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In-between Hope and Uncertainty: Phenomenon of Quality of Life among Young Adult Hemodialysis Patients

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Abstract. End-stage renal disease (ESRD) signifies the final stage of chronic kidney disease (CKD), often necessitating kidney transplants or hemodialysis for survival. Hemodialysis imposes significant limitations on patients' daily lives, potentially leading to psychological issues. This research aims to describe the lived experiences of young adult hemodialysis patients, understand their perceptions of life-and-death risks, and explore changes in their quality of life and mental health. The study employed descriptive phenomenological research with thematic analysis, involving five young adult patients undergoing hemodialysis. The key themes that emerged from the data included difficulty in understanding their situation, dealing with life's difficulties, life of uncertainty, and psychological impacts. These findings provide valuable insight into the experiences of young adult hemodialysis patients. A deeper understanding of these experiences can enhance care, support, and the overall quality of life for this patient population.

Key words: *hemodialysis treatment, quality of life*

Abstrak. *End-Stage Renal Disease* (ESRD) adalah tahap akhir penyakit ginjal kronis (*Chronic Kidney Disease*/CKD) yang biasanya memerlukan transplantasi ginjal atau hemodialisis untuk bertahan hidup. Hemodialisis memberikan keterbatasan signifikan dalam kehidupan sehari-hari pasien dan berpotensi menyebabkan masalah psikologis. Penelitian ini bertujuan mendeskripsikan pengalaman hidup pasien hemodialisis dewasa muda, memahami persepsi mereka terhadap risiko hidup dan kematian, serta mengeksplorasi perubahan kualitas hidup dan kesehatan mental. Studi ini menggunakan pendekatan fenomenologi deskriptif dengan analisis tematik, melibatkan lima pasien dewasa muda yang menjalani hemodialisis. Tema utama yang muncul meliputi kesulitan memahami situasi, menghadapi kesulitan hidup, hidup dalam ketidakpastian, dan dampak psikologis. Temuan ini memberikan wawasan berharga tentang pengalaman pasien dewasa muda. Pemahaman lebih mendalam dapat meningkatkan perawatan, dukungan, dan kualitas hidup kelompok pasien ini.

Kata kunci: *perawatan hemodialisis, kualitas hidup*

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Introduction

The last stage of chronic kidney disease (CKD) is the end-stage renal disease (ESRD). This happens when the kidneys' ability to work on their own has been severely compromised. To live longer with end-stage renal failure, a patient may need a kidney transplant or must undergo hemodialysis treatment (End Stage Renal Disease, 2021). Individuals with ESRD must adhere to a range of dietary, hydration, and lifestyle limitations to manage their condition. The daily lives of the patients are significantly impacted by these limitations, including how they perceive their condition, which can cause psychological problems, including depression and anxiety. Hemodialysis patients who also experience psychological symptoms are less able to adjust to their illness, search less for the necessary treatments, and have a lower quality of life (Senmar et al., 2020).

The burden of ESRD is significant, with recent statistics indicating a rising number of dialysis patients globally, many of whom are in the younger age bracket (Rao et al., 2025). In the Philippines, the number of individuals undergoing dialysis treatment increased by 22%, from 53,296 in 2023 to 64,845 in 2024, with 57.44% aged between 20 and 59 years (Montemayor, 2025). While national statistics do not provide a separate breakdown for those aged 18–30, this group falls within the broader working-age population affected by the disease. Experiencing ESRD during these formative years may interrupt higher education, delay career development, and strain personal relationships, making their circumstances distinct from those of older patients. These factors underscore the importance of examining the lived experiences and quality of life of young adult dialysis patients.

The experiences and quality of life (QOL) of hemodialysis patients have been the subject of numerous studies. QOL refers to how individuals perceive their position in life in relation to their cultural context, personal values, life goals, expectations, and standards, and it has become a key consideration in evaluating the care of chronic kidney disease patients undergoing hemodialysis (Yonata et al., 2022). However, it has not been thoroughly examined in the Philippines setting, or more specifically, among young adults (Aruta, 2023). Hence, this study aims to describe the lived experiences of young adult hemodialysis patients from Pamana Medical Center, to understand their perception about life and death risks, and to explore changes in their quality of life and its impact on their mental health. By studying and understanding the experiences of young adult hemodialysis patients, they can be provided with better care, support, and a higher quality of life.

