Registered Nurses’ experiences of caring for children with HIV/AIDS in South Africa

Sjuksköterskors upplevelser av att vårda barn med HIV/AIDS i Sydafrika

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Abstract

**Background:** Human immunodeficiency virus (HIV) is a global problem and the total number of people living with HIV is approximately 34 million. Little is known about registered nurses’ experiences of caring for children with HIV/AIDS in South Africa.

**Aim:** The aim of the study was to describe registered nurses’ experiences of caring for children with HIV/AIDS in South Africa.

**Method:** A qualitative research approach was used. Data was collected by interviews which were analyzed using content analysis. The interviews were conducted at a private hospital in Cape Town, South Africa.

**Results:** The following ten topics were found; self-fulfillment, being supportive, being hopeful, being adaptable, being non-judgmental, helplessness, loneliness, sadness, stress and frustration.

**Conclusion:** There is a constant balance between feelings of powerlessness and the ability of being mentally strong when caring for children with HIV/AIDS.

**Keywords:** HIV/AIDS, children, registered nurses’ experiences, South Africa
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1. Introduction

This degree project was conducted in South Africa by two students in Nursing Sciences at the University of Örebro in Sweden. The aim of the degree project was to get an in-depth understanding and knowledge of how Registered Nurses (RNs) in South Africa experience caring for children with HIV/AIDS. The reason why this subject was chosen is because of interest in becoming paediatric nurses as well as working abroad.

2. Background

2.1 The clinical picture and treatment of HIV/AIDS

HIV is a virus that causes progressive failure of the immune system by destroying specific lymphocytes. This eventually leads to opportunistic infections and different types of cancer. AIDS is not a disease itself but a collective term for an HIV-infection that has caused signs of severe immune deficiency, which cannot be explained by any other factor except HIV (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2008). HIV is transmitted through unprotected sexual intercourse, through transfusion of contaminated blood and drug users sharing contaminated needles. Other routes of transmission are between a mother and her infant during pregnancy, childbirth and breastfeeding (UNAIDS, 2012).

A primary HIV-infection gives flu-like symptoms such as fever, swollen glands, rash, muscle pain and headache. The primary infection eventually leads to a chronic disease without symptoms. The average time between the infection with HIV and the development of AIDS is 10-15 years without medication, but it varies from person to person (UNAIDS, 2008).

There is no cure for HIV infection but antiretroviral treatment (ART) can delay illness for many years. ART suppresses HIV activity and preserves the immune system. The treatment is lifelong and side effects such as nausea, vomiting and headaches are common (UNAIDS, 2009).

HIV/AIDS is a global problem and as there are cases of HIV in Sweden due to for instance immigration, it is important for RNs in Sweden to have knowledge about this subject. In the year of 2011 there were 465 cases of HIV reported to the Swedish Institute for Communicable Disease Control.

Millennium Development Goals are eight international goals that represent the world’s commitment to improve peoples’ living condition and health and to reduce global poverty. All United Nation members and many international organizations have agreed to achieve the goals by the year 2015. One of the goals aims to reduce mortality among children under the age of five. Another goal aims to combat HIV/AIDS. Universal access to ART, knowledge on HIV transmission and condom use contribute to reducing the spread of HIV and saving lives (United Nation Development Programme [UNDP], 2010). In the year of 2009 approximately 5.6 million people were living with HIV in South Africa (WHO, 2009).
2.2 Socio-cultural perspectives of HIV/AIDS

*Human immunodeficiency virus* (HIV) occurs mainly in Africa, Asia and Eastern Europe. The total number of people living with HIV is approximately 34 million, whereof 30 million are adults and 4 million are children under the age of 15 (World Health Organization [WHO], 2010). Annually, ten million children die before the age of five due to HIV, pneumonia, malaria and other diseases (United Nation Development Programme [UNDP], 2010). Acquired immunodeficiency syndrome (AIDS) was first described in 1981 and during this decade people were convinced that infectious diseases could be conquered by vaccinations and antibiotics. When modern science could not prevent AIDS, the disease became a threat and panic occurred. Fear and lack of knowledge of the disease led to discrimination and stigmatization (Kallings, 2008; De Cock, Jaffe & Curran, 2011).

Stigma became more strongly expressed against women than against men in South Africa due to their low socio-economic status and their dependency on men for economic support. The lack of control over their sexuality and sexual relations placed them in vulnerable positions for HIV infections and due to the social constructions they were blamed for transmitting the disease (Petros, Airhihenbuwa, Simbayi, Ramlagan & Brown, 2006; Dugassa, 2009). Another factor associated with the spreading of HIV is poverty which has led to prostitution among young women and children. The occurrence of child sexual abuse increased as there was a widespread myth that sex with a virgin, child or daughter would cure HIV/AIDS and other diseases (Lalor, 2008).

