Experiences of living with HIV/AIDS in Thailand
A qualitative study

Am Hast
ABSTRACT

This thesis and study is sponsored by Minor Field Study scholarship through University of Borås and is funded by SIDA (Swedish International Development Cooperation Agency). There are around half a million people living with HIV/AIDS in Thailand and it is one of Thailand’s most increasing public health diseases since 1984. There are several organizations working jointly with prevention and lifting the level of knowledge among the public and decreasing new infections.

The aim of this study is to describe experiences of persons living with HIV or AIDS in Thailand. In-depth interviews was carried out and analysed with a qualitative content analysis. Six persons, three female and three male, aged between 18 to 67 years living with either HIV or AIDS participated. The informants expressed that they were enjoying life and had plans for the future despite of the infection as they felt a sense of wellbeing, had an acceptance of the infection and themselves. It was important to have support from friends and family to cope with life and that support made them feel blessed and grateful. However the informants also expressed a feeling of no self worth and that they had giving up living because of feeling isolated, stigmatized, depressed, ashamed of themselves and being a burden with a sense of guilt that made them repress themselves. The conclusion is that these aspects were interlinked but the negative dominated among these with AIDs and the positive aspects were more common among the informants living with HIV.

Keywords: HIV/AIDS, Experiences, Thailand, Qualitative study, Sexually transmitted disease and Public health disease.
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INTRODUCTION

This study is a Minor Field Study (MFS), a scholarship through University of Borås, financed by Swedish International Development Cooperation Agency (SIDA), giving the opportunity to study a subject I am deeply interested in and to do so in the country I call “second home”.

This scholarship has also been giving the opportunity to raise a level of knowledge in international development including learning about Thailand’s culture and people.

Thailand is my birth country and it was a rather easy choice to do a study on HIV/AIDS there, because of the knowledge about the country and the language.

The aim of this study is to illuminate and describe infected Thai people’s experiences of living with HIV/AIDS, primarily in Bangkok. And the motive is to obtain a greater understanding of people’s experiences of living with HIV/AIDS.

This study may have great importance to all who wishes to work or are working as healthcare professionals both in Sweden and in Thailand. It can also give the reader a greater understanding of how HIV/AIDS affected experiences their lives.

It is important to illuminate how people with HIV/AIDS are struggling and experiencing their illness but also how they cope with everyday life. What their thoughts are and if they can get a sense of wellbeing, living with an incurable illness.

BACKGROUND

The first known case of HIV (Human Immunodeficiency Virus) infection has been dated since 1959 from stored blood from Africa, but it was not until between 1981 and 1984 proven to be caused by a retrovirus (Ericson & Ericson, 2009).

The epidemic of AIDS (Acquired Immune Deficiency Syndrome) started in late 1970 when the physicians of the American healthcare found remarkable and rare cases of illnesses. These illnesses were “kaposi’s sarcoma” (malignant tumor of the skin and lymphatic system) and “pneumocystis carinii” (fungal infection of the lungs). At that time, the connections between the illnesses were not known either (Moberg, 2000), until 1981 when the first cases of AIDS were described as caused by an HIV infection (Kallings, 2005).

The first cases concerning AIDS were made public in 1983 (Kallings, 2005). It was nearly three decades ago and today, around 31.1 million to 35.8 million people live with HIV/AIDS throughout the world (WHO, 2009). There are also issues of concern, regarding the spread of HIV in women. Half of new infections are among those under age of 25 and two thirds of paediatric cases of HIV/AIDS (UNGASS, 2010).

The HIV virus causes an infection which spreads by either contaminated blood, through secretions or body fluids (Kallings, 2005). The HIV virus is a retrovirus, which means that the virus is able to convert its RNA (Ribonucleic Acid) genetic to DNA (Deoxyribonucleic Acid) copy, within a host cell inside the human body by using the enzyme “reverse transcriptase”. When the DNA copy is made, the virus immediately starts to transfer its genes into the DNA molecule of the host cell and after a few hours,
the HIV virus has become a part of the genome of the host cell (Ericson & Ericson, 2009).

AIDS is the final stage of HIV infection, meaning a transformation of the body’s immune system and is characterized by that the individual becomes easily infected with severe infections, which often has a fatal outcome (Ericson & Ericson, 2009)(Kallings, 2005). The most common symptoms are periods of fever, weight loss, fatigue, pneumonia, various skin rashes and fungus in the mouth (Ericson & Ericson, 2009).

It takes about one to three months after being infected before the virus can be detected because of the high level of antibodies or low level of T-helper cells. T-helper cells are part of the body’s immune system and are decreasing until the immune system does not function sufficiently, when this has occurred it means that an HIV infection has led to AIDS (Kallings, 2005). CD4-receptors are cells in the human body, which are more likely to be susceptible to the HIV virus. These are Th2-lymphocytes, but monocytes and macrophages can also be receptive to HIV virus (Ericson & Ericson, 2009).

After the HIV virus has integrated its DNA to the host cell, the virus becomes latent. During this period the infected person seldom has any symptoms and it is at this period antiretroviral drugs is most effective (Ericson & Ericson, 2009).

An HIV positive can live with the infection for ten to fifteen years before the virus develops into AIDS. When this advanced stage of the infection has occurred, the infected is usually suffering from severe infections and AIDS related illnesses. Some of them are candida infections, pulmonary infections, kaposi’s sarcoma, pneumocystis carinii, relapsed pneumonia and tuberculosis (Ericson & Ericson, 2009).

**Thailand**

Thailand is a monarchy country and the only country in Southeast Asia that has never been colonized, and is one of the most visited countries for tourists (Macdonald & Parkes, 2009).

