RESEARCH ARTICLE

The experience of adherence among hemodialysis patients undergoing therapeutic regimen: a qualitative study [version 1; peer review: 1 approved, 1 not approved]

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Abstract

Background: Hemodialysis is one of the most widely used renal replacement therapies and the most efficient procedure for managing patients with end-stage renal disease. It can reduce the symptoms of the disease; however, it affects quality of life, resulting in major changes to all areas of life. Thus, patients must adhere to the therapeutic regimen of hemodialysis. Knowledge regarding the adherence of hemodialysis patients to their therapeutic regimens and their experience is needed as it forms the basis for developing comprehensive nursing care and broader nursing practices for renal disease patients. This study aimed to explore patients' experience of adherence to the therapeutic regimen.

Methods: The design of this study was formulated using a qualitative phenomenological approach with a purposive sampling method that involved interviewing 10 selected patients. Data analysis was performed using the Colaizzi method.

Results: The results of this study revealed five themes: (1) the most difficult period is the beginning of the hemodialysis program; (2) it is important for patients to perform self-care; (3) nurses play a critical role in improving adherence; (4) there is a decrease in patients' ability to perform physical activity; and (5) there are supporting and inhibiting factors of adherence to the therapeutic regimens in hemodialysis patients.

Conclusions: Adherence to the therapeutic regimen fluctuates. Thus, there is a need to optimize the role of nurses in improving adherence.

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Keywords

Patient experience, adherence, hemodialysis, therapeutic regimen, qualitative research, renal replacement therapy, end-stage renal disease, nurses

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Introduction

Hemodialysis (HD) is one of the most widely used methods of renal replacement therapies; it is the most efficient procedure for managing end-stage renal disease^{1–3}. Globally, the number of HD patients is increasing every year at an average rate of 7%–9%^{2–8}. Based on data from the United States Renal Data System (USRDS) in 2019, 86.9% of incident late-stage kidney patients began renal replacement therapy using HD in 2017⁹. In Indonesia, based on the 2017 data from the Indonesian Renal Registry, 77,892 patients undergoing HD and about 98% of patients with kidney problems still see HD as the best kidney replacement therapy¹⁰; most patients undergo HD twice a week, with each session lasting for four to five hours. According to the Center for Data Information of the Indonesian Ministry of Health in 2017, health care costs for kidney disease were ranked second highest, next to heart disease, in the Health Social Security Institution (BPJS)¹¹.

HD reduces patients' discomfort but cannot cure, recover, or completely replace kidney function. It also affects patients' quality of life and may cause major changes to their physiology, which can lead to disability^{12–15}. Patients need to self-manage their condition as well as adjust their behavior and lifestyle while adhering to the therapeutic regimen of HD, all of which rely on compliance with regard to their attendance at HD sessions, medication, fluid restriction, and diet^{12,16–19}. In addition to these four components, physical activity is another essential factor that must be carried out by patients as recommended. The National Kidney Foundation (NKF) recommends patients to undergo moderate physical activity for 30 minutes on most days²⁰, using a therapeutic regimen that focuses primarily on the recovery or maintenance of their quality of life²¹.

Adherence to the therapeutic regimen is central and paramount to achieving optimal, effective, and successful HD outcomes. Adherence is a crucial factor that helps patients achieve good therapeutic results. It contributes to reducing morbidity, mortality, and the side effects of HD, such as muscle cramps, malnutrition, sepsis, and infections. Moreover, it reduces hospitalization risk and promotes the maintenance of a good quality of life and health^{3,5,8,21–24}. However, failure to adhere to the HD regimen can lead to serious and occasionally fatal conditions, such as hypertension, muscle cramps, arteriovenous fistula (AVF) blockage, dyspnea associated with pulmonary edema, or heart attack due to hyperkalemia, and can lead to poor quality of life, decreased life expectancy, increased morbidity, mortality, and a higher cost and burden on the health care system^{3,16,17,25}.