The apartheid system in South Africa was introduced in 1948 and terminated in the beginning of 1990. The fundamental idea of apartheid was to keep white people separated from colored. Apartheid still has an impact on South Africa as there are social and economic differences between white and colored South Africans. Colored people are for instance referred to public health care due to economic circumstances while white people can afford private health care of high quality (The Swedish Institute of International Affairs, 2012).

2.3 Theoretical framework

Family-centered care is a concept which includes support and respect for the family's participation in their child's care. The family plays an important role in a child's life as the family represents the child's primary source of support (Cartagena, Noorthoek, Wagner & McGrath, 2012). Caring is a relational concept and involves a willingness to be open to others. Qualities such as compassion, confidence, competence and commitment are important when caring for other people. Caring is based on sharing a mutual respect and seeing patients as unique individuals with special needs, beliefs, desires and wants. Caring involves having a holistic perspective as a patient should be seen as a whole person and not fragmented into objective parts of the body. The caring relationship does not only involve the relationship between nurses and patients, it also involves the relationship nurses have with other nurses (Cronqvist, Theorell, Burns & Lützén, 2004).
2.4 Registered Nurses perceptions of caring for patients living with HIV/AIDS

Little is known about RNs attitudes and experiences of caring for children with HIV/AIDS in South Africa. The number of studies that has been done indicates that RNs in South Africa experience both negative and positive feelings of caring for patients with HIV/AIDS. Some RNs believed that they lack skills to implement HIV care and felt inadequate as they sometimes were unable to answer HIV-related questions (Horwood, Voce, Vermaak, Rollins & Qazi, 2009). RNs also experienced emotional stress and fatigue as well as feelings such as empathy and compassion towards patients and their family members (Smit, 2005; Richter, Chandan & Rochat, 2009).

2.5 Problem related issue

HIV/AIDS is not as common in Sweden as it is in South Africa. We have preconceptions about RNs experiences of caring for children with HIV/AIDS in South Africa, for instance fear of being transmitted during work and feelings of helplessness of not being able to provide good care. As a RN you can work globally and with patients in all different ages. Little is known about RNs views of caring for children with HIV/AIDS in South Africa. The absence of scientific articles of caring for children with HIV/AIDS underlined the great importance for us having the opportunity to conduct this study in South Africa.

3. Aim

The aim of the study was to describe registered nurses’ experiences of caring for children with HIV/AIDS in South Africa.

4. Method

In this study, which has a descriptive design, a qualitative research approach was used. Data was collected by interviews which were analyzed using content analysis (Polit & Beck, 2008).

4.1 Selection

Five months before departure contact was made with seven private hospitals and five public hospitals in Cape Town concerning a request for participation in the study. Inclusion criteria for the informants were; titled as RNs, good English verbal skills and at least one year of experience of caring for children with HIV/AIDS. An information letter (appendix 1) was sent by email and fax to the hospitals in Cape Town. One of the private hospitals responded to the request concerning the study.

The Human Resources Manager at the hospital sent us an email with a telephone number to the Hospital Manager. An appointment with the Hospital Manager was made by phone.
During the appointment at the hospital the aim of the study was presented and verbal approval was given by the Hospital Manager to perform interviews with RNs at the paediatric ward. To obtain informants as knowledgeable and experienced as possible, snowball sampling was used. This means asking early informants to make referrals to additional potential informants (Polit & Beck, 2008). The Hospital Manager introduced us to the Nurse Manager who made referrals to a RN on the paediatric ward. The first RN who was interviewed was asked to make referrals to additional RNs working at the same ward. Three more interviews were performed and two of the RNs made referrals to the Red Cross War Memorial Children’s Hospital. Contact was made with Red Cross Hospital but further prosecution was not possible. An ethical approval from the Western Cape Department of Health Policies and Hospital Research Committee Protocol was required and this process would have taken too long.

4.2 Informants

Selected informants at the private hospital were all women between the ages of thirty and fifty who had worked at the hospital for between eleven months and thirty years. The informants had families of their own. They were colored South Africans with Afrikaans as their native language. They all got their nursing education in South Africa.

4.3 Data collection

This study was conducted during September and October, 2012. A semi-structured interview guide with open-ended questions was prepared in advance (appendix 2). Open-ended questions give the informants freedom to respond in their own words. An important objective with a semi-structured interview is to give the informants an opportunity to provide rich, detailed information (Polit & Beck, 2008). The informants received verbal and written information concerning the aim of the study, the method being used and that it was voluntary to participate. Data was collected by performing interviews with four nurses working on a paediatric ward where the patients were children between the ages of a few weeks and twelve years. Permission was asked for recording the interviews, which was accepted by all the informants.

