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RESEARCH ARTICLE

Factors Affecting Non-Adherence to Treatment in End Stage Renal Disease (ESRD) Patients Undergoing Hemodialysis in Indonesia

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Abstract:

Background:

Non-adherence to treatment regimens is a widespread problem of great clinical relevance among hemodialysis patients. However, only few studies have addressed the factors of non-adherence in End Stage Renal Disease (ESRD) patients, and none conducted in the Indonesia.

Objective:

The present study explores the reasons of non-adherence in end stage renal disease patients undergoing hemodialysis in Indonesia seen from perspectives of patients, caregivers and health professionals.

Methods:

The study is conducted using qualitative methods and is set in the hemodialysis unit in a private hospital in Bandung. A total of 23 respondents were recruited in this study. All participants were selected through purposive sampling and invited to participate in semi-structured interviews with open-ended questions. The data obtained were written in verbatim and analyzed using thematic analysis.

Results:

The six main themes related to non-adherence emerged. These themes were categorized into two clusters namely: (1) factors related to patient (patient related factors) (negative perception and treatment belief, denial, lack of awareness and knowledge and negative feelings) and (2) factors related to the treatment (treatment burden and financial problems).

Conclusion:

The findings showed determinants of non-adherence in ESRD patients from perspective of patients, caregivers and health professional. The finding from this study can be used as a base for designing an intervention, aimed to increase the adherence to treatment in ESRD patients who are undergoing hemodialysis.

Keywords: End stage renal disease, Non-adherence, Hemodialysis, Dialysis, CKD, Factors.

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1. INTRODUCTION

In Indonesia, the incidence and prevalence of patients with End-Stage Renal Disease (ESRD) show an upward trend [1]. Although the incidence of ESRD in Indonesia is lower than other chronic illnesses, this illness attracted the serious attention of Indonesian government as the cost of medical service for dialysis patients is very high [2]. Adherence to dietary recommendations, fluid restriction, prescribed medications, and attendance at Hemodialysis (HD) sessions are essential for optimal and effective treatment of patients with end-stage renal disease undergoing hemodialysis [3]. However, it is estimated that about 50% of HD patients do not adhere to their dialysis treatment regimens [4]. Based on previous research, the main focus in most studies related to non-adherence factor was only on patients' perspective [5 - 7] Studies which explore caregivers' and healthcare professionals' experiences are important to be conducted to have comprehensive insights into non-adherence in patients. Besides, identifying the specific factors associated with non-

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adherence in ESRD patients in Indonesia is important to determine the focus of future interventions in order to increase adherence to treatment. Thus, this study aims to find the factors associated with non-adherence in Indonesian patients undergoing hemodialysis; seen from patients, caregivers and health-care professionals' perspectives. Given the lack of knowledge in this area, we chose an explorative qualitative design for our study.

2. METHODS

2.1. Participants

The study used qualitative methods and was conducted in the hemodialysis unit of a private hospital in Bandung. Participants were recruited from the outpatient hemodialysis clinic at a private hospital in Bandung, a private health facility that provided services to most of the hemodialysis patients in East Bandung area. A total of 23 participants (11 patients, 3 caregivers, 7 nurses, 2 general practitioners and 1 nephrologist) were interviewed. The inclusion criteria for the patients were: diagnosed with ESRD by a nephrologist, adult (more than 18 years of age), undergoing hemodialysis for more than 6 months, and have an adequate command on the Indonesian language. Patients who had a mental illness, disabilities, speech-hearing problems, and memory loss were excluded. The inclusion criteria for caregivers were: involved in ESRD patient's daily care; for health professionals: treating ESRD patients for more than 1 year in hemodialysis clinic and for general practitioners: treating or consulting ESRD patients. The number of participants was based on their willingness to participate in this study and time suitability with the interviewer. The interview with patients was conducted while they were undergoing hemodialysis. We asked 32 respondents for their availability based on inclusion and exclusion criteria. However, few patients could not be interviewed because of their health conditions (*i.e*. feeling weak, shortness of breath or sleeping while undergoing hemodialysis) and because the schedule did not match with the availability of the research assistant who was asked to interview the patients.

