



Mothers' Experience in Caring Children with Nephropatic Syndrome during Relapse: A Phenomenological Study

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Abstract. Nephrotic syndrome is a disease with a high relapse prevalence in children. This relapse could force the children to be hospitalized, causing physical and behavioral changes in the children, and disturbing psychological stability and daily activities of family members, particularly mothers. The study aimed to explore mother experience in caring for her child during relapse and the value of the experience. This was a qualitative study with a phenomenology approach. Respondents were six mothers of children who had been diagnosed with the nephrotic syndrome for more than one year and had a relapse in the last year. A purposive sampling method was used to select the participants. The main instrument was the author. Data collection was conducted with an in-depth interview, observation, and field notes. Data analysis used Colaizzi's method. Data was collected from interview results, turned to a transcript, classified, and sub-themes and themes were determined. This study showed six themes, which were Inadequate Knowledge of Nephrotic Syndrome, Being Worried about Child's Condition, Physical Changes During Relapse, Caring Children During Relapse, Concern About Social Support and Challenges in Caring. Various treatments for their children were conducted by mothers, including home treatment, using modern medicine in the hospital, and alternative treatment. Mothers require support from multiple sources to deal with the difficulties that they have in the children's treatment

Keyword: mothers experience, children, nephrotic syndrome, relapse



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INTRODUCTION

A nephrotic syndrome is a group of symptoms, including massive proteinuria, hypoalbuminemia, hyperlipidemia, and edema (1). There has been an estimated 6 per 100.000 children aged less than 14 years who are diagnosed with nephrotic syndrome in Indonesia (2).

Nephrotic syndrome is a disease with a high relapse for children (3). *International Study of Kidney Disease in Children* (ISKDC) reported that the relapse incident for children with nephrotic syndrome reached 76-90%, with 50% frequent relapse (4). Remission and fluctuated recurrence and changes in family activity due to treatment in hospitals will have a psychological and financial impact on the children and their families (1).

During a relapse, the hospitalization will change the children and their parents' daily activities. Admission will cause changes in family dynamics, delays in education, sufficient deficiency, maternal deprivation, physical and psychological aggression (5). Frequency of relapse and low socioeconomic status have a significant relationship to the abnormal behavior of children. Increased frequency of relapses is associated with many visiting clinics, absence from school, uncertainty and lack of children's activities, isolation from playgroups, and inability to study in school. Frequent visits to health care facilities will cause caregivers to lose work time.

Many studies of children with nephrotic syndrome have been conducted. However, no research focuses on mother experience in caring for her child during relapse.

OBJECTIVE

The study aimed to explore mother experience in a caring child during relapse.

METHOD

This was a qualitative study with a phenomenological approach that aimed to explore mother experience in caring for her child during relapse in child health facilities Dr. Sardjito Hospital, Yogyakarta. A purposive sampling method was used to select the participants. Six participants participated in the study. The inclusion criteria were: 1) Mothers who have children with nephrotic syndrome during relapse and admitted in INSKA RSUP Dr. Sardjito Yogyakarta; 2) Having experienced in a caring child with the nephrotic syndrome for more than one year, and children also experience a relapse in the last one year; 3) Interested in participating in research and sign an informed consent

The data collection technique in this study was in-depth interviews, observation, and field notes. The unstructured interview with open-ended questions was delivered to participants about 45 to 60 minutes. Each interview was recorded, and field notes were taken.

Ethical clearance was obtained from The Ethics Committee of Faculty of Medicine, Public Health and Nursing, UGM. After obtaining ethical approval, the researcher submitted a letter to carry out the study to Dr. Sardjito Hospital. The researcher contacted the head nurse and tried to identify eligible participants. The participants were told that their participation was voluntary, and they were assured that they could stop their participation without penalty. After the participants expressed their agreement to the head nurse, the researcher contacted the participants and explained the details of the study. After they were fully informed, the participants were invited to sign their informed consent. The interview started with the question, including self-information and then how they take care of their child. Each

participant was interviewed 2 to 3 times. Sampling was done purposefully and continued to reach saturation.

