

## Health care services need in hemodialysis patients: a qualitative study

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### Abstract

Qualified health care is health care that is provided based on the needs of the patient, not on what the provider institution has. Patients with chronic diseases such as kidney failure who undergo hemodialysis need more supportive nursing care, such as physical, psychological, and informational support about their condition. This study is intended to explore and identify the need for health services for patients who get hemodialysis therapy. This research is phenomenological qualitative. Data was collected using semi-structured and in-depth interviews with 17 participants with end-stage renal failure undergoing hemodialysis therapy, selected by purposive sampling. Thematic analysis was used to perform data analysis. The study found three main themes: services to fulfill basic needs during hemodialysis therapy; support received while undergoing hemodialysis therapy; and various health services that have yet to be received while undergoing hemodialysis therapy. It can be concluded that identifying service needs positively impacts service quality as healthcare workers will better understand patient expectations. Hemodialysis patients have basic physical, psychological, and support needs. Unmet needs include inadequate drug therapy, inadequate health workers, and unmet information needs. Healthcare providers should develop strategies to manage these needs, including physical and psychological modifications, improved facilities, infrastructure, human resources, and interdisciplinary approaches.

**Keywords:** hemodialysis; patient needs; qualitative studies; service

### 1. Introduction

Chronic diseases are the biggest challenge faced by the healthcare system, which causes huge healthcare costs for society and the government (Cockwell & Fisher, 2020; J. Wang et al., 2018). One of the chronic diseases considered a major health problem worldwide is chronic kidney disease (Ahmadpour et al., 2020). It is predicted that the prevalence of chronic kidney disease reached 850 million worldwide in 2017, higher than the estimated prevalence of diabetes and HIV/AIDS, which reached almost two times and 20 times, respectively (Jager et al., 2019). Globally, CKD ranks as the third fastest-growing cause of death. By 2024, it is expected to rank fifth as a common cause of death (Foreman et al., 2018).

The most common type of Kidney Replacement Therapy (KRT) worldwide is hemodialysis (HD), which accounts for more than 69% of all KRT (Bello et al., 2017) and 89% of all dialysis (Pecoits-Filho et al., 2020). HD outcomes vary globally, with high morbidity and mortality rates. Continued improvement in healthcare quality in HD patients is limited due to limited monitoring, variable outcome definitions, a lack of safety standards, and gaps in renal failure care, including shortages of health workers and healthcare information systems (Bello et al., 2019; Htay et al., 2021; Sautenet et al., 2018; Sola et al., 2020).

Physical, psychological, emotional, spiritual, social, and economic problems are things that are often experienced by patients who undergo HD to have an impact on their quality of life (Dingwall et al., 2021; Fadlalmola & Elkareem, 2020; Knowles et al., 2016). Patients undergoing hemodialysis experience much stress, family and social relationship changes, and sometimes isolation or social

restrictions (Theofilou, 2013). Complications can also occur in hemodialysis patients, among others: fluctuations in blood pressure, abdominal pain, headaches, sleep disorders, dry skin, itching, depression, and back pain (Gerasimoula et al., 2015; Zyoud et al., 2016).

In this case, health workers, especially nurses, are patients' main point of contact and are responsible for providing quality services by ensuring patient needs are met (Liu et al., 2018; Nikkhah et al., 2020). As a result, managing patients' diseases will improve with specific initial assessment strategies and meeting the needs of HD patients because it can help them define, plan, and actualize their goals (Xhulia et al., 2016). According to Ková et al. (2021), unmet nursing needs can threaten safety and management success in the implementation of nursing care, otherwise by providing patient-centered care, and nurses can help create a culture where patient safety is a top priority (Zaitoun et al., 2023). Hall et al. (2020) found that hemodialysis patients mostly do not get mobility, drugs, social support, and communication needs.

