



## Family Experience in Treating Children with Chronic Renal Failure Undergoing Hemodialysis Therapy

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### KEYWORDS

Chronic renal failure;  
Hemodialysis;  
Family experience

### Abstract

**Objective:** Children who enter phase 5 of chronic renal failure need hemodialysis as a therapy. In undergoing hemodialysis, children experience various physical and psychosocial problems. Parents, as caregivers, are required to be at their children's side to overcome these problems. This study aimed to explore the experience of families in caring for children with chronic renal failure undergoing hemodialysis therapy.

**Method:** This research method used a descriptive phenomenological approach with in-depth interviews of seven participants. Participants were families who had a child with chronic kidney failure undergoing hemodialysis in a top referral hospital in Jakarta for at least one month. Data were analyzed using the Colaizzi technique.

**Results:** Five themes were identified: *a)* families' response to child care; *b)* families' coping strategies; *c)* the impact of child care for families; *d)* family support, and *e)* families' perceptions of changes in children undergoing hemodialysis therapy. These five themes highlighted how hemodialysis for children affected family life.

**Conclusions:** Family experiences in treating children with chronic renal failure influence their life in economical, physical, psychological, intellectual, and religious ways.

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## Introduction

Chronic renal failure is a defect that usually occurs progressively and irreversibly over a period of several months to several years. Chronic renal failure in children constitutes a global health issue with an increasing prevalence, a critical prognosis, and high treatment costs. Approximately, 18 out of every 1 million children under age 19 suffer chronic renal failure with End Stage Renal Disease (ESRD)<sup>1</sup>. In 2011, approximately 12 thousand people suffered from chronic renal failure in Indonesia<sup>2</sup>. The primary causes of chronic re-

nal failure in children are congenital anomalies such as obstruction, vesicoureteral reflux, and renal dysplasia<sup>3</sup>. Data reveal that factors engendering chronic renal failure in children are obstructive uropathy (22%), aplasia/hypoplasia/dysplasia (18%), and reflux nephropathy (8%)<sup>4</sup>.

Children with chronic renal failure need lifelong medical treatment. One treatment is hemodialysis or dialysis, which is necessary if the chronic renal failure has reached ESRD conditions. Hemodialysis separates certain substances (uremic toxins) from the blood through a semipermeable membrane within the dialyzer. These are subsequently diffused

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throughout the dialysate fluid. Children who receive hemodialysis therapy over a long period typically get therapy three times a week for three to four hours each time. The main complication of hemodialysis is the possibility of infection and obstruction. Hemodialysis also intrudes on school, social lives, and family dynamics because of the therapy schedule<sup>5</sup>.

Problems that emerge in children receiving hemodialysis therapy require family involvement, specifically from parents. Parents serve as the caregiver or the primary source of affection and attention. Family can give support by taking care of family members who experience physical, psychological, social, economic, and spiritual problems<sup>6</sup>.

It is not easy to be the caregiver in this situation. Parents whose children have chronic renal failure are reported to have a low quality of life, difficulty taking care of their children, high levels of anxiety, and maladaptive behavior. Poor life quality of the children leads to mental health issues for the family<sup>7</sup>. Researchers investigated the experiences of family in treating and taking care of children undergoing hemodialysis therapy. This research assumes that health workers can consider the experience of the family while giving treatment to children, so that the focus is on the family as a whole.

## Method

This study used a descriptive phenomenology approach, which described some aspect of the human experience<sup>8</sup>. Purposive sampling was used to select family for the study. The sample was chosen based on the following inclusion criteria determined by the researchers: caregivers must have a child in treatment for one month minimum; children were undergoing hemodialysis therapy in a top referral hospital in Jakarta; families resided in Jakarta or cities around; and participants were capable of communicating and narrating their experiences using understandable Indonesian, and were willing to be the respondents. In-depth interviews were conducted with seven participants after determining that the sample achieved data saturation. Data were collected by means of a profound interview method to comprehend family experience. Interviewers used a recorder, a field note, and an interview guide so that the interview would not go off topic. The data were analyzed using the Colaizzi technique. The interview followed ethical research principles such as anonymity, confidentiality, beneficence, nonmaleficence, justice, and informed consent.

## Results

The data analysis identified five major themes: family response to childcare, family coping strategies, impact of childcare for families, social family support, and family perspectives of changes in children undergoing hemodialysis therapy.

### Family response to childcare

Families in this study had emotional, attitudes, and behaviors responses. Emotional responses were shown in the form

of sadness, fear, and anger. Responses of attitude were complaints, self-blame, exhaustion, and giving up. Behavioral responses were demonstrated by striking, focus on the therapy and taking children to a health facility or hospital. One parent stated her feeling:

"[...] Yeah, I feel guilty, yeah, I don't. If the doctor gets mad at me, I don't mind, I accept that. Indeed, I am wrong" (P3).

### Family coping strategies

Several coping strategies built by caregiving families were praying, seeking social support, interacting with others, and looking for information. This research showed that the majority of families had an adaptive coping mechanism while caring for their children. This adaptive coping mechanism enabled some of the hope that their children could be free from the disease and go back to school. As one parent in the study said:

"[...] I want my children to be healthy [...] I do hope [for] it [...]" (P2).

