

## Family Expectations on Hemodialysis Service Resilience in Disaster Situations: A Qualitative Study

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### Abstract

*Hemodialysis is a renal replacement therapy highly dependent on the availability of medical-grade water, stable electricity, and supporting technological systems. This dependency makes hemodialysis services vulnerable to disruption during disasters, particularly in earthquake- and flood-prone areas. Treatment interruption may increase the risk of serious complications and threaten patient safety. In this context, families play an essential role in maintaining therapy continuity; however, their perspectives in disaster mitigation remain underexplored. This study aimed to explore family expectations regarding the resilience of hemodialysis services in disaster situations. A qualitative exploratory approach with thematic analysis was employed. Primary informants consisted of two family members of hemodialysis patients, supported by source triangulation through interviews with one manager, one nurse, and two patients. Data were collected through in-depth interviews and analyzed using thematic analysis. The findings identified four main themes: (1) expectations for clear and structured hospital preparedness systems, (2) the need for technical education and risk communication, (3) clarity of emergency referral systems and alternative service networks, and (4) comprehensive protection of patient safety. The results indicate that families expect a structured mitigation system that is well-communicated and actively involves them in pre-disaster simulations and education. This study highlights that the resilience of hemodialysis services in disaster situations depends not only on infrastructure and hospital management but also on empowering families as integral components of the healthcare resilience system. Integrating families into preparedness planning may strengthen therapy continuity and enhance patients' sense of security during crises.*

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## INTRODUCTION

Hemodialysis (HD) is a renal replacement therapy used in patients with reduced glomerular filtration rate to sustain life and improve quality of life. In Indonesia, limited organ donors and financial constraints make dialysis the most commonly used renal replacement therapy compared to transplantation (1). Along with the increasing prevalence of metabolic diseases such as hypertension and diabetes, the burden of Chronic Kidney Disease (CKD) continues to rise. Data indicate an annual increase of 5–10% in stage 5 CKD patients, with the incidence of HD therapy increasing from 21.050 cases in 2015 to 61.786 cases in 2020 (2).

Hemodialysis services are highly dependent on technological and infrastructural support. Each session requires 120–150 liters of medical-grade clean water per patient, a reverse osmosis (RO) system, stable electricity supply, dialysis machines, and trained healthcare personnel (3). This dependency makes HD services highly vulnerable to disruption, particularly during disasters such as floods, earthquakes, or tsunamis. Disruption of water or electricity supply may halt dialysis processes and increase the risk of life-threatening complications (4,5).

Indonesia is among the countries with the highest disaster risk globally according to the World Risk Report 2024. West Sumatra Province is categorized as a high-frequency disaster area, and Padang City has specific vulnerability due to the combined threat of earthquakes and floods (6,7,8). These conditions place hemodialysis patients among highly vulnerable groups in emergency contexts.

International experiences highlight the importance of integrated preparedness. Following the 2011 major earthquake in Japan, HD preparedness systems were strengthened through patient registration systems, emergency communication networks, and routine emergency disconnection drills such as the “clamp and cut” technique. Pre-disaster mitigation in hemodialysis services is not solely the responsibility of hospitals but also requires active involvement of patients and families (9,10).

Families play a central role as caregivers, decision-makers, and primary support systems during crises. Education on safety procedures, administrative preparedness, and evacuation protocols is an essential component of family-based mitigation. Without such preparedness, the risks of panic, delayed evacuation, and medical complications increase. Despite various preparedness strategies being developed, family expectations regarding hemodialysis service resilience during disasters remain underexplored. Family expectations may influence risk perception, preparedness behavior, and adaptive strategies during service disruptions.

Therefore, this study aims to explore in depth family expectations regarding the resilience of hemodialysis services in disaster situations, particularly how families perceive system readiness, hospital support, and their role in maintaining therapy continuity.