Despite possessing sufficient knowledge of its detriments, poor adherence to the therapeutic regimen among HD patients has been consistently reported. For example, according to two previous studies, adherence to the prescribed diet was 24.0% and 27.7%, adherence to fluid intake restrictions was 24.5% and 31%, adherence to HD schedule attendance was 52.0% and 91.0%, and adherence to medication was 66.5% and 81.0%, respectively^{3,17}. Poor physical functioning is perhaps the most pervasive and disabling disturbance in patients' dialysis, and previous studies have suggested the benefits of

physical exercise²⁶. HD patients usually find it difficult to adhere to at least one of the therapeutic regimens. Adherence to therapy in patients with chronic disease is a multifaceted issue that requires holistic and varied approaches. Understanding of the experience of patients in regard to HD therapy adherence is needed to develop comprehensive nursing care and broad nursing practices for kidney disease patients²¹. Through the sharing of these experiences, other patients can become more aware of the lifestyle choices and behaviors that they may need to change, allowing them to improve their own adherence. Researchers who have a special interest in medical surgical nursing, particularly in hemodialysis, need to carry out comprehensive research to gain a deeper understanding of therapeutic adherence. Health workers, especially nurses, must pay attention to patients' experiences and perspectives.

Despite the number of studies that have been conducted on adherence among HD patients, none have explored the experience of patients in adhering to the therapeutic regimen. Thus, this study aimed to identify and explore HD patients' experiences of adherence to the therapeutic regimen regarding factors such as scheduled attendance, medication, fluid restriction, diet, and physical activity.

Methods

Ethical statement

Ethical approval was obtained from the Faculty of Nursing of University of Indonesia (No. 285/UN2.F12.D/HKP.02.04/2018), and the lead researcher attended qualitative research method training prior to the study. Patients who met the inclusion and exclusion criteria were identified by the researchers as eligible for the study. Eligible participants were informed of the objective and procedures of this research, and those who agreed to participate signed the informed consent form. To protect the confidentiality of the patients, patient names have been removed from all data.

Design

This qualitative study uses a phenomenological approach. Data were gathered through in-depth interviews recording the experiences of several HD patients on various issues relating to therapeutic regimen adherence. The research was conducted from October to December 2018. In addition, interdialytic weight gain (IDWG) data were analyzed to check if they support adherence to therapeutic regimen therapy.

Data collection

Sampling was performed using a purposive technique. The study was conducted at the HD unit of two hospitals in Semarang, Central Java, Indonesia by the first author. She is a lecturer in medical surgical nursing with Master's degree in nursing and specialist of medical surgical nursing focus on caring for patients with HD. Some training had been done in qualitative research methodology. In this study, she reported the findings to the other authors after data collection. The inclusion criteria were: (1) undergoing HD treatment twice a week for a minimum of one year, (2) aged 18 years or older, (3) able to verbally communicate in Indonesian or Javanese, (4) has no cognitive impairment, and (5) willing to participate.

Before conducting the research, the researcher and the chairman of the HD unit identified patients who could participate in the study. Subsequently, the researcher explained the study's objective, benefits, rights, risks, confidentiality, and procedure for participation. Thereafter, the researcher approached the patients and built a trusting relationship, then enquired about their willingness to participate in the study; a total of 10 patients agreed to participate and signed the informed consent form²⁷. None of the patients who were asked to participate in this study refused. We achieved data saturation from these 10 participants and found no new information; thus, no other patients were recruited.

Each participant underwent an in depth semi-structured interview for approximately 30 to 40 minutes in a room within the HD unit, where there were only the researchers and the participant. The interview was conducted using a guide²⁷, which was developed based on the concept of adherence to the therapeutic regimen and consultations with HD experts. The guide included questions relating to the experiences of the participants regarding adherence to the therapeutic regimen, such as scheduled attendance, medication, fluid restriction, diet, and physical activity. This concept was obtained by searching and reviewing references related to compliance of HD patients who were undergoing therapeutic regimens. From this arose questions that need to be asked to explore patients' experiences and the supporting and inhibiting factors in undergoing therapeutic regimens, including implementing HD, based on the program, medication, fluid restriction, diet, and physical activity. A list of questions was compiled. Before being used in research, this interview guide was reviewed by a clinical expert; a senior nurse who a Master's degree in nursing and has been working in the hemodialysis unit at a hospital in Central Java. During the review, the expert was asked to provide an assessment and feedback on whether the questions were formulated appropriately. After doing a review, the expert judged that the questions were appropriate. The expert suggested adding questions, "what is the impact or body's response when the patient could implement the therapy regimen and when they couldn't".

