

Conference Paper

Nurse's Experience As Educator in Hemodialysis Care to End Stage Renal Disease Patient in Hospital X: a Phenomenology Study

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Abstract

End Stage Renal Disease (ESRD) is progressive and irreversible damage to kidney function, which can reduce the quality of life of patients and death due to accumulation of uremia toxins in the blood. Hemodialysis is a temporary therapy used to prolong the life of the patient. The uncertainty of the treatment provides a unique response which became an interesting phenomenon for researchers to conduct research use the qualitative strategy for explore the nurses' experience and to describe it especially in the nurses' role as educator in hemodialysis care to ESRD patient in Hospital X. Aim of this study to provide an overview of nurse's experience as educator in ESRD patients during hemodialysis therapy in the Hemodialysis Unit Hospital X. this research used a qualitative method with a phenomenological approach has been conducted. The data collection technique used was using in-depth interviews. A purposive sampling was used to recruited the participant and, namely ten nurses were involved in this study with inclusion criteria as follows: (1) work as an executive nurse in HD unit, (2) have minimum Diploma III as basic education level. Data analysis using Colaizzi's method and then using thematic analysis. Four themes were found in this study: lifestyle changes, uncooperative patients, responsive patients, and patients do not want to stop dialysis. Future research can be conduct in fourth theme concerning withdrawal dialysis in ESRD patients in various perspectives including: ethical perspective and decision making for futile treatment, health coverage policies, and palliative care.

Keywords: Hemodialysis, Nurse Experience, Educator, End Stage Renal Disease

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1. Introduction

The global prevalence of Chronic Kidney Disease (CKD) is 13.4% which 48% have decreased kidney function and not undergoing dialysis and even as many as 96% of people with reduced kidney or kidney function are unaware that they have CKD [1]. In Indonesia, the prevalence of CKD's patients diagnosed by a doctor increases with age and increases sharply in the age group of 35-44 years 3.31 permil (‰), ages 45-54

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years 5.64 permil (‰), ages 55-64 years 7,21 permil (‰), and highest in the age group 65-74 years 8.23 permil (‰)[1]. Based on the Report of Indonesian Renal Registry (IRR) the number of new CKD patients who have to undergo hemodialysis therapy in 2015 were 21,050 people, in 2016 were 25,446 people, and in 2017 were 30,831 [2].

End Stage Renal Disease (ESRD) is defined as a decrease in kidney function in a person that cannot be recovered, which is fatal if dialysis or transplantation does not performed (Abbasi, 2010). This therapy is chosen more than other therapies [3]. However, in undergoing hemodialysis CKD patients frequently has not a good prognosis. In this case, maintenance of life-sustaining treatments only to prolong life without the real possibility to cure or at least eliminate critical conditions may be in vain so that such treatments can be stopped legally according to the rights of patients [4]. Hemodialysis treatment in ESRD patients is vegetative with aim to sustain and prolong the patient's life, but not to cure. So that it can be categorized as a futile treatment, for utility reasons, the issue of withdrawal dialysis in ESRD patients can be carried out.

On the other hand, nurses have five roles as the follows: care giver, communicator, advocator, counselor, and the last, educator in which role as educator, nurses have the responsibility to help clients learn about their health and health procedures and explain the reasons routine care activities are carried out as well as strengthening the patient's learning or behavior and evaluating his progress [5]. In the treatment of hemodialiasis in ESRD patients the role of the nurse as an educator is needed to provide education to patients about hemodialysis care that must be routinely carried out by ESRD patients. In addition, nurses must also provide education about treatment procedures, food intake that must be consumed by patients to maintain their own health. The role of nurses as educators is very important to be carried out as well as possible for the sake of improving the degree of health, maintaining and or healing patients in general, nurses provide health education to patients, then compliance in carrying out the recommendations will be higher [7].