### Impact of childcare for families

Hemodialysis undergone by children had effects on the family. The effects were economic, physical, religious, psychological, intellectual, and social. One family member said:

"[...] I have limited time to hang out with friends. I cannot do that, it limits my freedom [...]" (P1).

### Social family support

The majority of children undergoing hemodialysis therapy had complex issues. The family tried to provide practical and emotional support. The following excerpt was from one family:

"[...] therefore, we create an effort...to persuade and support him to go to school [...]" (P4).

### Family perspectives of changes in children undergoing hemodialysis therapy

Kidney disease in children causes complications such as hypertension, pulmonary edema, and growth and development delinquency. Participants of this study understand this matter. Participants noted physical, psychological, and behavioral changes in their children. Here is testimony from a participant:

"[...] usually, my boy will play with his bicycle somewhere. But now, he is just silent and passive [...]" (P3).

## Discussion

Chronic renal failure in children who require hemodialysis therapy results in various physical, psychological, and behavioral changes. These changes, apart from their direct correlation to the illness, are also associated with the side

effects of the illness. Physical change occurs primarily due to complications of chronic renal failure such as growth delinquency because of the disruption in calcium, phosphorous, and vitamin D metabolism; calorie reduction; and metabolic acidosis<sup>9</sup>. Physical changes in children alter their psychology and behavior as well.

Psychological alterations identified in this research are emerging feelings of difference compared to peers. These feelings make children feel inferior and therefore less inclined to mingle with friends. The results of this research are in line with a meta-analysis concluding that children with chronic disease have lower self-esteem than those who are healthy<sup>10</sup>.

The changes occurring in children undergoing hemodialysis therapy initiate stress for the caregiving family. Stress responses arise when the family members are dominated by emotional responses such as sadness, fear, irritation, and even approval. The result of this research is congruous with studies that conclude that families whose children have chronic disease have an average stress level and high level of anxiety<sup>11</sup>. According to Cavusoğlu (1995), Petr and Barrey (1993), Whaley and Wong (1985), stress appears because of the fear of losing children, dependency on machines, hospitalization frequency, and lifestyle and financial problems<sup>12</sup>. Other stressors for family are fluid and nutrition restriction, conflicts with life partners, and living in uncertainty<sup>13</sup>.

All sorts of stressors that impact family life come forth while nursing their children. In this research, the effects seen were economic, physical, psychological, intellectual, and social. Economic stressors included the limitation of funds and the inability to keep a job. Physical challenges included fatigue while some psychological factors were the emergence of household issues, lack of attention to other family members, and the feeling of being both burdened and strengthened. Intellectually, the participants felt that there was a significant increase in their understanding or knowledge. Socially, families saw decreasing social activity. These results are in line with research about psychosocial effects of children's cancer treatment on parents, which concluded that the negative effects of treatment, such as financial issues and changes of routine and relationships, arise along with the appearance of depression, anxiety, and post-traumatic stress disorder, and that factors influencing family psychology are gender, social support, and information attainment<sup>14</sup>.

Effects that emerge during the child's treatment period can trigger the family to try to cope. Coping is the ability to deal with problems or stress. Most of the coping tools found in the research are adaptive coping mechanisms such as praying, seeking social support, interacting with others, focusing on positive points, and looking for information<sup>15</sup>. This parallels the research about coping mechanisms often used while nursing or treating children, including praying, seeking information, mastering skills and knowledge, looking for social encouragement, concentrating on positive things, and considering that others may have worse conditions than oneself<sup>16</sup>.

Praying is a coping technique that was done by all participants. Praying is performed by asking God for strength. Not only participants but also the children undergoing hemodialysis therapy are taught about praying by their parents. Performing prayer is proven to be an effective coping mechanism not only in Indonesia, but in western countries

as well. Research conducted in America about families coping during a child's treatment exposes that prayer is a common coping tool. The family in that study asks for protection from God in facing the pressures of illness<sup>12</sup>.

Although hemodialysis undergone by children impacts the family, they still provide support as the experiences of families involved in this study. One form of social support found in this research was fulfilling the children's educational requirements. Chronic disease affects their education by causing frequent absence from school. This means that children cannot keep up with lessons, which manifests in the decline of their cognitive development and scholastic readiness. This research identifies chronic absence from school as the primary educational problem experienced by children undergoing hemodialysis. This research result is justified by other studies that examine the direct effect of chronic disease on children's cognitive ability, such as their ability to read and count, and the influence of children's emotional problems on their education. This result also illustrates a correlation between chronic disease in children and educational problems stemming from emotional and behavioral effects and intimidation from friends in school<sup>17</sup>. These educational problems demand that family provide support and encouragement. One form of such support is cooperation with school administrators. Though not all families have solved this problem, they always try to meet their children's educational requirements. The families all realized that children are a living investment in the future.

## Conclusions

Family experiences in treating children with chronic renal failure influence a family's life in economic, physical, psychological, intellectual, and religious ways. Nevertheless, most families have an adaptive coping mechanism when confronting stressors while treating or nursing children.

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