

# A Phenomenological Study of Indonesian Mothers' in Caring for Children in the Acute Phase of Kawasaki Disease

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**Abstract:** Kawasaki Disease (KD) is an acute febrile disease which attack children under 5 years old with unknown causes. Very few literature has been published related to the experiences of caring children with KD in Indonesia. A holistic understanding about KD is necessary to improve nursing care of children with KD. The purpose of this study was to explore mothers' experience in caring for children in the acute phase of KD. This descriptive phenomenology study used in-depth interviews to explore Indonesian mothers' experiences. Fifteen participants were selected through convenience sampling in Jabodetabek area. The transcripts were analyzed using Colaizzi's method. The study revealed five main themes: The nature of a mother: Struggling for the safety of children; when mothers' love conquer fatigue; sustainable family support; freak out of the high-priced and scarcely treatment; and challenges to access health services. These findings trigger the government to support Indonesian mothers for the treatment of their children in acute phase of KD, with caring attitudes as well as social, emotional, and financial supports.

## 1 INTRODUCTION

Kawasaki disease replaces Rheumatic Fever as a major cause of acquired heart disease in children in developing countries (Newburger, Takahashi and Burns, 2016). Kawasaki Disease (KD) is an acute disease that mainly affects children. KD is also known as mucocutaneous lymph node syndrome that has primary pathological characteristics of fever and rash due to systemic vasculitis (Ogata, et al., 2013).

Williams (2016) emphasizes that although KD attacks children of Asian descent with an incidence of almost 10 in 1,000, it can occur in other children from different ethnic backgrounds. Men are diagnosed twice as often as women (Maddox *et al.*, 2015).

Children who are affected by KD may develop Coronary Artery Abnormalities (CAA) up to 25% in untreated cases. It is very important to have early diagnose of the condition since timely treatment can anticipate the abnormalities development (Singh, Vignesh and Burgner, 2015).

Children who experienced illness will change the equilibrium conditions in the family. When a child experiences KD, it will affect all family members, especially parents. Research on KD which investigates the quality of life and psychosocial

function in children is still limited because in recent decades it has focused more on the etiologic and complications of KD (van Oers *et al.*, 2014). Qualitative research that focused on the quality of life and susceptibility of children with KD in the Netherlands has found meaningful themes such as, it explained that parents considered children with a history of KD to be more susceptible to other diseases than healthy children, even though in their daily lives the child appears healthy. The recommendation of this study was to conduct a parent-focused study by identifying the burden, stress level and parents' reactions to the unexpected thing in this rare child disease (van Oers *et al.*, 2014). Furthermore, there are recommendation in doing qualitative research on children diagnosed with KD from families in different geographical areas and cultural contexts (Chahal *et al.*, 2010).

The study aimed to explore the experience of caring for children with KD in the context of caring in Indonesia. Phenomenology provides a way to be able to adopt a holistic approach so that the experience of mothers in caring for children with KD can be more easily understood (Matua, 2015).

This holistic understanding about KD is necessary to improve nursing care of children with KD.

## 2 METHODS

### 2.1 Setting and Design

This study used a descriptive phenomenology approach to explore the experience of Indonesian mothers of children with KD. The participants were selected through convenience sampling with inclusion criteria as mothers who have treated children with KD in the 2012-2017 period. The participants were the most knowledgeable of the child's disease and care. The eventual sample size was contingent on data saturation (Jirwe, 2011). This research took place from March to April 2017 in the Jakarta, Bogor, Depok, and Bekasi areas.

### 2.2 Procedures

In-depth interviews were conducted by a single researcher used semi-structured interview guideline. The interview began with a question, "How did you experience in caring for a child with KD?". The researcher was the person who never had contact nor related to children who have KD. The researcher also had not been given nursing care for children with KD. Thus, the researcher who interviewed the participants perceived herself as having no preconceived ideas and assumptions about the participants' lived experiences. All interviews were audio-recorded with participants' consent and subsequently transcribed. Voice recording used Digital Voice Recorder with a capacity of 4 Gigabytes, 96 hours duration. Field notes were written following the interviews.