Trustworthiness was established following four criteria by Lincoln and Guba. These were credibility, transferability, dependability, and confirmability. Credibility was obtained by triangulation and members checking. The triangulation methods used in this study involved interviewing other family members and observation. Transferability was established by providing 'thick' or detailed descriptions of the phenomenon. Dependability was determined by expert review.

Data analysis was based on Colaizzi's data analysis with seven steps: 1) Write the results of in-depth interviews in a verbatim transcript. Field notes supported data transcripts; 2) Identifying each phrase or sentence of the mother or other family members that are directly related to the phenomenon; 3) Formulating meaning, which describes the meaning of each significant statement; 4) Arranging the whole meaning then formulating it into groups of subcategories, categories, and themes with the researchers' sentences; 5) Themes obtained from each participant who has a closeness of meaning are then grouped, described in the narrative to describe the perceptions obtained from the results of the research; 6) Formulate a complete description of the phenomenon with a firm statement in the form of a narrative so that easier to understand; 7) The researcher meets the participants to validate the description of the analysis results.

RESULTS

Characteristic of respondents

The participants of this study were six mothers who cared for their children with nephrotic syndrome relapse. Their ages were varied from 26 to 50 years old. Four participants were high school graduates, and two participants were elementary school graduates. All participants were housewives, with their family income ranged from one to two million rupiahs.

The children aged varied from five to fifteen years old, with frequent and infrequent relapse frequency. There were four males and two female children. The duration of nephrotic syndrome diagnoses varied from two to seven years old.

Key themes of mother experience in a caring child during relapse

Several key themes of mother experience in a caring child during relapse as follows:

Inadequate Knowledge of Nephrotic Syndrome

Participants understanding on definition and diet of children with nephrotic syndrome can be seen in the following interview transcripts:

".....NS is a leakage in the kidney, so we have to avoid salt, food coloring, and mmm..any preservatives" (P1)

"Well, as his disease often relapses, he can't have any salty food" (P3)

".....I think this is a genetic disorder, or caused by his food. However, his cousin also has this disease, so I think it is caused by genetic." (P5)

Participants were able to understand the medical side effects, depended on the type of therapy. The interview transcripts of this topic are:

".....I have been told that MMF could cause intestinal wound as its side effect" (P1)

"Yesterday, I was informed that frequent consumption of prednisone has side effects like chubby and hairy cheeks, and cyclo could cause nausea and vomiting" (P3).

Mother information sources varied, which some mothers only waited for information from a health care professional, but others actively sought information from the internet. The interview transcripts of this topic are:

"I only received information from the doctor" (P1)

".....I often search any article of the nephrotic syndrome from Google regarding what the things to avoid are, the type of medicines, and what are the medicines that I should avoid" (P1)

Being Worried about Child's Condition

Relapse is a period of emotional change and turmoil for the participants. They generally felt panic, fear, confusion, and had mixed feelings during the relapse. They were worried about their children's condition at that moment and in the future. The interview transcripts of this topic are:

"I had mixed feelings when my child relapsed. I was afraid of his disease worsened." (P1)

"....I was panic since my child has never been in this condition before...." (P5)

It was not easy for participants to cope with their children's disease and relapse. Some participants admitted their feeling and response to the first relapse were different than on the next relapses.

"In his previous relapse, I felt relieved when his condition was improved. However, now I am worried since his condition does not improve for too long. I afraid that if he suffers kidney failure" (P1)

"..... the change in his medication made me worried" (P3)

Participants' perspectives on their children's condition were also varied. The third participant (P3) felt this was a destiny that should be accepted, while the first participant (P1) thought that this was a trial from God, yet she was still optimistic that her child would recover, as seen in the following transcripts:

".....I think this is a destiny that I should accept" (P1)

"Well, while this is a trial of God, I believe someday he will fully recover." (P3)

The fourth participant (P4) thought that this disease was caused by her and her husband's mistakes, as can be seen in the following transcript:

"Well, this is probably our mistakes, maybe in the past, we did something wrong, since I think this condition is maybe genetic....." (P4)

Physical Changes During Relapse

All participants expressed that the main sign of relapse was swollen in some parts of their children's bodies. Some children had swelling only in the face, feet, and stomach, while the others had swollen in the whole body. The interview transcripts of this topic are:

".....When his body started to swell, I realize it was a relapse...The first swelling appeared in his eyelids. However, when he started his activity, the swelling was gone. The longest swelling was in the feet" (P1)

"The swelling appeared in his stomach and his feet, from here to here (pointing to the tibia). It felt hard. The stomach was enlarged and hardened, but sometimes it just became bigger" (P3).

