Poverty and uncertainties
Next of kin providing care for a close one with HIV/AIDS in Tanzania

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Examensarbets

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Abstract
HIV/AIDS is an important health issue worldwide, and in Tanzania the estimated amount of people living with HIV year 2012, was around 1.5 million people. Many of them are living a restricted life at home, leaving the responsibility of care to their next of kin. This leads to a big number of care providers lacking both financial and educational resources, making it difficult to provide care. The aim of this study was to investigate next of kin’s experiences of being a care provider for a relative infected with HIV/AIDS. A qualitative design with semi-structured interviews was chosen and data were analysed using the qualitative content analysis. The result showed that the majority of care providers lived in poverty and experienced a lack of resources, enabling them to give sufficient care to the patients. Many care providers were depending on the support of food, finances and practical help from organizations, neighbours and relatives. Common care providing tasks consisted of helping the patients with their personal hygiene, washing their clothes and bed sheets, cooking, cleaning and looking after the whole family. These chores limited them to attain a sustainable income, leading to a lack of financial security. The lack of security was also amplified by a lack of training in how to give good care. According to WHO, counselling must be offered to patients infected with HIV/AIDS. However, the result in this study shows the importance of including next of kin in the counselling criteria, as they are in need of advice and education in how to give care. Care providers’ commitment to the patients was particularly visible in the lives of women, who chose to put their own future plans aside for the sake of their sick close ones. As limited resources made it difficult to provide good care, more research needs to be done about the need of sustainable support to care providers in Tanzania.

Keywords: Care provider; HIV; Experience; Support; Feeling of security; Commitment;
ACKNOWLEDGMENTS

Many thanks to the non-governmental organizations that have been a big help during this research carried out in Tanzania. The help from the social workers have been very valuable and greatly appreciated in the recruiting process. Many thanks to the interpreter for her faithful service and flexibility, and to Frida Karlsson, the coordinator abroad. Thanks to SIDA for the scholarship of Minor Field Studies, and the opportunity to do this research abroad. Also, thanks to The University of Borås and the international coordinators for support regarding the research, as well as to Kristina Nässén, supervisor from The University of Borås. Without all their help this study would not have been possible. Finally, warm thanks to everyone making the time in Tanzania memorable and irreplaceable.
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INTRODUCTION

HIV/AIDS is an important health issue worldwide. In the year 2000 United Nation (UN) put together a plan to fight different world issues, called The Millennium Development Goals (United Nations 2000). One of the goals was to combat HIV/AIDS, which is something the government of Tanzania have been working on, yet HIV/AIDS is still one of the main health problems in the country. A survey done by the government shows that people living with HIV/AIDS encounter hostile attitudes and discrimination, and even if stigma hampers their search for help, there is support and treatment available for the individuals affected with HIV/AIDS (Tanzania HIV/AIDS and malaria indicator survey 2013, pp. 50, 63). According to UNAIDS (2012) 1,5 million people are suffering from HIV/AIDS in Tanzania, this means that a large number of next of kin are providing care to patients at home. As the next of kin has an important role in helping the patient to sustain health (Dahlberg & Segesten 2010, p 121) the focus of this study is to investigate their experiences of caring for a close one infected with HIV/AIDS.

BACKGROUND

HIV/AIDS

HIV/AIDS is a worldwide disease, 35,3 million people are living with HIV and people dying in illnesses caused by AIDS are around 1, 6 million people (World Health Organization (WHO) 2012). According to Ericson and Ericson (2009, p. 261) the first case of HIV was found in 1957 and since then 70 million people have been infected (WHO 2011). HIV stands for “human immunodeficiency virus”. It is a retro virus that can transform their own RNA hereditary factors to a similar copy of DNA. This leads to a latent and silent course of the disease (Ericson & Ericson 2009, p. 261). HIV is a chronic infection that will develop into AIDS (Acquired Immunodeficiency Syndrome) which is the most advanced stage of HIV. AIDS is characterized by the development of infections, cancers and other severe clinical manifestations. Being infected by HIV, it can take from two to fifteen years to develop AIDS. The development is individual, and also depends on the treatment (WHO 2013a).
Antiretroviral Therapy
Antiretroviral therapy (ART) is the medication used to fight HIV. It cannot cure HIV, but strengthens the immune system by controlling the viral replication. This helps the immune system to regain its capacity of fighting off the infections, helping the infected individual to live a healthy life despite the disease (WHO 2013a). The immune function is usually measured by CD4 cell count. An advancing HIV infection can be recognized through a falling CD4 count (AIDSinfo 2014). According to the U.S Department of Health and Human Services (HHS) it is recommended that ART should be used by everyone infected with HIV. It is most urgent for those with a very low CD4 count, AIDS, pregnancy or other HIV-related illnesses like cancer and tuberculosis. When using ART adherence is very important, otherwise there is a risk of drug resistance (AIDSinfo 2014).

Transmission
HIV is transmitted via unprotected sex, mother-to-child transmission and through blood exchanges. People in risk zones are those who are sexually active, those who inject drugs and unborn babies to HIV positive mothers (WHO 2013a). The symptoms of HIV vary depending on the stage. The first symptoms may be fever, headache and sore throat, but as the infection progresses and the immune system weaken, symptoms like weight loss, diarrhea, coughing and swollen lymph nodes appear. Without treatment, severe illnesses such as tuberculosis, meningitis and cancer can be developed. HIV is usually diagnosed by blood tests where HIV antibodies are detected. According to the recommendations of the World Health Organization (WHO), testing and counselling must include what they call “The five C’s”, which means informed Consent, Counselling, Confidentiality, Correct test results and finally, linkage to Care, treatment and other services (WHO 2013b).