All the interviews took place in a separate room on a paediatric ward at the hospital where the dialogue could occur in privacy. The interviews lasted between twenty and thirty minutes. Both authors were present at all interviews where one was responsible for asking the questions and the other one was observing and taking notes on body language and facial expressions on the interviewee. To prevent loss of information, a dictaphone was used for recording the interviews which later were transcribed and analyzed using content analysis (Polit & Beck, 2008).

4.4 Data analysis

The analyzing process that was used was inspired by Elo’s and Kyngäs’s (2008) article about the qualitative content analysis process. Analyzing was conducted using an inductive approach. The interviews were listened through several times and transcribed. A few times,
when uncertain of hearing a specific word, a guess was still written down and marked. The words that were guessed came up by discussing the interviews with each other. The purpose of guessing words that were difficult to hear was to maintain the meaning of the interview and to ensure that no conclusions were built on uncertain information. When hearing was not possible at all, a different mark was used.

Transcribed data was read through several times to get a general impression. The analyzing process (appendix 3) began with an open coding which means that quotes that described all aspects of the study’s aim were written down in the margins. The quotes were collected from the margins on to a coding sheet to get an overview. Describing claims were created from the quotes. Describing claims with similar content were grouped together creating subcategories. The last step was the abstraction process which involved grouping subcategories with similar content in to generic categories. From the generic categories that were found, a main category was created (Elo & Kyngäs, 2008).

4.5 Ethical considerations

The purpose of the study was not to control or compare the answers, or to make a moral judgment. The informants were provided with an information letter requesting written consent, which they all signed before the interviews were conducted (appendix 4). The information letter clarified that we were merely two guest students from Sweden with a genuine interest of learning more about this subject in South Africa.

Informants in the study were assured confidentiality which according to Polit & Beck (2008) means that no identity will be revealed and no name will be mentioned. To prepare for the study in South Africa, attendance in a preparation course by the Swedish International Development Cooperation Agency (SIDA) took place. Lectures on Swedish and International development projects, social media, culture and communication were held. The aim of the course was to get a greater knowledge about cultural, historical and gender conditions in foreign countries.
5. Results

Analysis of the interviews led to identification of ten topics representing a balance between feelings of powerlessness and the ability of being mentally strong. An overview of the results is shown in Figure 1.

![Figure 1](image)

**Figure 1** Overview of the results

5.1 Mentally strong

5.1.1 Self-fulfillment

The RNs experienced self-fulfillment as they loved to work with people, especially children. They felt satisfied when a child got well and could go home. The RNs expressed that their job was very challenging but at the same time rewarding as they got lots of appreciation from families. They experienced job satisfaction when they could make a difference, for instance help a child to feel better. The RNs expressed how important it was to respect the central role of the family in a child’s life. The parents also became patients, therefore it was important to take care of them as well. It was very self-fulfilling for the RNs being able to help a whole family.

“I love to work with people, it makes me feel so good inside, you know when you see you can help another human being” (RN talking about her job caring for children infected with HIV)
5.1.2 Being supportive

Another experience among the RNs was the ability of being supportive despite their tough job caring for seriously sick children. They described the importance of being present and supportive towards both the children and the parents. They explained that the parents were in vulnerable positions because of having a child with HIV/AIDS.

Beyond having to be supportive towards parents, the RNs had to have the strength to be supportive towards each other as well. They expressed how important it was to be there for one another in difficult situations and that they always had colleagues to refer to when in need of support.

“She really supports me, anything I just... I just run to her. I think for me she’s the one that’s supporting me the most, my colleague here is really number one for me” (RN talking about support in difficult situations)

5.1.3 Being hopeful

The RNs also underlined the value of never giving up. They expressed how they always kept fighting for each and every child to get well. The RNs described how they always gave their best to make a child feel better and how they never gave up hope. They meant that there is always something to hope for no matter how sick the child is, but what you hope for changes in conjunction with the different stages of AIDS.

“Even though you see there is no progress you never give up, there is always that hope” (RN talking about HIV-infection)

5.1.4 Being adaptable

The RNs experienced that an important characteristic feature was to be adaptable as all children are unique and that you do not nurse them the same way. The RNs expressed that they had to be adaptable relating to the child’s behavior and emotion. The RNs also expressed that they had to adapt themselves depending on the age of the child. They meant that you can still talk to and work with a teenager in a way you cannot with a toddler.