Another change experienced by children was sudden weight gain. This was caused by edema. The interview transcripts of this topic are:

"He gained 2 kg in 3 days" (P1)

"Yes, his weight rose to 19 kg, while normally he only weighs 17 kg" (P2)

Another sign was the child's urine condition. The frothy urine was associated as a sign of relapse. The interview transcripts of this topic are:

"....I remembered that if his urine is frothy, it means he is in relapse " (P2)

"In normal people, clear urine is good, but his urine was obvious, but it was frothy.

Even if his urine is yellow, but if it is not frothy, it is no problem" (P5)

Participants identified some factors that could trigger the relapse. The primary triggers were cough, flu, and fever. The interview transcript of this topic is:

".....cough, flu, and fever should be treated in less than a week before triggering a relapse. If these are treated immediately, his protein level will not increase, but if it is not, his protein level will increase and trigger a relapse" (P3).

Caring Children During Relapse

Nearly all participants immediately gave their children the medicine that was prescribed by the doctor. One of the medications is furosemide. The interview transcripts of this topic are:

"....from my previous experience, his swelling will go down after taking furosemide" (P1)

"He (her child) already knows to take furosemide and go take a piss" (P5)

The first and sixth participants immediately brought their children to hospital or policlinic when they relapsed or when their swelling would not go down. The interview transcripts of this topic are:

".....sometimes after taking furosemide, the swelling did not go down, so I immediately took him here (hospital)" (P1)

"....he took his medicine, went to school, but his swelling did not go down, so I took him to the hospital after he returned from school" (P6)

Some participants stated that they sought alternative treatment for their children, such as treatment with herbal, massage, energy therapy, or shaman. The interview transcripts of this topic are:

"....we used the alternative treatment twice in different places where my child had energy therapy" (P4)

"...my child drank coconut water to cure his disease... he also tried bay leaves or celery, but it increased his albumin, he also tried turmeric... He tried alternative treatment twice ..." (P5)

Alternative treatment did not always have a positive impact on children. The fifth participant explained that her child still had relapsed after taking alternative medicine. The interview transcript of this topic is:

"I had tried many alternative treatments, even when my child had to stay overnight" (P5)

Concern About Social Support

All participants have National Health Insurance. Therefore the majority of them felt no financial problem during the treatment. Furthermore, the second participant received extra funding from a foundation for other costs such as transportation, food, and medicine. The interview transcripts of this topic are:

"We had Class 2 Insurance from my husband's company. Now, we have National Health Insurance. For me, it does not matter which insurance, as long as my child is treated immediately ..." (P1)

"We receive other funding from Foundation.....they came to me, and said to report to them when my child had to buy medicine or had a check-up" (P2)

Other than financial support, participants also had moral support from all family members. The interview transcript of this topic is:

"Yes, thank God every family member helps me. They do not cover all expenses, but my mother-in-law supports us by bringing food" (P4)

Support from health care professionals is also crucial for children and their parents' physical and psychological condition. The health care professionals provide positive inputs for the parents. Some participants stated that there was good communication between them and the health care professionals.