Various unmet needs in health services in Indonesia increased from 5.03% in 2021 to 6.09% in 2022, while Central Kalimantan province increased from 4.18% to 5.18% (Badan Pusat Statistik, 2023). The results of a preliminary study at General Hospital X Central Kalimantan (the only referral hospital serving hemodialysis patients) found that the number of visits to hemodialysis patients during the January-August 2022 period was 7697 visits, while the interview results on 7 participants found that the types of unmet needs were physical needs such as oxygen; psychological needs such as decreased adherence in a liquid diet, getting bored and thinking of stopping living HD; The need for education and consultation is mainly about food and its diseases.

It is necessary to identify needs that produce a menu of services to meet the needs of patients. This helps health care providers, especially nursing, to make the best decisions in planning nursing care and effectively as a guide to manage the needs and improve the quality of life of hemodialysis patients. Although many studies have explored the concept of necessity in patients with chronic diseases, most of these studies have focused on cancer patients (Cheung et al., 2022; Evans Webb et al., 2021). Research on the need for health services in hemodialysis patients has not been widely conducted. Based on this, researchers are interested in exploring the healthcare needs of hemodialysis patients. This study aims to explore and identify the needs of hemodialysis patients at X Palangkaraya Hospital so that a nursing model in the form of a menu of needs services can be used to meet patient needs.

## 2. Research Methods

This qualitative research uses a descriptive phenomenology approach to obtain information related to health service needs in hemodialysis patients based on their experiences. According to Farragher et al. (2022), a key step for healthcare providers to provide effective and person-centered care is understanding the person's experience.

The sample selection used a purposive sampling technique with criteria for end-stage renal failure patients who received hemodialysis therapy at X Palangka Raya Hospital in October-November 2022, and they were willing to be participants. Data was collected with semi-structured in-depth interviews of 17 face-to-face participants, with an average interview duration of 30-40 minutes. Thematic analysis is used for data analysis. There are six stages in thematic analysis: data recognition, identifying code, determining the initial theme, reviewing the theme, defining and naming the theme, and making a report (Braun & Clarke, 2014). This research has received approval from the Ethics Committee of the University of Muhammadiyah Banjarmasin with a Certificate of Feasibility of Research Ethics number 295/UMB/KE/X/2022.

## 3. Results and Discussions

### 3.1. Results

#### 3.1.1. Participant Characteristics

The majority of participants were male (58%). Three-quarters (76%) of participants were in the age range of 46-50 (76%). The majority had a primary education level of 47% and worked as housewives and traders at 35% each, as shown in Table 1.

**Table 1.** Characteristics of participants

Characteristics	Frequency (n)	Percentage (%)
<b>Gender</b>		
Male	10	58
Female	7	42
<b>Age</b>		
40-45 years	4	24
46-50 years	13	76
<b>Education</b>		
Primary School	8	47
Secondary School	4	23
High School	5	30
<b>Occupation</b>		
Housewife	6	35
Trader	1	6
Farmer	1	6
Private Employee	6	35
Civil Servant	3	18

Source: Primary data

Based on the data analysis results, there are three main themes related to health service needs in hemodialysis patients: services to meet basic needs during hemodialysis, support received during hemodialysis, and unmet needs of hemodialysis patients.

#### **Theme 1: Basic Needs Fulfillment Services During Hemodialysis**

##### **Subtheme 1: Meeting Physiological Needs (Oxygen Needs, Fatigue Management, and Edema)**

Physiological needs in this subtheme refer to the fulfillment of oxygen needs characterized by patient complaints of shortness of breath.

“The shortness of breath made me think between life and death, and then I thought of my wife for dialysis” (P8)

“Cannot breathe ....tightness” (P15)

“Ouch... please, cannot breathe... hard to breath” (P17)

Participants expressed that they felt weak, not energetic. Weakness and lack of energy were symptoms of fatigue in participants.

“My body is weak, there is no energy..., need help” (P3)

“Cannot get up first, no limp” P7)

“Limp all over... cannot get up... take care of it first” (P11)

“Needs to be treated so that it is powerful... after dialysis.. assisted by a new nurse in good body condition” (P17)

Participants also had other needs that must be completed, namely overcoming edema.