HIV in Tanzania
Most people living with HIV are living in Sub-Saharan Africa (WHO 2013a). Tanzania belongs to this region of Africa; the estimated amount of people living with HIV in Tanzania year 2012 was around 1, 5 million people (Unaids 2012). The Government of Tanzania is aware of the problems HIV causes the country, and has started many projects to help alleviate these problems. Two main factors the government especially put their focus on, are educating young people, and making the relevant health care more available (Tacaids 2014 ).
Statistically there is a significant fall in HIV infected people in Tanzania. Year 2004 there were 7,0% of adults between ages 15-49 living with HIV, and 2008 it had decreased to 6 % (Tanzania: HIV/AIDS and malaria indicator survey 2013 p. 1). A survey done by the government also shows that people living with HIV/AIDS encounter hostile attitudes and discrimination (Tanzania HIV/AIDS and malaria indicator survey 2013, p. 63). This is referred to as stigmatization, which Alonzo and Reynolds (in Holzemer, Uys, Makoae, Stewart, Phetlhu, Dlamini, Greeff, Kohi, Chirwa, Cuca & Naidoo, 2007 p. 542) define as a powerful social label being attached to someone, leading to discredit and disgrace, radically changing how the persons view themselves and how they are being perceived. Even though there is support and treatment available for the individuals affected with HIV/AIDS, stigma hampers their search for help (Tanzania HIV/AIDS and malaria indicator survey 2013, p. 63).

The general living situation of a family affected by HIV/AIDS

Poverty is a major problem in Tanzania and many families struggle with economical problems. This study was carried out in a rural area, where many families maintained a small income by having small shops, selling fried fish and bananas outside their houses, or by working in the fields. According to UN (2011) the majority of the population is employed by traditional agriculture, and 90 percent of the people working in the fields are women. Farmers are depending on rainfall and use a few traditional hand tools when working in the fields (Narayan & Pritchett 1997). According to The World Bank (2014), the average income per citizen in Tanzania is less than 50$ (350 SKR) per month. Caring for a close one with HIV/AIDS is often time consuming and leads to additional worries (Tarimo, Thecla, Outwater & Blystad 2009 pp. 61-64). Due to many families’ strained economy, they cannot always afford hospital treatment when this is needed. This means that the essential daily care for the patients is being located to family level. When a family get affected by HIV/AIDS, it is often the woman who is pressured to mantle the heavy responsibilities of caring for the patient, the family and household, and the economical income. According to Tarimo, Kohi, Outwater and Blystad (2008, p. 64) she is often a mother, mother in-law or sister and many of these women are either singles or widows. Being able to handle all the responsibilities is almost an impossible task. Thus the family network is becoming of increasing vital importance in the care of patients with HIV/AIDS. A Swedish anaesthesia nurse1 explains that on occasions where patients are taken in for hospital treatment, it is still the families’ responsibilities to

1 Swedish anaesthesia nurse at a local hospital in the Kilimanjaro district, guided tour March 14’th 2014
care for the basic needs of the patient. At the hospital these needs involves cleaning the patient, washing the bed sheets and to provide meals for the patient.

**The importance of a next of kin**

According to Dahlberg and Segesten (2010, pp. 118-119) the patient perspective is raising the value of including family members in the caring process. In times of long lasting illness, they mean that it is especially important to involve the family, as they are playing an important part in the caring process (Dahlberg & Segesten 2010, pp. 118-119). The person close to the patient can be defined in many ways; close one, family, next of kin, relative or friend. According to Dahlberg and Segesten (2010, p 119) the caring science definition of a person close to the patient, is someone that have been chosen by the patient himself to have that role and who also agrees to take on the responsibilities. This does not necessary need to be a family member or a relative but can also be a neighbour or a friend. In this study a close one caring for a patient (care provider) is thus defined as next of kin, and includes anyone caring for the patient. The person in this study, who is infected with HIV/AIDS, is referred to as the patient.

As many people are suffering from HIV/AIDS in Tanzania, it means that a large number of next of kin are providing care to patients at home. Pallangyo and Mayers (2009, pp. 489-491) mention the issue of inadequate support to next of kin caring for patients infected with HIV/AIDS in Tanzania. They mean that governmental and non-governmental support is limited. Although the Tanzanian government now ensures that drugs are available at no cost, it is hard to follow the antiretroviral therapy (ART) directives without adequate nutrition. Their finding shows that this adherence requires environmental, nutritional and material support, and that existing support is minimal and not sufficient. In the absence of governmental state support, the importance of informal networks being developed by care providers when meeting each other at the clinic cannot be underestimated. According to Pallangyo and Mayers (2009 pp. 489-491) the care providers visit, help and share coping strategies with each other through the networks. Tshililo and Davhana-Maselesele (2009, p. 143) point out that next of kin are suffering from a lack of knowledge and resources, making it almost impossible to care for a patient infected with HIV/AIDS.
The feeling of security