"...when his swelling did not go down, I called his doctor ..." (P5)

Challenges in Caring

Some participants admitted that they still have a financial issue since National Health Insurance does not cover some medicines, therefore they had to pay by themselves or borrow money from other people. The interview transcript of this topic is:

"Well, even though National Health Insurance covers the treatment, we still have to pay for some of the medicines, like MMF and kolkatriol...We have to borrow some money so that our child could fully recover" (P1)

Some participants felt that some difficulties in treating children came from the children themselves. The children sometimes did not want to take their medicine, felt bored, or did not obey the diet that was arranged by doctors. The interview transcripts of this topic are:

"Sometimes he feels bored, delays his treatment..." (P1)

"Well, sometimes he doesn't want to drink a lot of liquids" (P3)

"Yes, he only wants to eat food from other places" (P2)

Some participants live outside the City of Yogyakarta, thus bringing their children to the hospital during relapse was challenging, as can be seen in these transcripts:

"Yes, the bus ride is exhausting, especially since sometimes I get carsick. So, sometimes I also have to take care of myself, not put all my attention to my child" (P1)

"When I ride the bus, sometimes I have to hold my child and my bag" (P2)

DISCUSSION

Inadequate Knowledge of Nephrotic Syndrome

Participants in this study don't have adequate knowledge about the nephrotic syndrome but generally understood that children with nephrotic syndrome require long term treatment with a risk of relapse. The challenge in treatment management involves the use of long-term immunosuppressants and steroids to reduce the risk of relapse, which includes low dose alternate-day prednisolone (7).

Parents' knowledge of their children the disease is fundamental to improve their understanding of the children's condition, manage the routine of children's treatment, and prevent complications. Hakim *et al.* conducted a study in Iran for 66 parents of children with nephrotic syndrome regarding their knowledge of the risk of relapse. The result showed that only 18.2 % of parents had proper knowledge, and there was a significant relationship between help from the fathers and the mothers' knowledge level ($p=0.01$). Moreover, there was no relation between the parent's age and knowledge level ($p=0.04$). Parents need a proper understanding of treating children with nephrotic syndrome (8). Xue-hong *et al.* conducted a study to evaluate parents' knowledge and understanding of the relapse in children with nephrotic syndrome. The study result showed a relationship between parents' knowledge and their residence location, education background, and relapse frequency, yet there was no relation to age and gender (9)

Participants in this study explained that they received information on nephrotic syndrome from doctors and nurses. One participant (participant no. 4) stated that she received information from students in a community service program in her area. Some participants also sought information about their children's disease on the internet. Reading literature regarding their children's condition is an internal coping method developed by the parents. To support the parent's internal coping, nurses should be able to provide information or reference to other information sources, support groups, or organizations (10).

Being Worried about Child's Condition

The relapse period is a period with emotional turmoil for the mothers. In this study, participants often felt afraid, worry, and fear when their children relapsed. Even though nearly all mothers can cope with their children's disease, it is normal if they frequently felt sorrow since several internal or external triggers (11).

Some participants associated their children's condition with destiny that should be accepted. They accepted their children's condition and tried their best to get their children to recover fully. Other participants still felt optimistic about their children's chance to fully recover even though they thought this condition is a trial of God. Cousino and Hazen conducted a meta-analysis on 13 studies and qualitative analysis on 96 studies regarding the stress level of parents of children with chronic disease. The result showed that the stress level of parents of children with chronic illness was higher than that of healthy children ($p=0.0001$). The qualitative analysis found that the high-stress level was related to the parents' high responsibility for their children's treatment and not related to disease duration and severity. The stress level also referred to parents psychologically coping with the children's disease and other things related to the disease, such as a frequent visitor to the clinic or therapy regiment demand (12).

Perception is a process when individuals select, organize, and translate the information inputs to produce a meaningful description. In this study, participants tried to describe their perception of having children with the nephrotic disease in long term treatment (13)

The fourth participant thought that her child's condition as a payback from her mistakes in the past. This perception occurred since the participants brought her child to alternative treatment. This is not a good perception as it could bring adverse effects on the children's psychological condition. Children could feel guilty and unfair if they think that their health is a payback from their parents' past (14).

Physical Changes During Relapse

The main sign of relapse that was recognized by participants is edema. Edema occurs slowly in the early phase, and it usually starts to appear in an area with low tissue resistance such as eyelids, scrotal, or labial. It then develops into general and massive edema that is called anasarca. Edema has a property of pitting and depends on body position; therefore, it is evident on the face in the morning and on the legs in the afternoon (15). Pitting dependent edema (pretibial, feet, sacrum, scrotum, labium, and periorbital) is followed by weight gain or ascites, is the most prevalent symptom of nephrotic syndrome. Diarrhea (caused by intestinal edema) or respiratory distress (caused by pulmonary edema and pleural effusion) also occurs (16).