2.2. Procedure

The healthcare professionals (nephrologist and hemodialysis nurse) informed the researcher about the eligible patients who were able to participate in this study. The research assistant approached the participants to explain the details of the current study and also asked them to fill an informed consent form. Participants who agreed to participate in this study were interviewed by a research assistant with a semi-structured interview of 20-60 minutes. In the patient group, individual open-ended interviews were conducted at the bedside while patients were undergoing dialysis. In the health professional group, the interview was conducted individually at the nurse station, while the caregiver was interviewed at the waiting room in hemodialysis department. All the interviews were conducted in Indonesian language and recorded using a digital voice recorder.

The interviews were conducted by 3 master students of clinical psychology who first received a 2-day training session by the researcher. The training covered information about (1) adherence in a patient undergoing hemodialysis, (2) general interview techniques and (3) how to administer the data. Each interviewer was supervised by the first author (KU) during their first interview and received feedback afterward. The initial questions for patients were about general characteristics, background (age, gender, marital status, education level, employment status, and insurance status) and duration of hemodialysis. After that, participants were interviewed on the following topics: (1) Participant's experiences of adherence in ESRD patients, (2) adherence issues relating to living with ESRD, and (3) exploration of factors affecting adherence.

All the interviews were audiotaped and the responses were transcribed verbatim in a Word document. The qualitative analysis software used was Nvivo version 12. Responses from the participants were read line-by-line and codes were assigned to each meaningful response. Similar codes were grouped into categories. All the categories were then reviewed to generate themes. The most commonly observed themes were considered as representing the whole meaning or quintessential experience of the dialysis [8]. In order to ensure the trustworthiness of data, all the notes from interviews and coding processes were kept as field notes. When there were disparate views concerning the interpretation of data, the team reviewed the raw data and created new categories until the agreement was reached [9].

3. RESULTS

A total of 23 participants (11 patients, three caregivers, seven nurses, two general practitioners and one nephrologist) were interviewed. As shown in Table **1**, the age of patients ranged from 24 to 61 years. The average time of hemodialysis was 42 month. The health professionals were involved in ESRD patient's treatment for more than five years.

3.1. Factors Related to Treatment Non-adherence

Six themes emerged from our data and were categorized into two clusters, namely: (1) factors related to the patient (negative perception and treatment beliefs, denial, lack of awareness and knowledge and negative feelings) and (2) factors related to the treatment (treatment burden and financial problems). In the remaining part of this section, we will elaborate on the six main themes.

3.1.1. Factors Related to Patients

Negative Perception and Treatment Belief. The majority of ESRD patients were non-adherent to the medical treatment because they consulted with traditional healing first and then visited the hospital for medical treatment. Traditional healing methods consisted of herbal therapy (using herb or plant ingredient), massage therapy, and spiritual therapy. Most patients had negative perceptions of hemodialysis treatment which was perceived as threatening. Negative perceptions regarding treatments also led to sceptical attitudes toward the benefit of treatment, as revealed by one of the participants:

Table 1. Demographic and characteristics of participant.

Variable	Participants				
	Patients	Caregivers	Health Care Professionals		
			General practitioner	Nephrologist	Nurse
Gender					
Men	4			1	4
Women	7	3	2		4
Age					
20-30	4				
31-40	3				
41-50	2				
51-60	1	1			
61-70	1	2			
Marital status					
Married	7	3			
Single	4				
Jobs					
Employed (full/part time)	3				
Unemployed	6	3			
Retired	2				
Educations					
High school	8	3			
Diploma	3				8
Physician			2		
Nephrologist				1	
Duration of hemodialysis					
< 12 months	2				
1 – 3 years	3				
4 – 6 years	3				
>7 years	3				
Health insurance					
Yes	11				
No	O				
Time caring for patients					
< 12 months	2				
1-5 years	4				
>5 years	5	3			
Time working as a renal health care professional					
1-5 years			1		4
6-10 years					3
>10 years			1	1	1
Relationship with patients					
Spouse		1			
Parents		2			