Thailand is locally called “Ratcha Anachak Thai” or “Prathet Thai”. With an area of 514 000 km² it is both bordering the Andaman Sea and the Gulf of Thailand. Border countries are; Burma, Cambodia, Laos and Malaysia (Landguiden, 2011).

The population is approximately 67 million and the capital, Bangkok, is overwhelmingly crowded with around 8 million inhabitants. Bangkok or “Krung Thep Maha Nakhon” in thai, which means “The City of Angels” is the largest city in Thailand. The name Bangkok comes from “Bang” standing for “riverside village” and "kok” meaning “a wild olive” (Macdonald & Parkes, 2009). The spoken language in Thailand is Thai, ethnic and regional dialects and English. National Thai is more commonly used than the distinctive northern or southern dialect, it is also the language that is practiced in schools (Landguiden, 2011).

Most inhabitants profess to Theravada Buddhism (94.6%) and other religions are Muslim (4.6%), Christian (0.7%) and others (0.1%) (in year 2000). Thailand consists of 75% Thai, Chinese 14% and other 11% (Central Intelligence Agency, 2011).

Buddhists believe in karma, which is built on good or bad luck depending on what path in life person concerned chooses to embark on (Landguiden, 2011). Macdonald and
Parkes (2009) emphasize karma as a way of living, which will have an impact on the afterlife for the person concerned. Buddhists’ consider life as suffering and with good karma, you will have a better afterlife. (Macdonald & Parkes, 2009).

**Healthcare system**

Before 2001-2006 thai people got health care depending on how much money they possessed. The less money you have, the less healthcare treatment you received (Macdonald & Parkes, 2009). In year 2001, the government of Thailand has developed a health care policy which meant a health care system to everybody (Landguiden, 2011).

Giving everyone the same opportunity to hospital care throughout the country and gave the underprivileged people opportunity to be able to afford medical care. It was introduced as the 30-bath regime, which is equivalent to about 5.85 SEK (Landguiden, 2011).

**HIV/AIDS in Thailand**

The first reported cases of HIV/AIDS in Thailand were in 1984 and it started with sexual relations among homosexual men but have increased with other risk factors such as prostitution and sharing a drug syringe. UNAIDS (Joint United Programme on HIV/AIDS) has reported that there are currently approximately more than half a million people living with HIV in Thailand and 210,000 of them are women (UNAIDS, 2010). It has also become one of the leading causes of death in the country and in year 2009 there were 28,000 reported deaths, caused by AIDS related illnesses (International HIV and AIDS charity, 2011).

The HIV prevalence rose from almost nothing to 40% between 1988 and 1989 in Thailand. This was among those who were using drug syringes but there were also the increasing numbers of 40% among sex workers in the north of Thailand, Chiang Mai. This increased the level of infections among their clients, their wives, partners and children. At that time it was also believed that foreigners could have contributed to the spread and even though basic actions was made no further actions by the government was conducted, since the epidemic was not yet extensive (International HIV and AIDS charity, 2011).

Newly infected increased in late 1990 and according to Kallings (2005), it might have been caused by cultural aspects such as married women has no saying in condom usage. Married women can therefore risk becoming infected, if their men are unfaithful, which can lead to a spread of infections to their children who may live unaware of being infected and pass it on to others. Newly increased infections may also have occurred due to lack of knowledge of transmission routes and the increasing mother to child transmission (Kallings, 2005).

It was not until 1991, actions regarding AIDS prevention and control became a national priority, leading to the deceleration of the epidemic. To decrease infection levels were partly to relocate the AIDS control program from the Ministry of Public Health to the Office of the Prime Minister (International HIV and AIDS charity, 2011).
To decrease HIV prevalence the launching of a public campaign on AIDS was made and prime minister initiated “The 100% condom program”, forcing clients and workers of brothels and massage parlors to use the free condoms that were given by the government (International HIV and AIDS charity, 2011).

In 1987, when the first public awareness of HIV was a factory worker, Cha-on Suesom, became an example of how people with HIV / AIDS could become more integral with the community. He got infected as a result of a blood transfusion and he and his wife lost their employments after he revealed being HIV positive. They got public sympathy after being exposed by the media and this allowed the public to raise their awareness of people living with HIV (International HIV and AIDS charity, 2011).

Along with the Ministry of Public Health and UNAIDS, the usage of antiviral was studied in Bangkok among pregnant women, using AZT (zidovudine)(International HIV and AIDS charity, 2011). By identifying HIV infection among pregnant women and treating them in the final stage of the pregnancy, it resulted in reduced contamination from mother to child (UNGASS, 2010).

The study successfully reduced 50% of the mother to child transmission and led to a demand from the government to be practiced in most hospitals in 1999. This is currently being monitored by the government since 2000 (International HIV and AIDS charity, 2011). This action has enormously reduced HIV infection in newborns, making it one of the main goals that was defined by the UNAIDS (UNGASS, 2010).

HAART (Highly Active Antiretroviral Therapy) is a combination of antiretroviral drugs, which has been used to treat the HIV infected in Thailand, since year 2000. This therapy has given them a prolongation of their lives by delaying the progression of AIDS. The numbers of the HAART receivers is increasing, making the reduction of deaths caused by AIDS related illnesses possible (International HIV and AIDS charity, 2011).

Currently, Thailand has been exceptional compared with other developing countries in terms of succeeding in reducing new infections rate by controlling HIV more frequently according to Kanabus and Fredriksson-Bass (2003) and is also known for their effectiveness and rapidness in HIV responses.

Thailand has up until present time reduced HIV incidence with 10% and is still moving forward. There are also more people living longer with HIV today, because of the success of antiretroviral treatment. Therefore, the progression of AIDS is declining, resulting in fewer deaths caused by AIDS related illnesses. WHO and UNAIDS are estimating that effective treatment that has been available since 1996, has been saving about 2.9 million lives (WHO, 2009).