According to Dahlberg and Segesten (2010, p. 83) the Swedish term “trygghet” is a phenomenon strongly related to health. It is related to words such as certainty, security, confidence, trust, protection and freedom from fear and anxiety. In this study, the expression “a feeling of security” is used to define experiences related to “trygghet”. There are several reasons that can lead to an experience of feeling secure. External security is a term related to good material conditions, a good environment, trustful relationships, knowledge and a sense of having control (Dahlberg & Segesten 2010 pp. 84, 89). As found in earlier studies, many care providers are lacking the external components mentioned by Dahlberg and Segesten. This may lead to a continual experience of insecurity. Ericsson (1994 se Dahlberg & Segesten 2010, p. 88) emphasizes the fact that insecurity is related to experiences of suffering and loss. Internal security according to Dahlberg Segesten (2010, p. 84), comes from nearness to others and the experience of purpose and context. Experiences found as meaningful and purposive, differ from person to person, but are generally born in fellowship with others (Dahlberg & Segesten, 2010 p. 77). To be devoted to a person infected with HIV/AIDS, means helping someone who really needs you. This may generate an experience of having a purpose and feeling meaningful. Dahlberg and Segesten (2010, p. 78) explain that the experience of purpose and context gives a person strength and vitality, and can help him or her to manage substantial hardships (Dahlberg & Segesten 2010, p. 78). Dahlberg and Segesten (2010, pp. 119, 126-127) emphasize the importance of trying, and wanting, to understand how health, sickness, suffering and caring is experienced in patients’ lives. According to the patient perspective, this may also be transferable to the care providers' life context, with the intention to support and strengthen them.

PROBLEM STATEMENT

Since a large number of the Tanzanian population is infected with HIV/AIDS, almost as many are care providers, fighting to get their lives together. Their experience of financial strains, are now added with the increased burden of having to provide care, without enough knowledge and support. Being in this situation makes it difficult for care providers to follow caring recommendations given by the health care. Further research on their experiences and needs, are important to be able to support and strengthen the care providers in an adequate way. Due
to this increasing problem, it is important to focus on the next of kin's experiences of caring for a close one infected with HIV/AIDS in Tanzania.

AIM

The aim of the study was to investigate next of kin’s everyday experiences of providing care to a person infected with HIV/AIDS.

METHOD

A qualitative design was chosen for this study to capture participants’ expectations, needs and experiences. This design aims to create a more profound understanding for the patients and their situations (Friberg 2006, p. 87). Qualitative research interviews were used to capture the care providers' experiences. According to Nunkoosing (2005, p. 699) qualitative research interviews are characterized by the unifying whole in participants stories, rather than independent fragments being studied separately. Therefore all aspects of their stories are equally important to the interviewer. There is no better way of receiving first-hand information about a lived experience, than by interviewing the person that is actually experiencing it (Nunkoosing 2005, p. 699). When analysing the data, there is always a risk that the analysis get somewhat influenced by the researchers' pre-understanding, hence affecting the credibility of the result (Lundman & Häggren Graneheim 2013 p. 196). Pre-understanding includes preconceived ideas, as well as theoretical knowledge and lived experiences. Researchers are debating whether one’s pre-understanding should be put aside during analysis, or used to deepen ones comprehension of someone's experience. However, fact remains that our pre-understanding often is unconscious and therefore impossible to put aside (Lundman & Häggren Graneheim 2013, p. 197).

Participants and settings

The population in this study includes next of kin being care providers for close ones infected with HIV/AIDS. The participants were recruited through a social worker connected with several networks in a rural area, in the district of Kilimanjaro, Tanzania. In collaboration with two different non-governmental organizations, eleven care providers were personally invited to participate in the study according to the following inclusion criteria: Care providers without
formal education, over the age of 18 years, caring at home for a sick person they considered a close one. Ten care providers accepted the invitation and one care provider did not wish to participate. While carrying out one of the interviews, it was discovered that one care provider did not meet the inclusion criteria. Thus was the interview completed as the other interviews, but not included in this study, leading to a total of nine interviews being used in the study. The care providers were both male and female and they were between 20 - 80 years old. Years of being a care provider were from 2 years up to 11 years.

Table 1. Participants

<table>
<thead>
<tr>
<th>CARE PROVIDER and AGE</th>
<th>PATIENT and AGE</th>
<th>YEARS OF BEING A CARE PROVIDER</th>
<th>CARE PROVIDER’S HIV STATUS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother (80 +)</td>
<td>Son (43)</td>
<td>7</td>
<td>Unknown</td>
</tr>
<tr>
<td>Daughter (22)</td>
<td>Father (69)</td>
<td>4</td>
<td>Negative</td>
</tr>
<tr>
<td>Daughter (20)</td>
<td>Mother (44)</td>
<td>2</td>
<td>Unknown</td>
</tr>
<tr>
<td>Father (56)</td>
<td>Son (11)</td>
<td>11</td>
<td>Negative</td>
</tr>
<tr>
<td>Aunt (54)</td>
<td>Niece (13)</td>
<td>10</td>
<td>Positive</td>
</tr>
<tr>
<td>Aunt (42)</td>
<td>Niece (18) Nephew (13)</td>
<td>11</td>
<td>Negative</td>
</tr>
<tr>
<td>Daughter (20)</td>
<td>Mother (47)</td>
<td>2</td>
<td>Negative</td>
</tr>
<tr>
<td>Daughter (33)</td>
<td>Mother (46)</td>
<td>9</td>
<td>Unknown</td>
</tr>
<tr>
<td>Mother (80 +)</td>
<td>Son (40 +)</td>
<td>5</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

Data collection

The interviews were conducted at a venue chosen by the participant; one was held at the social worker's house, two at the organization's office and seven at the participant's house. All interviews were held in English, and interpreted to the local language Swahili by a social worker, who also had the role of a translator. The interviews were between 20-60 minutes long and the central questions were focusing on daily experiences and what support they received, see appendix 2.

