Providing Home Care by Caregivers of School Age Children Who Are Infected with HIV/AIDS

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Abstract

The aims of this research are to study the situation of taking care of school age children who were infected with HIV or AIDS (HIV/AIDS) at home by a caregiver and then to study the factors involved in the care of a HIV/AIDS child. Data was collected from 10 caregivers of school age children who were infected with HIV/AIDS and was collected by using in-depth interviews, focusing on group discussions and through participant observations. After that, the data was analyzed by qualitative content analysis.

The results gathered are from insight into daily routine care, prevention of infection and HIV transmission, follow-up care of patients with unusual symptoms, making an appointment for an examination with a doctor, psychosocial care and seeking the network's home care. There are conditional factors related to care such as: the children and their caregiver's health, the potential for care both of the caregiver and children, the economic status of the family, the relationships within the family, home care service and the health care staff.

The study results demonstrate the need and give suggestions for the development of models of home care focusing on participation of home caregivers and developing health care personnel's potential to best meet the needs of all the people involved in the specific context of HIV/AIDS child home care.

Key words: *Home Care, School age children with HIV/AIDS, HIV/AIDS, Caregiver, Caregiver for School age HIV/AIDS child*

Introduction

HIV/AIDS infection is a growing epidemic and a major problem spread worldwide, furthermore it is found to have about a 40% increasing impact on school age children and teenagers (adolescents) (UNAIDS, 2007). The Province of Kaen Khaen has the largest number of HIV/AIDS patients in the the North-East of Thailand (the 6th Disease Prevention Control, Khon Kaen, 2008), of which Chum Phae District has the 2nd largest number of HIV/AIDS patients reported in Khon Kaen province. 34 children were infected with HIV, of which 24 have been hospitalized in Chum Phae hospital to obtain treatment. The ages of children who were admitted to the hospital are divided into the age group 0-5 years old, 6-13 years and 14-15 years, with the respective percentages being 8.3, 79.2 and 12.5. Looking at children's intelligence it is found that delayed mental ability is found in 5.2 percent of all children, and all of whom had inherited the HIV disease from their mothers.

When children are infected by HIV they are more negatively impacted and affected in their experience of quality of life as a child than through any other chronic disease (Howland et al, 2000). This sickness affects the body of the child [i.e.

morbidity and mortality (Chisanu Panchareun and Ausa Tisayakorn ; 2545, Rach Karnchanawanich et.al ; 2004)] and causes slow growth and delayed development (Pornpan Wanarith and Auchara Fongkuam; 2005, Auranee Sanmanee et.al ; 2005). It also has affects on psychosocial and spiritual wellbeing due to stress, anxiety, abandonment children and lack of care (Dutsadee Chareunsuk et.al; 2003, Theera Ramasut ; 2004), being socially undesirable, having lack of shelter, having lost the anchoring of soul, having mental depression and fear of death (Pan Wanarit and Auchara Fongkum; 2005, AIDSNet Foundation (Northern - East Office), AIDS Access Foundation and MSF-Belgium ; 2002, Usa Doungsa et.al ; 2001), low family income and family status being very poor (Floyd et al.; 2007, Jia et al; 2007). There are also limitations of the system related to health services, maintenance, care throughout of the fiscal year, limits of pharmaceutical care budget, lacking medical standards and quality of care (Department of Disease Control, Ministry of public Health, 2007).

Children who were infected with HIV/AIDS need full continuum and coverage of care. They need complete and continuous coverage when they return back home (Jeamjit Sangsuwan et.al, 2008) and need to maintain more holistic care at home (Pornpan Wanarit and Auchara Fongkum, 2005). However it is seen that the affected families still are faced with lack of resources, support, knowledge and skills to care. The researcher did a pilot study in Chum Phae district by in-depth interviewing and observing the 3 people who are caregivers of school children infected with HIV/AIDS at home. The caregiver had reflected that care must also include the caregiver being able to monitor and control actions and to do an activity for children. However, caregivers still have to deal with taking care of other duties, and when children get sick often they have other obligations, so they lack enough time to care for the sick children. Therefore, usually they have no option but to take the child to the hospital. This shows that the caregiver still lacks knowledge and skills to care for their child. Caregivers would like to see their children being more independent and able to take care of themselves and would like to have health personnel do visits at their home. Nurses, on their part, had reflected that home care is still not holistic yet. Nurses still are lacking the knowledge and professional skills in caring.

