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The care preferences of patients under hemodialysis

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ABSTRACT

Introduction: Patient-centered care is an approach to healthcare that focuses on the preferences and needs of the patients. Clarifying patients' care preferences helps facilitate and improve the process of advance care planning.**Objectives:** The present study was conducted to examine the care preferences of patients under hemodialysis.**Patients and Methods:** The present study uses qualitative content analysis to examine the care preferences of patients under hemodialysis. The data required for the study was collected through semi-structured interviews held with 20 participants selected according to purposive sampling and continued until data saturation was reached.**Results:** The analysis of the data led to the extraction of the two sub-themes of "dependence on dialysis" and "protection" for the main theme of "preserving life", the three sub-themes of "acceptance of hemodialysis", "receiving information" and "adapting to limitations" for the main theme of "self-care", the two sub-themes of "friendly relationships" and "competent staff" for the main theme of "expert care providers", and the three sub-themes of "support", "equipment" and "facilities" for the main theme of "proper care conditions."**Conclusion:** "Preserving life" comprised the main care preference of the examined patients under hemodialysis. Clarifying the patients' care preferences helps maintain their health and provide them with a more comfortable and satisfactory experience of hemodialysis.

Implication for health policy/practice/research/medical education:

Hemodialysis patients life, depend on dialysis, although hemodialysis is a threat for their life. Therefore the hemodialysis' patients should be cared based on their preferences. Authorities by selecting the expert care providers, creating self-care circumstance and appropriate care conditions can help maintain their lives, which are their care preferences.

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Introduction

Chronic renal failure (CRF) is a globally increasing conditions that is most commonly treated with hemodialysis (1). CRF patients undergo dialysis for at least 18 hours per week (2). Nurses comprise the main providers of hemodialysis care. The care provided to patients can be either inflexible or be provided with the patient's own participation (3). In general, the main responsibility of nurses is to identify their patients' care needs and to then meet them (4). Providing proper care requires the nurses to understand their patients' needs and expectations (5). Health research is moving toward patient-centrism in the modern world (6,7). In patient-centered care, it is the patients' values and preferences

that dictate the clinical decisions made (8). Establishing good relationships with the patients and investing in them through carefully listening to their needs and wishes are crucial tools for moving toward this new approach to care (9). Health care systems have also come to focus on the provision of effective evidence-based care building on the patients' expectations (10). The American Society of Nephrology also emphasizes the importance of increasing patient participation and understanding the patients' preferences and goals for improving the process of medical decision-making (11). Rix et al, however, argued that medical staff often lack ample time for listening to their patients and therefore cannot identify their needs or invest in identifying and prioritizing their problems and



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communicating more in-depth knowledge to them (12). The care preferences of hemodialysis patients originate from several years of living with this inconvenient treatment, nevertheless, little information is available on this subject (13). Clarifying the patients' preferences improves the process of nursing care, knowledge communication and job promotion (14) and further facilitates advance care planning (15). The present understanding and knowledge of the perspective of patients with CRF is limited and evidence suggests the inadequacy of the measures made to meet these patients' needs (16). The general indifference toward the patients' preferences might discourage them from continuing hemodialysis (9).

Qualitative studies help clarify the patients' profound experiences, priorities, values and beliefs and improve the aspects and techniques of clinical care in line with their preferences, including the clinical staff's relationship with the patients, the patients' participation in decision-making, health management and monitoring, the patients' sources of information and measuring the indicators of clinical quality (17). Despite their great advantages, few qualitative studies have been conducted in nephrology to date (17). Prior to May 2003, only 23 (0.4%) of the 6043 main research articles published in five nephrology journals with the highest impact factor were qualitative in design (17). A review study conducted by Wadd et al also emphasized the need for research about the experiences and needs of patients under hemodialysis for providing specialized nursing care based on the patients' experiences (2).

Objectives

The present study was therefore conducted to examine the care preferences of patients under hemodialysis as an answer to the need for qualitative studies on this subject.