Children in relapse also experience behavioral change, such as lethargic or temperamental. Children with nephrotic syndrome often experience emotional and behavioral disorders, particularly children with frequent relapse and children with steroid dependency. The emotional and behavioral disorder is related to the use of steroid during treatment (17).

Relapse often triggered by disease such as respiratory tract infection or caused by the virus. A family must contact the health care professional if proteinuria occurs for three days (+3) or proteinuria 2+ stays more than one week (18). Rahi et al. study of 120 children with nephrotic disease in Iraq found that the upper respiratory tract infection and pneumonia are the primary triggers of relapse for children with frequent and infrequent relapse (19).

Another relapse trigger in this study was an uncontrolled diet, where children often consumed food with a high amount of salt and preservatives. Tiredness after playing or doing other activities and emotional pressure (angry or stress) are other relapse triggers. The fifth and sixth participants explained that psychological pressure was the relapse trigger for their children. This is in line with the other studies, where emotional pressure or mental stress could trigger relapse in children. Stress could be caused by things related to school or worrying about the next check-up schedule in the hospital. Stress caused by things related to school usually occurs in the exam period. Several patients tend to have relapsed a few days before visiting a hospital, or commonly known as relapse-related to hospital visits (RRHV) (20)

Caring Children During Relapse

Participants immediately gave furosemide their children when they were swelling or not feeling well. Some participants have a supply of furosemide other diuretics in their homes. The central management of edema in children is by limiting the consumption of salt and diuretic therapy. The commonly used diuretic is loop diuretics, with furosemide as one of them. When restricting the consumption of salt and diuretic therapy cannot recover the children's condition, albumin therapy should be done to improve intravascular volume, diuresis, and natriuresis (21).

Mothers are strongly suggested to limit the consumption of salt for their children during relapse (proteinuria) or when treated with prednisone therapy. Salt will make the children thirsty and want to consume more water. This will create fluid excess and worsened the swelling (22).

Dealing with relapse is very important. Relapse often occurs after respiratory tract infection; thus, children should be limited to have contact with a patient of respiratory tract

infection. Deterioration could also occur after immunization. Hence routine immunization should be postponed until children in remission and six months free of prednisone (15).

Alternative treatment is a part of a general cultural perspective. It is estimated that 30 % of children had an alternative treatment. However, not all parents report this to the doctors. Some of the alternative therapies could be effective, while others could be ineffective or dangerous (23). Hermalinda conducted a study of parents taking their children with cancer to alternative treatment. Generally, this type of therapy uses herbal, such as roots, leaves, or stems of plants to be drunk or eaten by children or put directly on their bodies. Sometimes, the herbal is turned into an ointment and smeared on the children's body. In our study, participants also use herbal treatment for their children, such as bay leaves, sage leaves, turmeric, other ingredients from fruits or animal products, such as eggs (24).

Treatment with natural medicine is categorized as biological therapy, where this type of treatment uses vitamins, mineral supplements, and other natural products from animals, plants, or traditional diet. Participants explained they still believed in medical treatment and felt optimistic that their children would fully recover. Some participants had emotional support and information from other family members to try an alternative treatment, but they did not want to mix modern and traditional medicine. Meanwhile, other participants did not receive any information about alternative treatment (25)

Concern About Social Support

The financial factor is fundamental to sustain human life, as this support could overcome problems related to the material. Mothers admitted the National Health Insurance was the significant financial support in their children's treatment, as the government covered most of the costs.

As family experience in the depression stage is varied, the need for support also varies. The family should have three support sources, from health care professionals, family members, and the self-help group. Health care professionals are directly involved with parents to deal with their depression and to mobilize other medical or social aids. Health care professionals should be able to identify the stress factor and help the children and their parents to adapt by providing a method to face their problems constructively. Without the nurse's support, a family could experience a crisis, and other family members could use improper coping techniques that are not suitable for short and long term adaptation of the children's disease (14).

