



# Subjective adequacy of dialysis; a neglected concept in hemodialysis adequacy

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## ABSTRACT

**Introduction:** Dialysis adequacy is a predictive factor for mortality and hemodialysis outcomes.**Objectives:** Given the limited knowledge regarding dialysis adequacy, we sought to investigate the perceptions and experiences of patients as to subjective dialysis adequacy.**Materials and Methods:** This qualitative study was carried out using the conventional content analysis method. We enrolled 25 hemodialysis patients, their companions, nurses, and nephrologists residing in Mashhad, Iran. We selected the participants through purposive sampling. To collect the data, we used semi-structured interviews and recording field notes until reaching data saturation. The data was analyzed by using Hsieh and Shannon qualitative content analysis approach.**Results:** From the experiences of the patients regarding dialysis adequacy, five categories of inner wholeness, well-being, positive social interaction, effective self-empowerment and improvement of economic conditions were extracted.**Conclusion:** The obtained results can play a key role in implementation of effective interventions for models of hemodialysis clinical function to lower the rate of mortality and promote quality of life among dialysis patients.

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

In the present study, profound investigation of experiences of hemodialysis patients clarified the concept of subjective dialysis adequacy and determined its indices. The obtained results, along with expanding the nursing knowledge, pave the way for creating a specific tool for measuring the aspects of subjective dialysis adequacy in hemodialysis patients. This tool can play a key role in implementation of effective interventions in models of hemodialysis clinical function to lower the rate of mortality and promote quality of life among dialysis patients.

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## Introduction

End-stage renal disease (ESRD) is a stage at which the patient requires renal replacement therapies, such as hemodialysis, peritoneal dialysis, or kidney transplant, for survival (1). Conceptual (2), cultural, educational, structural, and organizational barriers to peritoneal dialysis (3,4) have made hemodialysis the most common life-sustaining treatment (5-8).

Neither the recent technical advancements in the production of monitoring tools nor improved quality of ultrafiltration machines and materials have been able to affect the consistently high mortality rate (15%-25%) in

these patients and promote their quality of life.

Studies have ascribed that hemodialysis adequacy is a prominent predictor of mortality and hemodialysis outcomes (9). Patients undergoing hemodialysis with optimum quality have an equal longevity as those receiving renal transplant (10).

The multidimensional concept of dialysis adequacy (11) entails two interwoven aspects of objective and subjective (12). Based on former studies, adequate dialysis can affect short- and long-term morbidity and mortality of hemodialysis patients (13) and can result in subjective well-being (14). Twardowski in 2003 illustrated that

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adequate dialysis is hinged upon a set of subjective and objective criteria indicating treatment efficacy (15).

The objective aspect of dialysis is associated with indices such as Kt/V that are able to gauge the physiologic aspects of hemodialysis efficacy (16), whereas the subjective aspect of dialysis adequacy cannot be dependent on blood and fluids clearance of waste substances or calculation of a clinical parameter disregarding the idiosyncratic features of each individual.

This subjective aspect is associated with the experiences and perceptions of a patient regarding an adequate dialysis, his/her subjective perception of the physical and psychological signs, as well as feelings and expectations from the level of well-being during dialysis (17).

### Objectives

Given the scarcity of studies and knowledge as to experiences of hemodialysis patients regarding dialysis adequacy and the limited perception of subjective dialysis adequacy, we sought to gain a profound understanding of subjective dialysis adequacy based on the experiences of hemodialysis patients.

### Patients and Methods

#### Study population

In order to delineate the perceptions and experiences of hemodialysis patients regarding subjective dialysis adequacy, this qualitative study was designed and conducted using the conventional content analysis

method during 2016-2017 (18).

Purposive sampling was performed from among hemodialysis patients who were willing to participate in the study (19). To have maximum diversity in demographic and phenomenological variables selective sampling was continued until reaching data saturation (20,21). Face-to-face semi-structured interviews were conducted with 25 participants living in Mashhad (19 hemodialysis patients, 2 patient companions, 2 dialysis nurses, and 2 nephrologists). Additional demographic characteristics of the participants are shown in Table 1.