Patients and Methods

Study design

A conventional qualitative content analysis was used to achieve the study objectives. The researcher carried out a systematic interpretation of the data extracted from the interviews and categorized them into classes and themes using the constant comparison method and inductive reasoning (18).

Setting and samples

The study participants were selected through the purposive sampling of patients under hemodialysis for a relatively long period at the dialysis department, who were willing to express their preferences without fear or embarrassment, and all their caregivers, nurses and physicians. Sampling continued until saturation was reached. A total of 20 participants were examined in this study, including eight patients, seven nurses, three caregivers and two physicians.

Ethical considerations

The research followed the tenets of the Declaration of

Helsinki. After obtaining a letter of introduction from the Ethics Committee, the participants were briefed on the study objectives and were ensured of the confidentiality of their data and their right to withdraw from the study at any stage. They then submitted their informed written consent and agreed on a time for the interviews. The interviews were recorded with the participants' consent.

Data collection

The data required for the study were mainly collected through semi-structured interviews conducted in a private room located in the hospital's medical center adjacent to the dialysis department in 2014, as it had the shortest distance to the hemodialysis department and as it allowed for the patients' better comfort in terms of physical conditions, temperature, odor, ventilation and lighting. Only the researcher and the participant attended the interview sessions. The participants were asked to talk about their experiences of hemodialysis nursing care and were then asked about the factors they believed affected hemodialysis nursing care. Follow-up questions were also posed based on the information each participant provided, so as to further clarify the concept under scrutiny. Future interview questions were designed according to the themes extracted; for example, "How is hemodialysis best performed?" and "Which issues do you think should be more taken care of in hemodialysis?" Exploratory questions were then posed to encourage the participants and to gain access to more in-depth information about the subject; for instance, "Can you elaborate on what you just said?" and "Can you give us an example?" At the end of each interview session, the researcher thanked the participants for their collaboration and asked if there were any other issues they wished to discuss. Interviews were also held with the caregivers, nurses and physicians working at the hemodialysis department and their experiences of hemodialysis nursing care were also used for data collection; the questions asked from this group of the participants included, "Can you describe to us an instance of hemodialysis care that you provided to a patient and tell us how you handled the whole process?" Each interview was assessed by the researcher at the end of the session and any ambiguities requiring clarification were identified and investigated in follow-up interviews. Depending on the participant's conditions and willingness, each interview lasted from 40 to 85 minutes. Data collection and data analysis occurred simultaneously using the constant comparison method.

Data analysis

The data obtained were analyzed using the content analysis method and based on the five steps proposed by Graneheim and Lundman (19).

Step 1 – Transcription: The interviews were recorded and immediately transcribed verbatim and used as the main data of the study.

Step 2 – Meaning units: The researcher listened to the recorded interviews several times and reviewed the

transcriptions and extracted meaning units from the data. *Step 3 – Abstraction:* Meaning units were abstracted from the data and codes were identified. Based on participants' experiences, paragraphs and sentences of their statements and indicative codes were taken to identify the overt and covert meanings of their words. The coding and abstraction of the data was thus completed.

Step 4 – Sorting the codes: Based on the constant comparison of the similarities, differences and compatibility between the data, the codes with similar implications were placed in one theme, and the themes and sub-themes were then grouped and axial codes were extracted. Any ambiguities that required further clarification were identified and assessed in follow-up interviews, so that the codes could be fixed in each theme.

Step 5 – Theme formulation: Formulating themes as the expression of the latent content of the text. From the analysis and interpretation of the data, themes were extracted. Then, the initial texts with the final classes were read and compared repeatedly again in order to be sure of their correctness (19).