Hospital X is the Y province has referral hospital for hemodialysis. According to the results of an initial preliminary study conducted at the Hemodialysis Unit, there were 162 hemodialysis patients at this hospital. There are 15 nurses in the hemodialysis unit and the average number of patients is 23-25/day. According to the results of interviews with the head of Hemodialysis Unit, patients undergoing hemodialysis are CKD patients in stages 4 and 5. Furthermore, she said that many patients came for hemodialysis therapy and we were overwhelmed because of the small number of devices in this hospital and there are no policies or regulations regarding withdrawal of dialysis for ESRD patients so there is no priority for all the hemodialysis patients. The results of interviews with

several executive nurses in the Hemodialysis Unit said they were not aware of any dialysis withdrawal procedures. Nurses also said that they had diverse experiences with ESRD patients undergoing hemodialysis.

The uncertainty of hemodialysis therapy in ESRD patients carried out gives a patients' unique response which nurses can observe while accompanying patients in therapy. This unique response became an interesting phenomenon for researchers to conduct research use the qualitative strategy for explore the nurses' experience and to describe it especially in the nurses' role as educator in hemodialysis care to ESRD patient in Hospital X.

2. Methods

2.1. Study Design & Sample

This study uses a qualitative method with a phenomenological approach to describe the nurses' experience as educator in hemodialysis care to ESRD patient in Hospital X. The research sample uses purposive sampling, with inclusion criteria as follows: (1) work as an executive nurse in HD unit, (2) have minimum Diploma III as basic education level, a total of ten participants were included in this study.

2.2. Instrument

In qualitative research, researchers have a role and function as human instruments, namely researchers who become instruments or research tools themselves (Hooloway & Galvin, 2017). The research team's input, and reviewers related to open questions, formulate probing questions and how to take notes during the study used by researchers to evaluate themselves and improve researchers' abilities in conducting in-depth interviews. The open question asked by participants was, "Can you tell your experience in hemodialysis care of ESRD patient in the context of your role as an educator in Hemodialysis Unit Hospital X?". Researchers also used a Sony ICD PX 333 voice recorder to record the interview process.

2.3. Data Collection Procedure

The data collection process was carried out for 2 months from May to June 2019. The first stage the researcher met the head of Hemodialysis Unit to get information related to

prospective participants. After getting a list of participants' names, age, and education level, researchers met prospective participants. If the prospective participant is willing as participant, informed consent procedure will be made. The researcher explained research mechanism by interviewing, the benefits of the study, and the length of time needed for the interview and giving participants the opportunity to understand and ask questions or clarify things that were not understood before signing the informed consent.

Before starting interviewed, the researcher clarified again related to the agreed interview time. The researcher then adjusts the comfortable position between the participant and the researcher before conducting the interview process and puts the recorder in a position that does not interfere with comfort. The researcher begins by recording the date and time the interview began, the participant's identity, and the participant's code. The researcher begins the interview by asking open-ended questions. To dig deeper information researcher use probing questions.

During the interview process, the researcher records the keywords that will be used as probing, difficult words or terms that researcher does not understand so that can be clarified by participants, non-verbal expressions, and environmental situations during the interview too as resumes. The interview process lasts approximately 20 minutes for each participant.

The researcher will stop the interview if there is no new information that can be obtained from participant, and the researcher believes that the data is strong enough to describe the nurses' experience.

2.4. Data Analysis

According to Creswell [8], data analysis on the phenomenological approach uses a systematic coding process. This process begins by listening to the participants' verbal descriptions, then rereading the verbatim transcript. In this study the analysis used by researcher is Colaizi method because it has several advantages including the steps used which are clearer, systematic, detailed, simple, and involve participants to make clarifications regarding the results of the analysis. The description of the analysis stage of the Colaizi method in Cresswell (2013) is as follows:

- 1) Read all the results of the transcript repeatedly to get a meaning from the participant's experience;
- 2) Look back at the data transcript and choose a significant opinion or relate to the phenomenon that you want to explore;

- 3) Formulating the meaning or significance of important statements;
- 4) Categorize the meaning into the theme and match it with the participant’s expression;
- 5) Form a description of the phenomenon;
- 6) Identifying fundamental structures;
- 7) Confirming or revalidating the description of the phenomenon to participants.