## **METHODS**

This study employed a qualitative exploratory approach with thematic analysis to explore in depth the meaning and expectations of families regarding hemodialysis service resilience during disasters. The research focused on subjective experiences and meaning constructions formed by families as primary caregivers.

The study was conducted in a hemodialysis unit of a hospital located in an earthquake prone area in Padang with 8 machine HD and 16 patients per day. Data collection took place in January 2026. Participants were selected using purposive sampling with the following inclusion criteria: (1) immediate family members accompanying active hemodialysis patients for at least six months, (2) willingness to participate, and (3) ability to communicate effectively. Six informants participated in this study, including two family members (primary informants), two hemodialysis patients, one HD nurse, and one hospital management representative. Patients, nurses, and management were interviewed for source triangulation to strengthen data credibility regarding family expectations within the service system context.

The number of participants was determined based on the principle of data saturation, when additional interviews no longer generated significant new themes. Data were collected through semi structured indepth interviews lasting 30–60 minutes and recorded with participant consent, observations and although there are documents. Data analysis followed thematic analysis procedures, including transcription, repeated reading, initial coding, theme development, and interpretation of meanings. Credibility was ensured through source triangulation, member checking with primary

informants, and maintaining an audit trail. Ethical approval was obtained (No. B/101/UN16.12.D/PP/2025). All participants provided written informed consent, and confidentiality was maintained through coded identifiers.

**RESULTS AND DISCUSSION**

This study identified four main themes related to family expectations in supporting the resilience of hemodialysis services during disasters:

1. expectations regarding hospital preparedness systems,
2. expectations regarding technical education and risk communication,
3. expectations regarding emergency referral systems and alternative service networks, and
4. expectations regarding patient safety protection and therapy continuity.

Table 1. Participant Characteristics

Participant Code	Gender	Role	Age Range (Years)	Length of HD	Highest Education	HD frequency
Inf-1	Female	Hospital Management Representative	35–40		Bachelor’s degree	
Inf-2	Male	Nurse, Hemodialysis Unit	40–45		Bachelor’s degree	
Inf-3	Female	Hemodialysis Patient	40–45	1 years	High School Diploma	twice a week
Inf-4	Female	Hemodialysis Patient	55–60	2 years	High School Diploma	twice a week
Inf-5	Female	Family Caregiver	45–50		Bachelor’s degree	
Inf-6	Female	Family Caregiver	35–40		Doctoral degree	

Table 1 presents the characteristics of six participants involved in the study, representing diverse stakeholder perspectives within the hemodialysis (HD) care context. Of the six participants, four were female and two were male, indicating a predominance of female representation. Participants reflected multiple roles, including one hospital management representative, one HD nurse, two HD patients, and two family caregivers. The results of the thematic analysis are presented in Table 2.

Table 2. Thematic Analysis of Study Findings

Main Theme	Subthemes	Summary of Findings	Key Quotations
<b>1. Expectations for Unit-Based Hemodialysis (HD) Disaster Simulation</b>	a. Need for family involvement	Families advocated for routine disaster simulations in every HD shift and emphasized the active involvement of caregivers. Existing disaster drills are general in scope and not tailored to the specific risks and operational characteristics of the HD unit.	“There must be simulations... invite families so everyone is informed...” (Inf-5)
	b. Limited knowledge of emergency procedures		“There has not been a specific HD simulation yet.” (Inf-1)
	c. Simulations remain administrative in nature		
<b>2. Gaps in Operational Preparedness</b>	a. Absence of HD-specific simulations	No HD-specific disaster simulation has been conducted to date.	“We feel confused if an earthquake happens during HD...” (Inf-3)
	b. Lack of continuous education	Although practical education had previously been provided, it was not delivered in a systematic or sustained manner. In crisis situations, responses tend to be spontaneous, potentially increasing safety risks.	“Currently, coordination is done through a WhatsApp group.” (Inf-2)
	c. Spontaneous crisis response		
<b>3. Limitations in the Referral System and Inter-Facility Coordination</b>	a. Informal referral practices	Referral coordination relies primarily on personal networks rather than formalized systems.	“There should be a guideline handbook...” (Inf-5)
	b. Absence of written guidelines	Families do not have access to an updated list of active referral hospitals, leading to uncertainty during emergencies.	
	c. Information uncertainty		
<b>4. Economic Vulnerability and Access Barriers</b>	a. Additional financial burden	Patients and families incur additional expenses during emergency referrals. Road inaccessibility and power outages further constrain continuity of dialysis therapy.	“What we worry about is not only HD, but also the cost of going to the hospital if it is far from home...” (Inf-4)
	b. Transportation and geographical distance		
	c. Disruptions in physical access and electricity supply		