The community still has improvements to make regarding stigmatization and discrimination towards the affected and the more people who share their experiences and feelings, the more the community will learn and understand the implications of living with HIV / AIDS.

The national organization, The Thai Red Cross Society has implemented an AIDS prevention campaign project for slum communities in Thailand. The project, with 350 volunteers, started in 1993 and has established in 54 communities (The Thai Red cross Society, 2008). The organization cooperates with “Bangkok Metropolitan Authority” and has a sponsorship from the Norwegian, “Save The Children” (an international non-
governmental organization) which main task is to help underprivileged HIV infected children (The Thai Red cross Society, 2008). They give information regarding HIV/AIDS and raise the public awareness. They also make the people living with the illness more accepting in the community and provide moral, social and financial support (The Thai Red cross Society, 2008).

HIV/AIDS and caring

The necessity of being professional and to approach people in suffering is being a good listener, sympathize and being there for the patients (Wiklund, 2003). To be able to be present for the patients is important for a nurse, without being the expert of care and “to do” for the patients. There can be a misuse of power in nursing, as a professional health caregiver (Oudshoorn, 2005). Nurses caring for the HIV/AIDS affected need to consider not only the wider aspects of the person’s life but also their physical symptoms as well as being engaged and to active listen to the individual’s experiences and feelings (Jenkin, Koch & Kralik, 2006). The importance is to diminish their lack of social support, related stigma and mental health issues (Li, Lee, Thammawijaya, Jiraphongsa & Rotheram-Borus, 2009).

Within the health care system, nurses can be a source of power for patients (Oudshoorn, 2005). There are according to Oudshoorn (2005) several sources of power, both at micro and macro level and it depends on one’s definition of power, to determinate the source of power. The micro level means that the nurse is empathetic and supportive, which is important in the caring process in order to make patients feel acknowledged, being heard and safe (Wiklund, 2003). Macro level means knowing limitations to empowerment, because everyone is not in need of it (Oudshoorn, 2005). Power is often use to dominate and to oppress and power must be shared, in order to be a positive concept in nursing (Oudshoorn, 2005). Oudshoorn (2005) refers to Gibson when it comes to empowerment as a process that strengthens and helps patients to obtain control of their lives again. Oudshoorn (2005) states that empowerment also can help to gain a positive self-esteem, an improved quality of life, well being and feeling of hope and health instead of feelings of despair and hopelessness, feelings that were expressed by many of the affected (Kylmä, 2005). It has been assumed that nurses forget the macro level aspects and are caught in the micro level and therefore they are failing with this level.

Wiklund (2003) clarifies the meaning of “lifeworld” being the world a person live in and experience through the physical body. Lifeworld and the body are merged and should therefore not be separated and within the Caring Science, it strives to human beings being a unity of body, mind and spirit. When a person is suffering, they want to feel confirmed, significant and heard. “To suffer” is when a person is isolated from oneself and the unity of oneself and “suffering” is the torment the person is experiencing (Wiklund, 2003). In the care of patients with such a stigmatized and chronic infections such as HIV / AIDS, it is of great importance for health care professionals to understand how people perceive their life situation.
FORMULATION OF THE ISSUE

To live with an incurable illness raises thoughts and questions among the affected and their friends and family. To have recently being diagnosed with HIV or having lived with HIV for a long time to experience the progression of AIDS, might have significant differences in both emotional feelings, psychological distress and how the affected perceive the world and surroundings.

It is important to learn more about how the affected are experiencing their illness or if they can experience any sense of wellbeing and in what way their lifeworld has been affected, in order to raise a level of knowledge about their life experiences.

AIM

The aim is to describe experiences of persons living with HIV/AIDS in Thailand.

METHOD

A qualitative empirical study with an inductive approach has been made with in-depth interviews about their experiences of living with HIV/AIDS (Kvale 1996). The duration of the study was from March to May 2011 and has been analysed according to the qualitative content analysis presented by Lundman and Häggren Graneheim (2008).

Selection of participants

The study took place in Bangkok at a big hospital, with the help from a contact person who had been working and had contacts there. A written consent and an explanation of the study aim were handed out to the nurses at the nursing department and participants that matched the inclusion criteria were selected.

My contact person, a former nurse, helped with recruitment of participants for the study at the hospital concerned. With the prior inclusion criteria such as native Thai people, infected with HIV or AIDS and ages 18 and up. Information was given in the department of the hospital in a written form and all participants got information about the purpose of the study. It was ensured that they had understood the meaning of the study and had given their consent before initiating the interviews.

The list of participants consisted of six native Thai people, which were three women of ages 18, 24, 56 and three men of ages 37, 46 and 62. All six of them were Buddhists and were receiving treatment and care from the same hospital.

Five of the interviews were conducted at the hospital and one at the interviewee’s home, since he was so ill. Two of the interviewees had a relative attending during the interview.
Data collection

Since the aim of the study was to examine experiences, individual interviews were elected. Dahlberg (1997) believes that interviews can reflect lifeworld perspective when illuminated, analysed and described.

To engage to a person’s lived experience with interviews, is according to Kvale (1996) a good method that allows the author to seize people’s lifeworld.

It is also difficult according to Kvale (1996) to disguise your involvement as the interviewer. There is no need for the interviewer to "place themselves outside" while conducting the interview. Instead, the interviewer should participate in the phenomena that are being studied and be a part of the creation of the text by stimulating the interview with further questions in order to extract what the interviewer is seeking (Lundman & Häggren Graneheim, 2008). Kapborg and Berterö (2002) underline the importance of cultural factor between the interviewer and the interviewees.