Data rigor

Lincoln and Guba's evaluative criteria were used to determine the rigor of the data (20). A prolonged engagement with the research subjects and a member check helped confirm and increase the credibility of the data. Time triangulation and maximum variation sampling were used to increase the rigor and confirmability of the data. A prompt transcription of the interviews, an external check and a review of all the data ensured the dependability or stability of the results. The researcher ignored his own assumptions during the collection and analysis of the data so as to ensure the verifiability of the results. The confirmability of the data was additionally ensured with the researcher's impartiality throughout the study, the achievement of a consensus on the codes and themes extracted and a review of the transcribed interviews and the extracted codes and themes and a peer check was also carried out by two faculty members. The transferability or fit of the data was also ensured through conducting interviews with participants from diverse backgrounds, using direct quotations and examples, providing a rich picture of the data and consulting with experts.

Results

A total of 20 participants entered the study, including eight patients (5 women and 3 men) aged 35 to 75 (with a mean of 51.37) and with a dialysis history of 3 to 21 years (a mean of 9.37 years). Six of the patients were married, one was single and one was widowed. The participants had 2 to 8 children (a mean of 3.25). Six of the patients had primary school education and two had high school diplomas. Two of the male participants were unemployed and one was retired. All of the female participants were housewives. Seven nurses (5 female and 2 male) were aged 37 to 60 (a mean of 46.5) and all had bachelor degrees in nursing. Four of the nurses were married, two were single

and one was divorced. Three caregivers (all male, 2 of whom were caring for their spouses and 1 for their son) and two physicians (1 male and 1 female) also participated in the study.

The analysis of the data revealed "preserving life" to be the main theme, consisting of "dependence on dialysis" and "protection" as its two subthemes. The other main themes extracted included "self-care", consisting of "acceptance of hemodialysis", "receiving information" and "adapting to limitations" as its three subthemes; "expert care providers", consisting of "friendly relationships" and "competent staff" as its two subthemes; and "proper care conditions", consisting of "support", "equipment" and "facilities" as its three subthemes.

Preserving life

"Preserving life" was a conceptual theme extracted in the present study. Hemodialysis patients wish to survive and live a happy life despite their CRF, dependence on hemodialysis and all the debilitating experiences caused by their physical, psychological, social and economic problems. Two sub-themes were extracted for this theme, including "dependence on hemodialysis" and "protection".

"Oh my God, undergoing dialysis and suffering so much and then dying at the end with blood pressure that is slightly low or high? That's a harsh faith! I want to live" (Patient 7).

Dependence on hemodialysis

Some hemodialysis patients refuse their first or first few dialysis sessions; however, faced with the risks of their refusal, they gradually realize that their life depends on dialysis. They then come to accept their hemodialysis schedule.

"I refused coming in to the dialysis department for one whole week; so fluid accumulated in my heart and lungs and I felt even worse. Now I know that I only hurt myself if I refuse dialysis. So I come here every other day to undergo dialysis" (Patient 6).

Protection

Hemodialysis patients tend to experience a number of complications during their treatment, some of which are common and some of which are life-threatening. They thus prefer to be protected against these complications.

"Once, during dialysis, I got sick. The filter on the machine was torn and water was entering my blood. I nearly died. My eyes couldn't see. Four or five minutes passed until I regained my consciousness" (Patient 5).

Self-care

"Self-care" was another conceptual theme extracted in this study. Upon accepting hemodialysis, the patients often get encouraged to seek further information on self-care and to thus adapt to their new limitations by making changes to their lifestyle and taking on the responsibility of self-care. The three sub-themes extracted for this theme included "accepting hemodialysis", "receiving information" and

“adapting to limitations”.

“Self-care is essential in hemodialysis. Patients should be able to take their own medications properly and to be aware of the side-effects they present, so that they can know the causes of problems arising and know how to deal with them by themselves” (Nurse 3).

Accepting hemodialysis

Hemodialysis patients should accept the loss of their kidney function and the need for undergoing hemodialysis. The majority of these patients often arrive at this belief within two to six months of getting their diagnosis.

“It is important for the patient to accept his disease. It took me six months to come to terms with my dialysis” (Patient 1).