### **1. Expectations Regarding Hospital Preparedness Systems**

Most families expressed the expectation that hospitals should have clear, structured, and well-communicated preparedness systems. These expectations included the availability of evacuation standard operating procedures (SOPs) for hemodialysis patients, backup power systems, and guaranteed water supply for dialysis processes.

Families perceived the hospital as the central authority responsible for patient safety during crises. Given the technological dependence of hemodialysis services, families recognized that even minor infrastructural disruptions could have fatal consequences. Conceptually, these findings align with hospital disaster preparedness principles emphasizing system redundancy, including backup electricity, water reserves, and alternative communication systems (9).

In disaster-prone areas such as Padang, such expectations are rational and grounded in lived experience, as disasters are recurrent rather than hypothetical events. Interestingly, family expectations were not solely technical but also emotional: they sought reassurance and a sense of security knowing that systems would remain functional even amid chaos.

### **2. Expectations Regarding Technical Education and Risk Communication**

The second theme highlights families' expectations for more practical and applicable education concerning emergency procedures, including understanding emergency dialysis disconnection techniques such as the clamp-and-cut method.

Families acknowledged that time is critical during earthquakes or floods. However, most reported never being involved in routine simulations or disaster drills. This lack of involvement generated anxiety, particularly regarding scenarios in which healthcare staff might be unable to provide immediate assistance.

Masakane et al. (2016) reported that dialysis units conducting routine disaster simulations including emergency disconnection and patient evacuation drills demonstrated significantly reduced clinical errors and patient complications during large-scale disasters (11). These findings reinforce that simulations are not merely administrative requirements but essential learning mechanisms for building coordinated and trained responses. When families understand basic emergency procedures and evacuation steps, collective responses during disasters may become faster and more coordinated.

### **3. Expectations Regarding Emergency Referral Systems and Alternative Service Networks**

The third theme relates to family expectations for a clear emergency referral system when hemodialysis services are disrupted. Families expressed concern about therapy delays exceeding two or three days, which may result in serious complications such as hyperkalemia or fluid overload. Families expected the availability of an updated list of alternative hospitals, cross-facility communication systems, and simplified administrative mechanisms during emergencies.

Field findings indicate that families desire systems that are not only responsive but proactively prepared before crises occur. This aligns with the concept of health system resilience, defined as the capacity of health systems to absorb shocks, adapt, and maintain essential functions (12). Hemodialysis represents an essential service with strict therapeutic intervals, where even a single missed session may lead to clinically significant consequences. These findings also demonstrate that families possess practical health literacy derived from caregiving experiences, even if not expressed in clinical terminology.

### **4. Expectations Regarding Patient Safety Protection and Therapy Continuity**

The final theme reflects family expectations for comprehensive protection during and after disasters, encompassing physical, administrative, and financial aspects.

Several families expressed concerns regarding financial access and logistical challenges if relocation to alternative facilities became necessary. They expected flexible and responsive policies during emergencies.

Yuan et al. (2013) found that dialysis patients with lower socioeconomic status experienced longer therapy delays during urban flooding events compared to those with higher socioeconomic status (13). Additionally, the Centers for Medicare & Medicaid Services (CMS) recommends that dialysis facilities maintain active referral lists, cross-facility communication mechanisms, and pre-arranged emergency financing agreements prior to disasters.

