases of care and social capital

Phase	Type of social capital
1. *Caring about*	In order to recognize your problem you have to have close and strong ties (*bonding social capital*) your needs are noticed.
2. *Taking care of*	It helps if you have *bridging and linking social capital* to take care of a problem.
3. *Care-giving*	Care-giving (if it is in the informal setting) requires *bonding social capital* and *strong ties.*
4. *Care-receiving*	Depends on the relationship between caregiver and care receiver (see 3).
All phases	For a well-integrated care process you need all forms of social capital.

Source: (Niehof, 2010) unpublished lecture.

Figure 1: Conceptual Framework adopted from Tronto (1993) and Ferlander (2007)
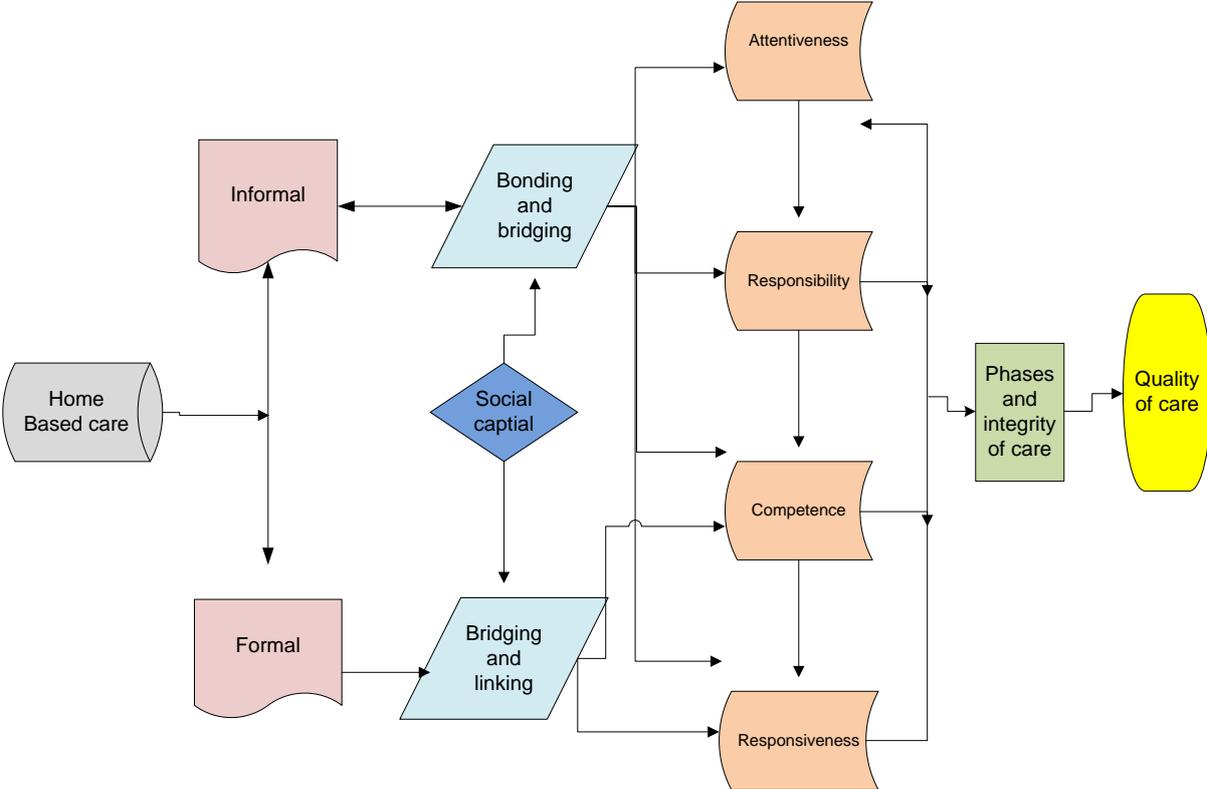
2.6. Study Context and Setting

Addis Ababa is the capital city of Ethiopia, with a population of well over 3 million inhabitants (UN-HABITAT 2008). It is divided administratively in to 5 zones, 25 woredas (classified as district) and 225 *Kebele* (the smallest administrative unit of Ethiopia similar to ward). Public health facilities rely heavily on the training of volunteers, who provide home-based palliative care, support drug adherence, and mediate patients' access to clinical treatment and NGO assistance (UN-HABITAT 2008).

OSSA is an indigenous humanitarian organization working in communities to reduce the spread of HIV/AIDS in Ethiopia. OSSA was founded in 1989 by a group of religious ministers from the various faiths in Ethiopia (Orthodox Christian, Catholic, Muslim and Evangelical) in conjunction with the Ministry of Health. The founding of OSSA was a response to the growing incidence of HIV/AIDS in Ethiopia (OSSA, 2011)

OSSA provides individual and family counselling for people living with HIV/AIDS; to build and support community based efforts to respond to the HIV/AIDS epidemic; and to provide care and support for families affected by HIV. The organization also provides group training at the community level in HIV prevention and care and support primarily through religious organizations and youth Anti-AIDS clubs. It facilitates community organization of an appropriate response to the problems generated by HIV and helps to build their technical capacity, community evaluation of their response and mobilization of community resources.

At present, OSSA with it 16 branch offices, has over 18 years experience in coordinating and facilitating community based response and assisting the national HIV/AIDS prevention. One of the branches is the Addis Ababa branch (OSSA, 2011). The Addis Ababa branch is engaged in the provision of care and support for people suffering from AIDS and OVCs in five selected areas of Addis Ababa cities: Yeka, Kirkos, Gulele, Arada, and Addis Ketema.

During the fiscal year 2010/2011 through its community and home based care support programs, the total of 1794 people suffering from AIDS(540 male and 1254 female) and 1289 OVC (652 male and 637 female) were reached with different services (OSSA, 2011). With regard to home based care service of the branch there are 93(31 male and 62 female) community based volunteers providing HBC service to clients.

This study was conducted among volunteers working with the OSSA home-based Care Programme in the five selected areas (see P, 21). Members of the communities are recruited as volunteers with the help of *kebele* (the smallest administrative unit of Ethiopia similar to ward) and community leaders. They are thereafter trained and sent into the affected homes as home based care givers.

Data collection at OSSA had to be postponed because there was a delay in obtaining ethical approval from public health association Addis Ababa. Eventually, I obtained permission to conduct the study from the management of OSSA. At the outset, unstructured interviews were held with key informants such as the Coordinators of home based care. These people were interviewed because of their vast experience in working with volunteers. A coordinator of home based care facilitated the sampling process. He was the person who made contact with the formal and informal care givers and care receivers as well. The sample was drawn from one organization, OSSA.

In the joint meeting with the informants it was decided that the interviews were to be conducted at the organization (OSSA). The researcher would have pay transport expenses of 32 participants travelling from their home to the organization. Because of this the research was conducted in one organization (OSSA) only.

Interviews were scheduled in the organization. Appointments with care receivers were scheduled and a suitable venue was booked in the ward. The participants also wanted to be interviewed in OSSA. The venue had comfortable chairs and was removed from the noise of ward activities. Informed consent was obtained from the participants, demographic data was collected and permission obtained to digitally record the interview and focus group discussions. The manager requested that I give him a copy of my research proposal, in order to allow carrying out my study in the organisation. Interviews were conducted with six formal care givers, six informal care givers, six care receivers and two coordinators. In addition two focus group discussions were held with six formal and six informal care givers separately.

Chapter 3

3. Methodological Design

The purpose of this chapter is to discuss the methods employed in this study. In order to understand the role of HBC in providing quality of care for people suffering from AIDS, qualitative study has been used. To accomplish the objectives of the study, OSSA was selected purposively because of the unique approach the organisation used in tackling the impact of HIV/AIDS and the large coverage of HBC service in Ethiopia. The study was carried out in Addis Ababa, the capital city of Ethiopia.

3.1.   Study design

The study employs a qualitative study design, also known as an exploratory and descriptive study, which explores a range of perspectives around the research questions. Qualitative methods has been used to explore in-depth the role of HBC in the arrangement of care and the roles of each type of care giver (formal and informal) in different phases of care. Narratives and people's own stories have also been used to get a detailed understanding of people's own views about the phenomenon being studied. Qualitative methods are called for because of the sensitive nature of the subject and the lack of knowledge on the issues to be investigated (Shears, 2002). The research process included the design of the study, putting together the sample, and formulating the research questions. However, the interview guide for data collection (see appendix I) was made flexible to incorporate relevant ideas/issues that maight be discovered during fieldwork in relation to the purpose of the study.