The inclusion criteria were at least 12 weeks of regular hemodialysis (3-4 hours each session), age >18 years, basic education, no history of drug or alcohol abuse, and no history of hospital admission due to psychological problems during the last year.

The interviews were initiated with general questions such as 'describe your experiences in a hemodialysis day' and then continued with more specific queries such as 'what is your expectation of an adequate dialysis?' The participants were asked to state their experiences regarding hemodialysis adequacy. To gain more in-depth information, exploratory questions were used. The interviews were performed during 40-110 minutes, and the setting was appointed with the agreement of the participants. Thereafter, the obtained data was analyzed by using Hsieh and Shannon's content analysis method (22). In this method, codes and categories were extracted from the raw materials inductively and systematically.

**Table 1.** Characteristics of participants

Sex- Age	Hemodialysis vintage (month)	Education	Interview time	Participant Number
F-49	171	Primary or secondary	53	1
F-73	40	Primary or secondary	41	2
F-42	32	Primary or secondary	49	3
F-52	41	College or university	43	4
F-76	75	Primary or secondary	40	5
F-52	-	College or university	16	6
F-29	-	College or university	18	7
M-70	69	College or university	51	8
M-66	120	College or university	112	9
M-39	69	College or university	47	10
F-30	12	College or university	47	11
F-30	45	College or university	48	12
F-26	50	College or university	46	13
F-33	18	College or university	45	14
F-37	24	College or university	41	15
F-35	12	College or university	42	16
F-35	16	College or university	53	17
F-40	192	College or university	61	18
F-72	40	Primary or secondary	40	19
M-30	72	Primary or secondary	67	20
M-37	75	Primary or secondary	75	21
M-33	75	Primary or secondary	63	22
M-47	264	Primary or secondary	92	23
M-56	-	Primary or secondary	33	24
M-49	-	Primary or secondary	16	25

The regular presence of the researcher in different working shifts at the hemodialysis ward and her/his long-time involvement with the subject, as well as selection of the participants with maximum diversity (in terms of age, gender, occupational status, marital status, financial status, and history of hemodialysis) bolstered validity of the study. Member check and rectifying the codes that did not accurately describe the point of view of the participants (based on their own opinion) improved reliability of the study. To promote confirmability, the researcher first recorded her/his own presumptions regarding the answers and tried not to emphasize on them. Finally, dependability was assured by immediate transcription of the interviews and use of external check and reviewing the data. Further, with precise delineation of the study procedures and stages, the readers were able to follow the steps and appraise them.

### Ethical considerations

The research followed the tenets of the Declaration of Helsinki. The observed ethical considerations in this study included obtaining approval from Ethics Committee of Mashhad University of Medical Sciences (code # IR.MUMS.REC.1395.309), taking informed consent from the participants after explaining the objectives of the study, roles of researchers and participants, and the methods of data collection and recording, providing a quiet and peaceful environment during the interviews, giving the participants the right to withdraw from the study at any time, assuring confidentiality of data, and providing the results to the participants in case they wanted them.

### Results

The mean age of the participants was  $43.9 \pm 5.8$  years and their mean duration of hemodialysis was  $71.8 \pm 65.1$  months. Sixty-one percent of the participants were female. Around 997 initial codes were extracted under five categories of inner wholeness, well-being, positive social interaction, effective self-empowerment and improvement of economic conditions. Each of these categories comprised of some sub-categories. Table 2 illustrates the process of shaping these categories, and subcategories.

#### Inner wholeness

Inner wholeness is an overwhelming feeling in hemodialysis patients, which makes them more tolerant and resilient in dealing with problems and stressful situations and managing them. The experience of internal wholeness in hemodialysis patients participating in this study was perceived as having emotional, mental, and spiritual well-being, as well as positive body image.