Analysis

The interviews were tape recorded, transcribed verbatim and analysed using the qualitative content analysis by Lundman and Härlgren Graneheim (2013, pp 177- 199). This design of analysing text is suitable for qualitative studies with interviews as data. It is important that the result of the interviews is analyzed with an awareness of the current culture, setting and lifestyle of the informants (Lundman & Härlgren Graneheim 2013, p 188).
First of all, the transcribed data were read through individually to get at complete view of the text. Thereafter the interviews were read through again, one at a time, and discussed. Sections and quotations especially meeting the aim of the study, was highlighted and numbered. These quotations were divided to meaning units and condensed and abstracted into a code system, making the meaning units more manageable to work with. Lundman and Häggren Graneheim (2013, pp. 189-191) illustrate codes as tools to help the researcher reflect on the data in a new way, as well as finding common relations between the different codes. The analysis continued by organizing the codes into different subcategories and categories. According to Lundman and Häggren Graneheim (2013, p. 191) it is important that all data which is answering the aim are included in the study, data must not fall between different categories, and no data should fit in more than one category. When doing research reflecting on people's experiences, the last part of the rule is difficult to satisfy, as experiences may be too interlocked to each other to fit in only one category (Lundman & Häggren Graneheim 2013, p. 191).

Table 2. Table of analysis example

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed meaning unit</th>
<th>Code</th>
<th>Subcategories</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;I am not feeling tired of helping my mom, because she is my mom&quot;</td>
<td>Because it’s my mom I don’t get tired of helping her</td>
<td>To help mother is not tiring</td>
<td>Motivated by a relationship</td>
<td></td>
</tr>
<tr>
<td>&quot;I suggested to help my son after diagnoses that he is now infected. I just started straight to be committed to my son without any obligations, just straight from my heart..&quot;</td>
<td>When diagnosed, I started to be committed to my son without any obligations, just straight from my heart.</td>
<td>Committed from the heart</td>
<td>Motivated by a relationship</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;[…] as long as I am the firstborn, I saw that I am really committed to take care of the family [...] responsible to take the family issues…&quot;</td>
<td>As I am the first born, I feel committed and responsible to take care of my family.</td>
<td>Feelings of commitment and responsibilities</td>
<td>Motivated by a relationship</td>
<td>Moral commitment</td>
</tr>
<tr>
<td>&quot;He can’t do anything, I support him with everything. He can’t go the toilet himself, so I helping. I do all the support to my son from morning to evening, even prepare his bed, changing clothing, showering or wash his clothes.”</td>
<td>I support him with everything from morning to evening. He can’t go to toilet, make the bed, shower, get dressed or wash his clothes himself.</td>
<td>Support patient with daily living activities.</td>
<td>To devote oneself to caring</td>
<td></td>
</tr>
<tr>
<td>&quot;[…] I wash all the clothes, cleaning the house and make sure my father get all the ransions, the food […] Everything I prepare we are eating together. I‘m like the mother of the house.”</td>
<td>I wash the clothes, clean the house and prepare the meals for my father and the whole family.</td>
<td>Support with household duties</td>
<td>To devote oneself to caring</td>
<td></td>
</tr>
</tbody>
</table>
Ethical Considerations

This study was performed to fulfil requirements for a Bachelor degree, thus no approval was required from the ethical committee, according to the Swedish law of vetting the ethics of research (SFS 2003:460). The setting and execution of the study was thoroughly discussed with the social worker and manager and personnel of the organizations, to eliminate any risks for the care providers when participating. The study was approved by the managers of the organizations, and a letter of information was handed out to the personnel, who explained the study to possible informants. When accepting to meet the researchers for an eventual interview, the letter was verbally translated and explained in a language each and one of the informants could fully understand. Through the letter and verbal explanation they were given background information about the project and were informed that participation in the study was completely voluntary and that they could withdraw at any time without further explanation. They were informed that there would be no direct benefit and that the choice of participating or not, would have no influence on the support they received from the organization. The informants were also assured of their anonymity and the confidentiality of the collected data. They were informed about the recording of the interviews on tape and when the informants agreed to participate, a form of consent was signed (see Appendix 1).
FINDINGS

During the analysis of the interviews, eleven subcategories developing into four categories, emerged from the data, describing the care providers' experiences. When the analysis was completed the subcategories were organized and summarized into four categories; “Moral Commitment”, “Living with meaning”, “Uncertainties” and “Possible Assets”.

Table 3. Table of subcategories and categories

<table>
<thead>
<tr>
<th>Subcategories</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>To devote oneself to caring</td>
<td>Moral commitment</td>
</tr>
<tr>
<td>Motivated by a relationship</td>
<td></td>
</tr>
<tr>
<td>Thoughtfulness</td>
<td></td>
</tr>
<tr>
<td>Spiritual encouragement</td>
<td>Living with meaning</td>
</tr>
<tr>
<td>Thankfulness</td>
<td></td>
</tr>
<tr>
<td>Hunger</td>
<td>Uncertainties</td>
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<tr>
<td>Financial concerns</td>
<td></td>
</tr>
<tr>
<td>Broken trust</td>
<td></td>
</tr>
<tr>
<td>Concerns about the future</td>
<td></td>
</tr>
<tr>
<td>Knowledge - the link to good care</td>
<td>Possible Assets</td>
</tr>
<tr>
<td>The importance of contributions</td>
<td></td>
</tr>
</tbody>
</table>

Moral commitment

Caring for a close one with HIV/AIDS required a lot of effort on a daily basis from the care provider. For many of them, it was a full time occupation. This means they were putting their own interests aside, for the good of the patient.