3.2.   Data Collection Methods and Procedures

Data were generated using a combination of methods. Literature review was done to search for both generic and contextual (Ethiopia) or information on home based care and HIV/AIDS. This information was used to compile the background of the report and to support findings from the results of the study. The literature search was focused on studies about care arrangements, phases of care, resources required for quality of care, major challenges and

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care in general. A relevant literature was searched and identified using Social Science Citation Index, Pubmed, CAB Abstracts and Google Scholar and Scopus. The following key words and combinations of key words were used: home based care, community based care, formal care, informal care, care giving, care receiving, phases of care, care arrangement individual, family, household, community; emotional support, spiritual support, psychological support, economical support; Ethiopia, Africa, and East African. Relevant evidence were reviewed and summarized to support the results. Primary data collection included: in-depth interview, key informants interview and focus group discussion.

Face-to-face in depth interviews

The first step in the research process was to approach the managers of the organization, which required preparatory work (asking permission to conduct the study from the management of the organization for social service for HIV (OSSA). After getting the permission the next step was to undertake field research. The researcher contacted home based care givers, both formal (community based volunteers) and informal (family) care givers for a face-to-face in-depth interview on the topic of interest using a semi-structured interview guide. Key informants interview were conducted with two staff members/experts working in the organizations on the practically existing care and support services, care arrangement and government's interventions respectively. In-depth interviews were conducted with six formal HBC- givers (community based volunteers) and six informal HBC givers (family) on their roles in different phases of care, duration of care giving, their experiences and the challenges they faced during the care provision process and resources needed for providing quality of care. In addition in-depth interview were also conducted with six care receivers (people suffering from ADIS) on the challenges they faced during care giving process, the feeling of closeness with family members and the required resources for quality of care.

The semi-structured interview guide consists of all open ended questions which were used to explore in-depth the roles of care givers in each phases of care and the challenges they faced during care giving process. Specifically the interview guide covered topics such as socio-demographic characteristics of home based care givers and receivers, phases of care, care arrangement, effect of care on other activities, major challenges, problems with caring

and suggestions on what could make their work easier. These topics were based on the phases of care by Tronto (1993) as explained in the theoretical framework and on the micro-ecological approach of Niehof (2004).

The in-depth interviews were conducted in the local language (Amharic) and recorded with consent from the interviewees. On average the interviews took 45 minute per interviewee. The recorded data were translated from Amharic to English by the researcher.

Prior to the start of the actual data collection, pre-testing of the research tools was conducted on a similar study subject not included in the study. This enabled the researcher modify the tool to ensure clarity and consistency, to determine the time needed for each interview, and to ensure that the tool could measure what it was meant measure.

Focus group discussion

Focus-group discussions (FGD) have gained prominence in social research as another source of information. In FGD participants may share knowledge about the issue, although they may have different opinions. Thus, meanings people attach to an issue may be clarified through discussion. Through group discussions, the participants' expressed their opinions on the challenges they faced in the process of caring based on their experiences, and the understanding they have about HIV/AIDS. In addition, FGD provides a rich source of data since the exchange takes place in the language of the people in the focus group and is not "translated into the terminology of the researcher"(Bloor et al. 2001; Michael et.al, 2001). These factors contributed to FGD being selected as a source of information for this study.

Since the purpose of the focus-group discussion is to allow interaction between group members, the researcher acted as moderator and allowed them to interact with limited interference, occasionally providing guiding questions for interaction. This allowed for a variety of responses and opinions to emerge on issues such as, challenges faced during care giving, the range of home care activities performed by care givers, the accessibility of resources in care provision and the benefit of integrating formal and informal care. From the discussions and conversations, I learned about the common views on the key challenges they faced during care giving and the benefits of integrating formal and informal care.

During the discussions, group members supplemented each others' contributions in an interactive process that clarified and verified group meanings.

A recorder was used to record the discussions and which were later transcribed. In FGD there are two group discussions were undertaken, which means the first group discussion was undertaken with six formal care givers, and the second group discussion was with six informal care givers. The discussions last from 30 to 60 minutes.

Combination of methods

Documentary sources also provide a rich source of data and information in a research. In order to understand the way organizations work, it is important to look at various documents relating to organizations. These may include final annual reports and procedure reports. In this study annual reports and work plans of OSSA provided an invaluable data source. Reports and documents from OSSA were also used to triangulate and support some of the data collected through interviews and focus group discussions. The combination of different methods enables the researcher to examine the evidence gathered more closely. Thus, the findings from one source can be checked against the findings from another source (Brewerton and Millward, 2001). This is in keeping with the principle of triangulation, in which different methods and data types are used in a single study.

3.3. Targeted population

The theoretical population of this study were home based care givers who had been working for a minimum of two years on the project by assuming that they had some care giving experiences to share during the focus group sessions as well as in the interviews.

Study setting

Addis Ababa is the capital city of the Federal Democratic Republic of Ethiopia. It is divided administratively in to 10 sub cities 180 kebeles. According to 2003 population and housing census, the population of the region is estimated at 2 million. The area was selected because the presence of OSSA. OSSA has been operating in the area for a long time.

It opened its first branch in 1996. Accessibility data was a main factor in the selection process. Since every study works with data obtained from someplace, consideration should be given to the ease with which the researcher can gain access to both the area and data (Field and Graham 2003). The critical element which generally guides the selection process includes: (a) resources in terms of time and finance; (b) response from host organisations. Data and field access are usually constrained by the time and other resources at the investigator's disposal (Field and Graham 2003). This is the first consideration when selecting the area to study. Investigators need to find areas which they can access without great impediments. In this respect, the researcher considered Addis Ababa to be an appropriate area for research. Moreover, having lived and worked in the city for three years, the researcher is well acquainted with it and its organizations. This had the advantage of saving time and of facilitating the collection of quality data.

Organization for Social Services for AIDS (OSSA)

The organization for social service for AIDS (OSSA) was founded in 1989 by a group of religious leaders representing the various faiths in Ethiopia (Orthodox Christian, Catholic, Muslim and Evangelical) in conjunction with the Ministry of Health. The founding of OSSA was a response to the growing incidence of HIV/AIDS in Ethiopia. Moreover, the community based home care and support project of OSSA is conducted through two religious community based organizations namely: Medical Missionaries of Mary and the Medhin Counselling and Social Support Organization. The organizations provide home-based services in different parts of Addis Ababa, Ethiopia.

Sampling

In qualitative research, sample size is reached by saturation of the data. The sample unit consisted of formal and informal HBC-givers and their clients. A list of names of formal home based care-givers (community based volunteers) was obtained from OSSA. Those with more work experience and service duration were recruited for the study by assuming that home based care givers who had more experience can provide more valuable information regarding care provision. After accessing the list of home based care receivers from OSSA the samples were selected based on people's willingness to participate. In addition, based

on the reference of the formal HBC-givers, informal HBC-givers and clients were selected using snow ball sampling.

Sample size

In-depth interviews were conducted with 20 individuals. Purposive sampling was employed to select six formal home based care givers (community based volunteers) and two experts for the interview. Similarly six care receivers and six informal care givers (families) were selected and interviewed based on the reference of formal HBC-givers. Thus the sample consisted of formal care givers, informal care givers and clients. Two focus group discussions were conducted with each six formal and six informal care givers who did not participated in the in-depth interviews.

3.4. Data analysis

The data analysis procedure starts with the process of data collection on a daily basis. At the beginning, the data were translated back to English and checked for consistency to ensure that responses were clear and logically reasonable. After editing the transcribed data, during which the researcher needs to be careful not to introduce own ideas, before the data were entered into the software program (Atlas ti) the researcher developed a coding scheme on the basis of the research question and theoretical framework. This scheme included predefined codes, definitions of each codes, and questions for each codes (top-down coding) (see appendix VIII) and then entered the data in to the software. The first step in data analysis was coding the data to enable, examining and interpreting the data (Bowling and Ebrahim, 2005).

The researcher assigned or imports the files in to Atlas ti, then after, the researcher started coding, the data was coded with the help of top-down coding, which is list a coding was generated based on the research objectives and theoretical framework of the study. Three coding strategies were used within Atlas.ti, which were open coding, coding by list and in vivo coding. Open coding was used when the researcher want to create a new code and associate it with an existing quotation or text segment then a code was created, in vivo coding helps selected text itself is a good name for the code for example, I used this coding

when the interviewee mentioned codes: stigma, discrimination, support each other, these words were good names. Finally, coding by list enabled coding of quotations with the help of a list of all codes in order to minimize repletion of codes. Codes were assigned to interview quotations with the help of the code manager of Atlas.ti. Some quotations received double codes, which meant that more codes were assigned to one quotation. Then, the family manager was applied to enable the division of codes based on research question which means the researcher grouped codes like: phases of care(caring about, taking care of, care giving and care receiving), challenges, social capital (bonding, bridging and linking) and characteristics of care givers and care receivers. The query tool was also used to see whether and which codes co-occurred and were summarized per participant. However, memos and the comment function of Atlas.ti was not used in the analysis.

Finally, findings were presented using personal quotes from the interview to illustrate the major themes. Information obtained from documents, FGD and interview from formal and (CBV), informal caregivers and clients were analyzed qualitatively and triangulated and integrated in order to cross check the validity of the data.