From the statistics data available from the hospital in 2008, it is seen that one child missed an appointment with a doctor five times; three children were treated at the outpatient and emergency departments frequently. Three of these children came with a chronic cough, runny nose, sore throat, fever, headache, rash on the body, fungus in the mouth and diarrhea, and a 10-year old child came with symptoms of chronic respiratory consecutive nine times. The discipline of drug resistance ≤ 95 percent found in one child. Found a condition of an antiretroviral drug resistance in one child and last two children who did not attend school because of the social stigma.

"Right now, I have no time to take care. I have to go to work to make money. I let my children take the medicine by themselves, and my kids said they did. But I am not sure exactly if they did take the medicine on time or not. If the children were lying because they went out to play, I do not know. In the hospital, doctors have told me to take medicine on time to take care but I forget when I should give it. So, I would love to get a home visit and someone who can teach me at my home" (IDI_C6, 35 years)

The quote above gives a picture of the problem of care at home. This instance here in the context of the Chum Phae district shows a need to review and research care given by adults in Thailand as the quote is a common problem according to this study targeting care by adults (Wanlaya

Thampanichawat, 2008). There are only two issues that have been studied in the care of school age children infected with HIV/AIDS, but it's a quantitative study. In these studies it was found that the caregiver role in caring for children infected with HIV was not able to adequately care for the child when they had a cold, pneumonia, diarrhea and ulcers in the mouth (Suthisa Lamchang and Pongnapa Aukarachinorate, 1998). Studies have been conducted to include factors like family relationship (Napawan Wiriyakul et.al, 2005), ability to care (Nicholson et al, 2005), income status, health belief, age and frequency of symptoms of HIV infection, the development of the child (Suthisa Lamchang and Pongnapa Aukarachinorate, 1998), cultural community bound by helping each other, the role of faith, the socio-economic conditions and availability of transportation (Rasamee Sridapeng, 2002).

The other study did not show the details of the whole picture of caring, how it is, and the study was done in varying contexts. Although, the qualitative study found one issue, its study only concerned children aged 0-5 years that were infected with HIV (Klunklin P, Suchaxaya P & Chanprasit C., 2004). So, up to now there has been no study found focusing on the age group of school age children. Therefore, the researchers were interested to study the caring of school age children at home who are infected with HIV/AIDS through qualitative research. These studies need to focus on quality to get in-depth knowledge, figure out a way to understand the phenomenon, the opinion, the action that led to the development of the care at home as well as to meet the conditions of the problem and the need for a truly contextual view.

Objective

1. This research needs to study the situation of the care of school age children infected with HIV/AIDS at home by the caregiver.
2. This research needs to study the factors that are involved in the care of school age children infected with HIV/AIDS at home by the caregiver.

Methodology

Type of research

This research is qualitative research.

Population and samples

The data was collected from caregivers of ten purposefully selected school age children infected with HIV/AIDS, for which care for the kid at home. Samples were collected through discussion and advice from nurses, obtained from volunteers club of Chum Phae who were infected with HIV and were treated in the hospital and participants who were welcomed into the research.

Research tools in this study

The tools used in this study were;

1) The researcher who has been trained in research and practiced in qualitative data collection

2) The questionnaires were selected for in-depth interviews and group discussions. For the first interview there were the open-ended questions that gave a broad overview of the illness of the child, then the researcher delved into in-depth interview questions, with showing in the box of the quoted word[i.e. "How do you feel about taking care of the child at home?", "How about a daily life at home?", How are you?", "How is the child's condition after being infected with HIV/AIDS?", "What is the change of the children or its impact on children after being infected with HIV/AIDS?", "What are the problems, then, how do you or your family deal with the changes or the impact of this illness?", "How do you or the families manage with those problem?", "What problems do you have which you cannot resolve, then, what do you do?", "What are the problems that children had been seeking help for themselves?", "What is the whole picture of the

problem to take care of a child at home, "What are the obstacles that are associated with child care at home?"].

