

ORIGINAL ARTICLE

Uncertainty, the Overbearing Lived Experience of the Elderly People Undergoing Hemodialysis: A Qualitative Study

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ABSTRACT

Background: The chronic kidney disease is a major health concern. The number of the elderly people with chronic renal failure has increased across the world. Dialysis is an appropriate therapy for the elderly, but it involves certain challenges. The present paper reports uncertainty as part of the elderly experiences of living with hemodialysis.

Methods: This qualitative study applied Max van Manen interpretative phenomenological analysis to explain and explore experiences of the elderly with hemodialysis. Given the study inclusion criteria, data were collected using in-depth unstructured interviews with nine elderly undergoing hemodialysis, and then analyzed according to Van Manen 6-stage methodological approach.

Results: One of the most important findings emerging in the main study was “uncertainty”, which can be important and noteworthy, given other aspects of the elderly life (loneliness, despair, comorbidity of diseases, disability, and mental and psychosocial problems). Uncertainty about the future is the most psychological concerns of people undergoing hemodialysis.

Conclusion: The results obtained are indicative of the importance of paying attention to a major aspect in the life of the elderly undergoing hemodialysis, uncertainty. A positive outlook can be created in the elderly through education and increased knowledge about the disease, treatment and complications.

KEYWORDS: Aged, Renal dialysis, Uncertainty

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INTRODUCTION

Chronic renal disease is a major health concern that incurs poor health consequences and high health care costs,¹ with greater prevalence among the elderly.² In the last two decades, the number of the elderly patients with chronic renal failure has increased in most countries. Hence, in terms of age pattern, this disease has been inclined toward the elderly.³ As in other age groups, dialysis-dependent renal failure has consistently increased among the elderly people over the last decade.⁴ Dialysis is an appropriate treatment for the elderly with renal failure, especially for those blessed with good quality of life.² Hemodialysis treatment increases the survival rate and life expectancy of the patients, but it involves numerous challenges for the patient.^{5,6} Patients with chronic renal failure are among vulnerable groups. Severity of vulnerability in these patients is expected to exacerbate when they reach old-age.⁷⁻⁹ Given their greater level of vulnerability, the elderly undergoing hemodialysis require greater care and attention; and since they are dependent on dialysis machine, they suffer several forms of stress, including psychosocial tension, disease comorbidity, and lack of social support.¹⁰

This article reports uncertainty as part of the findings of a larger phenomenological study exploring lived experience of the elderly undergoing hemodialysis. Some of researchers reported that uncertainty about the future is the most psychological concerns of people undergoing hemodialysis.¹¹⁻¹⁴ Based on the Mishel's theoretical framework, uncertainty is a commonality with any illness experience whether the illness is acute or chronic. This theory explains how patients construct meaning related to their illness utilizing cognitive processes. According to Mishel's definition, uncertainty is the inability to determine the meaning of illness related events and it occurs when the decision maker is unable to assign definite values to the objects and events. It can be positive or negative, but it is present in phases of diagnosis, treatment and prognosis.¹⁵ Uncertainty is a significant source of stress

in chronic diseases and is viewed as a major feature of the illness experience.¹⁶ Uncertainty can be important and noteworthy, compared to other aspects of the elderly life (loneliness, despair, co-morbidity of diseases, disability, and mental and psychosocial problems). Due to age changes, the elderly have different ideas and views on the disease, treatment and acceptance compared to other age groups. Age is an agent mediating how the individual experience and respond to chronic illness.¹⁷ Little is known about the experience of the elderly undergoing hemodialysis, particularly about lived experience of Iranian elderly. They have a particular view about disease and treatment because of their culture, living environment and level of education. The present paper reports a part of the elderly experiences of living with hemodialysis to explore and to discover the meaning of life in the elderly undergoing hemodialysis based on interpretative phenomenological study. Uncertainty emerged as one of the most prominent themes in this study. Because uncertainty is a dynamic state, its negative aspect can become positive with recognition of the elderly patients' conditions. This study contributes to the body of knowledge about the uncertainty in the specific group of population.