"In the beginning, I didn't want to do hemodialysis because there were a lot of people who said that hemodialysis would make you addicted. Once you do hemodialysis, you will have to do it for the rest of your life. I'm afraid that my blood will be mixed with other people's blood. So I chose alternative treatment because it's safer" (Patient, F.6)

The family also influenced the patients' perception about medical treatment. Information from friends, cousins or other patients who had an experience with traditional treatment motivated patients and their family to try other treatments aside from medical treatment. All the participants who consulted a traditional treatment became adherent to medical treatment after their condition got worst and they faced life risk emergency conditions, such as shortness of breath and loss of consciousness.

"It's better if I don't undergo hemodialysis...try alternative treatment first..I got the information from my neighbour..and she gave me a concoction that I need to drink every day, they gave me a lot of pills, there were 21 pills...I didn't know what's inside the pills. The medical expense was expensive but I forced it because I wanted to be healthy and refused to undergo hemodialysis. I used alternative treatment just for 3 months..my body couldn't take it anymore because I was fatigued. When they checked my HB, it was already low and I needed to undergo hemodialysis soon. Finally, I gave up and focus to undergo hemodialysis." (Caregiver, F.1)

Patients who did not have a caregiver usually became 'difficult patient'. The absence of a caregiver made the patients unmotivated, non-adherence and to experience difficulties in maintaining their health condition because there was no one to take care of them.

"the caregiver is important for the patient if there are

patients who never seen being accompanied by family member, their condition usually become worsened because no one take care of them, motivate them to adhere the new lifestyle as ESRD patient, patient's adherence or nonadherence was affected by their caregivers, more or less" (Doctor, F2)

3.1.1.2. Denial

. Although the ESRD diagnosis by nephrologist was very clear and revealed that the patients should undergo hemodialysis, majority of the patients did not want to believe it and they refused to undergo the treatment, as told by one of the participants:

"My complaints were actually swollen in my legs and shortness of breath...doctor said that I must undergo hemodialysis. I didn't believe it and assumed that the doctor misdiagnosed me..When I knew that kidney failure is incurable disease...I hardly accepted it. I must have had another illness..not kidney failure. " (patient, M.4)

Denial was expressed not only by the patients but also by their families. Health professionals often found that the patient's family was uncooperative because they thought the patient did not have to undergo hemodialysis.

"Psychologically, new hemodialysis patients and their families are unable to accept if patient's health condition requires him to undergo hemodialysis. Patients and their families are full of concern about the actual patient condition" (Nurse, F.3)

3.1.1.3. Lack of Awareness and Knowledge

. Lack of knowledge about ESRD and its treatment caused patients to not undergo the treatment recommended by the nephrologist. Majority of the patients perceived ESRD as a common illness and were unable to recognize the severity of their illness. They did not comply to undergo hemodialysis because of lack of knowledge of the treatment that should befollowed .

"I thought the disease was not serious, can be cured using non-prescribed medicine, massage can make me fit, it turned out that I need hemodialysis, the disease is the same level with cancer" (patient, M.11)

"I didn't know. I was 23 years old. I experienced shortness of breath suddenly. Everytime I felt stomachache or back pain, that was an ordinary sickness. I used generic medication and I could get well soon. But that was the early symptoms which means from first stage, second stage, third stage, fourth and fifth. When I was 23 years old, I was told to undergo hemodialysis" (Patient, M.2)

3.1.1.4. Negative Feelings

Some patients were confused and stressed since they faced deteriorating health conditions. In general, they thought that they would die soon and there was no need to adhere to the treatment. Nightmares and thoughts of death were common among ESRD patients. The patients felt exhausted and distressed due to their disease. Some patients reported that they almost felt like giving up.