“When it’s babies you have to pacify them, they cry. The bigger children you can still talk to, they can work with you, you can tell them ‘ok drink your medicine now’ where is with the babies you cannot” (RN talking about caring for children in different ages)

5.1.5 Being non-judgmental

The RNs pointed out that being non-judgmental is very important when working with people as everybody has the same value. It was obvious for the RNs to nurse every child the same way without judging anyone. The RNs expressed that they did not tell the children with HIV apart from the children with other diseases.
“We treat everybody the same way, you don’t judge anyone for being HIV-positive. We don’t tell them apart, you nurse them all the same” (RN talking about caring for children infected with HIV)

5.2 Powerlessness

5.2.1 Helplessness

The RNs experienced feelings of helplessness because of the fact that no cure is available. The RNs felt helpless as there was not much that they could do when there was no progress and the child became very ill. The RNs also felt helpless in situations when parents did not allow them to help the children. There were times, for instance when parents did not want their children to get injections, which made the RNs feel paralyzed as they could not fight against the parents will.

“She (the mother) refused we must give the antibiotic, the injection (...) it’s like because you can’t force them but at the end of the day then you know it’s not good for the babies, but what we do is we can report it to the doctor but your hand is like chopped off” (RN talking about parents not allowing them to do their work)

5.2.2 Sadness

The RNs experienced sadness as it was very touching caring for children with HIV/AIDS. They experienced sadness when there was no progress and when the children got worse. The RNs expressed it was very sad to see the children become so ill at the final stage of HIV and to see them die because of AIDS. It was very moving to see a whole family in sorrow. The RNs felt it was unfair that the children died before their parents as that is not the way it should be.

“You just do your work, but it’s very sad because at the end they (the children) become very ill and there’s not much you can do” (RN talking about final stage of AIDS)

5.2.3 Loneliness

The RNs experienced loneliness in difficult situations. They explained that no professional support such as social workers or psychologists was available for them. The RNs thought it would have been good with a support group of counseling at the hospital as they had to deal with difficult situations on their own, which at times could be tough.

“Here we don’t have any support. You are alone” (RN talking about professional support in difficult situations)

5.2.4 Stress

The RNs experienced stress when parents interfered in their work. The RNs felt at times that the parents were watching them like hawks which made them feel uncomfortable. Another stressor was parents’ attitudes towards the RNs as parents sometimes could be rude or have an impolite manner.
“Sometimes parents just sit there and watch your head you know, like ‘are you washing your hands?’ and it’s really difficult to do your work when they watch you like a hawk” (RN talking about parents as a stressor)

5.2.5 Frustration

The RNs experienced frustration of not getting sufficient information from parents as some parents not always told them the truth about their children being HIV-positive. The RNs had to find out the children’s HIV-status from the prescribed medication. Sometimes the parents even administered the medication themselves not to reveal their children’s HIV-status. The RNs felt frustrated when parents withheld such important information. They explained that people are still shy talking about HIV as there is still stigma attached to it.

The RNs expressed that it was horrible to see parents of children not having HIV being judgmental towards parents of children infected with HIV. It was frustrating to see parents wanting their children to be moved to another ward just because they did not want them to play with children infected with HIV.

“You hear parents in the dining area talking to each other and they end up saying ‘you know my child is HIV-positive’ and then the next minute when that parent leave, the other one comes to me and says ‘you know sister, I want to be moved’ (nurse sighing)… You still get those ignorant people, they don’t understand that HIV you don’t just get it by talking and touching and children playing together” (RN talking about judgmental parents)

The RNs were bothered by the fact that at times they got judgmental parents without enough knowledge of HIV/AIDS. The RNs believed it was sad to see that stigma is still attached to HIV.

6. Discussion

6.1 Methodological discussion

Since the focus was to describe RNs experiences of caring for children with HIV in South Africa, the method best chosen for this particular study was of a qualitative approach. A qualitative research aims to describe experiences and to get an in-depth understanding of a phenomenon by collecting narrative descriptions (Polit & Beck, 2008).