MATERIALS AND METHODS

This qualitative study applied Max van Manen interpretative phenomenological analysis to explain and explore experiences of the elderly undergoing hemodialysis. According to van Manen, interpretive phenomenology provides a systematic approach to study and interpret a phenomenon, and allows analysis and exploration of the phenomenon with an interpretative outlook to achieve a more profound understanding of lived experiences.¹⁸

Study population consisted of the elderly undergoing hemodialysis in 2 teaching hospitals in Sari town including Imam Khomeini and Fatemeh Zahra hospitals affiliated to Mazandaran University of Medical Sciences, Iran. The study inclusion criteria

were age 60 years and over, dependence on dialysis, experience of a minimum of one year of hemodialysis, fully able to communicate, with no cognitive disorders according to the elderly Abbreviated Mental Test (AMT) and medical records before the interview, willingness to share own experiences, and able to speak in Persian. Sampling was conducted following approval by the office of postgraduate education of University of Welfare and Rehabilitation Sciences, confirmation of the Ethics Committee, and obtaining a letter of introduction from the university, and necessary arrangements with Sari hospital authorities. Time and place of interviews were decided according to prior agreement between the researcher and participants. Purposive sampling, which is common in phenomenological studies, was used to obtain in-depth rich data from each participant. In purposive sampling, individuals are selected based on their specific knowledge.¹⁹

According to van Manen, sampling is terminated when open, brief, relevant, rich and in-depth results are obtained.²⁰ In this study, of the nine participants, six were men and three women. Data were collected using in-depth unstructured interviews, asking questions based on the study objectives. Interviews were done by a researcher familiar with interviewing techniques and supervised by a research team (Gerontologist, Nursing PhD, Specialist Geriatrics Medicine, and Nephrologist). An open question included “What does dialysis mean to you?”, “How do you feel about dialysis?”, followed by probing questions such as “Please explain more”, and “Can you give an example?”, based on the information provided by patients. The interviews lasted about 30-50 minutes. All interviews were recorded and transcribed verbatim immediately after.

Data were analyzed using van Manen’s 6 methodological steps as follows:

Step 1: Turning to the nature of lived experience. Step 2: Exploring the experience as it was lived through. Step 3: Focus

on inherent themes that characterize the phenomenon. Step 4: Art of writing and rewriting. Step 5: Maintaining a strong and directed relationship with the phenomenon. Step 6: Matching the study results according to the relationship between whole and parts.²⁰

Max van Manen’s thematic analysis process was used to separate thematic items and extract the themes from holistic and selective approaches. Based on this approach and after each interview, interview text was transcribed and then reviewed several times to gather a general understanding. Next, as a general understanding, the main concept of the text was written in two to three paragraphs (holistic approach), which helped the researcher immerse in data, and think more deeply about the phenomenon. Then, based on selective approach, each interview text was read several times, and statements that appeared to describe and reveal the essence of the phenomenon of the elderly living with hemodialysis were selected. Next, the research team members exchanged views on extraction of items and themes. To resolve any disagreement and discrepancies in interpretations, process of return to texts regularly and frequently continued until the resulting contents and themes were related together in the best possible way.

To increase the study rigor, Goba-Lincoln method was used with criteria of acceptability, reliability, transferability, and conformability.²¹ To assess the validity of the study, a trusting relationship was established with participants. For confirmation of the data, each interview text was made available to the participants (after analysis) and their views were sought. This study was also verified with participation of research team and several referees, and their suggestions and recommendations were incorporated. To achieve conformability, all stages of the study were precisely recorded.

Ethical Considerations

This study was conducted after approval of the Ethics Committee of Welfare and

Rehabilitation Sciences University (IR.USWR.REC.1394.44). Ethical principles observed included participation of patients with informed consent and assurance about confidentiality of personal data at publication of results. Explanations were given about confidentiality of data, and recording interviews, and written consents were obtained from the participants.

RESULTS

Characteristics of the study participants are presented in Table 1.

The results obtained initially showed 291 meaning units from nine interviews, which were compared, integrated and separated according to similarities and differences, resulting in emergence of 18 subthemes and seven main themes. The study results showed that experiences of the elderly with hemodialysis consisted of seven themes, including dialysis as life saver, problematic life with dialysis, contradictory feelings, faith in God, and uncertainty, dependence, and social support. The elderly know dialysis is their life saver. They have a good outlook at it and are adapted to it. At the same time, they experience many challenges and changes in their daily lives. Challenges create mixed feeling about the treatment. Some of them have hope and some are disappointed. In this situation, they believe and trust in God. They know their life is a kind of divine destiny. Lack of knowledge and fear of death is due to

uncertainty and it is very important for them. They were also dependent on hemodialysis machine and see it as their life line. Despite many challenges in their life, social support by family and staff has increased their satisfaction and their positive outlook. We reckon the experience of uncertainty was especially important for the participants. In this article, results associated with the theme “uncertainty” and related subthemes of obscure future, fear of the unknown, and regularity induced irregularity are presented.

Uncertainty

Uncertainty emerged from the experiences of participants in this study. Uncertainty is one of the main themes in the phenomenon of living with hemodialysis, and includes three subthemes of obscure future, fear of the unknown, and regularity induced irregularity. This theme refers to the fact that the elderly undergoing hemodialysis treat their future as obscured by uncertainties. The lack of information and doubt makes the patients see themselves in a limbo between life and death. Sometimes, the lack of change in the treatment process implies a lack of progress and a sense of returning to square one for the patient. Fear of death and the unknown following hemodialysis places the patients in an uncertain position, and makes them unable to have a regular plan in life. In chronic diseases, uncertainty is an important concept. Uncertainty puts the patient in an unknown position in relation to future (Table 2).