"I always feel exhausted, sad, and want to give up, want to stop, do not want to undergo hemodialysis anymore when I am praying, unconsciously my tears flowing…I ask forgiveness for all my sins, and there was also one pray that come from my mouth 'take me away' right now God … I am tired" (Patient, M.9)

3.1.2. Factor Related Treatment

3.1.2.1. Treatment Burden

Non-adherence in ESRD patients was associated with a variety of treatments that were supposed to be undertaken by patients. The threatening part of the hemodialysis process for the patient was the use of a needle and its long time duration. Furthermore, the size, smell, and bitter taste of medicine made the patients reluctant to consume it, as revealed by one of the participants:

"The most terrifying this for me is injection…now I need to be injected twice weekly. The needle is as big as a toothpick….I shivered before the injection…my heart beats fast, I bit my veil, I tried everything, hold onto something…." (patient, F.4)

Fluid restriction was also difficult to adhere to by most ESRD patients in Indonesia. Living in a tropical country, when the dry season arrives, the thirst becomes challenging for ESRD patients. Aside from the hot weather, the abundant quantity of medicines which is necessary to take made the patients difficult to adhere to the fluid restriction .

3.1.2.2. Financial Problem

Financial problem was a common problem for ESRD patients and their families. Most of them stopped working and their medical expenses were borne by other family members. Although all Indonesian citizens are able to apply for the national insurance program, but the transportation fee of the hospital, cost of providing high-quality food and accommodation fee pose a burden on patients.

"Although hemodialysis is free, I just have to undergo it, but my life expense as ESRD patient is expensive. For example, if my Hb is not good, nurse said I should consume meat and eggs, and that does not include transportation fee to the hospital..and if I need laboratory check, I have to pay because it is not covered by insurance" (patient, F.11)

The patient's condition often worsens and needs treatment as well as medication, all of which are not included in the insurance. The financial burden is felt by the family because patients have to bear high medical expenses to take care of their health.

"There are some medications which were not covered by insurance companies, so we were forced to non-adhere to prescribed medication by a doctor. The personal medical expenses must be available" (caregiver, F.2)

4. DISCUSSION

The Chronic Care Model requires that health care professionals, patients, and families share complementary knowledge to deal effectively with chronic conditions [10]. The six main themes related to non-adherence in ESRD

patients emerged from this qualitative study. These themes were categorized into two types of factors namely: factors related to the patient (negative perception and treatment belief, denial, lack of awareness and knowledge and negative feelings) and (2) factors related to the treatment (treatment burden and financial problem).

In the present study, majority of the patients perceived the dialysis procedure as a threatening and painful experience. Patient's belief regarding the importance of treatments is a predictor of the treatment adherence in patients [11]. ESRD patients try to find another way to avoid hemodialysis. In Indonesia, traditional treatment is a popular treatment and is perceived as an alternative solution for their health problem or as a complement to medical treatment. A study on Indonesian breast cancer patients shows that traditional treatment is perceived as less expensive, without surgery, and does not require expensive transportation fee because traditional treatments can be accessible nearby. Besides, women with breast cancer in Indonesia also prefer traditional methods of treatments because these are not only focused on the patient's physical symptoms, but also take into account the patient's feelings [12]. Traditional treatments are selected by many ESRD patients because they are perceived as 'comfortable', without the use of needle and do not cause 'addiction' unlike hemodialysis. This finding is similar to other research which shows that most people who use traditional medicines believe that traditional treatment is more natural and safe [13]. Utilization of herbal products has also become popular among Indonesian ESRD patients. The patients view the use of herbs as more natural because they lack chemical substances; although evidence-based medicine shows that many herbal products are risky to use by patients with failing renal function [14, 15]. In addition, seeking traditional help first often delays early diagnosis and initiation of proper medical intervention.