3.5. Strength and Limitations

The present study has certain strengths. Since it made use of a qualitative methodology, the researcher was able to obtain rich details about the experiences and challenges of caregivers and receivers. This research focused on examining the unique and complex experiences of caregivers who provide support for people suffering from AIDS and care receivers. Since very little research has been done on this in Ethiopia, this study may provide an important starting point for future research on the topic. Moreover, the results of this study may contribute to informing organizations and the government regarding home-based care for people suffering from AIDS. It has also recommendations for future caregiver training programmes and on providing quality of care for people suffering from AIDS. In particular, the findings related to the role of family, as well as the importance of providing care for people suffering from AIDS by HIV positive volunteers may have important implications for recruiting volunteers in future home-based care interventions in Ethiopia.

The study also has certain limitations. One main concern is that the research relied exclusively on self-report. This is problematic in that it is dependent on the subjective experiences of the respondents – therefore, what one individual reports as challenging may not be a challenge for others. In addition, part of the interview was conducted in the organization. This might affect the result if the interview especially the response of formal care givers. Furthermore, the sample of this study was acquired from one NGO (OSSA) situated in Addis Ababa. This may limit the possibility of the generalizability of the findings to all care givers and receivers in the study area.

3.6.   Ethical issues in ADIS related research

Any research using human beings as participants encounters dilemmas including the selection of the research area and research subject, deciding on the source of funding, conducting the field work, the interpretation, analysis and dissemination of results. According to Wiegers (2007) research involving people suffering from ADIS raises unique issues because of the sensitiveness nature of the topic. For instance, a study on ADIS impacts is bound to ask participants sensitive questions about their illness, relationships and the care they receive, which may cause psychological and emotional harm that is not expected by the researcher.

Moreover, sampling of people suffering from AIDS also raises ethical issues concerning confidentiality and participants may wonder why they are selected. Informed consent is also important ethical aspect in research, but obtaining informed consent is not easy in AIDS related research, as HIV/ADIS is associated with sexuality, death and violence and therefore difficult to discuss openly in many societies. Beside this, participants selected by the study may experience stigma and discrimination as they are labelled as HIV/AIDS affected by the society. In order to alleviate this, in this research, the researcher purposely selected participants who had received awareness creating training by the organization.

The main negative effect that the research may have on the selected participants is the added psychological, social and emotional stress. All these effects result from the sensitive nature of the research problem - HIV/AIDS. The psychological impact may come as a result of the questions respondents are asked, which may be embarrassing to them. Such questions

may also cause emotional stress if they are not well prepared to answer them. Respondents may be affected if their HIV/AIDS status becomes known to others without their consent and knowledge (Wiegers, 2007).

The immediate concern, therefore, should be how to obtain such sensitive data without affecting the respondents negatively. There are steps which the investigator should take in order to protect respondents and prevent them from potential harm. Respondents must be informed about the research objectives and about the way results will be disseminated, so they can make a well-grounded decision whether they should respond or not. Confidentiality should be guaranteed; for example, the use of names in the final report should be avoided (Wiegers, 2007).

In this study, permission to conduct the study amongst caregivers and receivers was sought and obtained from the manager of OSSA. A follow up meeting with all the volunteer and informal care givers (family) was held where the aims, objectives and nature of the study was explained. Questions were allowed in order to clarify all issues.

The objectives, relevance and procedures of the study were explained to the study participants. Before each interview, informants were given a consent form to read in Amharic (the national language of Ethiopia), where the principles of voluntary participation, anonymity, and rights of withdrawal without any consequence were described. However, some of the informants opted to give verbal informed consent. All the interviewees and FGD participants have signed consent forms that informed them about the details of the study and their rights as informants. Confidentiality of information was assured and protected by conducting the interview according to home based care givers and receivers preference. Furthermore, I first introduced myself and explaining the intentions of the research project. I explained that the study was purely academic and had no commercial aims. I emphasized that respondents may indirectly benefit from academic studies, when the organisation responds to the findings presented in the final report. Since I was required by OSSA to submit a final report, this feedback could influence organisation operations, thereby benefiting clients/members indirectly. This openness encouraged the informants to respond freely without expectations beyond those I had explained. The participants were informed

that participation in the study was voluntary, that there was no payment for participation and that they were also free to withdraw from the study at any time. Anonymity was secured by coding the participants' names and residences in the transcripts.

Chapter 4

4. Results

Overview of the chapter

This chapter elaborates on the results of the interviews with the twenty home based care givers and receivers and two FGD sessions. Section 4.1, describes the background information of study participants. In section 4.2, Tronto's frame work is applied. Thereafter, the themes found from the interview and FGD related to social capital are described per stratum (group), namely formal care givers, informal care givers (family) and care receivers (people suffering from AIDS) in Section 4.3. The chapter ends in Section 4.4 which elaborates the major challenges cited by interview participants.

4.1. Background of Study Participants

This section provides background information about the eighteen research participants. Sub section 4.1.1, addresses characteristics of the study participants. This includes such as age, gender, employment, duration of care, relationship of informal care givers and receivers and living arrangement.

4.1.1. Characteristics of Participants

Table 3 below shows an overview of the demographic characteristics of the participants in this study. Two of the formal care givers (CBV) revealed that they were HIV positive. In total, fourteen women and six men were interviewed between ages 29 and 70 of which sixteen were aged between 29 and 50. Almost all care receivers are living with parents, relatives and/or partners and only one of them lived alone. It is indicated that from both formal and informal care givers (n=12), ten of them are females and two of them are males. Available data shows that, care givers working in the selected NGO have spent from two to five years working as a care giver. Most of the formal care givers indicated that they had been

providing care to people suffering from AIDS for a longer period of time than they had been employed by OSSA.

Table 3. Characteristic of formal and informal care givers & care receivers

Characteristics of formal care givers(CBV)	Duration of caring	Characteristics of informal care givers(family)	Characteristics of care receivers	Relationship of informal care givers-receivers	Living arrangement
Female (45)	Two years	Female(65)widowed, unemployed	female, 41, divorced, unemployed, knew her status 3years ago	Sister	Together with informal care givers
Male(34) HIV positive	Four years	Female, 68,widowed unemployed	female, 29, widowed, self-employed, knew status 4 years ago	daughter	Together with informal care givers
Male(32)	Two years	Female(70), widowed, unemployed but sometimes sold onion and potatoes in the market	Male(33),single, unemployed, knew his status 5 years ago	Son	Together with informal care givers
Female (40)	Five years	Female **(**48), married employed (receptionist)	Female(30), divorced, part time(daily labourer, knew her status 3 years ago	Sister	Alone
Female(40)HIV positive	Two and half year	Female(43), married, unemployed	Male(57),part-time(daily labourer) knew his status 5 years ago	Husband	Together with informal care givers
Female (39)	Two years	Female(40), employed, married and with three children	Female(23), single, student, knew her status 3 years ago	Niece	Together with informal care givers

4.2. Applying Tronto's framework

In this section, the results will be related to Tronto's (1993) framework in order to enhance understanding and deepen empirical insights about the meaning of good care for people suffering from AIDS. The following paragraph describes results related to Tronto frame work of good care. It first addresses the first phases of care (caring about) there after the other three phases of care.

Caring about

According to Tronto's framework, (1993), quality of care starts with 'caring about'. It is important to recognize the necessity of care and to identify needs. This phase is related to the virtues of attentiveness to the particular needs of this specific person. During the interview, volunteers said that they are obliged to provide care voluntarily for people suffering from AIDS and they are aware of the need of care in general but they are not aware of the needs with regard to specific person and use the Phases of 'caring about' (attentiveness).

Volunteers mentioned that NGOs informed them about the situation of the care-receivers and this information was aimed at making volunteers aware of the needs of people suffering from AIDS. To these volunteers, the idea of identifying needs of people suffering from AIDS can be quite complicated since the sufferers themselves cannot always disclose their status and their needs to others, even to their neighbours due to fear of stigmatization. One interviewed volunteer said:

   "In the beginning I did not have any idea whether somebody needed my help, but after we were selected by the sub-city and received training from OSSA, I realized that someone was there who really needs my help". *P 3: Volunteer 3.doc*

Informal care givers also mentioned that, they are living together with care receivers (people suffering from AIDS) and therefore it is easy for them to identify care needs. In this regard, one family member mentioned that:

   "She is my daughter and I used to live with her after her husband died. One day she was

*really sick and I took her to a hospital and the doctor told her that she was HIV positive. And then she was really depressed and she told me her secret". **P 8: informal care giver 2.doc***

Another informal care giver also disclosed that it is easy for her to find out what is important for her husband, since her husband can always express himself verbally. Moreover, she argues that as they have intensive interactions, she can observe his facial expression and can address his personal needs easily.