Data collection

Qualitative data was collected using a variety of methods to get the coverage and depth of information. Then, using in-depth interviews with 10 caregivers, and when there was need for follow-up data, the same group was interviewed again. For the group interview, 10 participants at a time were interviewed using focus groups and participant observation techniques. This was done to help understand the overall phenomenon and can help to explain the context in which ideas and actions were presented in these studies.

Data analysis

The method has two phases: preliminary analysis of the data from data collected in the field and analysis in an intensive range of reports from the field. The study used a comparative analysis (Strauss & Corbin, 1998) and analysis of the story (narrative analysis) to analyze the sequence of events of the time (สุภางค์ จันทวานิช, 2543). The data was analyzed along with data collection by transcripts of tape recordings from the in-depth interviews and group discussion word-by-word. The field notes were recorded from observations by using the coding information (coding) and the data were analyzed by content (content analysis) rigidity (rigor) and reliability (credibility). Additionally, the validation process of this research was analyzed with the triangle (triangulation). In both of the data sets, the focus was the same for each interview from each data provider and informant interviews alone but was many times in the same issues. However, in the part of the data collected, the research had been collected in several ways, such as those observed for group discussion and interpretation of data acquired by consultation with expert advisors and qualitative research. This study was approved on checking ethics in human research by Khon Khen University.

Example of the data analysis

Event	*code*	*Recorded of the questionnaire*
1. *"I just take a look at the basics"*	general care	what general care is, what are the details in this general care? On routine or not, what's daily life doing, Routine or not? Do what?
2. *"Go to see the doctor"*	to treat them	When we go to see a doctor, if we do this action for treatment or not?
3. *"When do you go to see a doctor for treatment?"*	Where are you going to see a doctor?	Why do you see the doctor there? How did the doctor do treatment?

Results

1) General information of the caregiver

All of the 10 caregivers can be divided into categories or 3 groups: 1) Caregivers were mostly elderly people, aged 58-66 years, which among this group were six people with underlying diseases such as diabetes, asthma and gout. 2) Three were 32-40 years-old where the mother was infected with HIV 3) the last person was an aunt. The majority of the caregivers careers were farmers, and the type of family was the extended family. Among the caregivers were 8 people who had no experience in caring for people infected with HIV before. 10 children were under their care, with 4 of them currently attending primary school and another 4 currently attending the junior high school. The last 2 children had not gone to school. There were various histories of illnesses of the children who were participating in this study: one of them had been sick with tuberculosis, five sick with pneumonia, five children with a rash PPE (Pruritic Papulo Erythematous), one child who had bronchitis, two children who had been ill with diarrhea, two children who had fungi in the mouth, and one child who had Thalassemia. The overall percentage of CD level of white blood cells was 19-36% (500-1,235 cells / microlitre). Family details: 4 children were the only son of the family, 4 children had the same mother but had brothers and sisters not infected with HIV, one sibling who had a brother or sister with HIV-1 infection , and one child who had a brother or sister who already died of HIV.

2) Home-care of school age children infected with HIV/AIDS consists of the following:

2.1 Routine care

The daily routine life care which was observed in this research included cleanliness, eating in accordance with the family, care for study, providing to play happily, HIV care and treatment time under supervision and giving the medication on time, letting the child help the family in house chores, ensuring that the child has adequate sleep and rest time, and promotion of physical activities and exercise. However, the results show that among children 10-11 years, they are unable to care for themselves. They are still in need of getting direction, assistance and advice from the caregiver. But, for the children from 11-14-year, they were able to care and participate in compliance with the caregiver. Caregivers and the children in care are able to eat together in accordance with the food from a local northeast setting but avoiding bad foods that are not useful to their health. These children go to school by focusing on being happy more than proficiency and on being healthy. Furthermore, they were allowed to play after school and on weekends. For HIV care and treatment, the caregiver care was as follows: 1) Supervising the medication, observing HIV care and treatment time under supervision and taking the medication on time. 2) Preparing the medicine tablets to be available to on time. 3) Teaching and admonishing to take medicine on time. 4) Including them to take responsibility and providing ways of helping in house work in their family [i.e. helping prepare rice in the rice cooker, washing the dishes, sweeping the house, cleaning the home, doing gardening and farming, cattle raising, hiring them to do a few things so they can earn money such as harvesting nuts in the field, doing massage services and hair grooming. 5) Ensuring them to get adequate sleep, when those children get sick, making sure they rest from school and are able to relax at home. Watching television together and talking together before going to sleep, promotion of exercise by running and playing sports with friends at school or letting them play in the village after school and during weekend, providing information that recognizes that these children are infected or not infected with HIV but in a way that their friends are still at ease and do not refuse to play with each other.

Example of the box of the quoted word:

"They are not quite clean, are disobedient, and in the evening I have to tell them to keep clean by taking a bath, they cannot stay clean. I, his grandmother, have to keep reminding him, have to keep warning him continuously to cut his nails, rub soap, to do as I have shown him with his clothes and hair. Grandma has to help wash his hair, the elder sister has to wash the clothes because her brother's hands can get allergy very easily"(IDI_C9, 60 years).

"The school is located 10 km from home, ever since my nephew has gone to school, he has been happy. He likes the activities at the school. Grandmother hired a car to send him for 260 baht per month "(IDI_C2, 64 years).

"The doctor told me to tell my nephew to take medicine and not forget to take the medicine. He was taught to eat. I told him his mom was killed because of this illness. I saw him take it on time, but sometimes I did not see him eat. Sometimes he lied that he took the medicine, but I was not sure he did. When I asked he did not want to answer. Finally I counted the medicine and then knew. He did not take the medicine. He did not intend to take the medicine as I instructed him " (IDI_C8, 58 years).

2.2 Prevent infection and HIV transmission

2.2.1 Caregivers had taught and told the children how to prevent the infection, did not allow animals to sleep in the same bed or room and did not allow the use of private things together with other people. They had been taught to clean themselves during menstrual periods and dispose sanitary napkins into the bin and to be careful to not have sex with male friends.

Showing the example of quoted word

"Teach the kids about the relationship between woman and men; teach them to agree to get to know love till they are older and able to marry. When they are in love they cannot have sex with the man. Tell them this is prohibited. Teach the kid to ask the man, if he wants a woman to have sex with even if the girl is infected with HIV, ask the man if he wants to risk getting infected like you are. Does he still want to have sex with you? Then he knows if he does not mind" (IDI C: 9, 60 years)

2.3 Caring under abnormal conditions

Caregivers care for patients in accordance with symptoms and signs of abnormal conditions, through observation and monitoring with the help of former experiences. They manage unusual symptoms by trying to: lower fever with a wet towel or with warm water, drink plenty of water, keep the body warm, take fever lowering medicines and then bring them to the hospital. They take care of the symptoms of the illness [e.g cough and sore throat] by eating a soft diet, taking antibiotics to cure infection and eating bitter eggplant. When dealing with a runny nose, you can pat on the back to loosen and reduce nasal mucus or snot, and by taking medication to help reduce symptoms. When the children had diarrhea, the took care by drinking mineral water (ORS), drinking plenty of water, boiling water, eating boiled rice and taking medication to cure diarrhea then letting them sleep and rest. However, if the kid does not improve, then they take them to the hospital. For management of symptoms of skin rash and eczema, they treat them by taking a bath, taking medicine to reduce the rash and itch, cleaning the rash, applying calamine lotion to reduce the inflammation and taking the kid to the hospital.

"When a child has a high fever, I will take them to a doctor as soon as possible. The high temperature will decrease by wiping with a towel the whole night to get the fever down, then give

the child plenty of water to drink. For the medical care, take only 1 pill of paracetamol. Caring of the fever other than this you can not get extra care except with medicine from the hospital "(IDI_C3, 63 years).