To devote oneself to caring

Depending on how advanced the patient's illness had become, the patient's need for care reached different levels. There were especially some care providers who had a very heavy care providing role, as their close ones were in need of help in many areas. One patient could not walk without support and another patient sometimes urinated in bed. Both of the patients needed help with showering, preparing meals, washing clothes/bed sheets and cleaning the house. There was always work to be done. One care provider said:
"He can’t do anything, I support him with everything. He can’t go the toilet himself, so I helping. I do all the support to my son from morning to evening, even prepare his bed, changing clothing, showering or wash his clothes."

Many of the care providers expressed that they were struggling with economical problems. One young care provider was alone in carrying the economical burden for the family. To be able to provide for them all, the care provider could not have a normal job, as she needed to take care of her father and the house duties during the day. She solved this by working night shifts. She explained:

“Always I have a shift of evening hours, so I am working in the night. All the daytime I am at home. I come back in the morning, every day. I feel good because I can see my father is there, my son is there, my young brothers are there. Sometimes I feel tired, I feel like I make a different life, but I am committed.”

Some care providers did not support their close ones with any HIV-related caring duties, as the patients were healthy enough to take care of themselves. These care providers laid more focus on the daily duties. Preparing the food and the importance of good nutrition was often brought up, as well as the relation between ART and a good diet.

Some of the patients received restrictions because of their disease, and were not allowed to cook or carry heavy things. As a result, the daughters offered their time in order to take on these responsibilities. When the conditions of the patients got worse, care providers explained that they took their close one to the hospital for treatment.

**Motivated by a relationship**

A constant theme that kept the care providers motivated was found to be their heart for their close one and their feelings of responsibility. One mother explained:

“The Heart, my heart, he is my son. So I really feel to help my son, because he is hearted [...] if it was not for me, the life of my boy will be not well”
Many expressed their caring to be motivated by a feeling of responsibility. One daughter explained her caring role out of moral obligation as she was the first-born, but at the same time there was no other place she would rather be. The daughters' commitment also seemed to guide their future plans. When talking about the future, one daughter said she would like to spend more time with her mother for a long time.

One relative explained that as married into the family, he felt it was his task to take responsibility of being financially committed to them.

**Thoughtfulness**

The intent consideration for the patients, were many times seen in the explanation of the care they were giving. One daughter said:

“And also I know that my mother should not get stressed. When she get stressed I try to get her out of stress, because the people with HIV are not supposed to get stressed or to get angry, [...] I try to make sure that my mother connect to her friends and talk as usual, like other women doing, and also afford to do some small payment for the anything which is a contribution. Like yesterday there was a funeral there, when we do the collection, I try to give my mother a collection so she feel she can afford to contribute something as a normal person, I am making sure she is not isolated.”

Stigmatization was a subject brought up by two of the care providers, they highlighted the importance of being careful not to stigmatize the patient. One care provider explained how important it was with good communication. In their home he made sure they discussed and were open about eventual problems. The other care provider tried to make harmony with her mother by small actions such as drinking from the same cup and using the same utensils. Her mother also suffered from heavy bleedings, despite this she even made the choice of not to wear gloves when caring for her mother as she did not want to hurt her mother’s feelings.

**Living with meaning**

The interviews showed that caring for a close one, was meaningful to the care providers. They expressed that they had a purpose with their lives, and experienced positive emotions due to
the fact that they had the possibility to spend time with the sick person. In the midst of all their concerns, they many times spoke of thankfulness, and often related to their faith in God.

**Spiritual encouragement**

The majority of the care providers were either Christians or Muslims. Some of them received visits from church members or mosque leaders, who prayed and read the scripture with them. This was experienced as a resource to strength, and a help for the care providers.

“...they come and teach and read together Bible, and remind some words, good words to encourage us. That is general counselling of the Christians in bible words [...] yes, it means a lot...”

**Thankfulness**

Many care providers expressed feelings of thankfulness in the midst of their trouble. They were thankful for the support they received from the organizations, and some of them also gave thanks to God for support, strength and the patient's recovery. One care provider explained her thankfulness like this:

“*When I heard about my son's situation, then now he is infected, I just thank the Lord that I don’t have anything to do, rather than supporting him. I am not tired, I am happy in the way my son is recovering now. Before he couldn’t get up from the bed. He couldn’t use his hand, it was tough before. But now with the physiotherapy help from the organization, he can come up and sit up... Get outside and get sun on his body. Because of this improvement I am happy [...] It is God's mission, that is what I believe.*”

**Uncertainties**

Taking care of a close one infected with HIV/AIDS was closely connected to several uncertainties. Many families had a limited income and did not only struggle with illness in the family, but also with not having their basic needs provided for. The lack of food and money made it hard for the care providers to maintain good quality when caring. Donations from
different non-governmental organizations and churches were not always sustainable and therefore not reliable.

**Hunger**

As many families suffered from poverty, the lack of food was a constant worry. Every day was a struggle to survive. A very old woman, caring for her son, said:

“Nothing, I'm suffering, I hunger [...] My son is not working, also my grandson is not working, so we are suffering, of hunger... We don't have anything here.”

As nutritious food was one of the main focuses of the education they received, the need of good diets was expressed many times. Because of their situations, these instructions were nearly impossible to follow.