*" He is my husband and we live together, so it is easy to see whether he needs help or not. I know what is important for him because we are close with each other. Even if he doesn't say anything I can read it from his facial expression" **P11: informal care giver 5.doc***

Taking care of

The second phase of care in Tronto's framework is "taking care of" which implies assuming some responsibility for the identified needs and determining how to respond to it. This phase is linked with the virtue of responsibility. According to Informal care givers (family), they take more responsibility for their patients or relatives than they did before they knew about the patient's health status. This is expected from them by care receivers. However, they sometimes experience tensions concerning the responsibilities the patient expect from them. One interviewed care giver expressed this feeling as follows:

*"I feel that giving care to my niece is my responsibility and could not have left it to anyone else, because I am the only one who should take care of her". **P12: informal care giver 6.doc***

Another informal care-giver also said that, even if her son's behavior changed because of the disease, she strongly believed that care giving is her responsibility.

*"It is my responsibility to give care to my sick son. I feel that I could not leave the responsibility to anyone else because this is my job. Even if my son has "misbehaved" after falling sick with AIDS, I still love him and strongly wish to take care of him". **P 9: informal care giver 3.doc***

In HBC, formal care givers said that they are willing to take on responsibilities to take care of people suffering from AIDS. However, they usually want to focus on educating family members and providing counselling. Most of volunteers were unhappy with the additional

domestic tasks. They made it clear that they expected an active family role in the care taking process especially in household activities. For example, volunteers made it clear that the family has to do all household activities, like cooking, cleaning and help or support with transportation of their relative (to church or hospital). One of them, for example, mentioned her experience as follows:

"Families are not happy that I only provide counseling services. They ask me to help them on household activities as well. However, as I do have more patients to visit, I don't have time to do so". **P 2: Volunteer 2.doc**

Another volunteer, however, discloses that when the family members of people suffering from AIDS are not around or are unwilling to help, she took responsibility for her patient's needs including supporting with household activities.

"When the family members of people suffering from AIDS are not nearby, or are unwilling to help; I am happy to take all responsibilities for my patients, including making food for the patient, cleaning the house, taking them to church, bathing the patient if they are unable to do so themselves, checking that the patient takes his or her medication properly, and so on". **P 3: Volunteer 3.doc**

Care giving

This is the third phase and it calls on the virtue of 'competence' from Tronto's theoretical framework and it directly meets the needs of care. It emphasises the competence to perform physical care work for the one who needs care and it needs direct contact with care receivers in order to fulfil care receivers needs.

In this phase of care there are some tensions between volunteers and family members. Most volunteers mentioned that, they are willing to provide professional care for people suffering from AIDS, which is, educating patients about side-effects of medicines and how to maintain hygiene. They will also provide counselling and supervision to ensure that patients are taking their ARV medicines properly. However, family members (informal care givers) expect more from volunteers by saying that volunteers have to help them in household activities and visit the patient regularly. In line with this, one of volunteer says that:

"I am educating my patients about the side effects that they may experience for the first few weeks of taking the ARVs, and that they cannot drink alcohol with this medication. I also educate them about cross-infection, the importance of using condoms, even if both partners know that they are HIV positive, about healthy eating practices, as well as on how to maintain good hygiene by washing their hands. I am responsible for supervising ARV medicine taken by people suffering from AIDS". **P 1: Volunteer 1.doc**

Another volunteer also express her experience as:

"Family members of patients as well as the patients themselves often consider me as if I am paid by the organization to care for them. Because of this they demand me to do all the house chores and other caring activities for them". **P 2: Volunteer 2.doc**

In addition volunteers mentioned that, when informal care givers (families) of people suffering from AIDS are not nearby in addition to educating them they take all responsibilities including household activities. One of the volunteer said that:

"When the family members of people suffering from AIDS are not nearby, or are unwilling to help, I take over full responsibility for my patients. This includes making food for the patient, cleaning the house, bathing the patient if they are unable to do so themselves, checking that the patient takes his or her medication properly and so on". **P 3: Volunteer 3.doc**

Informal care givers also make clear out that they are glad to have volunteers but they want volunteers to help them in household activities and visit patient regularly. One of the informal care givers said that:

"I am glad I have a volunteer who helps me. When volunteers come to the home and talk with her I get relief because she uses to talk with him/her and she becomes happy, and I am happy too. In this world nothing makes me happy than seeing my daughter's happiness……… but I am expecting more from volunteers to visit my daughter more regularly". **P 8: informal care giver 2.doc**

Another informal care giver also said that:

"I do all activities by myself. Sometimes I feel depressed when I see my son feels bad; at this time I need someone who can help me on this. A volunteer visits him only once in two weeks

and I feel that it is not enough. They should visit the patient regularly as they have already agreed to provide care". **P 7: informal care giver1.doc**

Care receiving

Phase four of Tronto's model is 'care receiving' which is, the virtue of 'responsiveness'. The care receiver should be open to care. In general, Tronto emphasized that, care is an ongoing process that fulfils the needs of another person. This requires common understanding and communication even if care receivers are dependent on care givers. Informal care givers mentioned that due to close contact among informal care givers and care receivers, the feedback of care receivers about the care process is positive and it is easy for informal care givers (family) to notice if the care does not fit the needs of care receivers and to solve the problem.

However, care receivers said that even if care receiving from informal care givers is good sometimes informal care givers complain about the over-dependence of care receivers on them and the receivers in turn considered that this perception leads to care-giver fatigue and hence their care giving did not meet their needs of care. For example, one of care receivers expressed her feeling as:

   "My sister is my close friend and if I feel something she is the one who asks me again and again about what's wrong with me, but sometimes she feels tired and I can see that from her face. When she feels tired, she lacks the patience to take care of me and tells me to take care of myself. I understand her because it has been long time since she is taking care of me and my children". **P14: care receiver 2.do**

In addition during the FGD, participants from informal care givers also mentioned that it was difficult to provide care as needed and that they were stressed because of the behaviour of care receivers. One of FGD participants said:

   "Sometimes my sister becomes verbally and physically aggressive, which makes care giving harder and more stressful for me". **P22: FGD of informal care givers.doc**

The integrity of care

According to Tronto good care requires that, the four phases of care process and its five requirements must fit together in to a whole. This study shows that all phases and requirements play a role in the care giving and care receiving process. However, even if the care needs are identified by informal care givers and OSSA, there is a disagreement between formal and informal care givers' on who takes which responsibilities (phase 3) and the burden of care is still put on informal caregivers. It is difficult to say that there is integrity in care process without a good communication between formal care givers, informal care givers and care receivers on taking responsibilities. Moreover volunteers also mentioned that as they have their own life and families to take care of, it is difficult for them to visit patients regularly and be involved in household activities.

Table 4: Summary of results found from the interview and FDG related to Tronto's framework.

Phases of care	Formal care givers	Informal care givers	Care receivers
Caring about	Able to give HBC care, but informed of care receivers need by other parties (NGO and districts)	Able to give HBC care, well identified care receivers needs and to find out what kind of care they need	
Taking care of	Decide to become a volunteer and ready to take responsibility	Ready to take responsibility and taking active role on caring	Willingness to be taken care of
Care giving	Ready to give care together with family but family and care receivers expect more on aspects of taking responsibility of caring	Usually involved in needs of care and daily activities to provide care as needed	
Care receiving	Gather information on whether care is accepted or not from family, volunteers disagree on accepting care	Notice whether care accepted or not, family complains about care receivers dependency on them	Open to the care provided, care receivers expect more involvement of volunteers
Integration			

4.3.   The role of social capital

The following paragraph describes results related to the social capital and phases of care from the participants. During the interviews, all care givers and receivers talked about their interaction with each other and what kind of care was provided and received through this interaction. The following sections highlight some of these interactions:

Educational support

Volunteers in this study play a major role as teachers, or educators, in their communities.

According to them, they often have to teach people suffering from AIDS and their families about HIV, to dispel any misconceptions which they may have about the disease. For instance, the volunteers have to tell their patients that they can live healthy and fulfilled lives even though they have HIV, as long as they take their medications. Moreover, the caregivers teach their patients about healthy eating practices, as well as on how to maintain good hygiene by washing their hands after visiting the toilet. One of volunteers mentioned that:

"Most of the times I am providing counseling for the patients because I can be sort of a role model for others because I'm also HIV positive, and I'm normal...and I can advise them that they can be like me. I can show them that they can survive with HIV. Especially based on the experience that I have, I know how to deal with a HIV positive person because I'm also like them". **P 5: Volunteer 5.do**

Supporting each other

Volunteers also mentioned that they had close contact with each other in order to share experiences and solve common problems that they face during care giving processes. One of the interviewed volunteers, for example, said that:

"I am working together with other caregivers; we do not only support and encourage each other when we face difficult situations, but also we discuss about our successes. We can also come together and work as a team. This enables us to reduce personal stresses as well as helps us to learn from other caregivers about another way to help the needy people". **P 6: Volunteers 6.doc**

Two of the volunteers who are HIV positive themselves said that they understand the experiences of the people suffering from AIDS. Therefore as a fellow patient, they can easily understand the pain and loneliness that patients experience. This enabled them to provide the care and friendship that patients need. They therefore feel more involved in their care receiver's life than being 'passive visitors'. They also indicated that care receivers and informal care givers treated and accepted them as family members. One of HIV positive volunteers for example, argued that:

"I am HIV positive and my client's family is happy when I go to their home. Sometimes they

even tell me how the patient behaves and ask me advice about what they should do. I tell them that families have the sole responsibility of providing care at the home, because they are close to the patient and I teach the family about the necessary skills that will enable them to efficiently discharge their responsibilities to the patient". **P 5: Volunteer 5.doc**

Being close

Informal care givers mentioned that, they are involved in the care receivers' life more than before they knew the health situation of the care receivers. All informal care givers actually help their relatives with carrying out everyday activities in their homes like cooking, shopping, cleaning, going to church with them, praying with them when the patient were depressed and giving a bath when they are severely sick. These activities increased the strength of the family bond. Furthermore, when care receivers feel sick, informal care givers reported that they spend more time with the patients than they used to do, to provide the support the patients need in those critical times.

