



## **Mothers' Experiences in Caring for Chronic Kidney Failure Child with Hemodialysis: A Social Phenomenology View in Indonesia**



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### **Abstract**

Chronic Kidney Failure is a chronic disease in which children will receive holistic care for a long time. Various conditions impact the family, especially mothers as caregivers physically, psychologically, socially, and financially. The study aimed to get an overview of the mothers' experience in caring for children with Chronic Kidney Failure with hemodialysis. It is qualitative research with a phenomenological approach. The research instrument used interview guidelines and observation sheets. The results obtained three themes: the mother as a caregiver, the mothers' burden, and the mothers' coping mechanism. It is suggested that health workers support mothers in caring for children with chronic renal failure who undergo hemodialysis so that the quality of mothers' care for children will be better.

### **1. Introduction**

Chronic kidney failure is a disease that not only can be experienced by adults. It can also occur in children. Often patients with chronic kidney failure experience serious health problems with increased morbidity and mortality and causing biopsychosocial problems that are increasingly complex and affect the quality of life both for sufferers themselves and in their families (Yosef, 2019). The prevalence of kidney failure in the world from 2011 to 2013 has increased by 6%. In the world, kidney failure in children hospitalised is around 33.7% with a mortality rate of 13.8%. In the United States, 9,800 children experienced chronic kidney failure in 2017 (Chan & Rhot, 2002). Harambat et al (2012) stated that chronic kidney failure in children in Italy is 1,197, Belgium 143,

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Spain 605, Sweden 118, France 127 and Turkey 282. Based on Al Riyami, et, al., (2019) in Kidney The International Report reports the prevalence of chronic renal failure in children in the country of Oman reaching 208 cases with the most considerable age ranging from less than three years (63%) and (42.3%) at stage V.

Based on Harapan Kita Hospital's medical records, from 2008 to 2014, there were 18 cases of chronic kidney failure and 11 cases of acute kidney failure in children. There were 84 cases of chronic kidney disease treated from 2014 to 2015, while the number of children who needed dialysis in 2014 was 14 cases, and in 2015 there were 35 cases. The number of chronic renal failure patients undergoing hemodialysis therapy in 2018 was four patients, and in 2019, there was an increase of 16 patients. Meanwhile, the number of chronic kidney failure patients in 2018 was eight patients, and in 2019 there were 47 children.

Complications of hemodialysis therapy give a feeling of discomfort. Based on a preliminary study conducted through interviews with three mothers who had children with kidney failure with hemodialysis, one mother stated that she had difficulty caring for her child because she had to be more careful when letting her child play, the other two mothers said that he always pays attention to the health condition of his child and the importance of a mother knowing about dietary arrangements in treating children with kidney failure with hemodialysis, including hypotension, air embolism, chest pain, pruritus, dialysis balance disorders, muscle cramps, nausea and vomiting. If this happens to children, it can affect the child and family's quality of life, especially parents, both at the cognitive, emotional and daily routine levels. Parents of children with kidney failure who undergo hemodialysis have a role in making decisions, both clinical and non-clinical, in realising children's health. Besides, parents, especially mothers, have a role in supporting and accompanying children's growth and development (Agerskov et al, 2019) and are responsible for child care (Marlinda, 2011).

## **2. Materials and Methods**

This research is a qualitative study with a phenomenological study approach to determine mothers' experiences in caring for children with chronic renal failure with hemodialysis. Participants in the study were eight mothers who had children with chronic renal failure with hemodialysis as the main participants, while for the key participants, one father and one hemodialysis unit officer used a total sampling of eight participants. All main participants were mothers with an age range of 30 to 43 years. The participants of the Sundanese tribe are the largest, and there are 5 participants. The highest level of participant education is secondary education (SLTA) as many as 4 participants. All participants are Muslim. The most occupational mothers are housewives with 7 participants, the number of children owned by the participants on average is around 2 to 4 children. Basically, qualitative research does not pose a risk to participants, but researchers still pay attention to the rights of participants including; Researchers explain to participants the benefits of the research conducted, Researchers explain to participants about the benefits obtained by participants from the research conducted, Researchers explain and ensure that confidentiality of participants is prioritised by not displaying participant information and identities.