2.4 Getting follow-up treatment and keeping appointments with the doctor

The HIV infected child usually is brought to the hospital when they are severely sick with diagnosis and treatment and follow up the appointments at the hospital, but when their symptoms were mild or they had small illnesses they were brought to be examined at the clinic because it was easily reached and conveniently close to home and easier to get quick services. However, some cases were brought for diagnosis and treatment to the nearest government health care clinic, and 1 child was even taught and trained to go by himself because he was old enough.

"I told him to go to get treatment. I am not ashamed. If he was ill I brought him to the nearest government health care clinic, because it is near home and easy to get services quickly. If the symptoms are severe I take them to a hospital, never let it be. I always followed up on the inspection by appointment with the doctor. I need him to be healthy and get well. He can live a long life until he is old "(IDI_C1, 62 years).

2.5 Psychosocial care

The caregivers had reflected about the psychosocial care in respect to 3 aspects [i.e. They do not tell about the medical data to the infected children, they pay close attention to the child and win their hearts and they observe their religious beliefs and care towards good fortune].

"At first, I did not tell him. I was afraid to tell my grandchildren, I thought he would be at ill ease. I only told him that he was allergic, took him for treatment almost a year. Then I told him that he was infected with HIV "(IDI_C6, 35 years).

"I have faith in the Buddha. I help support his mind and help him get merit. I led the child to merit on the Buddhist Sabbath, on his/her birthday, join the community on the Buddhist festival, the child has attended the festival. Then the school too lets him join the activities they do. At school he participated. i.e. New Year's Day; was able to dress up for dancing. The kid is very happy that he able to show his talent. I had taken him to dress up, to participate "(IDI_C4, 32 years).

2.6 Searching for cooperation and networking to care at home, the following was found:

The local government gives help for living expenses with an allowance of 500 baht per month, scholarship for education and setting up means for employment for the child's caregiver. Chum Phae created a network of volunteers where you can receive care and professional assistance, where you can join a group of friends helping friends; they are there to encourage each other. And they can gain more knowledge and more insight into treatments of the illnesses, volunteers also come to do home visits by the HIV infected. Networks of care that had been established and maintained by relatives and neighbors are the relatives and neighbors available to help with looking for medicine and providing useful herbs to each member, passing on information and instructions on how to take care of it, providing and taking care by purchasing and passing out snacks and milk donating clothing and encouragement. There are networks of care that had been established and maintained by the monks. Monks have been helping and caring for a child because that child was socially undesirable. The child has not been able to study in school, so the monk helped him through ordination and then taught him to become a professional mechanic.

3) Factors related to the care of school children infected with HIV/AIDS at home.

This study found the factors that are associated with such care are the health of the children and their caregivers, potential of care of children and their caregivers, the economy of the family, family relationship, availability of home health services personnel visits and details of care and other associated factors, as shown in Figure 1.