### 2.3 Data Analysis

The study analysis was conducted manually used the Colaizzi's method (Shosha, 2012). Discussion among team members were held to review the transcript, discuss emerging themes, and assess the degree of saturation. In this study, the researchers gave freedom to participants to give their own pseudonym. Participants who were given the opportunity to choose their pseudonyms felt a meaningful process than when asked to choose candidates for pseudonyms from researchers (Allen and Wiles, 2015).

### 2.4 Ethical Consideration

This research has been reviewed by the Ethics Committee, and was conducted with approval of the Ethics Committee of Faculty of Nursing at

Universitas Indonesia, on March 23, 2017, with the certificate number ethics approval letter was 57/UN2.F12.D/HKP.0204/2017.

## 3 RESULT AND DISCUSSION

Fifteen Indonesian mothers were recruited in Jabodetabek area using the convenience sampling technique. Most participants were mothers who had a the first experience of looking after children with KD infection. The participants were between 28 – 46 years old and were the person who gave direct care in caring children with KD. The average interview length was 58 minutes. Five main themes emerged from the participants; The nature of a mother: Struggling for the safety of children; when mothers' love conquer fatigue; sustainable family support; freak out of the high-priced and scarcely treatment; and challenges to access health services.

### **The Nature of a Mother: Struggling for the Safety of Children.**

Participants revealed that in caring for children with KD in an acute phase, mothers have undertaken various efforts to overcome some problems such as, the mother tried to fulfill children's basic needs, maintain child safety, protect children because of the condition of children who are vulnerable, give medicine at home, and provide comfort to children. Participants stated that the effort was carried out extra than treating a child with a common illness like common cold.

While the mothers were struggling and felt effortful, yet they appreciated themselves as the only one to relied on in the course of caring for KD children. A mother even imagined herself to be called as an angel by her ill child, as shown in the following quotation.

*"I'm the one who do everything, I mean, everything... because... my child... He didn't want to be with other people, no one beside me. Hm.. maybe he thought, 'Mommy is an angel'.. Yes he thought me like that..."* (Wina)

*"... but I didn't think about it, I never thought .. oh the hospital is expensive. Uhm no... the important thing is my child was given the treatment. Wherever... Wherever it was, I will find out.. I'll do everything..."* (Tata)

Mothers of KD children had performed some efforts to enhance safety and comfort for the children. The continuous high fever was one of the signs of KD that mothers tended to be more worried about adverse effects of fever such as brain damage and seizures. This issue is confirmed with some studies as the mother participants stated unrealistic concerns about the improbable complications of fever, such as brain damage, unconsciousness, and loss of hearing/vision were believed (Kwak *et al.*, 2013; Marui *et al.*, 2011).

Mothers have the primary responsibility for caring for sick children physically and emotionally. The practice of handling physical care has consequences for changing the mother's pattern of daily activities. Families recognize the role of mothers in their sensitivity and responsiveness to children that fathers do not really know what to do with children when they are sick. Mother have the primary responsibility in the child's physical care and the achievement of planning care activities, but also carries emotional responsibility (Neill, 2010).

#### **When Mothers' Love Conquer Fatigue.**

At the beginning of the disease, mothers in the current study stated that their child had a high fever continuously. Most of the mothers felt worried and tried to do everything to comfort their children. The mothers accompanied the children, measured body temperature every two hours, gave fluid during the days and nights for several days.

*"... so, it was first in the room... the first night, the second night, the third night... too exhausted. I felt dizzy, painful headache. I had... I don't know (confused).. I just can't sleep right. The fever didn't go down ... so we can't sleep... my eyes closely fixed on him and then... I saw he delirious (teary eyes)."*  
(Namu)

In the period of caring children with KD, the mothers did not only experience physical exhaustion, but also emotional fatigue. The mothers felt that their children were experiencing too much pain. In the bottom of mothers' heart, they were hoping that the child sickness could transferred into the mother's body.

*"... he was physically ill, but I were also felt sick heartedly, so ... well it's ok.. the point is I learn to be strong ..."* (Pinky)

In the midst of fatigue, some of mothers were also grateful for having strength from God. The mother never told or showed how they really felt, but they chose to firm and keep their smile in front of the child.