“My legs are getting swollen... ask for the medicine” (P1)

“It hurts to walk because my legs are swollen... take care of me first” (P3)

“Please treat me, please... my legs are swelling even more” (P11)

### **Subtheme 2: Fulfillment of Self-Esteem Needs**

Confidence, independence, and involvement of patients in treatment (asking for the patient's opinion regarding the treatment performed) have a positive impact and help them undergo hemodialysis.

“Yes, we were asked, we were asked how much first, what weight, how much pull, first asked as much as we could” (P16)

### **Subtheme 3: Fulfillment of Spiritual Needs**

The spiritual needs of patients in the form of religious activities such as praying, praying have been facilitated by the hospital with religious services, one of which is the availability of a place of worship.

“There is no difficulty because to do worship, I am Muslim, I can do it in the morning, and for Dluhur praying, I can still do it at the hour where the average work is completed at 12 o'clock, so it does not leave the obligation” (P3)

### **Subtheme 4: Proximity and Concern of Health Workers to Patients**

Some participants expressed that coming to a health facility is to ask for protection through a sense of security and comfort while undergoing treatment. Patients expect the need for communication and closeness with health workers, and during interviews, researchers ask, what is the best need given? Almost all expressed empathy, were full of kinship, and greeted patients.

“So when it comes, it has been served, good, and very good. The nurses are also very friendly, full of brotherhood... So this makes patients feel at home, too, and the kinship is very high. Anyway, the service is good so that it makes the patient feel comfortable in undergoing treatment, sometimes I joke, laugh and I like that” (P6)

## **Theme 2: Support Received During Hemodialysis**

### **Subtheme 1: Instrumental support**

Instrumental support includes money loans, provision of goods and food, administrative services (BPJS), and the availability of medicines. Participants revealed that they received instrumental support in the form of payment of hemodialysis administration costs that had been borne by BPJS and also assistance from family.

“No, we only BPJS for one month 150. The children are the ones who pay” (P5)

### **Subtheme 2: Informational Support**

Informational support includes any material such as providing information, knowledge, instructions, suggestions, and feedback about the situation and condition of hemodialysis patients.

“What the nurse or doctor tells me is applied at home. For example, the water I consume is a maximum of 350ml, I apply it really at home, not exceeding what is said by nurses and doctors. Alhamdulillah so far there is no shortness of breath and no swelling” (P3)

### **Subtheme 3: Emotional Support**

Emotional support involves empathy, a sense of always accompanying the patient, and an atmosphere full of warmth and attention that makes the patient feel cared for and loved, comfortable,

confident, and enthusiastic about life. Patients from family, friends, and neighbors obtain emotional support.

“Well, it is also concerned that it is comrades in the office. It means they support and encourage. So many friends who provide support are the point. My family really plays a role in supporting me in the spirit of living this life. Neighbors too, ma'am, ask me to stay optimized, that is their response, give sincere and sincere support” (P3)

#### **Subtheme 4: Social Group Support**

Social group support includes communication and interaction with groups with similar interests and social activities. The third participant revealed that he often communicated with people who had experience undergoing hemodialysis to get information related to the treatment performed.

“Yeah, it means communicating with patients, asking for information related to their experiences during dialysis. They did it first, so I dug up much information from my previous patients” (P3)

### **Theme 3: Unmet Needs of Hemodialysis Patients**

#### **Subtheme 1: Health Services That Are Not Received During Hemodialysis Therapy**

Participants complained of discomfort due to pain and fever, especially in participants who installed double lumen catheter / CDL (P1, P12, and P15), but treatment from health workers was lacking.

“Yes, something is not fulfilled... body discomfort as well as pain in the area where the hose is installed” (P1)

“It is a lack of treatment... fever continues. This is what makes me uncomfortable”(P12)

“It hurts. It feels very uncomfortable where the hose is installed, very uncomfortable... but my complaint was ignored” (P15)

#### **Subtheme 2: Lack Of Number And Quality Of Competent Health Workers**

The lack of number and quality of competent health workers causes a decrease in patient safety, causes fear and anxiety, and is less than optimal in providing services.