6.1.1 Selection

The RNs who were interviewed at the private hospital made referrals to Red Cross War Memorial Children’s Hospital. Through personal contact an email address was gotten to a paediatric neurologist working in the Division of Paediatric Neurology and the Kidzpositive HIV Clinic at the Red Cross Hospital. An email was sent to the paediatric neurologist who forwarded the email to the Nursing Manager for approval. The Nursing Manager responded that in order for the study to be conducted, an ethical approval from the Western Cape Department of Health Policies and the Hospital Research Committee Protocol was required.
Further prosecution was not possible as the information they required could not be fulfilled and the approval process would have taken too long. Having done the interviews at a private hospital instead of a public hospital could have affected the answers. The RNs expressed that there are not as many cases of HIV/AIDS in private hospitals, therefore they made referrals to public hospitals. They also explained that people who can afford health insurances choose to go to private hospitals, and people who cannot afford it are referred to public hospitals. We believe that this may has to do with apartheid still having an impact on South Africa. The RNs at public hospitals have probably got more experiences of caring for children with HIV/AIDS.

A disadvantage of snowball sampling is that participants in the study tend to make referrals to people they know well, which means that the participants are much likely to share the same opinions, traits and characteristics. This can affect the results as different dimensions of the subject of interest are not gained. Despite the disadvantages of snowball sampling, it was the sampling method best chosen for this study as the study was conducted in a foreign country and possibilities of establishing contacts before departure were limited. An advantage of snowball sampling is that it is time efficient as additional participants are found quickly (Polit & Beck, 2008).

6.1.2 Informants

The informants had worked at public hospitals before their current job at the private hospital. This made the RNs compare their work experiences at the two hospitals. The answers may have been affected in a way that generated different dimensions of the subject of interest. The fact that all informants were women who had families of their own could have influenced the answers and thus the results. There were no men working as RNs on the paediatric ward. It would have been of interest interviewing men as well, as other perspectives of the subject of interest may have been gained. Additional dimensions of experiences of caring for children with HIV/AIDS may have been added if the informants had varied in gender, age, race, socioeconomic status and so on (Polit & Beck, 2008).

6.1.3 Data collection

A semi-structured interview was used to give the informants an opportunity to provide rich, detailed information. This type of interview encourages informants to talk freely about the topic of interest and ensures that the researchers will obtain all the information required. Open-ended questions were used as it gives informants freedom to respond in their own words and offers the possibility of giving spontaneous answers. Open-ended questions provide a richer and fuller view of the topic of interest. Follow-up questions were used to get more detailed information. Care was taken not to include questions that required one- or two-word responses, such as “yes” or “no” (Polit & Beck, 2008). All informants who were asked to be interviewed participated in the study. Although the RNs got to decide time and place for the interviews, they may have been a bit stressed as the interviews were conducted during their morning work session. This could have affected the answers and the time length of the interviews as it may have been hard for them to concentrate.
Facial expressions and gestures could affect the answers during the interviews and therefore we tried to maintain a neutral attitude (Patel & Davidson, 2003). There was a language barrier between us and the RNs in South Africa as their first language was Afrikaans and our first language was Swedish. We were aware that misunderstandings could occur as English was neither ours nor their native language. At some occasions the RNs were about to switch over to Afrikaans but they changed back to English as soon as they realized it. Having done the interviews in English instead of Afrikaans may have affected the answers. They would probably have been able to give more detailed answers in their native language.

6.1.4 Data analysis

The analyzing method best chosen was content analysis as it involves analyzing the content of narrative data (Polit & Beck, 2008). The aim of content analysis is to get a broad description of the phenomenon. An inductive approach is recommended if there is not enough former knowledge about the phenomenon and a deductive approach is used if the data is based on previous knowledge and the purpose of the study is theory testing. The approach best chosen for this study was in an inductive way (Elo & Kyngäs, 2008).

During the transcription it was sometimes difficult to hear specific words, but a guess was still written down. The words that were guessed came up by discussing the interviews with each other. The contexts of the interviews were understandable, therefore it was possible to come up with suitable words when hearing was difficult. The purpose of this was to maintain the meaning of the interview and to ensure that no conclusions were built on uncertain information. A practice interview with a stand-in should have been done in advance, so that improvements could have been made concerning the interviewing style and possible follow-up questions as the authors did not have any experiences of interviewing (Polit & Beck, 2008).

Analyzing data using content analysis was a challenge as content analysis is very flexible and there is no right way of doing it. This explains why the analyzing method that was used was inspired by Elo & Kyngäs (2008) article about the qualitative content analysis process and not “followed to the letter”. Unexpected difficulties are likely to arise during the analyzing process, for example realizing that a quote can be related to several categories. The categorization phase can seem difficult and chaotic as several subcategories can be related to each other, for instance frustration and stress. It is difficult to tell if frustration leads to stress or if stress leads to frustration. Feelings of helplessness and loneliness can also generate frustration which makes it difficult to determine what belongs to which category.