The interviews were recorded, with the participants' consent, to make it easier to transcribe them verbatim. To maintain data security and confidentiality, the audio recordings were coded and stored in locked cabinets and computer files protected with passwords, and not disseminated to unauthorized parties. In addition, the backup copy shall only be maintained for 10 years and used exclusively for research purposes and publication of the results. Field notes were also taken during the interviews. Hence, the data collected in this study included transcripts of in-depth interviews, field notes, and data from medical records relating to IDWG.

Data analysis

Based on the approach of Colaizzi²⁸, manual data analysis was conducted through the following steps: (1) we documented the collected data by creating verbatim transcripts of the in-depth interviews and the field notes. The transcripts were then stored electronically, and a hardcopy was made to facilitate the analysis.

(2) We repeatedly read all the transcripts. (3) Three researchers coded the data. We reviewed and analyzed the transcripts, selecting significant statements in connection with the research objectives, which we then highlighted as keywords. These keywords were referred to as initial coding, followed by axial coding. (4) Keywords with similar meanings were classified into categories. Similar categories were then grouped to form themes that fit the research objective (selective coding). (5) The results were elucidated and integrated using a deep and complete narrative description. (6) Finally, the new data that emerged were converted into a narrative description.

Rigor

The robustness of the study findings was based on the following four criteria: credibility, dependability, confirmability, and transferability²⁹. Credibility of the data obtained by the researcher conveys the results of the interviews that were analyzed, in order to verify that the data obtained is in accordance with their submission. In addition, discussions and consultations with experts regarding the categories and themes were conducted. Consultation was conducted with a Professor and lecturer from the Faculty of Nursing, University of Indonesia. She is an expert in a qualitative research methodology, author of books on qualitative research methodology and researcher with publications in national and international journals. The consultation was about the accuracy of the categories and themes. The state of the themes must be accurate and clear. Dependability was enhanced by thoroughly analyzing data using a structured approach, striving to interpret the results of the study correctly, and involving all researchers in developing the categories and themes. Confirmability was derived by showing the results of the interviews that were made temporarily, then creating themes after consulting with the expert. The researcher also codified the information and then conducted discussions and consultations with the same expert as for credibility. The discussion and consultation was about the coding process. The consultation was conducted after the researchers made a draft of data analysis that contained the groups of keywords from participant statements, categories and themes. The expert gave suggestions for rearranging the keyword groups because there were still participant statements that didn't match with the group. This process was conducted to reach agreement on the categories and themes obtained. Transferability is ensured by performing an external check where the researcher presented the results of the analysis to patients who did not store the results. The researcher asked two other hemodialysis patients who did not participate in this study to read the results of the study and asked for responses about the clarity the results study. Both of these patients stated that they understand the results of the study. They said that their experience of hemodialysis was similar to the patients in this study. The principle of transferability is a form of external validity, which shows that the research results from one study population can be applied to other settings or groups of participants³⁰.

Results

The characteristics of participants ($M_{age} = 48.3$ years; male-to-female ratio = 1:1) are shown in [Table 1](#). The average HD period was 3.15 years. Secondary schooling was the highest level

of education for most participants. The majority of the participants were married (60%), not employed (70%), had permanent vascular access (80%), and had an average IDWG of 4%–6% between their treatments (70%). Additionally, most of them had hypertension (60%) before HD and attended their HD treatment alone (70%)³¹.

Data analysis was based on the transcripts of the in-depth interviews of the participants' experiences regarding adherence to the therapeutic regimen, such as scheduled attendance, medication, fluid restriction, diet, and physical activity³¹. The five themes that were identified after data analysis are listed in Table 2.

Table 1. Participants' characteristics.