All interviews were conducted after the permission to tape record, with the open question: “Could you please describe your experiences of living with HIV/AIDS?”. Each interview took between 25 to 50 minutes and one interview had to be made another day, due to a participant who was very ill.

I listened carefully to each interview and during pauses or when the interviewees lost track I stimulated the interviews with subqueries such as: “Can you please describe further?” or “Can you please elaborate?”

According to Lundman and Häggren Graneheim (2008) the interviewer becomes a co-creator of the text and may most likely affect the outcome of the interview, by stimulating the interviews with such questions.

After each interview was completed, I transcribed it verbatim and kept it encoded by numbering each interview. This was made because of the chosen analyse method and because it will be more easy to encode the contents of the interviews into categories and sub categories, such as outlined by Lundman and Häggren Graneheim (2008) as the qualitative content analysis method.

To interpret

Thai language was used in the interviews since I know the language and therefore there was no need of an interpreter. Kapborg and Berterö (2002) say that it is rather difficult to translate into another language, given the complexity of the translation because of minor differences of the meaning.

Information references

The database of Cinahl was searched through from the Department of Nursing Science of the College of Borås to find scientific articles, that were later selected to be analysed and compared in this study.

The keywords that were used was; Qualitative research, HIV/AIDS, lived experience and Thailand. When choosing qualitative research, Thailand and HIV/AIDS in “Word in Major Subject Heading”, few articles were found on experiences of HIV/AIDS.
**Data analysis**

To analyze data a qualitative content analysis was selected (Lundman & Häggren Graneheim, 2008). It has within the nursing research been used to examine and interpret the texts of the transcripts of taped interviews (Söderberg & Lundman, 2001).

There are two methodological approaches within qualitative research method, deductive and inductive. Deductive approach analysis primarily model and theory, while the inductive approach analysis unbiased texts based on people’s narratives about their experiences (Dahlberg, 1997).

In the process of analysing the collected data I listened to and studied the interviews several times in order to find significance and meaning of the text content. The analysis begins, according to Dahlberg (1997) when the researcher read through all text repeatedly to become acquainted with it.

Transcribed materials allow the qualitative similarities and differences to appear in its entirety (Dahlberg, 1997). The processing of these similarities and differences allow for the qualitative different categories to emerge (Dahlberg, 1997). It may also give the author the possibility to review over the components that responds to the purpose of the study (Lundman & Häggren Graneheim, 2008).

Meaning units from the data was extracted to condense them; meaning that unnecessary words are being removed without losing the meaning of the context. The remaining of the condensation is a brief text, which allows the abstracting and coding to become more easy (Lundman & Häggren Graneheim, 2008).

Krippendorff (2004) underlines the importance of categories to be exhaustive and exclusive, meaning no data should fit into two or multiple categories. However, this can be difficult to satisfy, because the experiences can be so intertwined and easily fitted in two or more categories (Lundman & Häggren Graneheim, 2008). Maxwell (1992) states that categorization and encoding of meaning units are made in search for links and patterns.

The analysis was time consuming in the process of finding content areas and coding the meaning units. Even repeated reading of all six interviews took much time.

The reader must understand the significance of reading and interpreting the text without preconceptions. A text is given meaning by the reader and can be interpreted in multiple ways and still be valid, if it is read without preconceptions (Dahlberg, 1997).

**Ethical considerations**

This study required participants to give their narratives about their experiences, which must have been beyond difficult but very courageous of them.

Before each interview, I introduced myself, told about the intentions of the study and explained about integrity and anonymity he/she would have throughout the study. Protecting the integrity and anonymity of the participants was important and essential in order for this study to take place. Therefore confidentiality was ensured by encoding and numbering the interviews, which were accessible by me and my mentor only (Vetenskapsrådet, 1990).
After each interview, each participant was given a telephone number in case someone would wish to withdraw from the study. One participant withdrew from the study three weeks after the interview and I met with the interviewee to destroy all materials and to ensure the interviewee that none of the material would be used. She withdrew because she changed her mind about her feelings and expressions being in a thesis and did not want to share her experiences to the public.

RESULT

The result is presented with categories and subcategories and quotations have been made in order to substantiate the study, along with descriptions of the result.

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
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| To be enjoying life and having plans for the future despite the infection | • Sense of wellbeing  
• Acceptance of the infection and oneself  
• To have support and cope in life  
• Feeling blessed  
• Being grateful |
| To feel no self worth and give up living | • Being stigmatized  
• Sense of guilt  
• Being a burden  
• Ashamed of oneself  
• Feeling isolated  
• Being depressed  
• To repress |

**To be enjoying life and having plans for the future despite the infection**

The informants described that they were enjoying life and having plans for the future while they expressed good experiences in spite of everything, meaning that even if they were living with the infection, they felt a sense of wellbeing. They also stated having good experiences when having accepted the infection.
Sense of well-being

Some of the interviewees told that they shared feelings of well-being despite the illness. Some also explained that it could probably be because they had lived with the illness since birth and did not know of a life without it and that their illness has become a part of their identity and personality. One said that she feels she lives a quite good and enjoyable life despite her illness and another interviewee said that it is “fine”, despite what he knows about HIV.

They expressed a sense of hope and comfort in their voices. They even explained that good feelings were much easier to talk about than bad feelings.

“Now that you have all the knowledge and trust to the people who take care of you, my life is alright despite what I know about HIV” (Interview no. 2).