3. Result

TABLE 1: Characteristic of Respondent.

Code	Age (years)	Gender	Level of Education	Length of work (Years)
P1	30	Male	Diploma III Nursing	5
P2	31	Male	Diploma III Nursing	3,5
P3	30	Male	Diploma III Nursing	5
P4	27	Female	Diploma III Nursing	4
P5	44	Female	Diploma III Nursing	14
P6	43	Female	Diploma III Nursing	21
P7	28	Female	Diploma III Nursing	3
P8	51	Female	Diploma III Nursing	4
P9	35	Male	Diploma III Nursing	8
P10	41	Female	Diploma III Nursing	1

TABLE 2: Result.

Theme	Sub Theme
Change the lifestyle	Fluid Restrictions Family education Fruit diet
Uncooperative patients	Difficult to motivate patients Difficult to understand education
Responsive patients	Patient obedient Responsive patient
Patients do not want to stop dialysis	Withdrawal dialysis Do not want to stop dialysis

3.1. Change the Lifestyle

The role of nurses as educators is very important in educating lifestyles. Lifestyle becomes an important thing that needs to be considered by ESRD patients, which is about how to restrict fluid, what can be eaten by patient and the role of the family to educate at home. Non-compliance with diet is one of the problems in CKD patients undergoing hemodialysis [9]. One of things that can be understood by patients is the importance of changing styles for their survival.

Lifestyle is the part of life that most people control, and such behavior often changes. Lifestyle that must be carried out by ESRD patients is by taking the fluid consumed. The liquid that can be consumed by ESRD patients is 600 cc / 24 hours. Patients who can change their style can extend their age. Besides having to limit fluids, ESRD patients must also limit food consumption. ESRD patients should not eat foods that contain lots of fluids. Because if the ESRD patient does not maintain their food and drink intake it can result in a decrease in the quality of life. Health status and quality of life are very important concepts for patients with chronic kidney disease (CKD) and those undergoing hemodialysis [10].

3.1.1. Fluid Restrictions

Most participants said their experience of fluid restriction education. An increase in food and inappropriate fluid causes an increase in production of metabolites in the blood and poisoned fluids, which results in complications and premature death [11]. This is consistent with what the participants expressed (P1) and (P2):

"...yes usually education is given about reducing drinking..."(P1)

"...we also tell not to drink too much, especially if they edema maximal is 600cc / 24 hours..."(P2)

3.1.2. Family Education

During the education the nurse not only provides education to the patient but also the patient's family so they can continue treatment at home. This is in accordance with what was expressed by the participants (P9):

"...Early hemodialysis patients are usually rather difficult to provide education, we usually ask for help from their families to educate patients who are

usually the same house so that our education can run for these patients, education to the family is also very important to continue further therapy at home...”(P9)

3.1.3. Fruits Diet

Besides the liquid is also found in fruits, hemodialysis patients are advised not to eat fruits that contain lots of fluids. As expressed by participants (P2) and (P9):

“...then if the food is less eating fruit that can cause tightness, nausea, the safest fruit is papaya, don't have a lot of fruit that contains water...”(P2)

“...Usually, for hemodialysis patients, they must drink, food such as fruits cannot except papaya, but there must be a limit as well...”(P9)

3.2. Uncooperative Patients

The obstacle in carrying out the role of an educator is when the patient is uncooperative. The patient does not want to undergo hemodialysis and does not want to follow the advice given by the nurse. Lack of support and motivation is one of the reasons patients become uncooperative. Patients who undergo hemodialysis therapy need support from health workers [12]. Support of health workers is very important for patients undergoing routine hemodialysis therapy and is one of the factors that influence the compliance of CKD's patients to undergo hemodialysis.