No	Participants' characteristics	Total
1	Age (in years)	
	Mean	48.3
2	Gender	
	Male	5
	Female	5
3	Educational level	
	Uneducated	1
	Elementary	3
	Secondary	6
4	Occupation	
	Working	3
	Not working	7
5	Marital status	
	Married	6
	Not married	4
6	Duration of HD (in years)	
	Mean	3.15
7	Previous illness history	
	Hypertension	6
	Hypertension and DM	2
	Not known	2
8	Vascular access	
	Permanent	8
	Temporary	2
9	Attendance in HD	
	Accompanied	3
	Self-attendance	7
10	Increasing weight between HD schedule	
	<4% (light)	3
	4–6% (average)	7

HD, hemodialysis; DM, diabetes mellitus.

The most difficult period is the beginning of HD

This theme was generated from the responses of seven participants consisting of two categories, namely (1) the reasons given by patients who did not attend HD as scheduled and (2) those who were often hospitalized at the beginning of HD.

"I go to alternative therapy, I get a massage and do not need to undergo dialysis, I tried it, but unfortunately, I failed to keep at it" (p1).

"I felt better and decided not to undergo HD" (p5).

"Initially, I was not aware of the schedule, and as a result, I missed three sessions before being hospitalized" (p6).

Patients were often hospitalized after starting their HD therapy due to their deteriorating physical condition.

"I was hospitalized for at least a year at the beginning of undergoing HD" (p6).

Important for HD patients to perform self-care

This theme was generated from the responses of six participants regarding patients' self-care to perform the HD therapeutic regimen and feel better.

"I always attended scheduled HD programs despite the fact that my condition was deteriorating and I didn't have any money" (p2).

"I took the medication as prescribed to prevent my health from deteriorating, thereby making things difficult for my family" (p2).

HD patients were also expected to decrease their fluid intake and embrace a good diet.

"Sucking ice" (p1).

"Eating candy to decrease nausea" (p1).

HD patients usually felt better after performing the HD therapeutic regimen.

"I feel better when I restrict my fluid intake and only gain a little weight and I don't feel good when I drink a lot and my weight increases" (p3).

Nurses play a critical role in improving adherence to therapeutic regimens

This theme was generated from the responses of all 10 participants regarding the following issues: (1) the patients do not completely understand the therapeutic regimen they need to adhere to, (2) nurses are required to advocate adherence to their patients, and (3) nurses are required to possess high nursing skills. Participants did not adhere to the required medicine intake and understood that fluid and diet restrictions usually influenced their daily fluid and dietary intake.

"I did not take the medicine since I felt healthy" (p7).

Table 2. Categories and themes derived from data analysis.

Categories	Themes
The reasons were given by patients who did not attend the HD as scheduled Those who were hospitalized at the start of HD program	The most difficult period is the beginning of the HD program
Self-care of patients (human regulatory functions that individuals must perform by themselves or with others' help in order to maintain their life, health, and general welfare to perform the HD therapeutic regimen) Those who felt better after carrying out the HD therapeutic regimen as recommended	Important for patients to perform self-care
Patients engage with the HD therapeutic regimen according to their knowledge Nurses are needed to encourage patient adherence Nurses need to be highly skilled	Nurses play a critical role in improving adherence to therapeutic regimens
Limitation in physical activity The body's responses after physical activity	Decreased ability to do physical activity
Supporting factors Inhibiting factors	Supporting and inhibiting factors of adherence to the therapeutic regimens in hemodialysis patients

"I only took the hypertension drug, leaving out others, since I was afraid of the effect it will have on my womb" (p3).

"A glass a day may be" (p5, p6, p9).

"I never measure the water I drink, if I feel thirsty I drink a little" (p2).

"Whatever is served" (p4). "I eat as much as I want to, no restrictions" (p1). "I eat it all" (p7). "I rarely eat fruit" (p8).

However, patients who do not adhere to the HD therapeutic regimen or end their sessions before the scheduled time are usually asked by the nurses to sign a consent letter.

"I was asked to sign if I requested to be treated by HD for 4 hours" (p9).

In addition, one of the patients stated that nurses should possess high nursing skills, especially for handling patients with difficult vascular accesses:

"Every time I undergo HD, the nurses always find it hard injecting me. My friends and the nurses always pity me..." (p2).