#### Emotional health

Following an adequate dialysis, the participants reported less restlessness, anxiety, and bafflement. In addition, they were not depressed, irritable, or dissociable and felt more

**Table 2.** Study categories and subcategories

Emerg ed categories	Subcategories
Inner wholeness	Emotional health
	Mental health
	Spiritual health
	Positive body image
	Self-acceptance
Well being	Understanding Satisfaction
	Understanding the purpose
	Feeling good
Positive social interactions	Understanding security
	Normal social function
	Understanding support
Effective self-empowerment	Voluntary exploration of health literacy
	Voluntary adherence to treatment
	Focus on self-care behaviors
Improving economic conditions	Occupational prosperity
	Reduced treatment costs

peaceful. Participant No. 1 in this regard said; ‘When my dialysis is good, I feel happy and socialize with everyone, as people in Mashhad say ‘I have a wedding in myself (laughing)’. I like to work out to stay that way. I go to all events whether wedding or mourning. Even when I want to go to a wedding, I receive an additional dialysis session to be happy and have a good time’

#### Mental health

The participants experienced mental health after a high-quality dialysis; they had higher tolerance for irritating stimulants such as noise, unpleasant smells, heat, cold, and light.

They also felt relaxed and had excellent sleep. Maintaining a neat appearance, positive inculcation and tolerance of others were among the other experiences of the participants. Participant No. 13 in this respect asserted: ‘‘After an optimal dialysis, I feel so relaxed, I can tolerate anything, I’m in the mood for my nieces and nephews, I do not shout at them to go away, I can stand the noise from TV and I do not argue with anyone.’’

#### Spiritual health

Spiritual well-being after a high-quality dialysis was perceived as experience of patience in the face of illness and considering sickness as a divine test in our participants. They also established a better spiritual connection with God and along with a sense of thankfulness, relied on him and were satisfied with his satisfaction. In this respect, participant No. 21 confirmed; ‘‘believing in God and the fact that God does not leave us alone was the most important factor that I could get along with dialysis, and my trust in God has made me feel satisfied with my life.’’

#### Positive body image

The hemodialysis patients reported positive body image after a high-quality dialysis. Positive self-image entails an emphasis on strengths rather than physical flaws, focus on

skills and fulfillments, and positive attitude towards one's appearance and the new body shape with the catheters. Our participants did not compare their own appearance with normal people and were not willing to limit their social relationships because of the changes in their appearance or others' opinion about them. Participant No. 1 expressed 'When I look at the mirror, I don't think I look strange. Nothing is wrong with me and there is no reason for others to look at me. Until I roll up my sleeves no one understands I receive dialysis. My appearance is so normal that I came from work for dialysis and went back there for 10 years without anyone understanding it;

### *Well-being*

The sense of well-being in hemodialysis patients is a cognitive feeling that stems from the pleasant feeling of being well. This feeling comes along with a positive attitude toward the surrounding world and the pleasure of being alive. From the analysis of this category, self-acceptance, perception of satisfaction, sense of well-being, understanding of purpose, and understanding of security were inferred.

### *Self-acceptance*

Participants in this study, after an adequate dialysis, felt better with accepting their new condition. Participant No. 18 said; "My condition was very different before the illness, but this is the new condition and I have accepted it. I have settled with my illness, so it doesn't annoy me."

### *Understanding satisfaction*

A hemodialysis patient, experiencing a sense of well-being, is satisfied with his/her life and feels passionate interest about life. Participant No. 21 expressed: "one must be satisfied in every stage of life. I have God, I have my wife and we love each other. She is a healthy and patient woman and helps me a lot. I have healthy kids, who love me so much. I can work hard and make the ends meet. I'm happy."

### *Feeling good*

Participants in this study experienced a sense of well-being after an optimal dialysis that was accompanied with a sense of vitality and happiness. Participant No. 1 asserted: "I don't consider myself as ill. I come here and go on my own feet and I live my life and do my job. On the contrary, I feel that now I appreciate my life more. I feel happy inside."