Being together

The organisation encourages people suffering from AIDS to participate in different group activities. They perform many activities together including: coffee ceremonies to share experiences, aimed to make patients know each other and to create friendship among themselves. Care receivers described their experiences regarding their participation in these activities. Most of them said that they joined the group sessions primarily to share experiences and feel comfortable in being together with other people like them. One care receiver expressed this feeling as follows:

"After I joined OSSA I met many people and occasionally we have a coffee ceremony. In the coffee ceremony we discuss about the challenges that we face and how we deal with it. In general, we share experiences with each other. ". **P18: Care receiver 6.doc**

Another care receiver also said that, after she joined the organization (OSSA), she learnt not only how to relate with HIV positive people but also with other people and this contributed to a sense of togetherness for her.

"When I joined OSSA I met many people who are in similar situation like me and I learned many things from them. Once a month we go out together and have some drinks. This helped

*me to learn how to keep close relations with others and how to avoid any situation that may lead into stress. Thus, I eventually cope and get along with everyone in my home and outside my home". **P17: Care receiver 5.doc***

Financial support

Most of care receivers mentioned that they received emotional and financial support from informal care givers and other relatives. One of them said that:

*"My brother is helping me a lot. Before I started the medicine, I was so weak and it was my brother who helped me financially and emotionally, thanks God. My uncle also pays my house rent". **P15: care receiver 3.doc***

The summary of results found during the interview and FGD related to social capital, is discussed in table (Table 5) below according to the major groups of participants: formal care givers, informal care givers and care receivers.

Participants	Themes	Descriptions	Social capital
Formal care givers (CBV)	Support each other	-Personal contact among Each other	Bonding social capital
	Provide educational and counseling support to PSFA	Information for care receivers and family about how to deal with the diseases	Bridging social capital
Informal care givers (family)	Love, being closer, emotional support to PSFA	being part of the lives of their family members/being close with patient, concern about the wellbeing of care receivers, going to church	Bonding and bridging
Care receivers(PSFA)	Being at home, unity, being together, make friendship	Feeling of being at home and together with informal care givers	Old bonding social capital
		Feeling of friendship with other HIV positive person	New bonding social capital
		no personal contact with others (non HIV patients)	Bridging social capital
	financial support	Get financial support from other relatives and OSSA	Bridging and linking social capital

4.4. Challenges facing home-based care

This section expatiates on the major challenges mentioned by formal and informal care givers during the interview and FGD with regard to providing quality care to people suffering from AIDS in HBC programmes.

4.4.1. Challenges of formal care givers

Financial Constraints

Most of the patients are living in poverty and volunteers are constantly confronted with the practical reality of having to care for patients who do not have enough to eat. This makes care giving difficult, not only on monitoring drug adherence but also regarding the efficacy of the anti-retroviral drugs. This may create a problem for the poor with inadequate nutrition or irregular access to food. In addition, a common theme that emerged from focus groups and also reiterated in in-depth interviews are the volunteer's experience of helplessness and occasional compulsion to spend their money in order to assist patients who are in dire need. One volunteer, for example, explained her feeling as:

"Sometimes I spend my own personal money to buy food or medication for my patients when it is not available from the organizations (OSSA) and I spent most of my time providing care for patients and this affects me to find other jobs". ***P 2: Volunteer 2.doc***

Another volunteer from FGD also said that:

"Most of our patients who received this HBC and support services were those who are living in poor conditions. We are experiencing profound shortage of basic materials in the house, which are very essential for their daily life activities. As a result, the HBC activity has been affected. This makes us dissatisfied about the HBC giving process, mainly due to absence of basic materials and financial problems of the people suffering from AIDS. These problems prevented us from doing what we planned to do for the patients". ***P21: FGD of volunteers.doc***

Lack of proper training and volunteer's expressed needs

The need for personal development was a common issue raised by the volunteers. Participants in the interviews and the FGD expressed the need to be assisted by the organisation (OSSA) to build their capacity which will enable them to provide proper HBC services. One of the areas at which they believed assistance should be targeted is payment for their services. Most of them have no jobs and found it difficult to take care of their families without getting any source of income from their services under the organisation. In addition, shortages of volunteer caregivers made it hard to carry out activities and services effectively and which was also mentioned as a major challenge by volunteers. Although all volunteers reported that they want to continue volunteering, they admitted that if they found a paid job they would quit, because it would be difficult to combine both jobs due to the demanding nature of care giving for PSFA. During a FGD, one volunteer explained this as follows:

"We don't have sufficient knowledge and skills on HBC. We need training so that we can give proper advice to families (informal caregivers). There is not sufficient education on patient care. We need counselling skills to help patients to reduce the stress and to assist them to live positively because we are the ones who know the whole secret of the patient". **P21: FGD of volunteer doc**

Lack of resources and time

In the advanced stages of AIDS, the caregivers have to deal with severe symptoms like chronic diarrhoea. All FGD participants indicated that, when the PSFA are severely sick, it is most stressful for them to try and keep their patients' personal hygiene and clean any wounds they might have due to the fact that often they do not have access to gloves. They reported that, the patients' situation together with the lack of basic supplies makes caring more difficult especially for people who are in the late stages of AIDS.

"I was providing wound care and home remedies like rice water for diarrhoea. I perform these activities according to the patient's health conditions, the available materials in the patient's home, adequacy of equipment in my kit and the available time that I have. Some times because of lack of equipments like gloves, alcohol, simple pain killer and shortage of time due to transport problem and patient load, I can only provide a limited range of care". **P21: FGD of volunteers.doc**

However, during interview experts countered the claims regarding shortage of supplies by indicating that OSSA provides sufficient inputs and supplies like gloves, soup, and alcohol for volunteers in order to provide good care for people suffering from AIDS.

Some of the participants who were themselves living with HIV indicated that they were constantly confronted with difficult situations in their daily lives especially the dual challenge of being both an HIV patient as well as an HIV caregiver. According to them, these situations have the potential to have a negative impact not only on their mental and emotional well-being but also in the physical condition. One HIV positive volunteer expressed this as follows:

"I am providing care for people suffering from AIDS; I also have my own lives to think about, as well as the ways in which my own HIV status has affected the lives of my children. Sometime I feel physically exhausted". P 5: Volunteer 5.doc

Experts mentioned that at the beginning they assigned volunteers to patients living close to their homes. However, because of the confidentiality problem, they moved volunteers to other places and this put a lot of physical strain on volunteers.

These challenges confronting volunteers in their provision of care to the PSFA make it difficult for them to provide quality care to their patients and compel them to provide substandard care. Additionally, the interview highlights the fact that the caregivers may be unable to assist all of the people suffering from AIDS all the time. Most of the volunteers have children that they need to care for. They also have lives to live and aspirations to realize. Particularly for caregivers who are also HIV positive themselves, the daily confrontation with the dual challenge of being a patient and looking after others who are HIV positive has been demanding in emotional, physical and mental terms.

Adequately functioning referral system

Data from the CBV interviews, the FGDs and the key informant interview (of experts) showed that there were no formal functioning referral systems in the delivery of the HBC process. All participants particularly cited this as a serious gap in the HBC process. This referral gap appeared to be most acute between the health facilities and the homes. One HC team leader explained this gap as follows:

*"We don't have a link between OSSA and health centres regarding HBC and therefore, there is no formal referral system in HC process. There is a serious gap in this referral process. This gap appeared to be most acute between the health facilities and the home. Many patients come to our organization and they ask us to send them to a hospital but we cannot do that. The only thing that we can do is to subsidize the money they spend for medicine after they buy the medicine from a health centre". **P20: interview expert 2.doc***

The experts, however, explained that OSSA have had good collaboration with some governmental organizations and that there are effective communication linkages between OSSA and other key stakeholders in other parts of Addis Ababa and with other partner organisations and the government. According to the experts, the organization (OSSA) works with the government on recruiting volunteers and seriously sick people. However, they do not receive any financial assistance from the government concerning HBC.