Generating studies about the psychological problems experienced by hemodialysis patients are necessary to increase the caliber and volume of research in the context of dialysis. It has the potential to yield results and findings that can significantly improve the lives of patients in a variety of ways, such as reducing mortality rates by enhancing the process of care and addressing their symptoms, not just physically but also mentally (Flythe et al., 2019). According to Aruta (2023), the mental health of hemodialysis patients in the Philippines has long been disregarded.

Thus, several significant structural changes are necessary to ensure that this vulnerable group and marginalized group maintain their mental health and achieve the best possible level of well-being at this point in their lives. It is important to assess the mental health of these patients for it affects how they perceive their condition, which in turn affects the quality of their lives. The focus on young adults is particularly relevant as this age group is in a transitional phase of life, facing unique challenges related to independence, relationships, and community involvement. This study addresses an urgent research gap and seeks to provide evidence that could inform both clinical practice and psychosocial interventions.

Although there have been studies that used a quantitative approach, as there are existing scales for Quality of Life (QOL), the researchers have chosen this qualitative phenomenological approach as it allows to capture the raw ideas and thoughts of the participants' quality of life directly coming from their narratives without the aid of statements from an existing test. This study is anchored to Abraham Maslow's Quality of Life Theory. Maslow (1980) founded his theory of development towards happiness and true being on the human needs. This approach is an existential psychology of self-actualization focused on individual development.

This research holds significant implications for both academic and practical applications. One of its main objectives is to ascertain how the changes in the patients' lives brought on by receiving hemodialysis influence their mental health and how psychological problems such as depression and anxiety affect the patients' quality of life. By doing so, the researchers may give a thorough analysis of the experiences of young adult hemodialysis patients for them to get better care and support, and assist in developing therapeutic interventions to deal with these psychological issues.

Methods

Research Design

The descriptive phenomenological research design is used as a research strategy that seeks to describe, explore, and understand the lived experiences of young adult hemodialysis patients. This qualitative approach is well-suited to uncovering subjective perspectives and examining how individuals perceive life-and-death risks, changes in quality of life, and mental health impacts (Leigh-Osroosh, 2021).

Materials

A semi-structured interview guide formulated by researchers, tailored to the research objectives was used. It was validated by experts, and revisions were made based on the recommendations of the validators. The data were recorded using the Microsoft Teams application, and the researchers took notes of their narratives during in-depth interviews.

Study Location & Participants

The research took place at Pamana Medical Center, known for its accessible dialysis services. Participants were young adults (18–30 years old) with end-stage renal disease (ESRD), undergoing hemodialysis 2–3 times weekly for at least three months. Those with significant comorbidities (e.g., malignancies and organ failure) or psychiatric disorders were excluded. This age group was chosen due to the unique psychosocial challenges they face during a critical life transition.

Data Gathering

Semi-structured interviews facilitated an in-depth exploration of participants' experiences. Conducted virtually via Microsoft Teams, each session lasted 30 to 50 minutes. Participants shared their thoughts, feelings, and perceptions individually, ensuring confidentiality. All interviews were recorded and transcribed for analysis.

Ethical Considerations

The study has followed a Code of Ethics aimed at ensuring the physical and psychological safety of participants. Before the data collection began, the protocol (CLAC-Ethics 0064) was reviewed and approved by the DLSU-D Review Committee, ensuring that appropriate measures were implemented to protect the participants' rights and well-being. Participation was voluntary, with informed consent obtained after explaining the study's purpose and procedures. Participants were assured of their right to withdraw at any time without penalty. Anonymity and confidentiality were strictly maintained, with no identifying information included in any reports. Sensitive topics were approached with care, allowing participants to skip questions or withdraw if they felt uncomfortable. All data were securely stored and used exclusively for research purposes.

Results

Table 1.

Thematic Structure of Patients' Lived Experience

Superordinate Theme	Subordinate Theme(s)
Difficulty Accepting their Condition	● Limited Understanding of ESRD and Hemodialysis Treatment

	● Regret of Worsening the Illness
Dealing with Life's Difficulties	● Food and Water Intake Restriction ● Financial Incapability ● Experiencing Losses in Life ● Guilt over being Unable to give back to their family
Life of Uncertainty	● The Idea of Death ● Uncertain Future
Psychological Impact	● Low confidence ● Sadness ● Fear ● Anxiety ● Depressive symptoms

The table above shows the superordinate themes describing the lived experiences of young adult hemodialysis patients. Based on the findings, the researchers identified four superordinate themes: Difficulty Accepting their Condition, Dealing with Life's Difficulties, Life of Uncertainty, and Psychological Impact, each with their own corresponding subordinate themes.