Decreased ability to do physical activity

This theme was generated from the responses of seven participants relating to the limitations in physical activity and the body's responses after physical activity, as illustrated by these statements from the participants:

"Cooking" (p2, p9), "washing" (p2, p3).

"I only sweep" (p2).

"Taking care of grandchild" (p5, p9, p10).

"I no longer participate in any sporting activity" (p1).

In terms of physical activity, some participants gave the following response:

"I cannot walk far at the moment" (p6), "I tend to get out of breath" (p5, p9).

Supporting and inhibiting factors of adherence to HD therapeutic regimens among HD patients

This theme was generated from the responses of seven participants relating to supporting and inhibiting factors.

"All my family members supported me..." (p2), "wife" (p7, p8), "family" (p8), "husband, parents, others family..." (p3).

"It is my obligation to go for HD" (p1).

"From myself..." (p7), "and my children who are still small..." (p4).

"My colleagues supported me..." (p3).

"The nurses are friendly here; they like to joke around, and I love it. Alhamdulillah, all the nurses are nice and they always motivate me" (p2).

Apart from these positive factors, there are also factors that do not support adherence to the therapeutic regimen, such as seasonal weather, cost, and environment.

"I cannot drink less at home because it gets very hot during summers" (p1).

"Sometimes, the cost is an issue. I often borrow money from my nephew." (p2).

"I don't go for HD therapy whenever there is a flood" (p2).

Discussion

The most difficult period is at the beginning of an HD program

HD causes major changes in the lives of patients with chronic kidney disease, affecting all areas of their life. However, non-adherence to HD therapy usually results in the deterioration of the patient's psyche^{7,13,14}. For most patients, the initial period of undergoing HD is usually the most difficult, since they are in a transitional period and must adapt to changes. However, not all patients are well prepared, and some are unaware of the importance of attending the therapy as scheduled. Some patients even use alternative medication and do not undergo HD despite their kidney disease because they feel healthy. This finding is in line with that of a previous study stating that patients with chronic kidney disease experience a lack of adequate emotional support from nurses during the transitional period of undergoing HD³².

In addition, many patients experience health-related conditions that could cause them to become hospitalized at the commencement of their HD therapy. This may be attributed to their chronic kidney disease, which is usually asymptomatic and detected late. Additionally, some patients with many of the risk factors related to chronic kidney disease are unaware of its complications and how to prevent them; thus, their kidney disease eventually progresses to its end-stage, which involves kidney replacement therapy. Patients who undergo HD for the first time tend to have poor general health with high comorbidities since such conditions are usually reported late³³. Delayed referral from primary care usually limits the choice of dialysis, and inadequate time for preparation can increase the risk of complications associated with the central venous catheters used for dialysis³⁴.

Important for HD patients to perform self-care

HD has the capacity to reduce patients' complaints, but it cannot cure or enable them to fully recover from the disease despite undergoing HD permanently. As a result, patients face many challenges, changes, and stressful situations, such as fluid restrictions, diet, associated medical conditions, and loss of the normal daily routine that they were previously used to^{7,34}. Therefore, self-care is needed on the part of patients in order to maintain their quality of life, health, and general welfare. Patients must keep undergoing HD as scheduled, take the medications as prescribed, manage their fluid intake, engage in physical activities, and meet all their nutritional needs. Based on their experiences in this study, patients observe differences in their physical health when they undergo the HD therapeutic regimen. For example, they feel optimally healthy, experience no shortness of breath, and have better psyche when they regulate their fluid consumption. However, they complain of discomforts, such as body aches, shortness of breath, swelling, inability to sleep, and a swollen stomach whenever they fail to do so. This finding is in line with that of a previous study stating that patients have the ability to perform self-care by maintaining their lifestyles, in accordance with that recommended by the HD therapeutic regimen, such as taking medication, restricting fluids, and dieting, among others³⁵.

Nurses play a critical role in improving adherence to therapeutic regimens

Patients are responsible for many aspects of their therapy. For instance, most of the patients in this study restricted their fluid intake without a specific means of measurement, did not make any special modifications to their lifestyle, and ate what was normally available to them.

