

Research Paper

Understanding Coping Strategies and Quality of Life in Young Adults with Chronic Kidney Disease

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ABSTRACT

This study investigates the coping strategies and quality of life (QoL) of chronic kidney disease (CKD) patients below the age of 30 through narrative analysis. Using a sequential explanatory design, the research initially administered the Kidney Disease Quality of Life (KDQOL) questionnaire to CKD patients recruited through snowball sampling. After analysing the quality-of-life scores, only 5 participants were found to have a high or good quality of life. Subsequently, interviews were conducted exclusively with these 5 CKD patients to explore their coping strategies. Narrative analysis of the interviews revealed several coping strategies employed by the participants, including active coping, emotional support, positive reframing, planning, humor, acceptance of health condition, spirituality, distraction, avoidance/denial, substance use, and disengagement. Despite facing challenges associated with CKD, five participants demonstrated high QoL, attributing their well-being to effective coping strategies such as emotional support, positive reframing of thoughts, acceptance of their health condition, and spirituality. The findings underscore the importance of recognizing and supporting effective coping strategies among young CKD patients to enhance their overall well-being and QoL. This study provides valuable insights for healthcare providers and policymakers in developing interventions to improve the lives of CKD patients.

Keywords: *Chronic Kidney Disease, coping strategies, quality of life, narrative analysis*

Chronic diseases are defined broadly as conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both. Chronic diseases may have multiple impacts like mortality, long term morbidity, and impairment in quality of life (QOL). According to WHO, QOL is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. Chronic kidney diseases are reaching epidemic proportions and as per World Health Organization (WHO) Global burden of disease project, chronic kidney diseases (CKD) are 12th leading cause of death and 17th cause of disability. Prevalence of CKD varies across hospital and community-based settings and in presence of coexisting diseases. Burden of CKD is also different depending on availability and access to care, timing and quality of care also social support. It is suggested

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that QOL can theoretically encompass a wide range of domains and components like functional ability including role functioning, the degree and quality of social interaction, psychological well-being, somatic sensations, happiness, life situations, life satisfaction and need for satisfaction. QOL assessment is an important tool for evaluating the impacts of treatment interventions and benefits. As renal disease management itself is in initial stages in the state, studies on quality of life in CKD were scary.

CKD patients in renal replacement therapy are subjected to a higher prevalence of mood disorders than the general population. The predominance rates of anxiety and depression in hemodialysis patients are high, corresponding to between 30% and 45% and between 20% and 30%, respectively. This condition can represent an increase in the morbidity and mortality of dialysis patients, compromise their treatment compliance and modulate their immunological and nutritional situation, due to the depression or anxiety symptoms as well as to associated symptoms, such as loss of concentration, loss of motivation, sleep disorders, fatigue, depressive mood and difficulty to understand information. The present study was conducted to assess coping strategies among CKD patients.

CHRONIC KIDNEY DISEASE (CKD)

Chronic kidney disease (CKD) is the term used for heterogenous disorders affecting the structure and function of the kidney. The kidney disease is usually staged according to the glomerular filtration rate (GFR); it is the test to check how well the kidneys are functioning and how much blood is passing through the glomeruli (tiny filters of the kidney). As per the definition of KDOQI chronic kidney disease is the “kidney damage for more than or equal to 3 months, as defined by structural or functional abnormalities of the kidney, with or without decreased GFR or GFR <60 ml/min/1.73m² for more than or equal to 3 months, with or without kidney damage” (Levey et al., 2005a).

Table 1.1 Staging of Chronic Kidney disease.

Stages of kidney disease	Description of stages of CKD	GFR (ml/min/1.73m ²)
1	Normal or increased glomerular filtration rate with kidney damage.	>90 ml /min
2	Mild decrease in glomerular filtration rate with kidney damage.	60-89ml/min
3	Moderate decrease in glomerular filtration rate	30-59ml/min
4	Severe decrease in glomerular filtration rate	15-29ml/min
5	Kidney failure	<15 (or dialysis)

Source: (Levey et al., 2005b)

RISK FACTORS OF CHRONIC KIDNEY DISEASE

- Susceptibility factors; which means the factors that increase susceptibility to kidney damage. The factors are older age, family history of ckd, low birth weight, racial or ethnic minority status, low income/education.
- Initiation factors; which means the factors that directly initiate kidney damage. They are diabetes, high blood pressure, autoimmune diseases, systemic infections, urinary tract infections, urinary stones, lower urinary tract obstruction, drug toxicity and hereditary diseases.