**Financial concerns**

Several families struggled to survive their everyday life, and absence of money was a recurring problem. As a result to this, the wish for a start capital was often brought up by the care providers. It would enable them to create a sustainable income, releasing them from some of the constant worries.

“I wish to have something which will be sustainable for long time [...] I wish like if I had a business and get a capital, so I can keep on handling that business to make sure that every day...that capital is circulating and get profit, something ongoing project that something I wish to have, something to make my life go on sustainable”.

For some of the care providers, a capital would even mean that they would be able to have an ongoing project at home, making it possible to provide care to their sick close one and work at the same time. Yet, this was not the case in any of the families. Two care providers needed to work night shifts to be able to handle the economical situation because of their care providing role.

Due to the full-time job of providing care, a young woman caring for her mother, had no possibility to make any financial contributions to the household. This financial destitution
made her feel like a burden to the other family members, as they had to make all the payments for her, her son and her sick mother.

**Broken trust**

The support and help the care providers received was found helpful but as it was not sustainable the care providers could not rely on it as the only source of support. Many times it was seen how the promises of help were broken. One care provider had received food support earlier, but this was now cancelled. Another care provider had been promised a new house, but the promise was not held, which disturbed her. She said:

“...they have never come back and now I [...] keep on just wait to see if they will come back to renovate the house or to make a new house, but they haven’t come since like three years back [...] So they disturb me, because they just came and tell me, ask some questions, taking pictures, look inside and they promise that they will renovate the house, but they didn’t come back.”

Feelings of being abandoned in their care providing role were also found. One care provider explained that she had received training before, but that it was now cancelled, and she could not go there anymore to get support when problems arose.

**Concerns about the future**

There were many concerns related to the patients’ life-long disease. The patients were in need of special treatment to influence their recovery. As parts of the care were preventive, the lack of immediate recovery made it hard for one of the care providers to keep the motivation up. She asked:

“I am wondering why my son is not recovering well. Others, after taking drugs, get good health, but comparing with others, my son is not getting better. Why is it like that, why does he get worse? I am not happy with that.”

Knowing about the patients’ condition of HIV lead to different reactions within the families. One care provider explained how her other relatives refused to take care of the HIV infected children of her passed away sister, because of the fear of themselves becoming infected. This lead to her being the only possible care provider for the children.
Possible Assets

The experience of being a care provider was influenced by the help they could receive from either non-governmental organizations, neighbours or other relatives. The care providers expressed how every act of kindness was important to them, such as the support of food and different items, as well as practical help like babysitting.

Knowledge - the link to good care

One important area when being a care provider was the possibility to receive training in how to take care of a patient with HIV. Some care providers explained that when taking the patient to the hospital for treatment, the hospital staff gave them information about some important areas. One of these areas, well known by all the care providers, was the importance of good nutrition for the patient. Other areas were the usage of gloves for protection and how to take the medicine. These areas were also taught by different non-governmental organizations in the district.

“Sometimes when I took him to the hospital, explaining the situation of my son, I getting also the way of taking care of my son [...] from the hospital, I given also the way of giving him a good diet, the food with good nutritions... So they train me many ways of helping my patient.”

Most of the care providers expressed that they needed more training than they already had received. One care provider was a leader in the community and had the privilege of receiving more training and education than the other care providers in this study. There were also some that explained that they had not received any training or education in how to take care of a patient with HIV.

The importance of contributions

Many families only received food occasionally or during the big holidays, like Christmas and Easter from the non-governmental organizations in the district. Items such as maize, beans, cooking oil, sugar, rice, vegetables and soap was often brought up as examples of the kind of support given to them. Some of the care providers of patients who were children, received support in having the school fees, uniforms and exercise books paid for, foremost by different non-governmental organizations. Some of these organizations also provided a family with a
new house and one patient received physiotherapy. This lead to better recovery for that patient and a lighter burden for his mother as her son was able to use his hands and feet again.

Another big support for the families, were their neighbours and friends. Even as everyone suffered from poverty, they helped each other.

“Sometimes among those two women, one of them used to bring eggs and vegetables, soap, sugar. But not every day, sometimes when she have, because she has also her life.”

From time to time the neighbours also supported financially, but they often helped with smaller amounts, like paying the taxi for the patient to be able to go to the hospital.

Many of the care providers were in need of relief to be able to handle their everyday life. Relatives supported in various ways, such as picking up the medicine from the hospital or looking after the children. Some care providers were afraid to leave their close ones alone. When they had to go somewhere, other relatives assisted to look after the patient.

**DISCUSSION**

**Method discussion**

When collecting data to this study, some difficulties were encountered. Because of the language barrier, the importance of help from an interpreter was evident when connecting with the families. The interpreter was faithfully translating the interviews, and also explained cultural differences that were encountered along the road. Although the help from the interpreter was of great importance, the culture and language barrier was an inevitable limitation when analyzing the data. Reading literature and having the culture explained was valuable, but does not equal complete awareness and understanding of the culture, which may risk data to get lost in the process.

Parts of the families were recruited through home visits when the researchers accompanied the translator. This enabled the researchers to connect with the family, and the care provider had an opportunity to meet the researchers and learn about the project before an agreement was made. To fulfill ethical criteria, care providers were repeatedly assured that their participation was voluntary.
No names of any non-governmental organizations have been written down in this study, due to the obligation of protecting the participants’ anonymity.

The questions asked in the interviews were divided into two categories, the care providers’ experiences and their need of support. This categorization was made due to a pre-understanding that support was a scarcity needed to investigate. Gradually it was seen that support was one of many components in the experience of providing care for a close one with HIV. Support mainly included material and financial gifts rather than emotional support like therapy. Therapy was expected to be an important topic, but was never brought up by any of the care providers.