Patients do not always have a valid and accurate understanding of the amount of medication they should take. For example, average patients consume medication based on their personal knowledge and judgment. Moreover, they often build their understanding according to their beliefs and common sense and they further use this understanding as an alibi to justify what happens to them⁷. However, in practice, patients do not always follow what is recommended. Patients' education level and ability to understand the information provided as well as the nurses' methods of delivering the said information are vital factors. This finding is in line with that of a previous study stating that due to time constraints, patients neither receive all the necessary information, nor can they understand the behavioral modifications required since the information is too complicated for them to comprehend³⁴. However, knowledge is a vital tool to empower patients and stabilize their health. Hence, a lack of proper understanding is an obstacle and the information provided by doctors and nurses is crucial to achieve total compliance^{7,34,36}.

Most of the participants in this study found it difficult to limit their fluid intake mainly because of thirst. This finding is in line with that of a previous study stating that the most prominent theme is the challenge in controlling fluid intake³⁷. This difficulty in restricting fluids causes an increase in IDWG, wherein an increase of <4% is normal, 4%–6% is average, and >6% is hazardous³⁸. In our study, we found that majority of the participants (70%) fell within the average category. An average increase of 4%, 5%, and 6% was exhibited by 4, 3, and 1 participants, respectively. The IDWG should be lower than 4% of dry body weight³⁹. Difficulty in maintaining weight during the HD period is a very common problem among many patients⁷. IDWG is an indicator of excess fluid that needs to be removed during dialysis, and a greater percentage indicates problems in controlling fluid intake^{40,41}.

Nurses are directly responsible for providing care to patients before, during, and after undergoing HD. AVF cannulation is an important skill that all HD nurses should have. This is essential to patients who have trouble since they have temporary vascular access or small blood vessels. Such patients can experience greater levels of pain, discomfort, and anxiety. This finding is in line with that of a previous study stating that not all nurses show a sufficiently high level of competence, which makes the patients more anxious⁴². Needle insertion error is the main cause of recirculation^{43–45}. Negative experiences during cannulation contribute to patients' fear of AVF damage and distrust in the HD staff⁴⁴. The results of other studies show that nurses must have technical skills combined with appropriate experiences, such as the ability to perform venous puncture, as it plays an important role in enhancing patient comfort⁴⁶.

In our study, HD was carried out in accordance with a pre-determined time limit of approximately four to five hours for each procedure. However, there are patients who end their sessions before the allotted time due to medical and non-medical reasons; for example, some patients exhibit severe intra-dialysis complications and thereby discontinue the scheduled HD, while some cite lack of time and transportation. For patients who want to end HD prematurely, nurses usually explain the consequences to them first, and then ask them to sign an informed consent form, stating that they fully understand the consequences of their action and accept all the risks that their discontinuation might ensue. Ultimately, nurses can improve HD effectiveness by adhering to the accurate duration of each session⁴⁵.

Decreased ability to do physical activities

The ability of HD patients to carry out physical activities changes over the course of their treatment. The most noticeable changes are decreased mobility, limitations in performing certain physical activities, shortness of breath, fatigue, and weakness, all of which hinder patients from completing the course of the treatment. There are three main factors that affect physical activity: renal failure, side effects of renal replacement therapy, and worsening of comorbidities. Low physical ability is also caused by uremic intoxication, anemia, mineral and metabolic abnormalities, increased cardiovascular risk combined with high comorbid disease, uremic sarcopenia, decreased muscle strength due to muscle catabolism, and metabolic waste^{47–49}. Patients experience physical challenges in life, which are reflected by limitations in carrying out certain physical activities. These limitations are caused by low energy and weakness due to restrictions on food and fluid intake, excess fluid, and increase in metabolic waste in the patient's body³⁶.