Another challenge during the analyzing process is not to include too many different things in a single category. For example the two categories “being supportive” and “being hopeful” were at first one big category before realizing that it was possible to separate them. To resolve unexpected difficulties during the analyzing process it is necessary for the researcher to be prepared to go back to the data to check the trustworthiness of the categories. Credibility of research findings increases by simplifying the data and creating categories in a reliable manner. Credibility refers to confidence in the truth of the data and interpretations of them (Elo & Kyngäs, 2008; Polit & Beck, 2008).
During the analyzing process many interesting points not related to the topic came up. For example the RNs mentioned other aspects of their work such as salaries, nursing education and how the status of nursing as a profession has changed over time. It is therefore important for the researcher to keep the purpose of the study in mind throughout the analyzing process (Elo & Kyngäs, 2008).

Confirmability of research increases by describing the analyzing process in sufficient details and by demonstrating a link between the results and the data (appendix 4). Findings must reflect the participants’ voice and not the perspectives of the researchers. Citations increases the confirmability of the research as it points out from where or from what kinds of original data categories are created. Being two researchers increases the trustworthiness as both interpret the data according to their subjective perspectives and can come up with alternative interpretations. This can seem contradictory as confirmability refers to objectivity, but the challenge is to interpret having a neutral attitude (Elo & Kyngäs, 2008; Polit & Beck, 2008).

The findings of the study are limited by the fact that the interpretations of four relatively similar voices cannot be expectable to be applicable to all RNs working with children with HIV/AIDS in South Africa. There are also limitations by the fact that the study was conducted at a private hospital where cases of HIV are not as common as in public hospitals.

6.2 Result discussion

Feelings of helplessness and work-related stress were two experiences brought up during the interviews. An earlier study conducted in South Africa shows that feelings of helplessness and work-related stress are common among nurses providing care for HIV-positive children. Participants in the study experienced that caring for ill and dying children was extremely stressful and emotionally tough (Richter et al., 2009). In another study about nurses’ perceptions of caring for patients living with HIV/AIDS in South Africa, similar experiences were found. Participants in the study experienced feelings of helplessness because of the fact that no cure is available. They also experienced work-related stress due to heavy workload (Smit, 2005).

The RNs in the present study experienced frustration when parents withheld information about their children being HIV-positive as such information is essential for the RNs. They also felt frustrated when seeing parents wanting to separate their children from children with HIV/AIDS, because of the parents not wanting the children playing together. The reason why the RNs experienced frustration was, which they expressed, caused by judgmental parents. This may have to do with the stigmatization still attached to HIV as it became a threat when it was first described in the early eighties. Fear and lack of knowledge of the disease led to discrimination and stigmatization (Kallings, 2008; De Cock et al., 2011). The fact that some parents still avoid talking about HIV and do not have enough knowledge about the disease makes the RNs feel frustrated as they daily get in touch with these judgmental parents.

The fact that the RNs got frustrated as a result of judgmental parents not wanting to talk about HIV was a bit of a surprising and an unexpected finding. We had preconceptions about RNs having a hard time talking about HIV themselves as it is a sensitive topic. An earlier study
conducted in South Africa shows that some nurses working in health care with children with HIV/AIDS have judgmental attitudes. The nurses associated HIV with particular racial or socioeconomic groups. The nurses in the study expressed reservations and fears about discussing HIV with the mothers, saying it was painful and embarrassing to raise the topic (Horwood et al., 2009). Being non-judgmental, open and able to talk about sensitive topics, such as HIV, may be an important quality for a RN to have. Nursing care is respectful of and unrestricted by inter alia illness, race and social status (The International Council of Nurses [ICN], 2006).

The RNs in the present study experienced loneliness in difficult situations as no professional support was available for them. They expressed that they had to deal with emotionally tough situations on their own and as nursing is a challenging job it is important to be able to get support when it is needed. According to the ICN Code of Ethics for Nurses (2006) it is important for a nurse to care for his/her personal health to be able to provide good care.

Although caring for children with HIV/AIDS are both physically and emotionally challenging, the RNs in our study experienced a sense of self-fulfillment. This was also one of the findings in Smit’s study (2005). The participants felt that it was fulfilling to give nursing care of the highest standard in a non-judgmental manner and to make a patient comfortable.

The RNs in the present study expressed that being non-judgmental is very important when working with children as they all have the same value. The RNs expressed how they always kept fighting for the children to get well and that they never gave up hope. This approach can be related to the Convention on the Rights of the Child where the four core principals are; non-discrimination, devotion to the best interests of the child, the right to life, survival and development and respect for the views of the child (The United Nations Children’s Fund [UNICEF], 1989).