“Yes, less skilled in needle nusuk, until several times the needle. There are many patients but the medical personnel” (P2)

“Afraid... anxious if you die on dialysis... called the slow response” (P5)

“Less optimal service because the limited work of people... the patient should be monitored during dialysis” (P11)

#### **Subtheme 3: Unmet information needs optimally**

Participants felt less involved in the treatment, so they felt neglected and lacked information during hemodialysis.

“No one gives information and consultation about diseases and progress during dialysis”(P3)

“No one says anything, feels neglected” (P7)

“I am not considered... When is it involved?... ooh poor man” (P12)

“I was not given any information about his progress... either heal or die” (P13)

“It is sad...to feel ignored, not involved even though I want to know about myself” (P16)

## **3.2. Discussions**

The serum ureal and creatinine levels in renal failure patients usually increase along with a progressive decline in kidney function (Brisco et al., 2013; Lau & Vaziri, 2017). For those with

kidney failure, dialysis helps them maintain homeostasis or a stable internal environment (Murdeswar & Anjum, 2023; Vadakedath & Kandi, 2017). This study showed the positive impact of hemodialysis in the form of laboratory results of all participants that showed a decrease in ureal and creatinine levels.

Although hemodialysis can help restore the functional ability of the kidneys, hemodialysis can also cause various complications. Some previous research results showed hypoxemia occurred in 10% of kidney failure patients undergoing hemodialysis (Campos et al., 2016; Meyring-Wösten et al., 2016; Palamidis et al., 2014), with a decrease in PaO<sub>2</sub> by 10-20 mmHg during hemodialysis (Sonkar et al., 2016). Intradialytic arterial oxygen saturation and low central venous oxygen saturation in hemodialysis patients indicate an imbalance between upper body systemic oxygen supply and demand, which is at risk of increasing mortality (Kooman et al., 2021). HD patients in this study complained of shortness of breath while undergoing hemodialysis. Some factors contributing to hypoxemia during hemodialysis include anemia, the type of dialysate and type of membrane used, and the presence of impaired lung function (Cader et al., 2019). Based on patient complaints, oxygen is a basic need that health services must provide for hemodialysis patients.

Another problem that patients complained about in this research was weakness and lack of energy. Weakness and lack of energy are signs of fatigue (Tsirigotis et al., 2022). Fatigue is a problem often experienced by HD patients, with a prevalence of up to 60% (You et al., 2022). Fatigue is a complex issue with many aspects (Brys et al., 2021). Some factors associated with fatigue in HD patients include old age, depression, comorbidities, lack of information about the disease suffered, marital status, education level, and insomnia (Bipin Kumar et al., 2021; Gerogianni, Kouzoupis, et al., 2018; Tsirigotis et al., 2022). Statistically high levels of physical and mental fatigue were found in patients with primary education and those who were less or uninformed about their health problems (Tsirigotis et al., 2022). The patient's ability to understand information is associated with the level of education. This is similar to our findings that most study participants had low education levels and were poorly informed about their health. Knowledgeable patients can better understand their condition and adhere to their treatment restrictions, so patient knowledge is important to manage their disease (Gerogianni, Lianos, et al., 2018). Conversely, the lack of understanding of patients with low levels of education may be due to the absence of access to health services and health information.

Fatigue can cause social, cognitive, and physical health problems and decrease the patient's quality of life (Burdelis & Cruz, 2023; Ju et al., 2020). However, fatigue is often ignored and not treated properly (van der Borg et al., 2021) because fatigue symptoms are subjective and difficult to identify (S.-Y. Wang et al., 2016). The importance of education by health workers regarding the symptoms of fatigue and how to overcome them can help patients improve their physical, mental, and social health.

Decreased kidney function in HD patients causes them to be more susceptible to hypervolemia, which leads to edema (Canaud et al., 2019; Kim et al., 2022). Hypervolemia is associated with malnutrition and inflammation that indirectly impact the heart (Dekker et al., 2018). Health professionals should consider various factors that affect hypervolemia in hemodialysis patients. It takes targeted programs that teach how to limit fluids, control thirst, and improve patients' ability to manage their health conditions.