4.4.2. Challenges of Informal care givers (families)

Burden of care

Informal care givers expressed their feeling of being overwhelmed by the magnitude and multiplicity of tasks they had to perform. They said that they suffered from exhaustion and also felt loneliness and isolation, as care giving kept them within the house for most of the day**.** One of informal care givers, for example, complained that she could not go to funerals or weddings, not even to church, because she has to be with her patient all the time, or most of the time. She expresses this feeling as:

 *"I cannot go to funerals or weddings, not even to church, because I have to be with my son all the time. Sometimes If I want to go to church I couldn't stay in the church for more than 30 minutes because if I stay long he usually asks me question like "mom do you hate me or are you tired of take care of me"? **P 7: informal care giver1.doc***

In informal HBC, personal care and hygiene were given high priority. However, informal care givers mentioned washing clothes, particularly the bed linens, as the most time-consuming activity. Another problem is also the inability of bedridden patients' to properly manage

going to the toilet. As most informal care givers are elders it is difficult for them to carry the patient to the toilet and to provide basic personal care and hygiene.

Social/emotional hardships

Some of the caregivers had experienced starkly the still-existing fear and stigma surrounding HIV/AIDS. In these families, it was noted that stigmatization was directed towards the entire family as much as the patient. One informal care giver who was taking care of her daughter had strongly noted the difference before and after taking care of her daughter. FGD participants of informal caregivers also mentioned that if one of their family members is ill, it is difficult to them to organize care because of stigmatization. During the FGD, one participant argued that:

"If one of our family members is ill, it is difficult for us to organize care. On one the hand, we are worrying about the needs of those who are sick and on the other hand we worry about those who are healthy, trying to help your sick children and cope with the disease and facing possible stigmatisation from the community". ***P22: FGD of informal care givers.doc***

Most care receivers also mentioned that, they didn't have friends to talk to because of the stigmatization. One of care receivers said:

"I am glad to have a volunteer, she is not only my care giver but she is also my friend, I think she understands me because she is also HIV positive". ***P18: Care receiver 6.doc***

In addition the experts (HBC coordinators) said that when they distribute volunteers for caring they allocate volunteers in places where volunteers are not well known. This is because they sometimes faced complain from the patients claiming that they were stigmatised because they think that some volunteers told their stories to neighbours. Even in some places, people are not willing to rent out their home if they know that the person has HIV.

As can be inferred from the above, the isolation of people living with HIV is exacerbated in communities in which there is a high level of stigma. This makes the experience of people suffering from AIDS a lonely one, in which the caregiver is often the patient's only friend and contact with the outside world. Additionally, it is also highlights the fact that stigmatization

not only affects the people suffering from AIDS but their families as well. Moreover, informal caregivers are also isolated from social contact because of caring for their relatives.

Chapter 5

5. Discussion, Conclusion and Recommendations

Overview of the chapter

This study aimed to qualitatively examine the experiences of HBC givers and receivers, and the arrangement of care for people suffering from AIDS based on a theoretical framework about quality of care. This chapter will discuss the results of this study in relation to previous studies on this topic.

5.1 Discussion

According to Akintola (2004, 2006), home-based care programmes in South Africa entrench gender inequalities in that the majority of caregivers are women due to the traditional roles of women and girls. Unsurprisingly, ten of the twelve caregivers in this study were female; and from all 93 formal care givers 62 of them were females. Due to the fact that these caregivers live within the communities they serve, they too are affected by poverty and were unemployed before deciding to become a volunteer.

Care is inter- subjective as the needs can only be identified through observation and communication with the care receiver. Tronto (1993) distinguishes four phases in the process of care. In this study, care involves different people at different phases. Needs of care receivers are identified by informal care givers (families) and NGO's and volunteers are aware of about the need of care from the organization (caring about). In this phase, it often involves assuming the position of people suffering from AIDS to recognize their needs.

In addition volunteers in the research area feel obliged to take responsibility for the identified needs by informal care givers and OSSA (taking care of), but they are more responsible for the actual care giving process. This means, care is arranged by informal care givers and the organization (OSSA). According to Tronto (1993) taking care of is beyond driving up on the door of someone with AIDS, it is finding the way to provide care and coordination of different stakes in order to participate on the actual care giving process

Care giving involves the direct meeting of needs for care. It involves physical work and requires the care givers come in contact with people suffering from AIDS. There positive experiences are expressed with regard of the actual care giving process. Volunteers are more involved in counselling and educating families and people suffering from AIDS, but they are also involved in other activities if informal care givers are not around the patient. Informal care givers are also more involved in household activities like cooking, cleaning, being with the patient and bathing. However, they expressed that, they need help on this activity from volunteers. But, volunteers are not obliged with the expectations of informal care givers. This indicated that informal care givers have an idea about the comprehensive definition of care, which means care included not only educating and providing counselling also other activities that address the need of care receivers. In this phase of care, the experience less favourable for both volunteer and informal care givers. This result is in line with the broad definition of care by Tronto (1993). According to her care as "a kind of activity that includes everything we do to maintain, continue and repair our 'world' so that we can live in it as well as possible." She indicates that care is not a specific activity or action but it consisting of four interconnected phases. Which means it is difficult to separate 'caring about', 'taking care' and 'care giving', even if different people are involved in each phases of care.

The final phase of caring recognizes that the object of care will respond to the care it receives. According to du preez (2010) it is difficult to separate the experiences of care givers and care receiver because the experience of care giver is crucial as it may have the implications for further arrangement of care. In this study care givers (formal and informal) were complaining about the dependency and aggressive behaviour of care receivers. However, care receivers also were not happy by the care they received from the volunteers and informal care givers. As care receivers are socially isolated because of stigmatization, they need more contact with volunteers in order to maintain friendship as they need love and friendship. Care receivers said that they found it painful when informal care givers complain about their dependency. This makes them to feel not respected and loved by others.

HBC is defined as any form of care given to sick people in their homes. Such care includes physical, psychosocial, palliative and spiritual care. HBC draws on two strengths that exist

throughout the world: households and communities (WHO, 2004; Niehof, 2004). In order to effectively provide home-based care, certain social networks are needed. According to Ferlander (2007) different forms of social capital or social networks influence the health and wellbeing of individuals.

In this study, positive experiences are expressed by care receivers especially related to unity, being closer and emotional support from informal care givers and other relatives. The result is in line with the concept of bonding social capital of (Berkman & Glass, 2000; Ferlander, 2007), which stresses informal family connections may be good for one's health because they can provide sources of emotional and direct instrumental care giving, such as having someone to talk about personal problems. These forms of support mechanisms may affect health positively through stress reduction by providing a sense of belonging.

In addition to these, informal care givers also recognizes the care receivers need easily because they used to live together and they have close contact with care receivers. However, in order to organize care they might need to network with volunteer and NGOs (OSSA). Volunteers often need to act as mediators between the patient and his/her family members both in terms of trying to contact family members, as well as in helping the patient to deal with their diseases.

Volunteers also expressed that they have close contact with each other in order to share experiences and solve common problems that they face during care giving processes. This result is in line with Du Preez (2010) who argues that social capital is not only important for care receivers but also for care givers in all phases of care in order to access resources to provide quality of care. Volunteers are seen as leaders in their communities and as role models to their patients (especially when the caregivers are also HIV positive); they offer their friendship to the patients, and often see themselves as a member of their patients family.

According to Stegling & Jacques (2004) parents of HIV-positive children face the challenges of organising care for their children, worrying about the needs of those who are sick and those who are healthy and spent their time in trying to help their children cope with the

disease. In the study area, informal care givers have no social connection as they spent most of the time with the patient. Care giving restricts them from investing time in their social relations.

Additionally care receivers wants to continue their relationship with people who are in a similar situation with them (HIV positive) and it helps them to share different experiences and to create a bond of friendship among them. However, care recivers limit their relation with HIV positive people; it makes them unable to access resources and information outside their own social network. This coincides with Ferlander's (2007) ideas who argues that membership of more restricted networks is associated with poorer self-rated health.

Due to the fact that the home based caregivers(formal and informal) in this study area operate without help from the professional healthcare sector, they carry the full burden of caring for people suffering from AIDS both physically (for example, ensuring that their medication is taken correctly and doing all household activities); emotionally (for example, the caregivers provide their patients with emotional support and counselling); as well as engaging in accessing basic resources for their patients where these are lacking (such as food, necessary equipments like gloves and alcohol). In taking of full responsibility for the home-based care of people suffering from AIDS, the caregivers are often under a lot of care burden.

With regard to providing quality of care to people suffering from AIDS, it has been reported that several institutions are involved in the care provision process. Family members, friends, NGO caregivers as well as health care professionals all play important roles in caring for people suffering from AIDS (Akintola, 2004; Niehof, 2004). The situation for the caregivers in this study, however, does not reflect this ideal. Often it is up to the caregivers (volunteers and family) alone to ensure that people suffering from AIDS are cared for at any stage of their illness.