From a family resilience perspective, families act as primary support systems striving to maintain patient stability amid uncertainty. However, resilience has limits. If external systems are not adaptive, psychological and financial burdens on families intensify (14).

These findings illustrate that disaster mitigation in hemodialysis services extends beyond clinical considerations, intersecting medical, managerial, social, and psychological dimensions.

Following the 2011 Great East Japan Earthquake and tsunami, Japan experienced massive disruption to healthcare services, including hemodialysis. Numerous dialysis facilities were damaged, clean water supplies were interrupted, and logistics distribution was disrupted. Thousands of dialysis patients were transferred to other prefectures to maintain therapy continuity (11).

In response, Japan developed structured preparedness strategies, including:

1. National registration systems for dialysis patients
2. Cross-prefecture referral networks
3. Community-based emergency communication systems
4. Routine emergency disconnection drills ( $\leq 40$  seconds clamp-and-cut procedures)

Importantly, the Japanese approach did not focus solely on infrastructure but also on patient and family involvement. Following the 2011 Tohoku Earthquake and Tsunami, numerous studies in Japan emphasized disaster preparedness in dialysis services, particularly focusing on emergency dietary management, structured referral systems, and patient–family engagement.

Comparatively, this study reveals similar patterns of expectation:

1. The need for reliable backup systems
2. Clear risk communication
3. Structured emergency referrals
4. Active involvement of patients and families

The difference lies in the level of system integration. In Japan, these measures are nationally institutionalized, whereas in the local context of this study, family expectations suggest that such systems are not yet fully communicated or operationalized. Conceptually, these findings reinforce the framework of health system resilience. Resilience is not merely the ability to withstand shocks but also the capacity to learn from past disasters and develop adaptive long-term mechanisms. In addition, resilience in disaster contexts may also be strengthened by incorporating local knowledge systems. Evidence from the Indigenous knowledge for disaster mitigation and climate threats in Mentawai, Indonesia study demonstrates that indigenous practices such as reading natural environmental signs, traditional communication tools, and community rituals—play an important role in strengthening community preparedness and adaptive capacity. Integrating such local wisdom with formal health system strategies may therefore enhance disaster mitigation efforts by aligning institutional preparedness with culturally embedded community resilience (15).

This study has several limitations. First, the limited number of family informants restricts generalizability; however, qualitative research aims for depth rather than statistical representation. Second, the study was conducted in a

single dialysis unit within a disaster-prone region, making findings context-specific. Third, data reflect perceived expectations rather than objective evaluation of system capacity. Finally, psychological aspects such as anxiety levels and coping mechanisms were not explored in depth. Despite these limitations, the findings provide meaningful insight into the family perspective as a key component in sustaining hemodialysis services during disasters.

## CONCLUSION

This study demonstrates that the resilience of hemodialysis services in disaster situations is not determined solely by infrastructure and hospital management but also by the active involvement of families in preparedness, communication, and therapy continuity.

Family expectations center on four key components:

1. Structured and well-communicated hospital preparedness systems,
2. Practical technical education and risk communication,
3. Clear emergency referral systems and alternative service networks, and
4. Comprehensive protection of patient safety and therapy continuity.

In disaster-prone regions such as West Sumatra, family expectations for procedural transparency, routine simulations, and referral certainty reflect a demand for operationalized health system resilience. Comparisons with Japan's experience following the 2011 Tohoku Earthquake and Tsunami highlight the importance of involving patients and families in pre-disaster education and cross-facility coordination to maintain continuity of hemodialysis therapy. Conceptually, disaster mitigation in chronic health services such as hemodialysis represents the intersection between health system resilience and family resilience. Integrating these two dimensions provides an essential foundation for ensuring patient safety and sustaining life-saving therapy during emergencies

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