*"Alhamdulillah (praise be to Allah – God), I mean ... I was so tired, but I was still given a healthy body from God (sighing). Yes.. maybe God also knows the times, we... I mean to survive, to survive with it... I really have to be strong for my child"* (Diana)

Mothers were repeatedly saying that caring the children with KD is the hardest moment in life. It was totally different with caring children with other illnesses. Mothers really struggled for the safety of their child. In spite of geographical area, this theme also confirmed by the definition of a good mother in the Australian context, that a good mother is required to be loving and caring, to have "never-ending" supplies of patience, to willingly and regularly spend time with her children, and in this time provide her children with the right sort of attention, stimulation and guidance. Furthermore, a good mother required to remain calm and relaxed at all times, to be a good listener and communicator, and to be understanding and sensitive to children's needs (Dewi, 2011).

#### **Sustainable Family Support.**

Another unpleasant symptom experienced by children are headache and pain throughout the body. Children often become more irritable and tended to cry. To overcome these inconvenience symptoms, mothers provided comfort by hugging, giving gentle rocking, and kissing the child. Sometimes fathers and other family members also helped to hold the child, while mother feed food and medicines.

*"... I didn't exert by myself, there were my parents, parents-in-law, all kinds... accompanied me."* (Elsa)

During the treatment, the mother was also assisted by her husband in managing hospital's administration. The husband also helped the mother to get information about KD from the internet, social media, and other resources. Finally, the husband also provided psychological and emotional support throughout the process.

*"Yeah ... This is it, I was grateful if I see ... mm-hmm, at that time ... it could ... what is it ... a lot of help too... about information ... I got help and support from husband..."(Susan)*

The extended family also prayed the child from a distance. By using the video call WhatsApp application, the family could interact with the child. The mother and child did not feel too lonely even when they were in an isolation room. Above all of these efforts, mothers were so grateful for such viable supports sourced from all family member.

*"Well ... about everyone, Alhamdulillah. I have friends and family that really support me..." (Diana)*

This findings confirmed a previous study in that mother who received person-centered and family centered care felt more supported and were more likely to adjust with the stresses (Bruce, Lilja and Sundin, 2014).

#### **Freak Out of the High-priced and Scarcely Treatment.**

The mothers were not only surprised to know the name of the disease, for its unfamiliarity, but they were also shocked when they found out the price of the medicine. The mother received information that the treatment must be given immediately so that their child's heart will not be injured. All of the participants were freak out because they did not expect the price of the medicine.

*"It's really expensive, yeah.. The medicine... It's very expensive... huh ... it's expensive ... One ampoule it's about 9 million and I have to buy 5 ampoules for my child. 54 million must be... must be given to the hospital cashier. The drug were given in the evening and finished in the morning. Just like that.. 54 million rupiahs!! (loud voices). It was all depending on the children's weigh. If the child gets bigger, gets fatter, the more... the more immunoglobulin must children get" (sighing). (Cheryl)*

The mother was explained that the dose of the drug given was by the child's weight. Based on this, the family knew how much they must pay to the hospital. A mother said, this moment was the most stressful part, because they had to find money in a short time.

*" In the fact.. I am looking for loan. From everyone. I mean.. everyone. Because I'm not a kind of person who have a lot of millions rupiah in my account. (silent). In the end, I could get the money in an hour. At least I could give 80% of the deposit money to the hospital, right? For.. hmm.. For the IVIg thing.." (Mawar)*

Even though they cried for the expensive cost but in the end they showed a strong commitment to tackle the financial issue as the best they could, as illustrated in the following statement.