The study also showed that there are major challenges faced by informal care givers in the study area. One of these challenges is physical. Informal caregivers noted that as patient progresses into the later stages of their illness, is often needed to bath them and, lift them in addition to household chores. The caregivers in this study felt that feeding, as well as

changing and bathing their patients is a physically challenging task, especially if they cannot get anyone in the family to assist them. Emotionally, informal caregivers in this study also felt anxious and worried about their patients, especially when the patient is aggressive and depressed.

The volunteers were also providing care to people in difficult circumstances, in which often their patients do not have access to basic resources. Accordingly, they often need to go to each patients home and visit their clients. This is difficult for volunteers as they have also family and children to take care of. These results confirmed the study conducted by Akintola (2006), who found that HBC givers experience different challenges comprising the physical, social and emotional burden of caring for people suffering from AIDS.

Stigma surrounding HIV/AIDS has a negative impact on both prevention and treatment efforts (WHO, 2009). In addition, this study found that it also impacts negatively on efforts to provide home-based care to people suffering from AIDS. In conjunction with the challenges discussed above, the caregivers in this study are faced with stigma surrounding HIV and AIDS which further complicated efforts to provide care to care receivers in their communities. Furthermore stigma within communities further isolate care receivers, and make the care giving process more difficult.

Formal and informal care givers are thus faced with numerous challenges. In circumstances characterised by unemployment, inadequate resources, care burden, as well as the overarching stigma surrounding HIV/AIDS, care receivers often experience feelings of isolation and hopelessness.

5.2 Conclusion

The following section provides a brief conclusion of this research. Additionally, it addresses the scientific value of this research and gives recommendations for future research and its practical utility.

Good care involves, recognising the necessity of care and identifying needs assuming some responsibility for the identified needs and determining how to respond to it; direct meetings of needs for care and the object of care will respond to the care it receives (Tronto 1993).

HBC for people suffering from AIDS does not create quality care and a supportive environment that facilitates the principles of attentiveness and responsiveness. The large number of people suffering from AIDS and the stigmatized nature of the diseases are factors in this.

In addition, informal and formal care givers may disagree on aspects concerning taking responsibility of care and performing the actual care giving activities. The burden of care still put on informal care givers (families), even if volunteers are assisting families in some activities like counselling and educating informal care givers and receivers on how to deal with the diseases, they cannot meet the expectations of informal care givers and receivers because of the large number of patients who need care.

From the theoretical analysis of Tronto (1993), it is concluded that informal care givers (families), are more involved with the care process and their experiences are positive for the first (Caring about) and last (Receiving care) phases of good care. There is time; close contact and patience to recognize to care receivers' needs and to check whether the care meets the needs of patient. However, volunteers are less involved in this; they gather information from informal care givers about whether care matches with the needs of the patient.

The experiences are not positive for the phases of Taking care of and Care giving, as there are some expectations of informal care givers and receivers, HBC needs involvement and sharing of responsibilities among volunteers and family, which is sharing and carrying out different activities especially involving in household activities and regular visits are essential elements to create friendship, social bonding and involvement. Discussion among HBC givers (formal, informal), care receivers and OSSA is needed to address these expectations.

Social capital is essential for providing and accessing of care especially in communities where the majority of people are poor and cannot afford to access care easily. Different types of social capital imply different kinds of resources, support and influence and which can be linked to different phases of care. Informal care givers in this study are easily notice whether care is needed because having close contact and living together with the patient. Although care is arranged by informal care givers (family) and the organization (OSSA).it is evident that

the actual care giving is provided by informal and formal care givers. In this sense it needs bonding and bridging social capital, volunteers are involved in educating families and counselling and families are more involved on household activities. Care receiving is depending on the relationship people have with care givers. In this study people suffering from AIDS expect more from volunteers regarding visiting time and involvement than they actually give care, care receivers are happy especially when volunteers are HIV positive. Because of the similarity they have with the volunteers. In addition, care receivers feel hopelessness when informal care givers are complaining about their dependency. In this study positive experiences are expressed by care receivers, especially related to unity, being close to and receiving emotional support from informal care givers and other relatives

There are major challenges faced by informal care givers that is physical, emotional and social. The volunteers were providing care to people in difficult circumstances, in which often their patients do not have access to even the most basic resources and volunteers also have another responsibility to take care of. Volunteers practicing home-based care for people suffering from AIDS, carry a huge burden of being expected to provide a service with very limited resources and in most instances finding themselves utilizing their own resources because of the realities they are faced with. Lack of resources makes life very difficult for both volunteers and families they serve and severely impede the quality of home-based care service rendering

Within the communities the burden of providing home-based care to people suffering from AIDS is the sole responsibility of volunteers and family members, and there is a lack of interaction and collaboration between different healthcare sectors and OSSA.

In conclusion, the large number of people suffering from AIDS related, the lack of resources, the poor communication and division of responsibilities between formal care givers, informal care givers and care receivers, the lack of interaction and collaboration between the different healthcare sectors and OSSA and stigma and discrimination affect quality of care. Which means, without an integrated care process, it is not easy to provide quality of care for people suffering from AIDS.

5.3 Recommendations

Based on the findings some recommendations could be pointed out for use both by OSSA and other similar organizations as well as researchers who intend to pursue further and deeper studies.

The theoretical analysis showed that Tronto's ethical framework (1993) is a useful tool to discuss the care process in HBC. Since formal and informal care givers disagree about the responsibility and involvement of volunteers in the actual care process, appropriate volunteers training and education as well as communication with the family and patients are crucial. In addition, OSSA should specify some rules on what are the responsibilities of volunteers and families, and inform them clearly.

This study has highlighted the immense burden of care is placed on informal care givers. If OSSA is going to promote HBC program and provide quality of care for people suffering from AIDS, more needs to be done to ensure that there is good communication between OSSA informal caregivers and volunteers, and provided with adequate training should be provided in order to better equip them with the numerous challenges that they are faced with.

Funding is needed in order to ensure that caregivers are provided with adequate resources to deal with their patient illness – such as gloves and some equipment. More funding is also required for NGOs to be able to offer structured job placements for the volunteers. Additionally, HBC needs to include stakeholders from all healthcare sectors, and the role of t each stakeholders should be better defined in the provision of HBC for people suffering from AIDS.

Directions for future research

Future research should focus on the financial implications of promoting HBC and providing quality of care for people suffering from AIDS. More over the consequences of HBC on families and volunteers caregivers should be examined more closely in future studies in order to gain an in-depth understanding of the hidden costs of HBC. Additionally, future research should seek to gain a better understanding of how well create a link between

community members, families and volunteers to care for people suffering from AIDS and in order to continue care. Beside these, future researches should focus on the effect of providing care by HIV positive volunteer to HIV patients and .

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APPENDICES

Appendix I Interview guide for formal HBC givers

The interviews will start with a brief introduction:

Thank you so much for agreeing to take part in an interview, by doing so you are contributing to a better understanding of the role of home- based care in the arrangement and provision of care for people suffering from ADIS. Just a reminder that our conversation will be tape recorded and the interview will take about 45 minutes to an hour. The interview will be informal – please feel free to interrupt me or ask questions during the interview. If you do not want to answer any of the questions that I ask, feel free to say so, and we can move on.

1, **DEMOGRAPHIC DATA**

Age--------------

Gender-----------------

Marital status

Employment

Name of organization you work with--------------------------

What is your Position in the organisation? Are you volunteering or you are employed by the organisation

Relationship to people suffering from AIDS

 Interview Questions:

1. Research Question 1: -What are the roles of the different actors in the arrangement and provision of care?

1a. How long have you been providing care to people suffering from ADIS?

- What factors led to you becoming a caregiver?

1b. How do you determine who needs your help or not? (probe in detail)

2. Why you are caring for the patients?

1c. Typically, what do you do for the patient(s) on a daily basis – what are your daily activities?

- Which activities do you normally pursue during caring?

1d. How does it feel to be a caregiver of a people suffering from ADIS?

1e. How many hours per day would you say you spend providing care?

Research Question 2: what are the major challenges faced by home based care givers (informal and formal) and care receivers in care provision?

2a. Can you tell me about your experiences in caring for people suffering from ADIS at home?

2b. What struggles have you faced / are you facing in terms of providing care to the patient?

2c. In your experiences, what are the most stressful things that you have to deal with?

2d. What motivates you to continue to provide care to people suffering from ADIS?

Research Question 3: - To what extent is the care process integrated?

3a. In terms of the NGO that you work for, what is it like working together with other caregivers to help people suffering from ADIS?

3b. How close do you work with family members of the people suffering from ADIS?

3c. What happens when the family is not available to help the people suffering from ADIS?

Research Question 4: What resources are required for providing adequate quality care?