Acceptance of the infection and oneself

All of the interviewees stated at some occasion that they have accepted their illness, although the time period for each interviewee varied. Some have had it since birth and explained that their acceptance came early in their adolescent and it was truly excruciating living with the secret for long. They had to hide medicine from friends and lie to loved ones. They said that it feels good to have come to accept the illness, because of the feeling of being at ease with oneself. They said that when one can get a feeling of calmness and an acceptance of oneself, they feel good about themselves and can enjoy life and that it feels quite alright.

“It was devastating at first, but I have come to accept my illness now and it feels quite alright” (Interview no. 3).

To have support and to cope in life

To have support and help from friends and family was a very important feeling from most of the interviewees, in order for them to cope with everyday life. Some said that it would be very difficult if they did not have support and it has been giving them the opportunity to enjoy life. They also said that family is important and the only one you can trust and lean on when life becomes difficult and unbearable. To have support has giving them feeling blessed and they expressed being grateful for friends and family. Some said that the support is so important, that when friends and family accepted their illness, they could accept themselves being infected. One AIDS affected woman expressed her acceptance of herself as when she has help from family and friends.

“I feel fine nowadays with all the help that I get from hospitals and my family and friends” (Interview no. 4).
Feeling blessed
The participants said that having a wonderful and supporting family, was the reason they felt blessed. It was also a feeling of being loved and understood, which has been important for the affected to live an enjoyable life. They also had a sense of feeling that they should live their life to the fullest, when they felt blessed with a supporting and loving family. To live their lives to the fullest was also something that their family wanted them to do.

“I should really try to live my life to the fullest and I actually feel blessed with such loving family”
(Interview no.1).

Some have tried to live their lives like they did before they got infected. They explained that it is very difficult to do so. One said that she can never return to how her life was before she was diagnosed with HIV. She said that back then she did not have any medications or hospital visits in her agenda and all her plans must be made according to that “schedule”. It can at times be difficult to make plans for other things and especially plans for the future. Even though they were not as blessed as others that are healthy, they feel they are blessed with understanding friends and family and that their illness is under control. One AIDS affected stated that she feel blessed because her illness is under control, if she can manage to keep away infections.

“I feel blessed because my illness is under control and I have good prognoses...if I can keep infections away...” (Interview no. 5)

Being grateful
The participants were grateful to their friends and family for their support and understanding. Because without their family, they would not cope as well as they have done. One AIDS affected expressed feelings of being grateful, even though she has not told about her illness. Grateful for new friends and “family” in a support group, she had met on the internet one day. Another interviewee said that he is grateful for his family because they have done so much for him.

“...so I am so grateful for my family, who has done so much for me...” (Interview no. 2).

One interviewee stated that even though he was grateful, he also felt ashamed over the fact that his much younger sister is working in order for the family to afford his medical care. It felt difficult for him when his sister is both going to school and working in her spare time, in order for them to make ends meet. He felt that his sister should be out
with her friends and have fun, instead she has become a wage earner in the family. He also said that he felt that he has deprived her childhood, by letting her work. He has occasionally told her about how he felt about all this and she has just shaking her head and said that he was stupid for thinking that way. She said that she wants to help and that she loves going to work because she has her friends there.

“I am grateful for their help...but it bothers me that my baby sister has to work hard...” (Interview no.4).

To feel no self worth and give up living

Being stigmatized, having sense of guilt and being a burden has been requiring support from friends and family for the participants. It has been giving them a sense of guilt when they felt that their family has been taking care of them. The guilt of being ill and to be in need of their help. They also expressed feelings of being a burden. These feelings were felt when they felt their family has done much for them or has sacrificed and devoted their lives to taking care of them.

Being stigmatized

This subcategory is what all of the participants had plenty to share. The all had experienced the feeling of being alienated and excluded by what the participants refer as “people”. They also stated that they have felt like and treated like animals, when people point fingers at them and display their disgust. It has given them a feeling of wanting to disappear and the feeling of being disgusting. To be considered as an animal has been very difficult for the participants, who said it feels like people have been taking away their rights of being human.

They said that when it has been at its worst they can lean on their friends and family for both comfort and support. Because sometimes it can be very difficult to bare with so much prejudices and viciousness from the community and they sometimes have had their friends and family to talk to. One said that this has made it difficult for him to trust new people and to make new friends. He is afraid that people will talk behind his back and that they would think of him as disgusting and unclean. It made him feel sad when people say bad things about him, it made him feel less than a human, an AIDS affected expressed that people are freely criticizing and judging her even though they do not know her or know what she had been through.

“When people point fingers and whisper and stare at me, I feel disgusting and want to just disappear...” (Interview no. 1).

“People don’t know what I have been through and yet they feel free to criticize and judge someone like me”(Interview no. 5).
Sense of guilt

Sometimes the participants had a sense of guilt towards their loved ones. They also point out that these feelings will always remain and no matter how supporting or loving their family are, they will still feel some sort of guilt. They expressed that even when they think about afterlife, they felt guilty because it made their family sad. They also felt guilty for having the infection, they felt as if it was their fault. When their family is taking care of them, they feel guilty for having the need of being taken care of. An AIDS affected felt guilty because his family has devoted their lives to taking care of him. There were also feelings of guilt when some described about hiding their illness. They felt guilty telling friends and family because their family would get the sense of responsibility of taking care of them. It would be wrong to ask that they would take care of one, although that would be something that they would insist on doing.

“Life is hard most of the time living as an HIV positive...but it is far more difficult seeing your devoting family suffers because you have AIDS...because I did this to them...”
(Interview no. 3).

Being a burden

The participants also described the feeling of being a burden to their family. The participants described that they felt they were a burden, some said they felt like they “were in the way”, another that it felt bad when they do everything for them and it did not feel good to make phone calls to them everyday to ventilate. Some participants are living alone and the others are living with their family. To live alone also has its disadvantage, which is lack of conversations to others and is forcing bad thoughts to emerge, when being lonely with thoughts. Their family has been very patient and has always been there for them whenever they needed help or needed someone to talk to, and it has left the participants feeling like a burden.