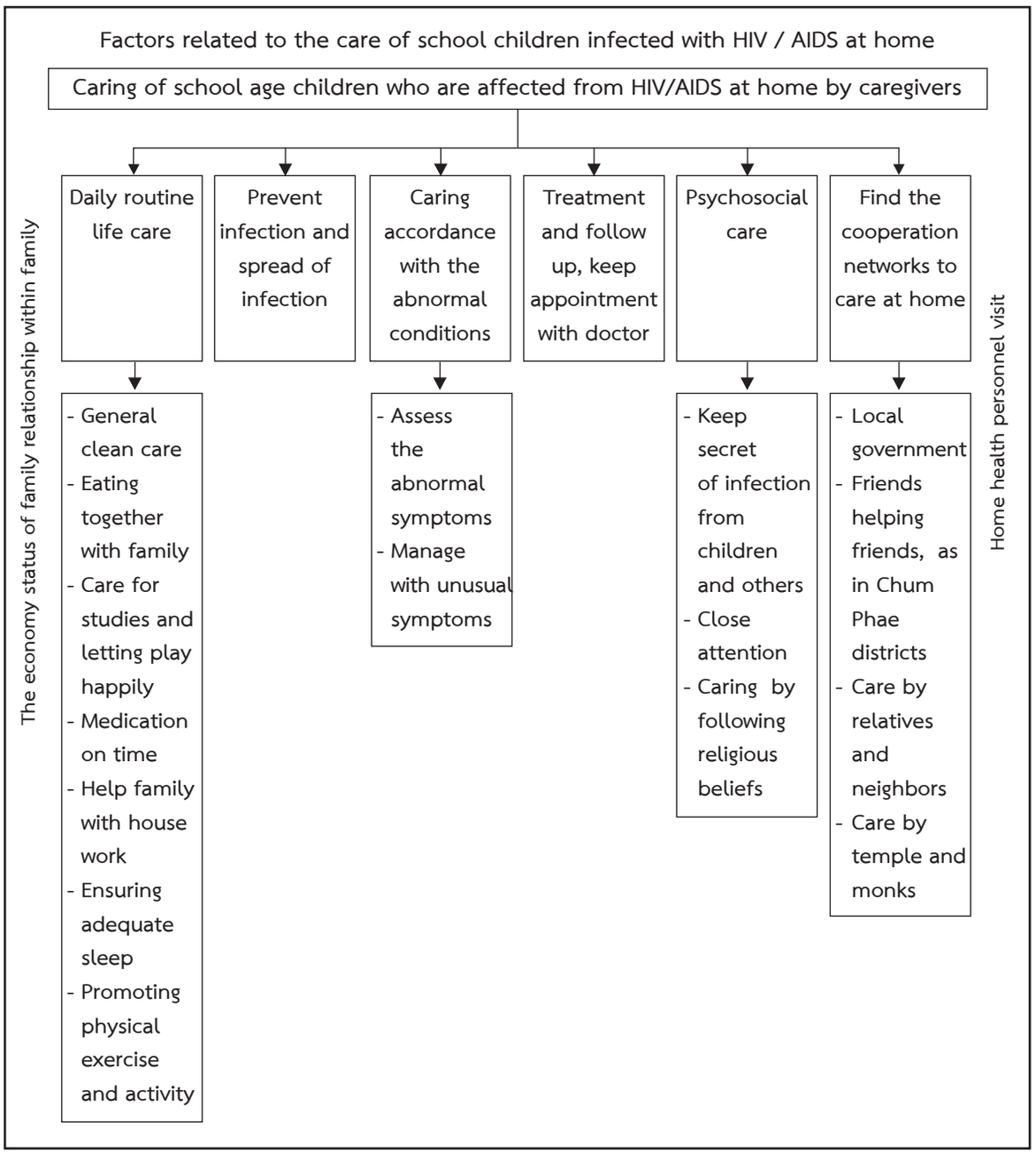

Figure 1 showing diagram of the care of school children infected with HIV/AIDS at home by caregiver and shows related factors.