4a.What resources (personal and material) do you have that aid you in your ability to provide care?

4b. How available and accessible are these resources to you in daily provision of care?

-   How does the lack of these resources impact on care giving?

Appendix II Interview guide for Informal care givers

1. **Demographic Questionnaire for Informal Care givers**

Age--------------

Gender-----------------

Marital status

Employment

Relationship to people suffering from AIDS--------------

Duration of caring---------------------

Living arrangement-----------

Interview Questions

1. How do you determine X needs your help or not? (Probe in detail)

2. Typically, what do you do for the patient(s) on a daily basis – what are your daily activities?

   - Which activities do you normally pursue during caring?

3. How does it feel to be a caregiver of a people suffering from ADIS?

4. How many hours per day would you say you spend providing care?

5. Do you experience any difficulties in providing care for X? What are they? What did you do about these difficulties?

6. Has caring for this patient affected your work?

7. How close do you work with formal home based care givers of the people suffering from ADIS?

8. What happens when the formal home based care givers is not available to help the people suffering from ADIS?

9. What resources (personal and material) do you have that aid you in your ability to provide care?

10. Have you felt pressure to do these things because of the illness in your family?

    Stop going to school

    Stop going to work

11. What is the main care giving tasks carried out by family-based care providers for patients with AIDS at the household level?

Appendix III Interview guide for HBC receivers

Age--------------

Gender-----------------

Marital status--------------

Employment---------------------

Relationship to care givers--------------------

Daily care received from HBC givers-----------------

Interview Questions

1. How many friends do you have these days?

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

3. What do you think about the care you received from formal HBC givers?

   Do you think the care you received is good?

4. Do you experience any difficulties in receiving care from HBC givers? What are they? What did you do about these difficulties?

5. How was/ is the feeling of togetherness or closeness in your family?

6. What type of support have you received from the rest of the family, and formal HBC givers the health services providers?

7. Do you needs assistance with the activities of daily living?

   Bathing

   Dressing, using toilet, feeding

Appendix IV Open ended questions for FGDs

1- Would you describe the range of home care activities that performed by VHC providers for people suffering from AIDS in your community?

Probe:-

Would you explain further?

Would you give us an example?

Is there anything else?

2- What are the key challenges experienced by caregivers of AIDS patients?

Probe:-

Would you explain further?

Would you give us an example?

Is there anything else?

3- How has caring for AIDS patients affected the caregivers' life?

Would you explain further?

Would you give us an example?

Is there anything else?

4- How well the partnership working? (NGO/Government home care team/ medical facilities)

Probe:-

Would you explain further?

Would you give us an example?

Is there anything else?

5- What constraint do VHC givers encounter as they provide care for people suffering from AIDS at home?

Probe:-

Would you explain further?

Would you give us an example?

Is there anything else?

7- Do you have any suggestions on how the work of the VHC teams can be improved?

Would you explain further?

Would you give us an example?

Is there anything else?

8. What are the key challenges experienced by caregivers of AIDS patients?

Probe:-

Would you explain further?

Would you give us an example?

Is there any thing else?

Appendix V Consent format for focus group discussions

Date of FGD: _____

No. recruited for FGD: _____

Venue: _____

Time started: _____ Time ended: _____

Facilitator/moderator name: _____

Introduction:-

You are all welcome. I am here to collect information about home based care givers for people suffering from AIDS. Its aim is to study about the experience of community based volunteer home based care givers (CVHBC) in HBC of people suffering from AIDS and to identify the major challenges in HBC that help to improve the quality of HBC provision for people suffering from AIDS.

You have been purposively selected to participate in this discussion because we believe that, you are one of the key informants in this community, and also you have vital information and experience to share with me on this subject. There is no right or wrong answer. All comments, both positive and negative are welcome. I would like to have many points of view and to be open discussion, so feel free to express your opinion honestly and openly.

In order not miss any point of the discussion; I am using a tap recorder. Your name as well as address is not recorded in this interview to protect your confidentiality. Individuals are free to decide on whether or not to participate in the discussion. I am also encouraging members to feel free to say anything concerning the topic of discussion, because your information is very important to evaluate and improve the program. Again, we would like to confirm to you that all your comments are confidential and used for research purpose only.

Thank you very much again

Appendix VI Participant information sheet

My name is Selamawit Goitom, and I would like to invite you to take part in my study. I am conducting research for the purposes of obtaining a Masters degree in Public Health and Society in Wageningen University. My area of focus is that of the provision of home based care for people suffering from ADIS. This research aims to examine the role of home- based care in the arrangement and provision of care for people suffering from ADIS. More specifically, I would like you to take part in an interview which will take between 45 minutes to 1 hour. Your participation in the interview process is greatly appreciated as it will provide in-depth, detailed information about your unique experiences of care giving. With your permission this interview will be audio taped to make sure that I collect accurate information about your experiences; the tapes will be destroyed once the research report has been completed. Your participation in this study is purely voluntary – you do not have to take part if you do not want to. If you choose not to participate, no negative consequences would result. If you feel uncomfortable at any time, you are free to stop your participation in the study without prejudice. No one will know who you are except me and the translator. The translator has signed a document which ensures that he will keep your identity secret. I will write your responses in my research report, but I will give you a different name so that no one will be able to identify you. This research will contribute to a better understanding of the experiences of home based care givers-receivers in Ethiopia. Once the study is finished, a short summary of what was found will be sent to your organisation. If you want to contact the researcher regarding any questions about the research, you may use the following contact details:

Appendix VII Work Plan

Time schedule for study – Practices of Home based care and HIV/ADIS

Activities	Months												
	08	09	10	11	12	01	02	03	04	05	06	07	
Approval of proposal		■											
Proposal presentation		■											
Data collection tools construction			■										
Pre-test data collection tool			■										
Training of fascinators			■										
Fieldwork				■	■								
Data analysis and interpretation					■	■							
Report writing							■						
Dissemination of findings								■					

Appendix VIII Top down Coding Scheme
Appendeix VIII

Coding scheme

Sl. no	Themes (Top Down)	Measure	Data source			
			FGD		In-depth Interview	
			Infor mal care giver	For mal care giver	Care recei ver	exp erts
		Phases of care Tronto, 1993	√	√		
	Caring about (Attentetivnes	. The recognition that care is necessary, identification of care. . Relationship with care receiver? . How do you identify your daughter needs your help or not? (Probe in detail . How do you identify who needs your help or not?	√	√		
	Taking care off (responsibility)	. in this phase feeling responsible and doing something about it, .Why you are caring for the patient? . What factors led to you becoming a caregiver	√	√		

	Care giving (competence)	. directly meeting the needs for care by physical work in face-to-face contact
		
		Typically, what do you do for the patient(s) on a daily basis – what are your daily activities?
		      - Which activities do you normally pursue during caring?
		How many hours per day would you say you spend providing care
		
		. How close do you work with family members of the people suffering from ADIS?
		
		what happens when the family is not available to help the people suffering from ADIS
		
		. Do you needs assistance with the activities of daily living?
		      Bathing
			√	√		

		Dressing, using toilet, feeding			
	Care receiving (Responsiveness)	What do you think about the care you received from formal HBC givers? Do you think the care you received is good? . Do you experience any difficulties in receiving care from HBC givers? What are they? W. Do you experience any difficulties in providing care for X? What are they? What did you do about these difficulties? -What did you do about these difficulties? How does it feel to be a caregiver of a people suffering from ADIS?	√	√	√	
	Background characteristics of participants				
	gender		√	√	√	
	Marital status		√		√	
	Years of care giving		√	√		
	Employment		√	√	√	
	Social capital Social relations and the resources that can benefit people irrespective of whether they are part of organised networks. Measures associated with social relations including number of friends they have, involvement in different activities and organizations that one is a part of, as well as the understanding that one can receive support (care) from these ties and connection.				
	Bridging social capital Bonding and bridging	How close do you work with family members of the people suffering from ADIS? What resources (personal and material) do you have that aid you in your ability to provide care? How was/ is the feeling of attachment or closeness in your family?	√	√	√	

Linking social capital	In terms of the NGO that you work for, what is it like working together with other caregivers to help people suffering from ADIS? How was the feeling of closeness with formal care givers, other patients and people from the organization? . How many friends do you have these days? How many times in the past month have you got together with friends to have food or drinks, either in their home or your home?				79	
	Challenges					
-Lack or resource -Stigma and discrimination Stress Social isolation	. Do you experience any difficulties in receiving care from HBC givers? What are they? What did you do about these difficulties? . In your experiences, what are the most stressful things that you have to deal with? . What struggles have you faced / are you facing in terms of providing care to the patient? What resources (personal and material) do you have that aid you in your ability to provide care? - How does the lack of these resources impact on care giving? What struggles have you faced / are you facing in terms of providing care to the patient?	√	√	√	√	
New themes (bottom-up)	Repetition of the words or particular theme like					