The RNs also experienced that being adaptable and supportive was important when caring for children with HIV/AIDS. They expressed that it was important to be adaptable regarding the child’s age, behavior and emotion. This can be related to the concept of caring where sharing a mutual respect and seeing patients as unique individuals with special needs, beliefs, desires and wants is important (Cronqvist et al., 2004). When working with children with HIV/AIDS it is important for a RN to have in mind that the family plays an important role in the child’s life as the family represents the child’s primary source of support. The RNs expressed that they had to be supportive towards the parents and to let them participate in the children’s care (Cartagena et al., 2012). When the RNs talked about being supportive towards the parents, they hardly ever mentioned the fathers. The RNs expressed that the mothers were the ones taking care of the child and therefore needed more support than the fathers. This may have to do with South African families having more traditional perceptions of gender roles in the family. To be able to give support to parents, patients and colleagues it is necessary to have built a caring relationship, which is an important part of the concept of caring as well (Cronqvist et al., 2004). In an earlier study about nurses’ perceptions of good clinical care for HIV-positive patients in Zimbabwe, the nurses underlined the great importance of taking an
interest in their patients’ lives as HIV/AIDS is more than a medical condition (Campbell, Scott, Madanhire, Nyamukapa & Gregson, 2011).

The findings of the study cannot be transferred to or have applicability in other settings or groups as it reflects personal experiences. The purpose of a qualitative study is not to be able to generalize the data, it is to get a greater understanding of the subject of interest. It may be possible to get similar findings if the study was repeated in a similar context with similar participants, but as earlier mentioned the results reflects individual experiences (Polit & Beck, 2008).

7. Conclusion and clinical implication

The significance of the findings is that a balance between feelings of powerlessness and the ability of being mentally strong is required when caring for children with HIV/AIDS.

One of the international millennium development goals aims to combat HIV/AIDS. It is important to have knowledge about the disease as it is a global problem and a continuously developing subject. There are cases of HIV/AIDS in Sweden, therefore it is important for RNs in Sweden to have knowledge about this subject. Little is known about RNs’ experiences of caring for children with HIV/AIDS in South Africa.

8. Future research

For future research it would be interesting to conduct a similar study but in a larger context at a public hospital in South Africa. It would also be of interest to focus more on the gender perspective by interviewing both men and women working in health care as RNs. Participants in the present study experienced that they did not get any professional support at the hospital in difficult situations, therefore it would be interesting to conduct a study that focuses on what kind of support RNs need and how to establish for example support groups at hospitals that do not provide it.
References


World Health Organization. (2009). *Number of people (all ages) living with HIV.* Downloaded 27 October 2012, from WHO. [http://apps.who.int/ghodata/?vid=22100](http://apps.who.int/ghodata/?vid=22100)
Appendix 1

Information letter of intention and request for participation in an interview, entitled: “Registered Nurses’ experiences of caring for children with HIV in South Africa.”

Dear participants,

We are two students in Nursing Sciences at the University of Örebro in Sweden, now doing our exam project. The aim of our exam project is to get an in-depth understanding of how Registered Nurses in South Africa experience caring for children with HIV. We both want to become paediatric nurses as well as working abroad, and therefore we are interested in this subject for our project. We are merely two guest students from Sweden with a genuine interest in learning about this subject in South Africa. Our purpose of this exam project is not to control or compare the answers, or to make a moral judgement.

We intend to go to South Africa in September 2012. We will be performing interviews with 4-5 Registered Nurses working at a hospital in Cape Town. Each interview is expected to take about 20-30 minutes and will be recorded in a time and place you decide. Collected data will be used for this study alone and all participants identities will be kept confidential in the results. We will analyze the interviews using content analysis. Data will be reported as an essay. Your participation in this study is voluntary and you have the right to withdraw at any time without giving any reason.

Best regards,

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Appendix 2

Questionnaire

Background questions

Could you tell me the reasons for choosing to work in healthcare as a Registered Nurse?

For how long have you been working as a RN?

For how long have you been working at this hospital?

Further questions

Can you tell me your thoughts and feelings about working with children with HIV?

Do you experience any difference in meeting children in different ages?

Can you describe a meeting that gave a sense of satisfaction?

In what way? Anything specific?

Can you describe the opposite?

In what way? Anything specific?

Any difficulties in experience working with children with HIV?

What kind of support is available for you in difficult situations?