Hemodialysis patients experience problems such as depression, anxiety, and poor quality of life (Um-e-Kalloom et al., 2020). Practicing religious beliefs and practices in the context of spirituality and/or religiosity as coping mechanisms, especially as a source of calm, peace, comfort, strength, and support, can help improve hope, mental health, and quality of life for patients (Abu et al., 2018; Bravin et al., 2019; Santos et al., 2017; Tavassoli et al., 2019). Religious services, including spiritual



intelligence training, can be done to serve the spiritual needs of hemodialysis patients (Hosseinpour et al., 2020).

Low self-esteem may reduce HD patients' adherence to treatment (Poorgholami et al., 2016). Social support, family, friends, and others positively affect self-esteem (Mehrabani et al., 2022). Self-esteem is defined as psychological well-being, where patients feel satisfied with their lives, which can be seen from acceptance of themselves / positive self-image and can adapt well to the change process when undergoing HD (Poorgholami et al., 2016). Often, patients' beliefs and desires are not met or respected. They feel rejected because they are not included in the treatment. HD patients' involvement in treatment has a positive impact on patients, which helps them undergo hemodialysis. Some participants in the study felt confident because they were involved in care. The nurse always discusses the action to be performed with the patient. Patient involvement in care can improve patient satisfaction and health outcomes (Krist et al., 2017). Årestedt et al. (2019) found that patient involvement in care includes receiving advice from health workers, expressing opinions and decision-making, and sharing feelings and information. Although some informants felt that they had received information and support related to their condition, others felt that they did not get enough information regarding the development of their condition.

The professional closeness between patients and health workers is also a major factor in the success of therapeutic treatments (Antonytheva et al., 2021). Establishing communication can create good relationships and foster empathy and mutual trust between health workers and hemodialysis patients. Without going beyond professional boundaries, such proximity can be a source of coping (Xhulia et al., 2016), resulting in quality care, increasing health worker satisfaction, and improving patient outcomes (Antonytheva et al., 2021).

The research found that hemodialysis patients receive a range of support: instrumental support, informational support, emotional support, and social group support from family, friends, neighbors, and health workers. Instrumental support is mostly obtained from the family. The family manages medical funds, looks after and cares for participants in the hospital, helps with daily activities while being treated at home, and provides comfortable rest facilities. According to Made et al. (2020), this instrumental support is by the economic function, where the family is a source of financial, material, and time allocation to meet the needs of family members. The higher the family support HD patients receive, the better their quality of life (Isdiarti & Ardian, 2020).

The main target of HD patient management is to improve the quality of life (Bakarman et al., 2019). Several previous research results showed that education programs about HD significantly increased the knowledge and quality of life of HD patients (Bakarman et al., 2019; Fadlalmola & Elkareem, 2020). Education is a form of informational support for HD patients. Early education about the patient's situation and condition is the basis for deciding to undergo hemodialysis (Rao et al., 2021). Educational program interventions improve patient understanding of hemodialysis, vascular access management, potential complications, dietary and fluid restrictions, treatment regimens, and strategies for coping with disease and hemodialysis (Fadlalmola & Elkareem, 2020).

Information for patient families related to informal access to caregivers and the provision of knowledge resources to assist in the management of patient symptoms at the initiation of hemodialysis treatment and general information about caring for hemodialysis patients can generally be provided by doctors, supported by several nurses (Matthews et al., 2022). Family support is the most important thing because, at the beginning of hemodialysis, patients consider it the biggest problem because they feel between life and death. Support from children, wives, and husbands made most participants want to routinely and enthusiastically undergo hemodialysis. Increasing family involvement in therapeutic regimens is an important issue in applying effective holistic treatment to

hemodialysis patients. Integrating the patient's family into a multidisciplinary group of health professionals is one of the most effective ways to improve treatment adherence (Xhulia et al., 2016).