3.2.1. Difficult to Motivate Patients

In the hemodialysis unit, there are new patients and old patients. Some nurses said that they had difficulty motivating new patients because according to him new patients could not accept the reality of the disease. In addition, the level of education affects the patient's understanding of the disease which results in being difficult to motivate as expressed by the following participant (P3):

“...The most difficult thing is we motivate new hemodialysis patients, because they think why do I have to experience this disease. Motivate the patient at least want to come to the dialysis room first...”(P3)

3.2.2. Difficult to Understand Education

In addition, the obstacle obtained as an educator is that it is difficult for patients to understand education due to several factors, namely the lack of education as expressed by participants (P7):

"...constraints of social status, their understanding is different from ours so we explain in detail. First, we explain to give examples of re-understanding or not education that we provide about fluid restriction. They are ordinary people who do not understand, they still deny that they must dialysis, do not accept the disease..."(P7)

3.3. Responsive Patients

Patient compliance in undergoing hemodialysis, as well as following the education provided by nurses is one of its own pleasures for nurses. The nurse is happy when the patient is responsive to the education of the fluid consumed. Because the patient's condition will not worsen if following the nurse's direction.

3.3.1. Patient Obedient

Another experience that is almost felt by some nurses is cooperative patients. Feelings of pleasure arise when patients are cooperative in carrying out the education provided to limit fluid and routinely carry out hemodialysis on schedule. As stated by the following participants (P2):

"... if the routine patient has understood what the food is, what are the restrictions, what should we do, well then we as nurses are happy too ..."
(P2)

3.3.2. Responsive Patient

Based on nurses' experiences that positive responses from patients such as listening to education provided, limiting fluid consumption, and undergoing routine hemodialysis make nurses happy and easier to do their work as expressed by participants (P5):

“...likes patients who are responsive one of the education is the management of drinking well he asked me how can I drink how much, can I eat anything and then according to it, it’s a cooperative patient...”(P5)

3.4. Patient Do Not Want to Stop Dialysis

No patient wants their hemodialysis therapy stopped. Because according to them the condition will worsen and will die if hemodialysis is not done. Death is one of the reasons patients do not want to stop hemodialysis. Because they undergo hemodialysis to prolong their lives.

3.4.1. Withdrawal Dialysis

Regarding the experience of withdrawal dialysis, some nurses are know about withdrawal dialysis. But the participants did not educate the patients because there were no patients who wanted their hemodialysis therapy be withdraw.

“...I’ve heard about withdrawal hemodialysis, but here there are no patients who want withdrawal hemodialysis and nurses here also never recommend it ...”(P3)

“...There is no withdrawal dialysis, patients also do not want to be withdrawal dialysis because they know that if they don’t do hemodialysis they can die ...”(P4)

3.4.2. Do Not Want to Stop Dialysis

Death is the main reason patients do not want withdrawal their hemodialysis. This is a rational reason because the goal of treatment is to preserve the patient’s life. Hemodialysis is considered as one of the therapies used to prolong a patient’s life by removing toxins from his body as expressed by respondents (P1):

“...Nothing, nobody wants to withdrawal because they know that if they are withdrawal they will definitely drop because the poison isn’t wasted ...”(P1)

4. Discussion

4.1. Change the Lifestyle

Education for lifestyle changes was revealed by all participants in patients who present with edema, shortness of breath and hypertension. Patients who present with an edema state that the patient does not limit the fluid that should be consumed. The role of the nurse as an educator is very important in this regard. The role of nurses expected by others towards someone who meets the qualifications and has a position in the health care system [14]. A large part of nursing education is carried out in clinical environment [13]. Nurses must be diligent in educating patients to restrict fluid. In addition, food restrictions also need to be limited by patients. Fruits that contain a lot of water are prohibited from being consumed by ESRD patients.

Fluid management is a skill in identifying problems, setting goals, solving problems, making decisions in response to fluctuations in signs and symptoms, taking action in response to physiological responses to lack of body fluids, monitoring and managing symptoms [16]. An increase in food and inappropriate fluid causes an increase in the production of metabolites in the blood and fluids that are poisoning resulting in complications and premature death [11]. Education about fluid restriction is education that must be given to patients, so patients can know how much they consume fluids and food. Non-compliance with diet is one of the problems in patients with CKD undergoing hemodialysis[9].