Some of the interviews were held in a room close by to where the patient and other family members were located. It was difficult to discern if this affected the answers given by the care providers.

Many of the experiences interacted with each other and could be suitable in more than one category and subcategory. As Lundman and Hållgren Graneheim (2013, p. 191) bring up this as a common difficulty, the data were analyzed carefully with the awareness of this matter.

A strength in the study is the selection of participants, included persons taking the main responsibility for the sick persons. The selection included care providers for patients in various health situations and ages, both grown-ups and children. Due to the care providers' different experiences, this lead to an extensive data collection.

When looking at the inclusion criteria, next of kin was the most usable term when referring to the care providers. On the other hand, it turned out to be only immediate family members and relatives being care providers in this study. According to Dahlberg and Segesten (2010, p 119) the caring science definition of a next of kin, is a person close to the patient, chosen by the patient himself to take on the caring responsibilities, and that the chosen one agrees to this relationship. In the case of the patients in this study, only one patient had chosen whom she wanted to have as her care provider. Together with the fact that all care providers were relatives to the patients, another concept than next of kin could have been used. Although, the
problem when using the concept of family, is that family can be interpreted to either immediate or extended family. The interpretation of what family means, is further complicated due to culturally different family concepts.

**Result discussion**

A reoccurring matter was the lack of resources to be able to give sufficient care to the patients. Many care providers were depending on the support from organizations, friends, neighbours or other family members. Common care providing tasks consisted of helping the patients with their hygiene, washing their clothes and bed sheets, cooking, cleaning and looking after the whole family. For two care providers this represented a fulltime occupation, giving them no other choice than doing night shifts to get the economy somewhat together, leading to a minimum of time for recreation and rest. All care providers expressed that it was their own choice to provide care for the patient. One care provider explained that she was the only one left to care for the patient, as all the other family members refused, due to their fear of transmission.

Three reoccurring themes were found in the result, and therefore chosen for further discussion. These central themes were “The Commitment”, “Aspects of feeling secure” and “Knowledge”.

**The commitment**

All care providers expressed that it was their own choice to provide care for the patient. Some care providers said that there was no one else to care for the patient, although, that does not contradict the independent choice of committing one’s life to a sick close one.

According to the research carried out by Tarimo et al (2008, p. 64) the care provider is usually a woman, not seldom single or widowed, which also appeared to be true in this study. Tarimo et al (2008, pp. 61-68) mean that the care providing role naturally is taken on by any woman with kin or family ties, and very rarely by the men in the families.

In this study, the majority of care providers were daughters, followed by mothers, aunts and one father. The daughters were found to change their future plans to consolidate with life at
home, for the sake of their sick parent and other family members. They admitted that the care providing role could be tiresome, but did not complain. Even though the majority of care providers were women taking care of the practical duties, it was occasionally seen that male relatives took a financial responsibility for the family. Although, as many female care providers were either single or widowed, only a few were financially supported by other relatives.

Aspects of feeling secure

A recurring theme in the care providers’ life worlds was a feeling of insecurity. They experienced they were not adequately trained in how to give care, and did not have the material and resources needed. They did not have the security of knowing what tomorrow would bring, if they would have food to eat, or if they would afford hospital treatment if the health of the patient got worse. The poverty in Tanzania lead to a feeling of insecurity regarding the lack of sustainable income, food, shelter and available health care.

This study showed how spiritual encouragement was valuable to the care providers and how their faith contributed to feelings of meaning, hope and security. Despite their vulnerable situation with limited resources and support, they were thankful to God that they were able to help their sick close ones.

It was also seen how some of the care providers became motivated to continue providing care because they could see the recovery of their sick close ones. At the same time, some care providers were worried about the health conditions of their close ones.

Tshilolo et al (2009, p. 139.) mention in their study that care providers lost their hopes when a close one got infected with HIV. Many strong feelings, such as fear and guilt, arose while caring for the sick person. If these emotions were ignored, the health of the care providers could also be in danger. Unlike their study, the care providers in this study did not express those feelings, instead many of them mentioned concerns for the future. Some of the care providers explained how this concern could be reduced if they got a capital to start their own business. They felt that in that way they could have a sustainable income and not have to depend so much on the donations from organizations and friends. Compared to the study
carried out by Tshilo et al, the participants in this study seemed to bring up practical concerns rather than emotional concerns.

**Knowledge**

The World health organization (WHO 2013) talks about five criteria that need to be brought up during HIV testing. Two of these; Counselling and linkage to good Care, were seen as areas particularly important to the care providers. They were the ones caring for the patient at home, and in need of good education in how to maintain a good caring quality.

When looking at the recommendations of WHO, it was at first difficult to understand what the term “counselling” stood for. WHO (2013b) mentions it both as a form of mentorship, but also as a context where they provide information and training. When carrying out the interviews, there were some difficulties in how to separate the two implications. Sometimes counselling was used in a sense of talking about feelings as well as receiving guidelines. This kind of support was as mentioned before rarely seen among the care providers.

Secondly, the term counselling was used by the interpreter when talking about training. Training was provided by the non-governmental organizations and the local hospitals, but mainly to the patients. It was seen to be very important also for the care providers to receive this kind of education, as it would help them to give safe and better care. WHO’s guidelines are focusing on the patient infected with HIV and their need of counselling and linkage to care, but it needs to be established that also the care providers should be included in WHO’s recommendations. More focus and support must be directed to the next of kin. A study done in South Africa (Mieh, Iwelunmor & Airhihenbuxa 1990, p. 701) reports similar findings. Limited training, support and resources are barriers that unable the care providers to care in a more effective way.