In this study, patients denied that they had an illness although it had been very clear that the patients received ESRD diagnosis from a nephrologist. Most statements from the patients reflected fear of the 'unknown' and dialysis. Due to the fact that the end-stage renal disease, along with the treatment of hemodialysis, causes significant restrictions on maintaining the quality of life of these patients, the denial of the disease and need for treatment is a logical option. Patients who deny to have any treatment often show a stubborn attitude towards their treatment such as . missing follow up meetings and not taking the prescribed medication [16].

Related to the state of denial, patients were observed to be unclear and confused about their health condition . Some refused to seek further treatment and make changes in their lifestyle because they claimed that they did not feel the symptoms at all and reported that they felt themselves 'fine' and 'healthy'. Patients were not inclined to undergo the treatment because they were unable to understand the treatment procedure that must be followed. We found that patient's knowledge about their illness and treatment determined their ESRD treatment adherence. This fnding is in line with another study that showed that few patients got frustrated and hopeless, some of them even thought to end their lives due to the declining health condition [17]. Thoughts about early death and current dying condition were experienced by almost all the patients. The thoughts about death are one of the symptoms of clinical depression [18]. In patients with both Chronic Kidney Disease (CKD) and ESRD, the psychological burden of having an illness that may imply future morbidity and mortality may lead to depression [19]. Recent studies have shown that even patients with CKD who are not on dialysis have rates of depression up to 3 times higher than those in the general population [20]. Depression in ESRD patient is a predictor of patient's non-adherence to treatment and also emerges as an important predictor of adherence [21, 22].

In the early phase of hemodialysis, some patients were afraid of the dialysis procedure, such as the usage of a needle and found it excruciatingly painful. Some patients experienced panic attacks and were unable to control themselves. This condition is similar to that reported in a study that shows that anxiety is one of the common complications in patients with renal failure [23]. Even though WHO recommendations highlight the importance of fostering self-care, ESRD patients' decision-making on medical regimen adherence is not well characterized. In this study, most patients experienced difficulties in controlling fluid restriction and medication adherence. There is evidence that ESRD patients were prescribed 10-12 tablets per day on average to manage their multiple comorbidities [24].

The treatments for ESRD patients are expensive. Although the hemodialysis fee is covered by health insurance, but patients are required to pay for some medications and laboratory examination. On the other hand, the transportation fee to the hospital (at least twice a week) becomes burdensome to patients coming from out of town. Insufficient health insurance represents another formidable barrier to chronic illness self-management, limiting patients' ability to adhere to prescribed medications [25]. ESRD patients also require frequent hospitalization because of their declining condition and intensive care. This finding is in line with the condition of ESRD patients in developing countries such as in India and Pakistan; frequent and long-term hospitalization increases financial burden and medical cost that is self-funded by most of the patients [26].

The majority of ESRD patients are unemployed and rely on health insurance to undergo medication. A study on CKD patients shows similar findings. The ability of CKD patients to work and lead a productive life is hampered by CKD as they can no longer work and are unable to provide for their families [27, 28]. In this study, more than half of the patients receiving dialysis were not able to maintain their professions and some of them had to take retirement after undergoing dialysis.

CONCLUSION

Findings clearly indicate that there is a considerable psychological burden experienced by ESRD patients who are undergoing hemodialysis. Low adherence in ESRD patients is a common problem because of the obstacles faced by the patients, caregivers and health professionals in undergoing the medicaltreatment .

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The study was approved by the Research Ethics Committee of Universitas Padjajaran under the ethical license No. 349/UN6.KEP/EC/2018.

HUMAN AND ANIMAL RIGHTS

No animals/humans were used for studies that are basis of this research.

CONSENT FOR PUBLICATION

Informed consent was taken from all the participants.

AVAILABILITY OF DATA AND MATERIALS

Not applicable.

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CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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