This fluid restriction was revealed by the participant where the nurse had to educate the patient about drinking water, ie how much fluid was entering the body. This is in accordance with the instructions for patients undergoing hemodialysis according to Thomas [15] by encouraging patients to drink in small glasses instead of large glasses. Fluid restriction is very important for patient survival.

4.2. Uncooperative Patients

Difficulty to motivating patients provides their own experiences for nurses. Lack of patient acceptance of the disease he suffered is one of the causes of the difficulty of patients being motivated. Participants said that the motivation of hemodialysis patients was done by persuading patients to come to the Hemodialysis Unit.

Motivation and hope are factors that can increase patient compliance. Motivation is something that can encourage someone to act to achieve certain goals [17]. Rahma Dani (2015) said that patients undergoing hemodialysis therapy need support from health workers. Health worker support is very important for patients undergoing routine

hemodialysis therapy and is one of the factors that influence the compliance of patients with CKD to undergo hemodialysis.

Low social status and education are also factors that are difficult for patients to be motivated, because they do not understand about their illness. The nurse's job is to inform the patient of the disease in a language that is easily understood by the patient, this is expected to be able to give patients a good understanding of the disease so that they can have a strong motivation to carry out therapy. It can be understood that in individuals there are various motives that encourage and move them to carry out activities in achieving their goals and meeting the needs of life in order to maintain their existence [18].

Sagala & Sitompul [19] said based on motivation owned and received from 79 CKD patients who underwent hemodialysis more than half received and had low motivation in the category of 47 people (59.5%). In patients who have just been diagnosed with ESRD it is difficult to be motivated that they have to undergo hemodialysis. Self acceptance of disease makes it difficult for a person to have motivation.

4.3. Responsive Patients

Nurses revealed that they were quite happy if the ESRD patients were treated cooperatively i.e all suggestions were received and carried out appropriately by patients. Compliance of patients with CKD following treatment is very important to prevent complications [20]. Compliance is defined as the tendency of the patient's behavior to carry out the orders suggested by the authorized person, here are doctors, nurses, and other health workers [21].

Patient compliance in undergoing hemodialysis and fulfilling the advice given in education by nurses is one of its own pleasures for nurses. The nurse felt that what was done had a positive impact on the patient. This is a implementation of beneficence in nursing, who nurses must try their best for their patients. Nurses do more than their obligation to continue to motivate patients to follow all the education that has been given and ensure that everything has been carried out according to instructions.

4.4. Patients Do Not Want to Stop Dialysis

Participants revealed that no patient would want to stop hemodialysis because according to them the patient did not want to if his condition worsened and was afraid of dying if he did not undergo hemodialysis. Humans are basically afraid of negative things

happening to him. Death is one thing that is feared by humans. When the patient is sick and undergoing therapy there is a tendency to think negatively and the feeling of fear dies. Patients will do everything they can to heal. This is human instinct to survive.

Although on the one hand hemodialysis treatments for ESRD patients are essentially vegetative, and hemodialysis is done only to prolong the patient's life and not to heal. In the context of Indonesian culture, there is still a difference in the extent to which vain treatment can be stopped. Ethical parameters are needed to assess case by case. Hemodialysis in ESRD patients in Indonesia can be considered a unique phenomenon because vain treatment can be continued. There are many considerations behind this of course. Some of them are cultural, religious and social environment influences.

5. Conclusion

There are 4 themes, namely lifestyle changes, uncooperative patients, responsive patients, patients do not want to stop dialysis. Further research is needed on the fourth theme specifically about withdrawal hemodialysis in ESRD patients in a variety of perspectives including: ethical perspectives and decision making for treatment that is futile, health coverage policies, and palliative care.

Disclousures

The authors declared no real or perceived vested interests that relate to this article that could be construed as s conflict of interest

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