Supporting and inhibiting factors of adherence to the therapeutic regimens in hemodialysis patients

There are additional factors that influence adherence; some are supporting, while others are inhibiting. Supporting factors usually stem from patients, their families, nurses, and colleagues at work. Inhibiting factors include seasonal weather, cost, and occupation. Supporting factors can motivate individuals to continue the therapeutic regimen as recommended, thereby reducing the risk of hospitalization; therefore, the ability of patients to self-motivate is very important⁵⁰. Meanwhile, their family and friends could counsel and encourage them to undergo the HD therapeutic regimen as recommended. The availability of adequate support could reduce economic costs, and increase patients' participation, respect, cooperation, hope, trust, welfare, family health, and ultimately, adherence to the therapeutic regimen⁵¹. This finding is in line with that of a previous study stating that support has a positive influence on chronic kidney disease patients through several means that help them cope better, minimize their stress, assist with practical problems (e.g., accessing health services), and improve their psychosocial functions and adherence to therapy⁵².

Nurses also play an important role by ensuring that the patients undergo their therapy programs as recommended. They also

accompany patients undergoing HD and are involved in long-term intensive interactions with patients. Additionally, nurses educate and counsel while administering the therapeutic regimen, motivate and convince patients to undergo the program, provide them with emotional support, and participate in monitoring, evaluating, and maintaining long-term communication with them. This finding is in line with that of a previous study stating that nurses play a key role in supporting patients undergoing HD, understanding the patients' lives, and ensuring that the information provided will help them adapt to the situation, needs, and demands of HD⁷.

Meanwhile, the inhibiting factors are environmental and economic in nature. Environmental factors such as the weather prevent patients from going to the hospital to undergo their HD therapeutic regimen. Indonesia experiences two seasons: dry and wet. In the wet season, flooding makes it difficult to reach the hospital to carry out HD. In the dry season, hot temperatures make it difficult for patients to comply with their fluid restrictions, since they are thirstier than usual and hence, drink more than the prescribed amount. This, in turn, causes weight gain during the HD treatment. Thus, fluid restriction adherence is very difficult in tropical regions⁵³.

In addition, income, cost, and transportation are the major economic inhibiting factors. Patients generally experience a decrease in income since they cannot work. Moreover, those who sell food and beverages for a living find it difficult to undergo HD as the temptation to eat and drink the products they sell is great. Most HD patients in Indonesia receive financial assistance from the BPJS. However, they still must pay for the process in terms of transportation, their food, and for their accompanying family members. Sometimes, they may need to buy medications that are not covered by the BPJS. The results of one study showed that the cost of transportation to access HD service facilities is the highest cost factor for patients with health insurance⁵⁴. This is different from the United States where transportation and transit services are provided by the health system for disabled people, including patients with end-stage kidney disease⁵⁵.

In this study, the minor theme is the importance of educating patients regarding adherence to the HD therapeutic regimen. The participants are sufficiently educated, but poor adherence to the therapeutic regimen in HD patients is still consistently reported. Therefore, nurses, as one of the key health workers with the responsibility of educating patients, should promote patient adherence to the HD therapeutic regimen.

Conclusion

The experience of HD patients of adhering to the HD therapeutic regimen is fluctuating and personal in nature; it is influenced by factors that support and inhibit the process. The initial period is usually the most difficult, since patients experience multiple unfavorable conditions that they need to adapt to. Nurses play a critical role in improving adherence to therapeutic regimens. Based on the experiences of patients regarding being able to carry out therapeutic regimens in accordance with

the recommendations as well as being unable to make changes to their conditions, it is important for them to practice self-care to maintain their physical condition.

Nursing implications

Adherence to the therapeutic regimen is fluctuating; hence, there is a need to strengthen the supporting factors and weaken the inhibiting factors. Nurses are one of the health professionals tasked with the important role of providing clinical care and support needed by patients to achieve success during hemodialysis therapy. Thus, they must exercise their role, especially in preparing and assisting patients during the initial period of undergoing HD. They can achieve this through related education and counseling with respect to the therapeutic regimen, thereby making patients more likely to undergo the process as recommended. Nurses also need to continuously improve their knowledge and skills in carrying out nursing care. Lastly, they need to improve the quality of their interaction with patients during HD.

Limitations of the study

In this study, the data obtained from medical records were only those of body weight. Laboratory examination data supporting the therapeutic regimen such as phosphate, sodium, and albumin levels were not obtained, because laboratory tests are rarely carried out and are not covered by BPJS. Thus, future studies should address this issue.