*"InsyaAllah (If God wills so).. I will pay all the needs. I just prayed in that way." (Lisa)*

The mother as the primary caregiver of the child was shocked at the high cost of the IVIg. They never thought of such an expensive drug and did not have much money in a short time. Intravenous Immunoglobulin (IVIg) remains the treatment of choice for KD (Singh, Vignesh and Burgner, 2015). The dose administration of IVIg was changed from its initial dose of 0.4 g/kg/ d over 4 day to a single pulse dose of 2g/kg in 1991. Newburger *et al.* (2004) signified improvement resolution in this regimen that is now widely used. It was also stated that the beneficial effects of IVIg in preventing development of CAA are more when the IVIg is administered in the early phase of the illness. Moreover, McCrindle and Selamet Tierney, (2017) stated Acetylsalicylic Acid (ASA) as a combination also has been used for treatment of KD for its anti-inflammatory effects and antiplatelet effects, and is recommended as standard therapy during acute illness by both American Heart Association and the Japanese Society of Pediatric Cardiology and Cardiac Surgery.

Some mothers were worried but not too long until they decided to do all efforts including to debt from other people, as long as the child could be treated immediately. This kind of situation happened because not all mothers had a well-established financial condition. Today Indonesia is one of developing countries. Indonesia has made an impressive breakthrough in alleviating poverty, supported by high per capita income growth and programs efficient and well-targeted poverty alleviation. However, there are large income inequality and even increased over the past decade (Elias and Noone, 2011). Similar to Indonesia, the cost of IVIg is prohibitive and in most instances the parents in developing countries like China and India

have to bear the expenses (Singh, Vignesh and Burgner, 2015).

Despite of Indonesia, the availability of IVIg in China and India is not an issue and several brands are available. However, many other developing countries do not have ready access to IVIg. The fractional facilities in China are freely available therefore the products that are marketed are made from local plasma. Nowadays, India does not have large scale of fractional facilities and most of the marketed product are based in plasma that has been fractioned overseas. Though several brands of IVIg are marketed in India, only two amongst these are approved to be administered by the United States Food and Drug Administration (USFDA)/ European Medicines Agency (EMA) and becoming the most expensive brands. The cost of the former is 2-3 times the cost of other brands which do not meet the safety requirements (Singh, Vignesh and Burgner, 2015).

Regarding the selection of the IVIg brands, the mother said that the doctor initially explained the type, price, the advantages and the disadvantage of each of the IVIg. The physician had given the decision entirely to the family. Some of the mothers ended up using IVIg that was made from China because the price was more affordable. This is similar with Singh, Vignesh and Burgner, (2015) that in practice one still ends up using the latter brands because of economic consideration, but the option to select a brand must be given to the parents after appropriate counselling. The information must be clearly understood that IVIg, as a human blood product, has the potential in inducing serious anaphylactic reactions and transmitting blood-borne infections.

#### **Challenges to Access Health Services.**

In providing care to children, participants tried to reach supporting health facilities. Participants found obstacles to find health workers during holidays, limited availability of the drug supply, and the difficulty of finding special medical personnel or cardiac specialist child. However, mothers continued to strive for children to access the needy health facilities. The following are some participants' statements:

*"I went to the drug store by my own ... I went to several pharmacies. I don't care, the point is I have to grab it fast.*

*The pharmacist said, it's difficult. They don't have much. Even if we have one. It's*

*impossible to get started. because there's no way it can be stop in the middle of the treatment. We can't give half of IVIg and stop, then we continue. No we can't! The IVIg must be continuously given". (Mawar).*

*"Confused.. Overall I am confused ... Uhm.. I've just heard such a disease. I don't know what to do. What kind of doctor do I had to find, because there're still not many pediatrician that specializes in the child's cardio. I can't look for an adult Cardiologist, cause it different, right? It different with pediatrician who take child's right? (Mawar)*

In the way of finding the right health care for the children, mothers felt confused because the lack of paediatric cardiologists in their neighbourhood for treating the children. This is similar with the study that stated mothers felt frustrated when they encountered deficiencies within the healthcare organizations (Bruce, Lilja and Sundin, 2014). Mother have to struggle for resources and to face barriers in accessing health service (Bristow *et al.*, 2018). Another study also corroborates the needs of governmental program, policies, and adequate formal supports for family who have children with rare disease (Baumbusch, Mayer and Sloan-Yip, 2018).

## **4 CONCLUSIONS**

Caring children with KD is still a rare experience, especially in Indonesia. These findings trigger all government parties to support Indonesian mothers in her effort throughout the treatment process in acute phase of KD, with caring attitude, social, emotional, and financial policy support.

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