Difficulty Accepting Their Condition.

The majority of the participants admitted that they had a limited understanding of the hemodialysis process. The patients described how receiving hemodialysis signals impending death for the person receiving it, as Patient 3 said, *"I was shocked when I learned about that. When* *the doctor said I should be on dialysis, I immediately thought I would die."* Moreover, the patients expressed feelings of regret over unhealthy practices they had done before, which led to damage to their kidneys. Some of them believe that they could have taken action to avoid needing dialysis, which resulted in feelings of guilt and regret.

Dealing with Life's Difficulties.

Undergoing hemodialysis requires patients to limit their food and water intake since too much of it can affect their ability to breathe. Patient 1 shared that *"Before, I loved drinking. But now, even if you are so thirsty that you want to cry, you should not drink."* Another major concern of patients is financial incapability. Most patients solely depend on their parents, relatives, and financial assistance from the government to support their sessions.

Patient 4 shared, *"The most challenging part for me is asking for and processing medical assistance since we have no means to support my treatment. I need to process my medical assistance in Manila. We asked everywhere just to have money for my treatment."* Similarly, patients expressed guilt for being unable to give back to their families. Patient 4 stated, *"I planned to work so that my mother could stop working. Since I got sick, she is still working at 57."* Moreover, being a dialysis patient means having to deal with losses—missed opportunities to fulfill dreams, loss of physical capacity to work, and loss of social life.

Life of Uncertainty.

Hemodialysis treatment is a lifetime commitment, yet it does not guarantee a long life. Patients have expressed that the idea of death has crossed their minds on a daily basis, as Patient 1 stated, *"I sometimes think that I will die. Sometimes, when my wife is at work, I wonder if she can see me alive once she gets home."* Some patients also ceased to think about the future. Patient 5 shared that *"My anticipation for the future decreases because I am uncertain of what the future holds. It is like, 'Am I still alive next year?' Should I set goals for next year or just this year? I stop myself from imagining far ahead because I am sick."*

Psychological Impact.

Participants have reported having negative consequences for their psychological health, such as low self-confidence. Patient 5 said, *"My confidence decreased. I am also afraid of making friends because they might feel uncomfortable, especially with the physical state of my arms. That is why I always wear long sleeves."* Participants also reported having negative feelings towards themselves, constant feelings of stress, fear, and anxiety. As seen in the following statements by Patient 4, *"There are many thoughts inside our minds. "What will happen to me? I cannot do what I used to do because of dialysis." Similarly,* Patient 3 stated, *"Sometimes, I feel so exhausted because I have no choice. I wanted to give up. Whenever I have anxiety, I cry alone."*

Discussion

The present study aimed to describe the life experiences of young adult hemodialysis patients, to understand their perception about life-and-death risks, and to explore changes in their quality of life. As a result, the researchers found that young adult hemodialysis patients are dealing with life's difficulties and life of uncertainty, experiencing difficulties accepting their condition and the psychological impacts caused by their illness. The superordinates that resulted from this analysis are both like and distinct from those found in prior research that has investigated the subject.

Most participants expressed that they have a limited understanding of ESRD and hemodialysis treatment, and have difficulty accepting their condition, as they believed that they could have done something to prevent undergoing hemodialysis treatment which resulted in regrets. According to Inkeroinen et al. (2021), the patients have reported inadequate patient education regarding chronic kidney disease and its treatment, as well as information being withheld. Learning knowledge concerning their disease and its treatment is essential for patient empowerment and enhances both medical and psychosocial aspects (Inkeroinen et al., 2021).

Hemodialysis patients experienced difficulties in life, such as restrictions on their water intake and diet. Drinking and eating too much can put them at risk. In a study conducted by Özkan & Taylan (2022), patients undergoing hemodialysis must be proactive in many facets of their treatment to successfully manage their disease, including adherence to fluid and dietary restrictions. Hemodialysis patients in the study described diet and fluid restriction as a difficult process that required ongoing effort; that it is the most demanding part of the treatment.

Moreover, participants also expressed that one of their major concerns is their financial capability. All participants rely solely on their family members and financial assistance to cover the cost of their treatment sessions. Ng et al. (2021) discussed that financial hardships and lower socioeconomic status are associated with poorer quality of life. This research indicated that the patients' physical and psychological symptoms are adversely affected by their financial situation.