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- Progression factors; which means the factors cause worsening kidney damage and faster decline in kidney function after initiation of kidney damage. They are higher level of proteinuria, higher blood pressure level, poor glycemic control in diabetes, possibly dyslipidemia and smoking.
- Environmental pollution, pesticides, analgesic abuse, herbal medications and use of unregulated food additives also contribute to the burden of chronic kidney disease in developing countries (Jha V,2004). Nephrotoxic effects can result from consumption of potentially toxic herbs, incorrect substitution of harmless herbs with toxic herbs, contamination with toxic compounds, such as heavy metals, or interactions between herbs and conventional treatments. Herbs can cause acute kidney injury, tubular dysfunction, electrolyte disturbances, hypertension, renal papillary necrosis, urolithiasis, chronic kidney disease and urothelial cancer.

END STAGE RENAL DISEASE (ESRD)

End-stage renal disease is the term for stage five chronic kidney disease, which is characterized by permanent damage to the kidney. The kidneys fail to filter out waste from the blood, which leads to the accumulation of urea in the blood. This condition is called uremia (Zemaitis et al., 2019). Uremia is the characteristic feature of end-stage renal disease and characterized by fluid electrolyte and hormonal imbalance in addition to metabolic abnormalities. Usual clinical features of uremia are nausea, vomiting, fatigue, anorexia, weight loss, muscle cramps, pruritis and changes in mental status (Zemaitis et al., 2019). End-stage renal disease is the last stage of kidney disease where renal replacement therapy becomes the most needed thing for the survival of the individual. Hemodialysis, peritoneal dialysis and kidney transplantation are the renal replacement therapy recommended for individuals undergoing dialysis. Kidney transplantation even though most effective, it is most often not accepted due to fewer donors and financial crisis. Hemodialysis and peritoneal dialysis are the most common dual modalities in the present scenario (Queeley and Campbell, 2018).

TREATMENT MODALITY

Hemodialysis, peritoneal dialysis and kidney transplantation are the renal replacement therapies recommended for an individual for end stage renal disease (Zazzeroni et al., 2017).

HEMODIALYSIS (HD)

“Hemodialysis is defined as a medical procedure to remove the fluid and waste products from the blood and to correct the electrolyte imbalance”. This is accomplished using a machine and a dialyzer, also referred to as an “artificial kidney”. This therapy maintains the blood pressure and regulates the essential minerals like sodium, potassium and calcium in blood (“Hemodialysis | NIDDK,2018”).

PERITONEAL DIALYSIS (PD)

Peritoneal dialysis (PD) is a medical procedure to treat kidney failure in which the blood is filtered through the lining of the abdomen. This lining is called the peritoneum. A nephrologist places a soft tube called catheter, in abdomen few weeks before the first dialysis (“Peritoneal Dialysis | NIDDK,2018”).

TYPES OF PERITONEAL DIALYSIS

Continuous ambulatory peritoneal dialysis and automated peritoneal dialysis are main two types of peritoneal dialysis. The main differences are schedule of exchanges, former is done

by hand and other by a machine. Both the types can be done at home, work place and even while travelling (“Peritoneal Dialysis | NIDDK,2018”).

CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)

In this method the exchanges can be done by hand in any clean surface. About 30 -40 minutes is the stipulated time for each exchange. With the CAPD the solution is kept inside the belly for four - six hours or more, which is called dwell time. The solution is changed atleast four times a day and can sleep with solution even at night. There is no need to wake up at night to do exchange. During an exchange individual can read, watch television, or sleep (“Peritoneal Dialysis | NIDDK,2018”)

AUTOMATED PERITONEAL DIALYSIS (APD)

In this method, a machine called a cyclor fills and empties the belly three to five times during the night. In the morning, the individual can begin the day with a fresh solution in the abdomen. The solution is left in the abdomen all day or can do one exchange in the middle of afternoon without a machine. This method is also called continuous cyclor assisted peritoneal dialysis (CCPD) (“Peritoneal Dialysis | NIDDK, 2018”). A study done on comparison of peritoneal dialysis and hemodialysis suggests peritoneal dialysis patients showed better score for quality of life domains. This therapy is more patient-friendly, and productivity of an individual is maintained. In developing countries, this therapy is not much recommended due to inadequate facilities, inadequate training and proper reassurance for the people (Wakeel et al., 2012).