“...I think it would lift the burden of my family, I think they would be better off without me...”
(Interview no. 6).

Ashamed of oneself

Most of the participants felt ashamed of themselves and over being infected and ashamed of the fact that it has affected friends and family that they had the illness. There were also concerns among the participants about what other people thought of them. Most of the time it was unbearable to go outside, because it usually made all of the bad feelings worst. Some described the feeling of being exposed outside the world, being seen as someone “bad”. Someone that has got infected because he/she was incautious. When they are being seen as HIV infected or AIDS affected, it makes them feel bad and sad.
...because outside...people see me as a bad person, when they know about the illness I have...it makes me feel ashamed of myself...” (Interview. no. 2).

**Feeling Isolated**

The participants described isolation as a solution to hide from the outside world. Although it made most of them depressed, they were convinced that it was for the best if they wanted to keep out all the bad things that people said and thought about them. This made their lives more bearable and was at some point the only way they could cope with everyday life. The reason of isolation was so that people would not see them. Even if it did not show on the outside that one is HIV positive, they wanted to hide about their condition. The isolation was what their escape when they started to notice people talking bad things about them and the only safe place was at home. To isolate meant for some a miserable and lonely life.

“I started to isolate myself from everybody I knew, my family and friends and I started to report sick to work...” (Interview no. 4).

**Being depressed**

In this matter the interviewees declared that they all have felt depression during some period of their lives. One said that she was living with an agony all by herself and described it as unbearable when she was hiding her illness, another that she became depressed when she started to lie and make different excuses for herself and when she started to see less of her loved ones, she became more and more depressed. Some experienced depression during the first period of knowing about the illness, which has been described as getting a “death warrant” and others say that the depression struck after they have told family and friends, when thoughts of death were more tangible. It was also depressing to think about leaving loved ones with grief.

“The thought of that I can be leaving my family in near future makes me truly depressed...” (Interview no. 4).

**To repress**

A man chose to repress his illness for some time when he thought that it would reveal his sexual orientation and another, which was the only one of the participants that was currently living with the secrecy of her illness. She stated that she was not sure if she will ever reveal herself. She feels her choice of hiding, is a way of protecting them from harm. She also thought that they all would not understand if she told them that she got infected from a man she barely knew. The thought of them judging her and looking at her differently are far more terrifying than keeping her secret. She has been able to hide
her illness from her surroundings by denying her illness. To be able to cope with everyday life she said that she is forced to repress her emotions and thoughts when her friends and family are around. She also expressed her hatred towards herself. When asked why she did not want to tell or talk to someone about her illness, she explained that she was afraid that everyone would hate her and she would eventually end up alone.

“I have no wish to tell friends and family about my condition...they would not understand anyway...and would probably abandon me if they knew...”
(Interview no.5).

DISCUSSION

Discussion of method

To interview was a difficult task to carry out as it was a new experience. The chosen approach, allowed the participants to freely share their experiences and feelings (Lundman & Hällgren Graneheim, 2008). Dahlberg (1997) believes that a qualitative interview is an expression for ontology, meaning it contributes to a person’s lifeworld by describing the essence of that person. Freed (1988) states that it is preferably if the culture of the interviewee and the interpreter were the same, in order to obtain the interviewee to express themselves more easily since it is their own language. The interviews that were given were truly sincere and the interviewees were expressing themselves easily. Although, there is also the relevant body language while making interviews, which can say quite much about the person in general.

In this study six participants, in the age range 18-62 were interviewed, including three women and three men. However one informant withdrew her participation, another informant was included instead. The participants were found at one of the largest hospital in Bangkok. The reason for choosing this particular hospital was because the contact person had contacts there. The location of the interviews was held on the nursing department at the hospital. This was another way of protecting the interviewees from being disclose, which was a respectfully gesture from the nurses at the hospital. They also provided a private room so that the interviews could be in progress in a quiet and a peaceful environment. This made the interviewee more calm and was able to relax better and felt less stress before the interview. This made a huge difference in terms of sharing narratives with all of the interviews, except for one that was held outside in the corridor of the private room. This was a bothersome environment and was probably more tough on the interviewee, who seemed a bit restrained with her narrative. Interviews that were being held in the private room were slightly more calmed and improving in terms of being more describing and elaborating. The same applies to the interviewee that wanted to give her interview at home, where he said he felt more safe.

The interviewees only wanted to participate if they could be promised that their names would not appear in this study or no one would listened to the tape recorded narratives they had given, which they were ensured according to Vetenskapsrådet (1990) principles. The participants were given a consent form to confirm their participation and were free to withdraw from the study at any time. I also met with all of the interviewees...
again after the interviews had been transcribed and showed each their copy and erased what was in the tape recorder. Except for one interview that was made the final week of my field study. The reason for doing so, was of respect for the participants and to give them an opportunity to see their narratives in transcribed form, which they appreciated.

During the transcription work, the translations was made by me as it is my second language. Kapborg and Berterö (2002) claim that using an interpreter may lead to a summary of the narratives, which can affect validity of the results. Freed (1988) also believes that there are factors to consider while interpret qualitative interviews, such as the interpreter’s roll and personality.

Before the interviews I had have a personal contact with an HIV infected but had never interviewed someone about experiences of having HIV before. It is not always an advantage to have earlier experiences of the subject matter, because of the fact of interfering by having your own thoughts and feelings, which is a disadvantage according to Kvale (1996) in making qualitative interviews.