Table 1: Demographic characteristics of the elderly undergoing hemodialysis

Participant's code	Gender	Age (years)	Education	Occupation	Marital status	Hemodialysis history (years)
P1	Male	76	Diploma	Retired banker	Married	3
P2	Male	68	BSC degree	Teacher	Married	5
P3	Male	88	6 th year primary school	Machinist	Married	2.5
P4	Male	69	3 rd year secondary school	Retired forestry employee	Married	3
P5	Male	85	Illiterate	Farmer	Married	2
P6	Female	80	Illiterate	Housewife	Married	7
P7	Female	66	Illiterate	Housewife	Married	4
P8	Female	80	Illiterate	Housewife	Widowed	6
P9	Male	64	Diploma	Retired	Married	4

Table 2: Theme, Subtheme and Meaning Units of uncertainty

Theme	Subtheme	Meaning Units
	Obscure Future	Incurable disease No changes Lack of awareness of end of life with dialysis Lack of information about treatment with dialysis Future concerns Future Unknown Perhaps treated with dialysis Requires knowledge
Uncertainty	Fear of Unknown	Fear of death Die every elderly Getting worse Young people are treated Dead end Fear of dying with late dialysis Well-being and sometimes worse Fear of hospital Fear of hospitalization Hurry up having to go to the dialysis unit
	Regularity induced Irregularity	Disturbing the normal life Lack of planning on living Being constantly ready Constantly waiting Disrupting life

1- Obscure Future

Many elderly people undergoing hemodialysis were not sure about their future. Given their disability, disease comorbidity, and greater mortality, the elderly undergoing hemodialysis considered their prospects obscure. Patients’ description of treatment process and their lack of information about recovery or otherwise suggest unclear future. In the process of dialysis, patients like to experience a better future, but they are hindered by doubts and obscurity. One of the participants stated: “We don’t know whether we are getting better or not. I’m told I’m getting better. But, I know if I am or not. What’s going on, we only undergo dialysis”.

The same participant added: “Thanks God, I want to see how far I go in life”. Another participant said: “I’m frightened, so I come for dialysis. I keep thinking if I no longer come, I’ll be sick and useless at work. I’d say I might get better with dialysis and I get better. Tomorrow is my turn for dialysis. I wish it was today. So I could come and get better. But I know I won’t get better. The young ones

become better with kidney transplant. We get worse every day”.

Sufficient information about the disease and respective treatment can change the patients’ perspective of life from negative to positive, and remove any obscurity in the patient’s mind about future. This requires greater interaction between patients and medical team to increase the patient’s awareness. Also, the patients’ knowledge of stages and process of treatment may reduce uncertainty. One of the participants explained: “No one knows what to do to avoid this disease. What to eat or not eat. They don’t know, or they don’t tell us. There’s no getting better with this disease; it ends in death. Everyone dies, that’s all”. Another participant emphasized: “I’m still on the first step after 5 years. I get the same medicine and the same instructions, and I’m still in the same way I was before, with no change”.

2- Fear of the Unknown

Some patients are frightened of conditions in the dialysis ward and picture events ahead. Fearing death, fearing dialysis equipment,

and the future were among stressful and frightening issues for patients. For instance, a senior woman noted: "I'm scared. I don't know what will happen on dialysis bed, will I die? I didn't like to come for dialysis. I don't like hospitals at all". Another participant stated: "I get worse if I miss dialysis for even one day, and I get better with dialysis. I like to come for dialysis a few days before my turn; its takes a couple of hours, and I come one hour before. I cannot bear it and I'm scared of getting worse and dying. So I come early because I'm worried I might die". A senior man stated: "I was frightened from the start; sticking a needle in you to take even a drop of blood is so difficult. Now our blood is churning and churning in the machine. We take life from blood".

According to the participants, the lack of information about the disease and treatment measures causes fear and stress for the elderly undergoing hemodialysis. Given their old age and seeing themselves closer to death than young people, they get through this period with fear. The elderly consider hemodialysis a life line and a savior and fear death and facing with it.