The result of this study also showed the importance of finances and sustainable income to enable the care providers to give the qualitative care they wished to give. Tshililo and Davhana-Maselesele (2009, p. 143) point out that the lack of resources is well known as an area that hampers the quality of caring.
In this study, the training families received, focused a lot on how good nutrition contributed to the patient’s recovery. The majority of the families were poor, and some even suffered from hunger. To afford food with specific nutrition was not always a possibility. It was seen that the families lived a life in uncertainty and insecurity. Although Dahlberg and Segesten (2010, p. 83) are talking about the feeling of security from a Swedish context, they mean that experiences such as lacking good material resources, not having enough knowledge and not experiencing to have control over ones situation, contribute to the experience of feeling insecure.

Good caring quality includes secure care. The fact that one care provider risked her own health by avoiding gloves when handling her mother’s body fluids, proved her thoughtfulness not to stigmatize, but also corroborated her ignorance in how HIV is transmitted. It was a tender gesture but can hardly be seen as safe care, as she was risking her own health to maintain a harmonic relationship with her mother. This was a useful example where involving both the patient and the care provider in a conversation would help to sort out any misunderstandings or preconceived ideas, to improve the quality of the care.

**CONCLUSION**

The result of this study presented the life of care providers who lived with limited resources. Poverty and the lack of training made it difficult for the families to feel secure in their role as care providers. This role was often a full time occupation, therefore many care providers’ whole lives were devoted to care for their sick close one. Because of this, the care providers had a limited income and no possibility to also be financially responsible for the family. More research needs to be done about the safety network in Tanzania and the need of sustainable support.

**Clinical implications**

In this study a broader understanding was developed in how important a family’s role can be in the caring process, and for the recovery of the patient. The care providers in this study exposed a genuine caring through their thoughtfulness and actions, despite lack of economical resources and a life in poverty. A better knowledge has been gained in what it actually means
to put your own plans aside and devote yourself to another person. The importance of including the patients’ families in the caring process cannot be underestimated. The result of this study can help nurses and other health care workers to gain understanding in how valuable it is to also include next of kin when educating a patient. It is important that next of kin also understand the new situation which the patient is facing, and in what way they can support him or her.
REFERENCES


Information for informant

**Facing HIV/AIDS within the family; family members experience and need of support**

You are being invited to participate in the study above. The study is a part of our Bachelor degree in the program of Nursing Science. We would like to meet with you for an interview. The study is being carried out and organized with the help from Tanzania Volunteer Agency, in agreement with ____________________________.

The aim of the study is to investigate how You as a family member experience being a caregiver for a close one infected with HIV/AIDS. During the interviews we will also be focusing on available support, and eventual lack of it. We estimate the interview to take approximately one hour and it will be held by Linda Norén and/or Rut Lindén, in collaboration with an interpreter from the organization, if needed. Together with You we will look for a suitable venue where the interview can take place.

With Your permission, we would also like to record the interview on tape. The recording will be locked in and kept in a place where no unauthorized person will be able to take part of the content. The result of this study will be anonymously presented, with no availability to identify You.

Participation is completely voluntary and You may withdraw at any time with no need of explanation. Whether You wish to participate or not, will not influence the support you receive from the HIV/AIDS organization. The study will not have any immediate positive impact. Our hope is that the result of the study may lead to better understanding of the need of support to informal HIV/AIDS caregivers.

If you have any questions or concerns, please do not hesitate to contact us or the Organization.

Yours sincerely,

Linda Norén and Rut Lindén
Nursing Students

Phone nr: +255682667134
E-mail: s112832@student.hb.se
**Form of consent**

I have taken part of the information about the study *"Facing HIV/AIDS within the family: family members experience and need of support"*.  

I am also informed that participation is voluntary and that I can withdraw from the study at any time, with no obligation of explanation, and with no consequences for the support I receive from the HIV/AIDS organization.  

I hereby give my consent to partake in the interview and I accept that it will be tape recorded.

---

*Signature of Informant*

__________________________________  
Place, Date

__________________________________  
Signature

__________________________________  
(Phone number)
APPENDIX 2

Questions for the interviews

INTRODUCTION

–Age and gender of the caregiver
–Caregiver's relation to the caretaker
–Caretaker's age and HIV/AIDS status
–Years of being a caregiver
–Caregiver's HIV status
–Occupation/source of income
–Family situation (people living in the household, marital status of caregiver "Tell us about your family")

BEING A CAREGIVER

–Can you tell us about your experience of caring for a person with HIV/AIDS?
–Can you give more details or any examples of these experiences?
–Please describe what a day as a caregiver looks like for you?
–What kind of activities do you pursue during caring?
–How would you describe the role of a caregiver?
–How would you personally define the word "family member"/"close one". According to you, who are your close ones and your family members?

SUPPORT (Practical/physical, social/emotional, spiritual, economical)

–What kind of support do your receive? What does it look like?
–What does support mean for you?
–From whom do you receive support?
–Who is able to receive support?
–When do you receive support?
–Is there any support you wished you received, that you do not receive at this time? In what way would this support help you in your role as a caregiver?

FINAL QUESTIONS

–Is there anything else you would like to tell us?
–Is there anything you find important that we haven't asked you about?