MORTALITY AND MORBIDITY OF END STAGE RENAL DISEASE

Global & Indian Context

The global burden of kidney disease is gradually increasing, becoming the 5th cause of life lost by 2040 (Li et al., 2020). In 2017, 1.2 million people died from CKD. About 697.5 million all stage CKD cases were detected. In 2017, CKD led to 35.8 million disability-adjusted life years (DALYs). The burden was observed to be high in regions like sub-Saharan Africa, Latin America and Oceania, but the burden of disease was much less in western, eastern and central sub-Saharan Africa, east and central Europe. Impaired kidney function has resulted in 1.4 million cardiovascular-related deaths and 25.3 million cardiovascular DALYs (“Global, regional, and national burden of chronic kidney disease, 1990–2017,” 2020).

Nationally one in five adults is suffering from chronic kidney disease. Diabetes is the usual contributor to CKD or ESRD in India. The other etiologies in the country accounts upto hypertension (13%), glomerulonephritis (14%) and undetermined causes (16%). This high burden of disease brings serious implications in rural regions of the country (Jafar et al., 2020). Due to the absence of renal registries assessment of accurate burden of disease is still incomplete. In India, with a population of greater than one billion, the estimated age-adjusted incidence of ESRD is 229 per billion population, and greater than 100,000 people enter renal replacement therapy annually in India. As the resources for renal replacement therapy is scarce in the present scenario of the health sector, only 10 % of the Indian ESRD patients receive RRT therapy (Anand et al., 2015).

Quality of Life

Quality of life of an individual can be stated as “perception of their position in context of culture and values where they live, in relation to goals and expectations of their life” (Ravindran et al., 2020). "Quality of life" in healthcare refers to the overall well-being of

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individuals and societies, encompassing physical, mental, and social health factors rather than disease and disability alone. It is a broad concept affected by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment (WHO). The quality of life for chronic kidney disease (CKD) patients faces significant challenges, with multifaceted reasons contributing to its deterioration (Kraus et al., 2016). Among those undergoing dialysis, various components of quality-of-life experience profound impacts. Both the psychological and physical aspects are notably affected, resulting in decreased social engagement (Moraes et al., 2015). Top of Form.

Coping Strategies

Coping strategies for CKD (chronic kidney disease) patients refer to various techniques and approaches individuals use to manage the physical, emotional, and lifestyle challenges associated with their condition. These strategies can include medication adherence, dietary changes, stress management, seeking support from friends and family, engaging in physical activity, and attending support groups or therapy sessions. The goal is to improve quality of life and maintain overall well-being despite the challenges posed by CKD.

Need and Significance

This qualitative study aims to investigate the quality of life and coping strategies of young adults living with chronic kidney disease (CKD). Despite the increasing prevalence of CKD among young adults, there remains a significant gap in understanding their unique experiences and needs. Drawing upon existing literature, which predominantly focuses on older CKD populations, this study seeks to address this gap by conducting in-depth interviews with young adults aged 18-30 diagnosed with CKD. By adopting a qualitative approach, the study aims to capture the subjective experiences, perceptions, and coping mechanisms employed by young adults facing the challenges of CKD.

This sequential explanatory study investigates the quality of life and coping strategies of young adults aged 18-30 living with chronic kidney disease (CKD). The quantitative component assesses the quality of life through validated surveys, while the qualitative part explores in-depth the coping strategies employed by those who report a higher quality of life. This approach allows for a comprehensive understanding of how young adults manage CKD's challenges and which strategies correlate with better well-being. Existing research primarily focuses on older adults with CKD, highlighting a gap in understanding unique to younger individuals, particularly in areas such as identity, social relationships, and career impacts. This study aims to bridge this gap, offering insights that could lead to targeted support and interventions for improving life outcomes for this demographic.

Statement of the Problem

Chronic Kidney Disease (CKD) presents significant challenges to individuals, particularly among young adults, impacting their quality of life and necessitating the adoption of coping strategies. Despite various studies shedding light on the experiences of CKD patients, there remains a gap in understanding the unique perspectives and coping mechanisms utilized by young adults facing this chronic illness. This qualitative study aims to explore the quality of life of CKD patients among young adults and to elucidate the coping strategies they employ to navigate the physical, emotional, and social complexities associated with the disease.