Is there anything more you would like to tell us that we haven’t thought of?
**Appendix 3 Analyzing process**

<table>
<thead>
<tr>
<th>Quotes</th>
<th>Descriptive claims</th>
<th>Subcategories</th>
<th>Generic categories</th>
<th>Main categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>“When a child gets well and goes home, that’s when you feel satisfied. You’ve done your work”</td>
<td>Job satisfaction</td>
<td>Self- fulfillment</td>
<td>Mentally strong</td>
<td></td>
</tr>
<tr>
<td>“Just the fact that parents are thankful for everything that we do, makes you feel so appreciated”</td>
<td>Appreciation from parents</td>
<td>Self-fulfillment</td>
<td>Mentally strong</td>
<td></td>
</tr>
<tr>
<td>“Parents is also patients, so you’ve got to nurse the parents as well”</td>
<td>Being supportive towards parents</td>
<td>Being supportive</td>
<td>Mentally strong</td>
<td>Balance between feelings of powerlessness and being mentally strong</td>
</tr>
<tr>
<td>“You can say we’re there for one another”</td>
<td>Being supportive towards colleagues</td>
<td>Being supportive</td>
<td>Mentally strong</td>
<td></td>
</tr>
<tr>
<td>“Even though you see there is no progress you never give up, there is always that hope”</td>
<td>Never giving up</td>
<td>Being hopeful</td>
<td>Mentally strong</td>
<td></td>
</tr>
<tr>
<td>“You get these children that are rebellious and you get the ones that are just so sweet and you get the naughty children but it’s nice because you treat each and every child like differently. They are unique, each and everyone. You don’t nurse them the same”</td>
<td>Being adaptable relating to behavior</td>
<td>Being adaptable</td>
<td>Mentally strong</td>
<td></td>
</tr>
</tbody>
</table>
“Being a teenager they are in a difficult stage of their lives, and uh... for those ones you handle with care but you need to be firm with them as well. With your younger child you are more... not that you are less supportive to the teenager, but you are more supportive to the little ones”

<table>
<thead>
<tr>
<th>Being adaptable relating to age</th>
<th>Being adaptable</th>
<th>Mentally strong</th>
</tr>
</thead>
</table>

“We treat everybody the same way, you don’t judge anyone for being HIV-positive. We don’t tell them apart. You nurse them all the same”

<table>
<thead>
<tr>
<th>Treating everybody the same way</th>
<th>Being non-judgmental</th>
<th>Mentally strong</th>
</tr>
</thead>
</table>

“At the end they become very ill and there’s not much you can do, you know, there is no cure”

<table>
<thead>
<tr>
<th>Feeling helpless as no cure is available</th>
<th>Helplessness</th>
<th>Powerlessness</th>
</tr>
</thead>
</table>

“She (the mother) refused we must give the antibiotic, the injection (... it’s like because you can’t force them but at the end of the day then you know it’s not good for the babies, but what we do is we can report it to the doctor but your hand is like chopped off”

<table>
<thead>
<tr>
<th>Feeling helpless when parents decline treatment for their babies</th>
<th>Helplessness</th>
<th>Powerlessness</th>
</tr>
</thead>
</table>

“You know obviously it’s very sad, it’s very moving, very touching, and... yes and you just do your work, but it’s very sad to see them just dying”

<table>
<thead>
<tr>
<th>Feeling sad seeing children seriously ill</th>
<th>Sadness</th>
<th>Powerlessness</th>
</tr>
</thead>
</table>

Balance between powerlessness and being mentally strong
| “Here we don’t have any support. You are alone” | No professional support in difficult situations | Loneliness | Powerlessness |
| “None, none here. We don’t have trauma counseling, we don’t have social workers. We can’t just pick up a phone and say ‘we need a psychologist here’ We cannot” | No professional support in difficult situations | Loneliness | Powerlessness |
| "Sometimes parents just sit there and watch your head you know, like ‘are you washing your hands?’ and it’s really difficult to do your work when they watch you like a hawk” | Parents as a stressor | Stress | Powerlessness |
| “People (parents) don’t always tell you, they don’t tell you the truth. People are still shy, they wanna just like sweep it (having a child being HIV-positive) under a rug. You will just find out from the medication that they’re on” | Frustrated of not getting sufficient information | Frustration | Powerlessness |
| “You still get those ignorant people, they don’t understand that HIV you don’t just get it by talking and touching and children playing together” | Frustrated because of parents not having enough knowledge | Frustration | Powerlessness |
Written, informed consent for participation in the study.

I have been informed of the purpose, how data is collected and confidential, processed and handled. I am also aware that my participation in the study is voluntary and anonymous and that I may drop out at any time without giving any reason. I agree to participate in the study.

Date_____________________________________

Signature of participant__________________________________________

Researcher’s signature___________________________________________

Printed name____________________________________________________

Supervisor’s signature___________________________________________

Printed name____________________________________________________