Discussion

1) In this study the findings of the care of school age children at home infected with HIV/AIDS consist of the following six categories: 1. Routine care 2. Prevent infection and spread 3. Care according to the illness symptoms 4. Follow-up and making appointments with a doctor when there is something wrong 5. Psychosocial care 6. Looking for available network for care at home. These results are similar and in accordance with the other study (Klunklin, Suchaxaya & Chanprasit Klunklin P, Suchaxaya P & Chanprasit C., 2004) of children aged 0-5 who were infected with HIV by the caregivers. The different points were: toilet training, taking care following the developmental level, health care and safety. Because the age and development of the child is different, in school age children there was physical development and intellectual maturity. Likewise, this study found that children aged 10-11 years old can take care of themselves; furthermore, they are able to take care of themselves together along with the caregiver. It also found some aspects of care that are different in the area of psychosocial care, and the pursuit of home care. This is because school children have the cognitive development to understand the more abstract, their opinion and idea as being reasonable (rationality, understanding). Their understanding of the impact of the infection has a negative effect on the mind. So, caregivers have a clear defined role of psychosocial care for school age children. Through the quest for a suitable network, the administrator had found this in the context of education for administrative support and resources in the area and can help with corresponding with the study of รัศมี สีดาเพ็ง (2545) that had been studied in the context of the northern part of Thailand (i.e. getting help from the public and private organizations in the area of the economics, funding, living allowances and education of children). This is because the north region is an area where the children infected with HIV were pilot studies that the researcher has been able to visit , study and then practice the concept and idea to convey concrete treatment and practice. Caregivers had been caring by following the way of life, in the context of cultural practice and treatment. This care is in accordance with the duty of care and social responsibility and social ties of being a mother with a close relative who is caring and supportive. That care is based on culture. This is consistent with the studies of Bumpenjit Sangchart (1999), Jintana Tungvorapongchai (2008) and Leininger (1991) that say caring is a feature that is inherent in the human. It is based on the perception of administrative contexts; it has maintained a close relationship with each other. This behavior is caused by a binding relationship to the blood relatives as a matter of morality and emotions. And it is the relationship between the individual human plus the treatment (Morse JM. Et al, 1990). The results of Wanlaya Thampanichawat (2008) found that taking care with love and hope by the caregiver is an important condition to care for children infected with HIV. The family involvement can do such things as providing teaching skills (which the warnings cannot do, the emphasis being to encourage the child), training the child, and if the child cannot do it, then the caregiver will be an assistant to complete the task (Morse JM. Et al; 1990, Watson J.; 1988). The caregiver can give care regarding the following: the perception of disease, the care and supervision, assessing potential and experience, to be guided by the assistants and understanding and believing. Even though AIDS is a disease that has strong social stigma, in this study there was no problem encountered with social stigma or scorn towards the child from the caregiver. This is because of the influence of the experience of caregivers who have cared for HIV before. They have the knowledge and awareness about AIDS and the education of the children who are affected by AIDS as well over a longer period. However, in the area of holistic care, in this study,

there were no spiritual dimensions of care in the most prominent cases but most were of the mental, emotional and social aspects. This may be explained by the impact on children and families who are most affected by psychosocial care to see the obvious. Or maybe the study was not deep enough to see a clearer picture of the spiritual care yet.

2) The researchers found factors involved in their care including health of children and their caregivers. Six of the caregivers were elderly so this limited their ability to help themselves. Because their bodies were declining with age, and they were with persistent disease such as diabetes and gout. Three people had asthma and three of them were the mother infected with HIV and were being treated as well. The status of health of the child is found to have been unhealthy. They have illnesses often. The result is that they need more than normal supervision. The ability to take care of children and caregivers is that children and their caregivers need to know how to care for themselves more. Meanwhile, the caregivers may have limited memory and be subject to their dementia. The school children are still unable to fully care for themselves, so the caregiver still must be able to help in some part. In the area of economic status all of 10 families were poor and the caring was done conventionally as they were poor families. In the area of relationship within the family, it was found that the relationships were good they got along very well, took good care of each other and had love and attachment to each other. And in the area of services and home health personnel visits that are not covered, these factors are consistent with former studies of researcher Jintana Tungvorapongchai (2008) through this study of school age children for with chronic disease through a similar context of the east of Thailand. However, the factors are also consistent with studies in the context of other parts of Thailand such as in the area of education of Napawan Viriyasirikul (2005) and Rasamee Sridapeng (2002). This may be because of the context of the cultures of Thai people are very similar in terms of cultural beliefs and economic status of health care in a child infected with HIV/AIDS.

Recommendations from this Research

1. The administration of nursing: The research is the guiding policy of caring for children infected with HIV/AIDS and the development of potential in nursing and to support the fund for development in child care at home who were infected with HIV/AIDS.

2. The education of nursing: The academy or the course instructor should develop the training programs by integrating the care of children infected with HIV/AIDS into the subject or related topics in the classroom into subjects or topics related to teaching. Additionally, there should be a conference for nurses to care for children infected with HIV/AIDS.

Recommendations for further study

Research in nursing should be done aimed at developing a model of care development administration such as qualitative research on the care of school age children infected with HIV/AIDS and related health care personnel, education, other chronic diseases among school children at home and study of children infected with HIV/AIDS in other ages.

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Thai Language

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