Definition of Key Terms

THEORETICAL DEFINITION

Quality of life

According to WHO (World Health Organization),

"An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns."

Coping Strategies

According to The National Kidney Foundation,

"The various techniques and approaches individuals use to adapt to the physical, emotional, and lifestyle challenges of living with chronic kidney disease."

CKD patients

According to National Kidney Foundation,

"Chronic Kidney Disease (CKD) as kidney damage or decreased kidney function present for three months or more, regardless of the cause, based on evidence from structural or functional abnormalities of the kidney. CKD is categorized into stages based on the severity of kidney damage and the estimated glomerular filtration rate".

Operational Definition

- **Quality of life:** Quality of life refers to a multidimensional assessment encompassing the physical, psychological, and social domains of health, as experienced by individuals with chronic kidney disease.
- **Coping Strategies:** The strategies and techniques employed by CKD patients to manage the physical and emotional challenges associated with their condition, such as lifestyle changes, social support, and psychological approaches.

Objectives of the Study

MAJOR OBJECTIVE

The major objective of the study is to understand the Coping strategies of CKD patients among young adults with high Quality of Life.

SPECIFIC OBJECTIVES

- To understand the quality of life of the young adults with CKD (below 30)
- To identify the coping strategies for the CKD patients.
- To identify high quality life groups among young CKD patients.
- Generate insights to the low quality of life people.

Organization of the Report

This study has five parts. The first part is the introduction which consists of introduction of the topic, need and significance of the study, statement of the problem, major and specific objectives of the study, also definitions of the key terms used in this study. The second part is the review of literature, and it consists of theoretical review of the study variable and review of related studies on variables and populations. The third part is methodology. It consists of populations, measures, procedures for data collection and statistical techniques employed for analysis. The fourth part is the result and discussion of the study, which includes the result of statistical analysis and its discussion. The fifth part is summary and conclusion which consists of a short summary of the study, that is, our major findings,

implications, limitations of the study and the directions for the future research. The research report is prepared according to the 7th edition of APA.

REVIEW OF LITERATURE

Chronic kidney disease (CKD) significantly impacts patients' quality of life (QOL), especially for those undergoing hemodialysis (HD). Various demographic and socio-economic factors contribute to this impact. Younger patients often have better QOL scores, potentially due to fewer comorbidities and a higher capacity for resilience (Thennakoon et al., 2022). Males generally report better QOL compared to females, possibly due to social and cultural factors (Dahal et al., 2021). Higher education levels correlate with improved QOL, as educated patients are likely more knowledgeable about managing their condition and accessing resources (Dhouchak et al., 2022). Employment status is another crucial determinant, with employed individuals experiencing better QOL due to financial stability and social engagement (Gul et al., 2022).

Mental health issues are prevalent among CKD patients and include depression, anxiety, and sleep disorders, all of which significantly reduce QOL. Depression is particularly common, linked to the stress of chronic illness and its associated lifestyle restrictions (Gul et al., 2022). Anxiety also affects many patients, stemming from uncertainties about disease progression and treatment outcomes (Anum et al., 2022). Sleep disorders, prevalent due to both the physical discomforts of CKD and the mental stress, further exacerbate poor QOL (Abdel-Kader et al., 2021).

The interplay between physical and psychological health is critical in managing CKD. A holistic approach to care that includes regular mental health assessments and interventions tailored to individual needs can substantially enhance overall well-being. Strategies may include counseling, support groups, and medical treatments for mental health conditions, alongside traditional CKD management. By addressing both the physical and psychological aspects of CKD, healthcare providers can help improve the QOL for patients undergoing hemodialysis, enabling them to lead more fulfilling lives despite their condition.

METHODOLOGY

Methods are specific procedures for collecting and analysing data. It enables the investigator to look the problem in a sequential order and it depends on the method used and tools adopted for data collection and analysis of those collected data. The approach used in this study is sequential explanatory design method.

The quantitative approach is used to collect the data of 16 respondents of CKD patients among young adults and filter it from those respondents to find 5 respondents who all have the high rate of quality of life. The qualitative approach used to analyse coping strategies from the respondents who have high quality of life.