Mothers also require support from their friends to share experience, because sharing experience, feelings, and other difficulties in treating their children, mothers will find available resources and ways to access them. Helping other parents of children with a similar condition will provide emotional support and information. The parents could motivate each other to care for their children and themselves. The support could also increase mother confidence and self-image (26)

Challenges in Caring

Mothers, as the primary caregiver of their children, often have an uncomfortable experience that disturbs them during relapse treatment. One of the obstacles is the financial factor since the insurance did not cover other expenses. There were also other expenses, such as transportation costs and routine check-up in the hospital. Prasomsuk *et al.* conducted a study of another chronic disease, thalassemia. They found that financial problems are caused by the loss of income and the increasing expenses for treatment, transportation, and other living expenses (27).

There are numerous changes in the family of children with chronic disease, particularly for mothers as the primary caregiver that should be able to fulfill their children's

needs even without any social support. Being a caregiver is challenging, complex, full of surprises, and uncertainties. The daily life of the family will be centered on the children and their treatment. This will limit other personal relationships to children, other family members, health care professionals, and parents of children of similar disease (26).

Chronic disease will affect the family structure and the emotional condition of other family members. Family needs social support in forms of material, emotional, information, and affection. Thus, the knowledge of the family function and dynamic is required in the treatment to arrange the strategy to cope with a chronic condition as an essential step to improve the service quality (28).

The healthy child in the family of children with chronic disease also has his problems. Family member's attention will be focused on the sick child, particularly during hospitalization, thus making the healthy child felt neglected (28). However, in our study, one participant explained that her other child also helps their sick sibling during home treatment. Unfortunately, other families must leave their children with other family members during hospitalization.

CONCLUSION

This study shows the meaning of the lived experience of mothers who cared for children with nephrotic syndrome during relapse. The description of the meanings of the mothers' experience is: were Inadequate Knowledge of Nephrotic Syndrome, Being Worried about Child's Condition, Physical Changes During Relapse, Caring Children During Relapse, Concern About Social Support and Challenges in Caring. The finding of the study indicated the fact that a child's condition with nephrotic syndrome, particularly during relapse, is a stressful event for mothers. In most cases, the concern occurred is because relapse comes suddenly and often. Sometimes mothers choose self-medication as a prior method to the doctor's visit. Therefore, they visit the physician in case of ineffectiveness of self-medication in controlling relapse. This study also highlighted the need for various sources of social support for mothers. It is suggested that health professional intervention, such as counseling and emotional support is needed to understand and facilitate mother' feeling and to help them cope with the child's condition

REFERENCES

- [1] Wong DL, Hockenberry ML, Wilson D, Wilkelstein ML, & Schwartz P. (2008). *Buku Ajar Keperawatan Pediatrik volume 2 ed* . Jakarta: EGC, (2008)
- [2] Unit Kerja Koordinasi (UKK) Nefrologi Ikatan Dokter Anak Indonesia (IDAI). (2012), *Konsensus tatalaksana sindrom nefrotik idiopatik pada anak*, Badan Penerbit Ikatan Dokter Anak Indonesia. Jakarta.
- [3] Guha P, De A, Ghosal M. Behavior profile of children with nephrotic syndrome, *Indian J Psychiatry*. 2009; 51(2), Apr-Jun 2009.
- [4] Sarker MN, Islam MMSU, Saad T, Shoma FN, Khan HA, Afrooz F, Fatmi LE, Alam A, Salimullah ASM, Uddin MR, Saha T. Risk factor for relapse in childhood nephrotic syndrome – a hospital-based retrospective study, *Faridpur Medical College Journal*, 2012;(1), Jan 2012.
- [5] Costa WKDS, Moreira RTDF, Lucio IML, Cavalcante LPFC. How mothers perceive their children with nephrotic syndrome. *J Nurs UFPE online*. 2015: 9(2) : 624-32.
- [6] Streubert HJ, & Carpenter DR. (1999). *Qualitative Research in Nursing, Advancing the Humanistic Imperative*. Lippincott Williams & Wilkins.
- [7] Uwaezouke SN. Steroid-sensitive nephrotic syndrome in children: triggers of relapse and evolving hypotheses on pathogenesis. *Italian Journal of Pediatrics*. 2015; 41(19)