Receiving information

Most hemodialysis patients prefer to receive more information on self-care. When they acquire more information, their self-care capacities increase, their disease and treatment complications decrease, their need for hospitalization becomes less frequent and their medical costs also drop.

“I have educational books and CDs about dialysis and the walls in my room are covered with brochures instructing on types of food allowed, so that I can properly look after myself” (Patient 5).

Adapting to limitations

The majority of the hemodialysis patients interviewed had come to terms with the limitations imposed by their disease and preferred to adapt to them so as to face fewer problems.

“I’ve been under dialysis for 15 years now. I’m no longer a farmer. I used to have livestock in my farm, but I’m unable to take care of such heavy work now because I have to take care of my fistula” (Patient 8).

Expert care providers

Another conceptual theme was “expert care providers”. The patients preferred their hemodialysis care to be performed by expert providers. Two sub-themes were identified for this theme, including “friendly relationships” and “competent staff”.

Friendly relationships

Three to four hour hemodialysis sessions performed by nurses each week led to the establishment of an ongoing friendly relationship between the nurses and the patients.

“The nurses’ relationship is perfect with all of us and they attend to us whole-heartedly” (Patient 1).

Competent staff

To provide proper hemodialysis care, nurses require knowledge, skills, experience and accountability.

“Having skills and knowledge is essential for nurses to perform dialysis, as they should be able to create a match between each patient and the dialysis machine and

thereby improve the quality of dialysis and have each patient switched off the machine with success” (Nurse 6).

Proper care conditions

Proper care conditions comprised another conceptual theme in this study. The interviewed patients wished their hemodialysis to be performed under proper physical conditions within the department and with safer equipment and facilities and considered support as necessary to this goal. This theme included three sub-themes, including “support”, “equipment” and “facilities”.

Support

Support included receiving empathy from family members, establishing relationships with friends and peers and benefiting from social organizations and charitable contributions.

“My daughter comes and makes dinner for us. My wife insists that I go remarry, but I wouldn’t do that. I constantly cheer her up and accompany her to every dialysis session. God knows I have spent over \$30K on her disease so far” (Participant 3, a caregiver).

Equipment

The patients emphasized the hospital’s need for receiving better equipment, especially standard hemodialysis needles and quality filters, which ensured a less painful and an easier dialysis for them.

“Sometimes, when their needle insertion attempts fail and no blood can be drawn. Nothing works properly here, not the plumbing, not the filters, not the needles and not even the machine” (Patient 3).

Facilities

The participants expressed their desire for having access to such welfare facilities as quality food, comfortable beds, clean linens and mattresses, a hygienic environment, a proper ventilation system, efficient cooling and heating systems, a large noise-free space and plenty of entertainment.

“I am incapacitated and have to make do with a small income now. Although I have insurance, I have to pay for my own medications. They don’t serve lunch here, and have even stopped giving us our little portion of milk and cake in the morning. But it is their job to feed us” (Patient 4) (Figure 1).

Discussion

The findings of the present study clarify the care preferences of patients under hemodialysis. The main theme extracted was “preserving life” and included the sub-themes of “dependence on dialysis” and “protection”. Dialysis is a means to survival for these patients and controls their uremic symptoms (21) and restores happiness to their life (22); however, undergoing different treatments decreases the chances of survival and rehabilitation in these patients (23). Hemodialysis patients often feel fear, denial and depression and have death ideations (24). In the present