Uncompleted needs of individuals with chronic diseases refer to needs not met by their region's chronic care system. These needs pertain to prevention, medical care, rehabilitation, and health care and are based on the difference between their current state of health and their perceived optimal state of health (X.-T. Ke et al., 2021). The results of this study show that the comfort needs of hemodialysis patients related to pain and fever have not been met. Patients complain of unresolved low back pain that sometimes appears during HD. Pain and fatigue are common symptoms in chronic renal failure patients (Almutary et al., 2016). The prevalence of pain was higher in hemodialysis patients (63%) than in patients undergoing kidney transplantation (46%), with musculoskeletal pain being the most common pain (45%) (Lambourg et al., 2021). Previous studies have shown similar cases and severity of chronic pain in HD patients ranging between 33% and 82%, while for acute pain, it was 21% and 92%, respectively (Brkovic et al., 2016). Pain is an aspect that should not be underestimated, so pain management in services is a very important aspect that must be met.

Some patients in the study also developed a fever while undergoing HD after double-lumen catheter (CDL) insertion or at home. Patients undergoing hemodialysis (HD) are at risk for infection, which usually originates from the cannula or CDL (Fysaraki et al., 2013). Villalon et al. (2018) found that 53.6% of HD patients had a fever, most of whom had high levels of bacteremia, especially in patients who used catheters. When viewed from the wounds of HD patients in this study, there were no symptoms that pointed to infection, but some patients had a fever that persisted from the beginning of CDL insertion until now. This caused some participants to want to stop undergoing HD. According to Pateinakis et al. (2014), it is important to include periodic febrile syndrome in the list of possible causes of fever of unknown origin in patients of all ages since some variants can appear later in life.

Services cannot be done immediately, so hemodialysis patients with positive Hbs Ag in this study also complained about making patients wait a long time. Health workers serve these patients last to avoid contamination with non-HBS Ag-positive patients. Participants also wanted the treatment room to be sealed with glass walls so that health workers would be more free to monitor and patients would feel calm during HD. Other complaints patients submit include machine errors during HD and some outdated devices. The results of this study are in line with the results of research (Biniaz et al., 2018), which showed that the lack of timely and accurate monitoring of the dialysis process in the form of less application of dialysis standards, accelerated hemodialysis time accuracy, and efficiency of dialysis devices is lacking. Error and obsolete hemodialysis machine equipment are obstacles to high-quality dialysis services.

The unmet needs of HD patients are further related to insufficient human resources in quantity and quality. This is one of the obstacles to HD services (Nobahar & Tamadon, 2016). The quantity and quality of human resources of health workers affect the satisfaction of the needs of chronic disease patients, especially hemodialysis patients (X. T. Ke et al., 2021). Competent nurses play an important role in maintaining safe and effective healthcare by combining knowledge, skills, and attitudes to enable healthcare workers to adapt to the ever-changing healthcare environment (Fukada, 2018). The lack of competent health workers causes the non-fulfillment of patients' rights to optimal service and reduces patient safety.

In contrast to the findings of this study (Culp et al., 2016), the authors identified three main unmet needs of HD patients: bereavement support, spiritual support, and end-of-life care discussions. The lack of provider training on communicating prognostic data may contribute to the limited number of end-of-life care discussions with this chronically ill population (Eneanya et al., 2015). Patients complain of short visits with their nephrologists, and nephrologists also complain of similar things in the form of limited time with patients and a lack of privacy in communication (Hall et al., 2020).



## 4. Conclusion

This process of identifying service needs produces a menu of services that positively impact service quality so that health workers know what the patient's expectations are in determining the type and quality of service desired. The needs of hemodialysis patients include basic needs (physiological, self-esteem, spiritual, closeness, and care of health workers) and support (instrumental, informational, emotional, and social groups). Unmet needs of HD patients include not being given treatment therapy when needed, a lack of competent health workers, and information needs that have not been optimally met. Healthcare providers have a major challenge in developing strategies to improve HD services by managing the various needs of HD patients, including physical and psychological modifications; improvement of facilities and infrastructure; improvement of service quality, including improvement of human resources; increased support for patients and families; and the application of interdisciplinary approaches.

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