Narrative interviews has been according to Kvale (1996) an ideal implement to examine experiences of people. Also, it is preferable not to be influenced by one’s own preconceptions, in order to become more objective (Dahlberg, 1997). Content analysis aims to describe the variability and when there is a mixture of gender and different ages, it is most likely to get the study area illuminated by various experiences. Analysis process involved a condensation to shorten the text and the abstraction brings the contents on a logical level, which shall be verified to the meaning units and the condensed text to be valid. This was made with repetitive reading of the interview material. The text was then interpreted and processed, in order to give comprehensive and meaningful meaning to the results. To strategically select participants is also relevant for the validity of the results (Lundman & Hällgren Graneheim, 2008).

To transcribe was very time consuming and difficult at times, when there were difficulties hearing the tape recorder, which could consist sobs and cryings. Once I had to ask one interviewee if she can meet for second interview to confirm her statements. Lundman and Hällgren Graneheim (2008) emphasize the importance of the selection of participants could affect the reliability of the result and it is also preferable to have variety. The narratives were translated from Thai to English by using Swedish as a “base” whenever the translation got difficult. By doing that, it became more easy and manageable to write down the transcription verbatim. However, Lundman and Hällgren Graneheim (2008) believe that the interpretation should be made with an awareness of the participants’ history, living conditions and their culture.

I believe that this study would have improved if more people would have shared their experiences. It would enhance the understanding on how the HIV or AIDS affected are experiencing their lives. It would also help to strengthen the validity of the study as Lundman and Hällgren Graneheim (2008) described. It was difficult to interview all of the interviews because of the complexity of their illness.

What should be underlined is that each one of the participant are experiencing their own subjective feelings, therefore it should not be generalised to all Thai people. Nor should it be generalised to all HIV or AIDS affected since each experience is unique and each person is unique. When it comes to enjoying life and having plans for the future in spite of the infection in the context of living with a chronic and an incurable illness, can be obtained if they get an understanding from the community (Jenkin et al., 2006).
Discussion of the results

The informants expressed that they were enjoying life and had plans for the future despite of the infection as they felt a sense of wellbeing, had an acceptance of the infection and themselves. It was important to have support from friends and family to cope with life and that support made them feel blessed and grateful. However the informants also expressed a feeling of no self worth and that they had giving up living because of feeling isolated, stigmatized, depressed, ashamed of themselves and being a burden with a sense of guilt that made them repress themselves. These aspects were interlinked but the negative dominated among these with AIDS and the positive aspects were more common among the informants living with HIV.

To understand and comprehend experiences is a difficult task, especially when it concerns an incurable illness. The result is giving an overview of how the participants are experiencing their lives.

It may also seem odd that one can experience “health” or wellbeing and still get the feeling of being “ill” but according to Wiklund (2003), health and suffering are connected. “Health” requires suffering and if the person can endure the suffering, the person can attain “health” (Wiklund, 2003). The feelings they had was that they experienced a sense of wellbeing, which has given them a key to be able to live an enjoyable life. Had it not been for the support and understanding from friends and family, they would probably have struggled and suffered more, with feelings of despair and hopelessness (Kylmä, 2005). To have wellbeing in life can make a difference in someones life quality and it is important to acknowledge that even with feelings of despair, hopelessness and suffering, there can be feelings of wellbeing (Wiklund, 2003).

It is also important to understand HIV/AIDS affected feelings because according to Kylmä (2005), it is with that understanding one can help and prevent negative consequences of negative feelings. In addition, Kylmä (2005) claims that when all hope is lost, hopelessness represents the severe state of despair.

There were also feelings of acceptance among the participants in this study. Acceptance was mainly felt after revealing the anguished secret and they were able to share their fear and suffer with someone. Some of the participants in this study even expressed it as being “relieved” and it eased the agony. To accept and to be accepted as oneself can provide a sense of wellbeing for the HIV or AIDS affected (Pierret, 2007). With these feelings they can also feel appreciated and a part of the community, which is according to Wiklund (2003) a necessity to find meaningfulness and completeness in life.

To have been recently diagnosed with HIV provides numerous questions and thoughts about living with an incurable illness, which will eventually lead to existential thoughts (Pierret, 2007). Some in this study explained it as getting “a death warrant” and life has now come to an end. All of the participants in this study had thoughts about dying and that they will leave friends and family with heavy grief. Some even expressed that they had no fear of dying, instead they feared more for those who are left behind.

Some of the interviewees in this study said they have changed after they received their illness, in terms of becoming “someone else” and according to Wiklund (2003) who refers to Merleau-Ponty, the physical body shows a person’s identity and it is through the body we experience the world and when the body alters, the experience of oneself will change. The interviewees in this study described it as being stigmatized, ashamed
and depressed. These were feelings they rarely had prior to the illness. Furthermore stigmatization (Goffman, 2011) was a common feeling among the participants in this study and as to experiencing “people look down on me” is often what HIV or AIDS affected feel and Li, et al. (2009) claim that the feeling of being a accused by the community of being a spreader of AIDS is quite common.

Regarding depression among HIV/AIDS affected, Jenkin et al. (2006) claim that being depressed is a major issue among the affected and it has led to sleep deprivation. In this study, the participants have felt weary and decrepit at times, but they did not expressed any significant sleeping disorders.

The informants in this study expressed that they had hidden their illness from family and friends at some point in life. To hide the truth about their illness was important for having a normal life as an HIV or AIDS affected (Pierret, 2007). For some of the participants in this study, their family were angry at first and blamed it on the participants for getting infected, leaving them feeling ashamed, depressed and guilty. The fear and the shame determine sometimes whether to keep the illness as a secret or not and Li, et al. (2009) say it is a very stressful and lonely life, to keep such secrets. For a long period of time, it can harm the person, both physically and mentally (Li, et al., 2009).