Being a dialysis patient means enduring lots of losses. Patients shared that they have missed opportunities in life, lost their jobs due to losing their physical strength, and lost their social life. In a similar study, Rohini T., & Punitha V. Ezhilarasu (2016) derived abounding losses as one of their themes. It is discussed that hemodialysis patients experience a life filled with many losses. According to the participants in the study, losses ranged from a loss of physical strength to a loss of employment and prosperity. Moreover, hemodialysis patients live a lonely existence, especially if they feel that their friends and family have abandoned them (Rohini T., & Punitha V. Ezhilarasu, 2016).

Because of the difficulties experienced by these patients, particularly with their financial constraints, the participants expressed guilt that their parents and other relatives are still providing for them rather than being able to repay them for their sacrifices. In the Philippines, family responsibilities are highly emphasized and instilled in children at a young age. The principles of *utang na loob* (debt of gratitude) are also essential to Filipino society. As a method of repaying their parents for raising them, children are required to care for their parents under these ideals (Garcia et al., 2018). Young adults are expected to become financially independent and begin to assume responsibility as involved and active members of their communities during this period of transition in their lives. However, since these participants are suffering from the consequences of their condition, they are unable to care for and support their parents financially, which causes guilt.

Patients mentioned that they have been thinking about the idea of death. Some of them are still scared about it, and some are already accepting what might possibly happen to them. A study mentioned above was conducted by Rohini T., & Punitha V. Ezhilarasu (2016) stated that the majority of their participants acknowledged that they frequently had thoughts of death; that undergoing hemodialysis reminds them of the unpredictability of their future.

Undergoing hemodialysis is accompanied by psychological impacts. Patients reported feelings of low self-confidence, stress, fear, and anxiety. Patients expressed that they tend to have low levels of self-confidence due to the changes in their appearance caused by hemodialysis. In a study conducted by Sharif Nia et al. (2022), it was discussed that patients with ESRD frequently struggle to accept their changing physical appearance, which contributes to their social anxiety, decreased self-efficacy, and lower quality of life. Furthermore, patients reported feelings of stress, fear, and anxiety brought by the condition and hemodialysis treatment. George et al. (2022) concluded from their research that hemodialysis patients suffer from severe levels of stress and anxiety due to lifestyle changes, limitations on social activities, and concern about the future, which is also aligned with the present study.

According to Abraham Maslow's Quality of Life Theory, achieving all eight of the necessary needs is a lengthy road to happiness, true being, and the ideal life. The needs are the physiological needs, need for peace of mind and safety, need for love, need for respect, need for knowledge and understanding, need for creativity and aesthetics, need for self-actualization, and need for transcendence. As discussed earlier, hemodialysis patients are living a restricted life, which involves controlled food and water intake, feelings of unsafety due to their condition that might lead to death, lost opportunities, jobs and social interaction, and suffering from psychological issues. These restrictions may impede these patients' efforts to live happily, which in turn results in a lower quality of life.

Conclusion

The purpose of this descriptive phenomenological study was to describe the lived experiences of young adult hemodialysis patients in Pamana Medical Center, to understand their perception about life-and death risks, and to explore changes in their quality of life and its effects on their mental health. The data were collected utilizing semi-structured interview questions delivered during five online interviews. Four superordinates emerged from the data analysis using thematic analysis. These include difficulty understanding their situation, dealing with life's difficulties, a life of uncertainty, and psychological impacts.

The findings of this study shed light on the life experiences of young-adult hemodialysis patients. They face a lot of challenges, such as limited food and water intake, financial drain, lack of understanding about ESRD and hemodialysis, regret of worsening their illness, losses in life, guilt over being unable to give back to their family, constant thoughts of death and uncertainty, and experiencing anxiety, fear, stress, and low self-esteem caused by hemodialysis treatment. It is possible to improve the care, support, and quality of life for young adult hemodialysis patients by learning about and comprehending their experiences. However, since this study mainly focuses on young-adult patients, the findings of the study might have limited generalizability.

Suggestion

This study mainly focuses on the lived experiences of young adult hemodialysis patients, their perception towards life-and-death risks of their condition, changes in the quality of their life, and its effects on their mental health. The participants chosen were young adults in a single institution in the Philippines setting, which focuses on their subjective shared experiences and perceptions. Given the exclusionary categories of the participants, the findings of the study may have limited generalizability. The researchers therefore recommend that future studies include a wider variety of individuals from various age groups and institutions, in order to enable more extensive comparisons and aid in the creation of more thorough and generalizable results.

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