Research Design

In this research, a sequential explanatory design is used, which begins with the collection of quantitative data to identify broad trends and general patterns among the participants. After analysing this numerical data, data was gathered for the qualitative research using detailed interviews and observations. This approach allowed to explore the initial findings more deeply, providing richer context and insights into the reasons behind the observed trends. This two-phase approach was crucial for developing a comprehensive understanding of the experiences and behaviours of our participants.

PARTICIPANTS

- **Universe of the Study:** CKD patients in Kerala is the universe of the study.
- **Participants:** 16 Young adults (below age 30) with CKD.
- **Population:** Young adults (below age 30) with CKD in Kerala.
- **Sample size:** 16 for quantitative and 5 for qualitative research method.

Inclusion Criteria

- Age under 30 years (young adults) with Confirmed diagnosis of CKD.
- Willingness to participate in the study and provide informed consent.

Exclusion Criteria

Individuals with severe cognitive impairments that may affect their ability to provide informed consent or participate in interviews.

Method for Data Collection

In this research, a sequential explanatory design was used, which involves two distinct phases of data collection and analysis. Initially, quantitative data was collected using the KDQOL questionnaire to assess various aspects of participants' health-related quality of life. This quantitative phase provided a broad understanding of the relationships between different variables. Subsequently, qualitative interviews conducted with a subset of participants who exhibited high quality of life scores. These interviews allowed to delve deeper into their coping strategies, experiences, and perceptions related to their kidney disease. By integrating both quantitative and qualitative data, the researcher was able to gain a more comprehensive understanding of the factors influencing quality of life among individuals with kidney disease.

Tool Used for The Study

The Kidney Disease Quality of Life (KDQOL) scale is specifically designed to evaluate the health-related quality of life in patients with chronic kidney disease (CKD). It comprises various forms, including the KDQOL-SF™, which integrates 36 items from the SF-36 with additional kidney disease-specific questions, yielding a comprehensive assessment tool. The instrument covers a broad spectrum of life domains such as physical functioning, emotional well-being, social interaction, and disease-specific concerns like symptoms management, effects on daily life, and work status. Responses are typically scored on a five-point Likert scale, with results transformed to a 0-100 scale where higher scores denote better quality of life.

The KDQOL is recognized for its reliability and validity, with Cronbach's alpha values often above 0.80, reflecting strong internal consistency across most subscales. The scale takes about 20-30 minutes to complete and is suitable for patients with at least a fifth to sixth grade reading level. Utilized widely in clinical settings, the KDQOL helps monitor patient outcomes, evaluate treatment effectiveness, and guide healthcare policies, ensuring that the specific needs of CKD patients are addressed comprehensively.

PROCEDURE FOR DATA COLLECTION

Phase 1: Initial preparation

Phase 1 of the study involves conducting the test for finding CKD patients with high quality of life with KDQOL. The selected population of CKD patients were between the age of 18 and 30 from different parts of Kerala. The sample consisted of 16 participants with different

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occupational status. Also, both female and male populations were present in the study. So, among the 16 sample, the investigator found 5 CKD patients with high quality of life and conducted structured interview via telephone in these 5 samples selected from the pool of sample.

Tool used for pilot study

The Kidney Disease Quality of Life (KDQOL) scale is specifically designed to evaluate the health-related quality of life in patients with chronic kidney disease (CKD). It comprises various forms, including the KDQOL-SF™, which integrates 36 items from the SF-36 with additional kidney disease-specific questions, yielding a comprehensive assessment tool.

Phase 2: Data collection

Phase 2 of the study involves the collection of data as designed in the phase 1 of the study. Analysis from phase 1 was followed for data collection, through structured interview of selected 5 samples.

Structured Interview

A structured interview is a way of collecting information where the interviewer asks a set of specific questions in the same order and format to everyone. This method is used to gather data in a consistent and standardized way, making it easier to compare responses. The researcher used structured interviews to gather information from the chosen group of people. This helped ensure that all participants were asked the same questions, making the data easier to analyse and understand.

Telephonic interview

A telephonic interview is a method of conducting a survey or interview in which the interviewer and interviewee communicate over the phone. This format enables interviews to be conducted remotely, offering flexibility and convenience for both parties. While telephonic interviews cannot capture non-verbal cues such as body language, they allow the interviewer to pick up on vocal tones and pauses, which can provide insights into the respondent's emotions and engagement levels.