### *Understanding the purpose*

The experience of a sense of well-being by the participants was accompanied by a sense of success and achievement. Participant No. 21, who after 75 months of dialysis, still continues to work as a builder, says: "when I think, I find myself as a successful person because with this disease and its problems I still can make ends meet. I could resolve all my problems and get all the things I aspired. When I think

of these things, I feel very good and relaxed."

### *Understanding security*

The sense of security was another experience of the hemodialysis patients in this study. Participant No. 21 said; "Now I feel more secure. First of all, I rely on God and then my family and children. I have no concern for future, I'm so assured."

### *Positive social interactions*

After an adequate dialysis, the hemodialysis patients participating in this study had a high inclination for interaction and had social communication with others, which included a positive social interaction with family members, relatives, acquaintances, friends, colleagues, or doctors, nurses, caregivers and other patients in the dialysis ward. These interactions caused the hemodialysis patients to gain support from others. From the analysis of this category, normal social function and perceived support were inferred.

### *Normal social function*

The participants also mentioned improved social relationship. Following an adequate dialysis, they felt more power over their life and were more determined for decision-making. On this subject, participant No. 23 who was a factory manager said; "When I have a good dialysis, I feel so different that everyone at home becomes surprised that I'm smiling. As if I choose a better way for my life. When I feel well, I manage everything better. My motivation is higher and I'm more determined for a good life."

### *Understanding support*

Participants, using positive social interactions, could benefit from experiences of other dialysis patients and attract the support of their family and healthcare team. Participant No. 22 stated; "My family didn't know what dialysis was. They thought my blood needs to be filtered and only my dialysis friends and nurses and doctors had my back and could help me a great deal."

### *Effective self-empowerment*

Effective self-empowerment is a voluntary, active, and purposeful behavior in hemodialysis patients, who are motivated to protect their mental and physical health, meet social and psychological needs, or prevent accidents and illnesses. Effective self-empowerment includes voluntary exploration of health literacy, voluntary adherence to treatment, and focus on self-care behaviors.

### *Voluntary exploration of health literacy*

After having optimal dialysis and due to the good feeling following that, the participating hemodialysis patients were interested in finding information that sustained this pleasant mood and sought to answer health-related questions from any valid or invalid source. Participant

No. 15 said; "I have read the educational pamphlets in the ward for the complications of dialysis. Sometimes I use the Internet to answer my questions."

#### *Voluntary adherence to treatment*

A behavior is deliberate and purposeful when the patient matches his or her behaviors with treatment recommendations provided by health care providers such as a doctor or nurse. Participant No. 9 asserted; "When I have a good dialysis, I take more care of myself and the fistula, I'm careful about what I eat, I try to do whatever my doctor has recommended".

#### *Focus on self-care behaviors*

These behaviors are focused on taking medications, adhering to diet, changing lifestyle, or observing continuity in clinical referrals. Participant No. 9 responded; "I don't go to overcrowded places to avoid catching a cold, flu, or other diseases. I'm so careful about food's salt and oil and I meticulously pick fruits and snacks. I disinfect the house with Espand."

#### *Improving economic conditions*

The economic conditions in a hemodialysis patient's life after an adequate dialysis change in such a way that family income increases at least as much as the dialysis expenses. The improvement achieved in the economic context can be the result of a greater chance of finding a job with better conditions or reducing the disease-related costs. The up-growth in the economic status involves occupational prosperity and reduced treatment costs.

#### *Occupational prosperity*

The participating hemodialysis patients, after performing high-quality dialysis, had better job conditions due to better physical status, increased strength and energy for work, and changes in their psychological conditions, and consequently, they had better economic conditions. Participant No. 22 claimed; "My boss has promoted my payment. He's more satisfied with my work because my physical power is relatively higher. I can work more easily."

#### *Reduced treatment costs*

Participants experienced a better economic situation after an optimal dialysis due to reduced hospital admissions or fewer doctor visits or less need for expensive drugs. Participant No. 7 expressed; "Well, obviously, when dialysis is adequate the medication and physician expenses are lower, as well."