3- Regularity Induced Irregularity

A lack of control over one's life and a lack of regular planning is a huge problem for many of these patients. Change in dialysis schedule causes irregularity in the life of these patients, and they feel they are constantly on-call, and have lost control over their own lives and the disease has taken over. It seems that order in dialysis has caused disorder in their lives, and together with the lack of planning; it has led to their loss of energy and reduced quality of life and life expectancy. A senior man stated: "You cannot plan for anything, and your whole life is mixed up. I had a service providing company, but I cannot plan for it. They just phoned me and told me I could only go for dialysis tomorrow and not the day after. Well, that ruins your life". The same participant added: "You cannot do or plan anything. I was going to sort out the

house, but then I thought what for. We cannot be one hundred percent hopeful". Another participant said: "I could easily plan my whole life and travel; not now. You have to make difficult arrangements and plan if you want to go somewhere". One of the participants explained: "I cannot do anything. I cannot move. I have to be here in the morning, every other day. I have no other plans".

DISCUSSION

The elderly undergoing hemodialysis experience emotional burdens such as obscure future, fear of unknown and regularity induced irregularity that further impact on their mind and cause uncertainty. Uncertainty is a psychological challenge and disease comorbidity for hemodialysis patients.

In a study conducted in Durham, the trend of kidney disease was discussed by the elderly patients and nephrologists, and the results showed that patients felt uncertain and had little information about the impact of disease on their daily lives, which can lead to fear and false hope. In this study, participants were not sufficiently ready for future events, and wanted to focus on their current performance irrespective of readiness for future events.²² Another study on experiences of hemodialysis patients in South Karnataka reported that most patients experienced uncertainty and fear of future.²³ Results of a study on the experience of people undergoing hemodialysis from a certain group of immigrants in America called "Hamong" showed that they felt weak, unwell, and uncertain. Feeling of uncertainty and fear for life, death, dialysis, future, and also kidney transplant was clear in this study.²⁴ The present study results confirm those in above studies.

Results of a phenomenological study on experiences of home peritoneal dialysis patients showed that the unpredictable process of disease led to the patients' fear and uncertainty. In this study, the elderly considered their lives lost, and feared the end of life.²⁵ This study also confirms the result of

the present study, and according to patients, unpredictability of the disease and failure to plan for life reduce the quality of life; this agrees with a study by another researcher, in which patients considered their life was lost.

Results of another study on experiences of automatic peritoneal dialysis patients showed that patients were uncertain and feared their prospects. Since they were getting older and unable to have this kind of dialysis, they were worried about how long they were going to live with this disease.²⁶ In the present study, patients also feared their own lives, and believed it would end in death.

Results of one study showed that patients undergoing dialysis developed a new identity and sense. In this study, uncertainty was the main theme of life in hemodialysis patients.²⁷ Also, the results of a study showed uncertainty as one of the main themes, and according to patients, living with uncertainty was associated with fluctuations in their health. In this study, the participating elderly argued that one cannot decide one's degree of disability with uncertainty. Using a metaphor, participants asserted "We are seated in a moving chair, and don't know if we are going to crash or not?"²⁸

The present study results agreed with those of other studies, and confirmed that uncertainty is a major theme in the life of patients, especially the elderly with chronic diseases. Patients are faced with obscure future, a lack of information, many unknown stuff about dialysis, and fear of death. A lack of planning and control over their lives can place them in a precarious position, and affect their quality of life. Unlike the present study findings, the results obtained by another study showed that the elderly wanted to focus on their current situation, and uncertainty emerged as a main theme.²² In the present study, the elderly were concerned about their future, and expected to receive better information, and be better prepared for their prospects. They expected to have better lives, and liked to be able to live better and longer.

Our results confirm that the elderly

undergoing hemodialysis treatment are uncertain about their life with obscure future, fear of unknown, regularity induced Irregularity. Some authors have found that patients experience uncertainty with lack of information and unpredictable course of disease, standing between life and death, and lack of planning.^{22,27-29}

Many researchers have found that uncertainty is inevitable and is created in patient's mind in the course of disease, and people are forced to live with uncertainty and confusion when many things can go wrong or further disability is likely with the progress of the disease.^{27,30-33} Researchers reported that when the level of uncertainty was higher, it was more likely to be assessed as a risk or menace.³⁴

The main limitation of this study was the difficulty experienced during interviews, because old age people could not be able to speak for a long time and also setting the time for interview was somewhat challenging.

Implications for Health Care Teams

Learning about experiences of the elderly undergoing dialysis enables the specialists from various medical and care groups, such as gerontologist, doctors and nurses, to better identify and meet their psychological, physical and social needs and design a good plan for them.

CONCLUSION

The elderly undergoing hemodialysis are in an uncertain position and have a short life expectancy. They are afraid and cannot properly plan their lives. They need to know about treatment and future so that they can decrease their worries. Providing education and sufficient information by gerontology specialist and care providers can reduce uncertainty and turn patient's fear into acceptance of the disease and treatment, thus increasing the patients' quality of life. It presents various implications for gerontology and care providers. Knowledge about the elderly undergoing hemodialysis concerns enables the gerontology specialist and other medical groups to better help and

plan for them.

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