An AIDS affected in this study that has chosen to hide her illness from her surroundings expressed being lonely and depressed most of the time and that her constant planning of life has left her with tiredness and distress. Even with these feelings, she expressed that she is not ready to reveal herself, due to the anxiety of being abandoned by her loved ones. She cried the whole time while she was telling about her repression of the illness, which is a common reaction when living a life in secret and later share the repressed emotions (Pierret, 2007). It could also have been that she was repressing her illness for such a long period of time; it was resurfacing and becoming more real to her again. Oudshoorn (2005) claims that nurses should be empathetic and supportive and as well value the individuals own control of their lives, by understanding that “health belongs to the individual”. A nurse should have openness to patients and to their beliefs and values (Oudshoorn, 2005). Although she is living a double life, as she calls it, she has no desire of telling about her AIDS. She believed it would bring more harm than relief. Another interviewee also stated that he hid being an HIV positive because he thought that it would reveal him being homosexual. He was feared by what the community would think of him and afraid of being an outsider to the world (Goffman, 2011). Pierret (2007) says that it could be difficult to hide medications and repeated absences at work and to keep HIV a secret, requires constant vigilance.

Dahlberg (1997) expressed that some can feel appreciation to share their experiences and feelings in interviews, which can bring them a good feeling of being a part of something meaningful and was for the participants in this study something they wanted to do, in order to help others with the same unfortunate illness. It has therefore been important for the participants in this study to have friends and family to talk to and lean on. Without feeling confirmed and heard, their sense of dignity will be threatened and they will experience feelings of being ashamed. Li, et al. (2009) claim and it would also be more difficult for them to get an inner acceptance and hope.

Empathy is according to Wiklund (2003) a concept of focusing on providing a sense of support and security. These are good guidelines while performing interviews as well as
in meeting with suffering people, especially during many of the interviews when almost all of the participants cried.

It is important that all people are being understood in terms of how they experience and perceive the world and how they relate to the world, in order to learn more about their life world (Wiklund, 2003). There are different changes of the participants’ lifeworld in terms of various feelings and experiences and lifeworld is something that changes along with the illness for an HIV affected (Pierret, 2007). They are forced to plan their lives according to hospital visits and medications, but also by stigmatization and discrimination by the community (Goffman, 2011).

To be ill and not be accepted or seen as a human being is dreadful and devastating for the affected. To be able to cope and to live a decent life, they are in need of more respect and less prejudices from the community (Goffman, 2011). Therefore it is just as important as necessary that they are able to share their experiences, in order for other people to get a greater and a deeper understanding of their lives, their thoughts, feelings and perceptions (Kallings, 2005). Everyone deserves to be acknowledged and respected as human beings regardless what illness they have.

**Conclusion and clinical implications**

The findings in this study and other studies are essential to highlight to those who wishes to learn about the daily life of an HIV/AIDS affected. Those who may benefit from this study are relatives and friends of those affected, but also those who desires to learn more about experiences of living with HIV/AIDS in Thailand or in general.

It can be very useful for healthcare professionals as well, in their search of lived experiences with HIV/AIDS, in terms of understanding a patient’s thoughts and feelings. An understanding of how ill people perceive their position may facilitate their caring and also alleviate their suffering, which can be seen as optimal care from their both points of view.

To get an experience-perspective is important in the quest for a greater understanding of how people struggle or cope with their illness. Friberg (2006) emphasizes the need of qualitative studies in evidence-based caring, meaning that healthcare professionals can improve in meeting with a person’s experiences, expectations and needs.

**Future research**

Further research on experiences of living with HIV or AIDS is needed because it is so stigmatized, discriminatory and prejudiced in the community. There should also be more research about experiences living with HIV/AIDS in both Thailand and in all of Asia, because of limited research.

The focus could be on experiences over a long period of time or experiences of getting infected by birth. Future research can also focus on children’s experiences of living with an HIV infected parent or a child’s perception of being infected by the mother. Another interesting aspect is the guilt HIV positive may have of infecting others and are forced to live with guilt and shame for the rest of their lives.
Another focus can be on AIDS affected and how they perceive people’s prejudices and discrimination or help from health care. It would also be interesting to investigate the gender perspective by comparing experiences of women and men. To be able to achieve further decrease of the HIV prevalence, the government is doing its best in focusing on prevention, which is already in progress. Rasamimari, Dancy and Smith (2008) suggest interactive prevention methods of HIV prevention, such as interviewing people living with HIV/AIDS to raise an awareness and seriousness of the illness.

The perceptions and experiences of HIV/AIDS are important to be brought up so their voices can be heard and the world can learn about their experiences and enhance the knowledge of their feelings of the community’s perception of their illness. It is therefore important to highlight and describe the experiences of people living with HIV and/or AIDS and there should in the future, be more research done on the subject matter.

**Acknowledgements**

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REFERENCES


## APPENDIX

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<td>Feeling depressed of living a life with agony</td>
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<td>“...It felt like a death warrant, I knew I was going to die within a couple of years...I was so depressed...”</td>
<td>The knowledge of dying within a couple of years was depressing</td>
<td>Feeling depressed thinking of dying</td>
<td>Being depressed</td>
<td>To feel no self worth and give up living</td>
<td></td>
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<td>“I have no wish to tell friends and family about my condition... they would not understand anyway...and would probably abandon me if they knew...”</td>
<td>Hiding the condition from friends and family because of the fear of their abandonment</td>
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<td>“I hate myself for being a liar to the ones I love...I try not to think about my illness...”</td>
<td>Hating oneself for being a liar and is trying not to think about the illness</td>
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