#### **Discussion**

The findings of this study showed that hemodialysis patients, after optimal dialysis, have pleasant non-physiological experiences indicating the psychological, social, educational, and economic concepts of hemodialysis adequacy.

Gregory et al, in a qualitative study on ESRD patients

showed that these patients shaped a new identity for themselves, which is constantly changing and is the result of perception of the patients regarding their vague future, the disease-related needs, and constant dependence on dialysis machine, drugs, and care providers (23). Likewise, in this study, we noted that patients with adequate dialysis accept a new self that is adapted to the new conditions; this acceptance produces a sense of well-being in them. Kimmel et al pinpointed that disease perception in hemodialysis patients was associated with lower probability of survival and adherence to treatment (24). Additionally Mittal et al confirmed that hemodialysis patients, compared to those inflicted with other chronic diseases, find their physical health significantly reduced (25). Chilcot et al in a study on hemodialysis patients illustrated that disease perception is an important predictor of disease adaptation (26). Similarly, individuals benefiting from adequate dialysis accepted dialysis and its limitations in the form of self-empowerment.

Former studies proposed that outcome of an adequate dialysis is the sense of subjective well-being (27). Our results also indicated that hemodialysis patients after a high-quality dialysis feel healthy, well, happy, safe, successful, and comfortable, which were entitled sense of well-being.

The performed studies on quality of life illustrated the prominent effects of age on the physical aspect of quality of life. HEMO study with a large cohort of patients demonstrated the elderly patients perceived the reduced quality of life less than younger ones (higher quality of life among elderly patients), and compensated for the deteriorated physical status with spiritual aspects (28). This finding confirmed our results. In the current study, elderly hemodialysis patients (older than 65 years) experienced higher life satisfaction than younger ones, which could be due to the fact that the limitations caused by the treatment disrupted younger patients' life to a larger extent.

Approximately all the dialysis patients had worries regarding their sexual health after treatment, which affected their quality of life (29). Based on the evidence, about half of the 20-50 years old men were suffering from erectile problems (30). Strippoli et al indicated that 84% of hemodialysis patients were suffering from sexual problems (31). Furthermore, Kim et al showed a significant reduction in all aspects of sexual relationship (i.e., desire, arousal, lubrication, orgasm, and pain) in hemodialysis women. Song et al (32) and Soykan et al (33) also presented that dialysis adequacy (Kt/V higher than 1.3) had no significant effect on improving sexual disorders. In our study, hemodialysis patients after having a high-quality dialysis experienced more satisfaction with their marital relationship which created a sense of well-being.

Depression was one of the most prevalent disorders in hemodialysis patients (34). There were some reports on better quality of life and diminished depression with enhanced spiritual perception (35). Some other studies

indicated the positive effects of spirituality on the rate of mortality and sense of well-being (36-38). Likewise, in our study, spiritual well-being arising from the perception of spiritual experiences, such as trust in God and praying for healing, led to the feeling of inner wholeness.

Kabahizi et al ascribed that dialysis adequacy had a significant positive relationship with physical well-being and higher physical function, such that high dialysis adequacy resulted in high-quality physical role and significantly decreased role limitations due to lack of physical health (39). In congruence, we found that quality of dialysis enhances occupational prosperity and economic conditions by improving physical condition and increasing the individual's energy and power to carry out tasks.

### Conclusion

In the present study, profound investigation of experiences of hemodialysis patients clarified the concept of subjective dialysis adequacy and determined its indices. The obtained results, along with expanding the nursing knowledge, pave the way for creating a specific tool for measuring the aspects of subjective dialysis adequacy in hemodialysis patients. This tool can play a key role in implementation of effective interventions in models of hemodialysis clinical function to lower the rate of mortality and promote quality of life among dialysis patients.

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### Conflicts of interest

The authors declare no conflicting interest.

### Authors' contribution

VB developed the original idea and the protocol, abstracted and analyzed data, wrote the manuscript. HKM, RF and AE contributed to the development of the protocol, abstracted data, and prepared the manuscript.

### Ethical considerations

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

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