This research emphasises data credibility testing. It is conducted by extending observations, increasing persistence in research, triangulation, discussions with peers, negative case analysis, and member checks (McKenna& Cutcliffe,1999). The identification of research themes was carried out through a data analysis process using an inductive approach following six phases of analysis according to Braun & Clarke (2006), to find essential themes from the interview results that describe the experiences of mothers caring for children with chronic renal failure with hemodialysis.

### 3. Results and Discussions

Based on the study's objectives, namely: identifying the characteristics of parents with children with chronic renal failure with hemodialysis based on age, religion, latest education, occupation, ethnicity, number of parents in caring for children with chronic kidney failure with hemodialysis. Three themes were identified from in-depth interviews, observations, and field notes during the data collection and collection process. The eight themes identified, namely; 1) Mother as a caregiver, 2) Mother's burden, 3) Coping Mechanism.

The mother is the closest person to the child. She is the caregiver beside the child almost all the time, especially when they are undergoing hemodialysis therapy in the hospital. The mother generally meets all the child care needs that need. Based on the study results, all participants stated that the mother is the primary caregiver where the mother plays a role as a provider of care, manages medicines, monitors restrictions on diet and fluids in children.

Children undergoing hemodialysis therapy have special needs that urgently need health care and supervision (Pourghaznein, et al 2019). This is in line with research conducted by Pourghaznein, et al (2018) which states that mothers are the only caregivers of children, mothers are unable to separate from their children because children with chronic kidney failure with hemodialysis depend on their mothers. The time-consuming hemodialysis process, strict medication, therapeutic regimens, adherence to fluid intake and dietary recommendations, and various other therapies make mothers spend part of their time, energy, and abilities on sick children.

The second theme describes the burden of mothers in caring for children with chronic renal failure with hemodialysis. Physical burden, where the mother feels tired when caring for a child with chronic renal failure with hemodialysis, the distance from the house to the hospital, the control schedule and the child's condition that sometimes has to be cared for, the lack of rest time causes the mother to feel tired.

According to the research conducted by Pourghaznein, et al (2018), mothers feel tired from travelling to the hospital for haemodialysis therapy, and their children are often hospitalised. Research by Wighman et al.(2019) states that caregivers/mothers experience fatigue due to lack of time to rest.

Mothers also experience the psychological burden with chronic kidney failure children who are undergoing hemodialysis therapy. Based on the interview, mothers feel sad when their children have to get extended hemodialysis therapy. Moreover, mothers also feel sadness when they see their children's health worsening and when they have many complaints. It is appropriate with Pourghaznein et al (2018) research that mothers who have children undergoing hemodialysis have experienced psychological and emotional stress.

The social burden experienced by mothers with children with chronic renal failure with hemodialysis, lack of time, mother and child attachment to the hemodialysis schedule causes the mother to miss social contacts that mothers usually do. Research conducted by Pourghaznein, et al. (2018) states that mothers are always present and allocate time to accompany their children on hemodialysis therapy, travelling from house to hospital, which is a factor for mothers to limit their social activities. The importance of mothers' presence during the dialysis process and mothers' role in extended care are considered barriers to connecting with other people, including family and friends.

The mother's financial burden, the number of care costs that are sometimes unexpected even though they have been assisted by government health insurance, but these costs are still burdensome for the mother.

Following the research of Wightman, et al. (2019), mothers have difficulty paying for medical expenses. The mother manages the living expenses, the cost of care and the costs of the children's needs and other expenses. The mother's coping mechanism changes where initially she feels she does not accept then accepts all the child's health conditions and carries out routine hemodialysis treatment. According to research conducted by Pourghaznein, et al. (2018), mothers do not believe, are angry, ask for help, and then accept their child's condition. After experiencing the stage of anger, distrust and bargaining, then mothers begin to ask God and finally accept the illness suffered by their children and take care as a test from God, and this is God's will. Wightman, et, al (2019) stated that when mothers find their condition in a difficult situation and try to accept this condition, they try to think positively and focus on solutions and enjoy the therapy process.

#### **4. Conclusion**

Based on the results of this study, it is concluded that the formation of a theme that describes the needs of mothers in caring for children with chronic kidney failure with hemodialysis at the Children's Hospital and Bunda Harapan Kita Jakarta, namely three themes: 1) as a care giver; 2) mother's burden; 3) mother's coping. Next, it is suggested that health workers support mothers in caring for children with chronic renal failure who undergo hemodialysis so that the quality of mothers' care for children will be better.

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