Data availability

Underlying data

Zenodo: Underlying data the qualitative study: The experience of adherence among hemodialysis patients undergoing therapeutic regimen: a qualitative study. <http://doi.org/10.5281/zenodo.4301296>³¹.

This project contains the following underlying data:

- Interview transcripts in English in DOCX format
- Interview transcripts in original language in DOCX format
- Demographic and clinical characteristics of each participant in XLSX format

Extended data

Zenodo: Extended data the qualitative study: The experience of adherence among hemodialysis patients undergoing therapeutic regimen: a qualitative study. <http://doi.org/10.5281/zenodo.4301338>²⁷.

This project contains the following extended data:

- Informed consent in English.docx
- Informed consent in original language.docx
- Interview guidance in English.docx
- Interview guidance in original language.docx

Reporting guidelines

Zenodo: COREQ checklist for “The experience of adherence among hemodialysis patients undergoing therapeutic regimen: a qualitative study”. <http://doi.org/10.5281/zenodo.4301114>⁵⁶.

Data are available under the terms of the [Creative Commons Attribution 4.0 International](#) (CC-BY 4.0).

Acknowledgements

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This article represents the dilemmas hemodialysis patients (HDs) are facing in relation to their therapeutic regimen. This is an important aspect of the concern in the health care delivery continuum for HDs. Despite the qualitative nature of the study, applied small sample size and the purposive sampling method, its findings could make major contributions to planning of evidence informed therapeutic interventions and therefore to a better outcome in patients who might otherwise have poor adherence to the prescribed therapeutic regimen. The identified themes that correspond to the supporting and inhibiting factors of therapeutic adherence in the studied HDs are important additions to the scientific literature and could fuels development of comprehensive nursing care for HDs.

This manuscript is well written and all required details about the conducted qualitative study was provided by the authors. This include details about the importance of this study, the methodological procedures followed and findings with their robust interpretation. No further amendments are required and my suggestion is to accept the paper as it is.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Health promotion and behavior change

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 21 June 2021

<https://doi.org/10.5256/f1000research.30660.r86135>

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Purpose:

The stated purpose of this report was to “explore patients’ experience of adherence to the therapeutic [hemodialysis] regimen.” Specifically, the authors set out to identify themes regarding attendance, medication, fluid restriction, diet, and physical activity adherence in a sample of ten individuals undergoing hemodialysis therapy in two hospitals in Indonesia, using a phenomenological approach. While the study adds to the extant body of literature regarding adherence in end stage kidney disease (ESKD), there are some areas that require additional attention and are not entirely consistent with the available literature. In particular, there is literature that explores the adherence to various aspects of the ESKD therapeutic regimen as a whole, and individual components e.g., dietary and fluid restriction.

The authors state that “Despite the number of studies that have been conducted on adherence among HD patients, none have explored the experience of patients in adhering to the therapeutic regimen.” - This is not true, and demonstrates a lack of full exploration of the extant literature.

Methods:

We would have expected there to be more delineation about specific aspects of the regimen given the background - this is no different than the body of literature that already exists. The Rigor section is extremely long and provides an unnecessary amount of detail, while detailing regarding the methods for potential reproducibility is minimal.

Results:

Example quotes generally lack context and do not always support the themes as described. The emphasis on the role of nurses does not appear to be consistent with the stated purpose of the analysis. Despite providing quotes that describe symptoms and symptom burden, that concept is not described in results analysis

Discussion:

We feel the authors could have clearly articulated the following given the data available: how what they found differed or supported the current literature, implications of their results, and recommendations for the future.

Overall, this paper would work better if it focused on its specific context of the experiences of Indonesian HD patients who are on long term dialysis (>1 year). Then we can compare these results to the existing literature to see how the themes here may be different from data found in other HD populations.

English language translation is good overall but there are some spots where there is a barrier to understanding the authors' intentions because of language issues. We recommend another English language edit to improve clarity.

Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

No

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

No

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Chronic kidney disease, patient experience, outcomes, symptom and self-management, disparities in chronic illness

We confirm that we have read this submission and believe that we have an appropriate level of expertise to state that we do not consider it to be of an acceptable scientific standard, for reasons outlined above.

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