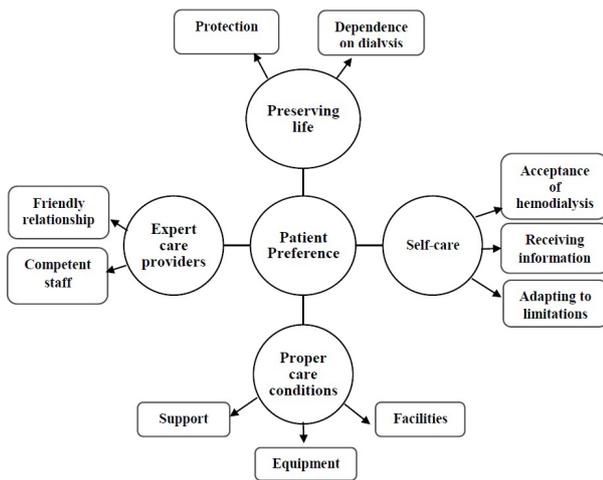


Figure 1. The care preferences of patients under hemodialysis

study, the patients under hemodialysis considered their life to be dependent on dialysis and believed this treatment to be as vital to their survival as breathing. One of the preferences expressed by these patients was protection. They had frequently experienced the many complications of hemodialysis. The need for hemodialysis, on the one hand, and the high-risk nature of this potentially harmful treatment, on the other, demonstrate the importance of the need for protection by nurses in these patients. Hemodialysis patients experience many symptoms and complications of CRF and their treatment and sometimes have to bear the nurses' multiple attempts to access their veins (25).

Self-care was one of the abstract themes extracted in this study. The interviewed patients preferred to have greater self-care capacities, as they were well aware that they, themselves, comprised the key element in self-care. Self-care can lead to an improved medical adherence, promote health behaviors and weaken physical and psychological symptoms in the patients (26). The participants preferred to accept their need for hemodialysis as soon as they could and to take on the responsibility of self-care after receiving all the necessary information. The patients also wished to receive more information about dialysis and stressed the importance of hemodialysis self-care training. Hemodialysis patients always seek new information on their treatment, as they know that this information can lead to better self-care measures (26).

Expert care providers comprised another abstract theme extracted in this study. The patients preferred to establish friendly relationships with their nurses. In a hemodialysis department, the patients and the nurses are in contact with each other for many years, which encourages the establishment of friendly relationships (27). The patients expressed their desire to have capable nurses take care of them and teach them empowering techniques (28).

Proper care conditions comprised another abstract theme extracted in this study. The participants express their desire to have their dialysis be performed in a peaceful physical and mental setting and stressed the importance

of getting support from their family members, having the companionship of friends and relatives, the formation of interactions with fellow patients, getting the support of social organizations and receiving charitable contributions. The thought of being supported comforted and consoled them. The family has a supportive role in ensuring that the patient has a quality hemodialysis experience (29). Different studies have emphasized the importance of getting support from the society, family, friends, relatives and other patients. The study participants also stressed the importance of being provided with proper equipment and new hemodialysis machines. The lack of adequate machines and the worn-out conditions of the existing ones had placed excessive pressure on the machines, which then led to their frequent malfunction and alarms going off, which then made the process of dialysis very stressful for the patients. In a study conducted by Borzou et al, the majority of the patients had experienced the harms and discomfort caused by worn-out dialysis equipment (30). The present study participants said that they wished to be provided with proper welfare facilities during their dialysis. To have a comfortable experience of dialysis, the patients require a peaceful setting with plenty of facilities. Bad odors, noise and visual, gustatory and tactile disturbances comprised some of the annoying sensory stimuli the patients wished to avoid (30).

Conclusion

"Preserving life" was the main care preference of patients under hemodialysis. Clarifying hemodialysis patients' care preferences helps maintain their health and provide them with a more comfortable and satisfactory experience of hemodialysis.

Limitations of the study

Since findings might have been affected by the cultural context of the Iranian population and similar to other qualitative studies, the sample population examined, were restricted that cannot be generalized to the target population.

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Authors' contribution

AAV: preparation of manuscript, final revision. MN; study design, data gathering, data interpretation, preparation of manuscript and final revision.

Ethical considerations

Ethical issues (including plagiarism, data fabrication, double publication) have been completely observed by the authors.

Conflicts of interest

The authors declared no competing interests.

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