- [8] Hakim A, Madhooshi S, Valavi E. A study about knowledge of parents of children with nephrotic syndrome toward recurrence of the disease. *Jundishapur Journal of Chronic Disease Care*. 2013;2(4):49-55.
- [9] Xue-hong C Et al. Survey on cognition of parents of children patients with recurrent nephrotic syndrome and analysis of the related influencing factors. *NC J*. 2010;30(2):71-75.
- [10] Gordon J. An evidence-based approach for supporting parents experiencing chronic sorrow. *Pediatric Nursing*. 2009; 35:115-120
- [11] Tomey AM, & Aligood MR. (2014). *Nursing Theories and Their Work 8th edition*. Philadelphia, Mosby Elsevier.
- [12] Cousino MK, Hazen RA. Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology*. 2013;38(8): 809–828.
- [13] Sunaryo. (2004). *Psikologi untuk Keperawatan*. Jakarta : EGC.
- [14] Theofanidis. Chronic illness in childhood: psychosocial adaptation and nursing support for the child and family. *Health Science Journal*. 2014;2
- [15] Albar H. (2006). Tata laksana sindrom nefrotik kelainan minimal pada anak. *Sari Pediatri*. 2006;8(1): 60-68.
- [16] Behrman RE, & Kliegman RM. (2010). *Nelson esensi pediatri ed.4*. Jakarta : EGC
- [17] Manti P, Giannakopoulos G, Giouroukou E, Angelaki HG, Stefanidis CJ, Mitsioni A, Stergiou N, Mihas C, Chrousos GP, Magiakou MA, Kolaitis G. Psychological and cognitive function in children with disease and treatment variables. *BioPsychoSocial Medicine*. 2013; 7(10):1-7
- [18] The Sidney Children's Hospital Network. (2016). Nephrotic Syndrome: Management in Childhood. Practice Guideline.
- [19] Rahi K, Al-Badri AAS, Salih BJ, & Hasan FO. Childhood nephrotic syndrome, frequent and infrequent relapses, and a risk factor for relapses. *The Iraqi Postgraduate Medical Journal*. 2009;8(3)
- [20] Takahashi S, Wada N, Murakami H, Funaki S, Inagaki T, Harada K, Nagata M. Trigger of relapse in steroid-dependent and frequently relapsing nephrotic syndrome, *Pediatr Nephrol*. 2007; 22:232-236.
- [21] Duffy M, Jain S, Harrel N, Kothari N, Reddi AS. Albumin and furosemide combination for management of edema in nephrotic syndrome: A Review of Clinical Studies. *Cells*. 2015; 4:622-630,
- [22] The Kidney Foundation of Kanada. Childhood Nephrotic Syndrome. 2007. <http://www.kidney.ca/childhood-nephrotic-syndrome>
- [23] Ikatan Dokter Anak Indonesia (IDAI). (2016).
- [24] Hermalinda. *Pengalaman orang tua dalam penggunaan pengobatan alternatif pada anak yang menderita kanker di Jakarta*. (2011). Tesis Fakultas Keperawatan Universitas Indonesia.
- [25] National Center for Complementary and Alternative Medicine (NCCAM). CAM use and children. 2007. <http://nccam.nih.gov/health>
- [26] Baltor MRR, Matos APK, Wernet M, Ferreira NMLA, Dupas G. The perceptions of families with children having chronic diseases and their relationships with healthcare professionals. *Rev Esc Enferm USP*. 2013; 47(4):808-14
- [27] Prasomsuk S, Jetsrisuparp A, Ratnasiri T, Ratnasiri A. Lived Experiences of Mothers Caring for Children with Thalassemia Major in Thailand. *Journal for Specialists in Pediatric Nursing*. 2007;12(1)
- [28] Silva MEA. The implication of the chronic condition of the child for its family., *Cienc Cuid Saude*. 2014;13(4): 697-704