Phase 3: Analysis

To analyse the data collected from the selected sample which was descriptive, narrative analysis is done. Narrative analysis is a qualitative research method used to interpret and make sense of the stories or narratives shared by participants, providing deep insights into personal and cultural contexts. This method involves several key steps to systematically dissect and understand the data.

ANALYSIS METHOD

Narrative analysis starts by collecting stories from participants through interviews or writings, ensuring their personal experiences are captured. Researchers then carefully read these stories multiple times to spot common themes or patterns, using codes focused on elements like plot and character changes. Each story is treated as a case study to understand the broader context influencing the narrative. The next step involves reconstructing these stories to answer specific research questions, emphasizing important psychological or social factors. Finally, the findings are combined and presented as a cohesive story or series of short stories, making the main insights accessible and engaging for a wider audience.

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Overall, narrative analysis allows researchers to delve deeply into how individuals narrate their own lives, providing a rich, contextual understanding of their experiences. This method is particularly useful for exploring how people make sense of events and organize their experiences into coherent stories, thus revealing deeper truths about their lives and identities.

RESULT AND DISCUSSION

SECTION A

Table 4.1 Result of KDQOL Questionnaire

ID	Symptom / problem list	Effects of kidney disease	Burden of kidney disease	SF-12 Physical Composite	SF-12 Mental Composite
AJ	70.83	59.38	31.25	42.00	42.52
AS	14.58	6.25	0.00	32.19	33.86
AT	43.75	12.50	18.75	31.45	46.54
AR	31.25	34.38	6.25	31.07	32.30
TV	89.58	56.25	25.00	47.20	51.34
RH	95.83	59.38	100.00	49.70	56.80
NV	54.17	34.38	31.25	33.53	36.41
JS	50.00	37.50	25.00	33.08	41.83
AA	72.92	53.13	25.00	42.55	39.35
JA	79.17	59.38	31.25	33.03	44.08
KP	72.92	59.38	18.75	35.40	36.13
PA	33.33	25.00	25.00	32.66	37.17
JO	50.00	40.63	25.00	38.11	42.16
CL	33.33	53.13	31.25	42.00	42.52
MR	52.08	59.38	18.75	34.56	43.99
AO	56.25	34.38	31.25	38.54	44.39

The KDQOL (Kidney Disease Quality of Life) questionnaire data provides a comprehensive look at how chronic kidney disease (CKD) impacts patients across various domains: symptom management, the effects of the disease, and perceived burden, alongside physical and mental health as measured by the SF-12 Physical and Mental Composite scores.

- (1) Symptom/Problem List: This metric shows how intensely patients perceive their symptoms. Lower scores (e.g., AS with 14.58) indicate fewer symptoms, while higher scores (e.g., RH with 95.83) suggest more intense or numerous symptoms, yet this doesn't necessarily correlate with a lower quality of life.
- (2) Effects of Kidney Disease: Reflects the perceived impact of the disease on daily living. Values vary significantly, suggesting differences in how the disease affects individuals' lives.
- (3) Burden of Kidney Disease: Scores show the psychological or lifestyle burden patients feel due to CKD. Lower scores denote less perceived burden.
- (4) SF-12 scores: These scores provide insights into physical and mental health, with higher scores indicating better health states.

People with high quality of life.

RH, TV, AA, JA, and KP are people with chronic kidney disease who have managed to keep a high quality of life. RH has a lot of symptoms and feels a big impact from the disease but still has good physical and mental health scores. TV also has many symptoms and feels the

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disease's impact moderately, but good health scores suggest he handles the disease well. AA and JA both experience a moderate number of symptoms and impact but still have better health scores than many others. KP, who feels the least impacted, also has decent health scores, showing he manages his condition well. These examples show that even with kidney disease, people can still have a good quality of life if they manage it well.

SECTION B

DOMAINS

1. Active Coping:

Clients who actively cope with their kidney disease take charge of their health. They do things like taking their medication properly, eating healthy foods, and staying active. This helps them feel more in control and better able to manage their illness. All the 5 subjects RH, TV, KP, AA, JA report that they take medication well and adapt a healthy lifestyle.

2. Emotional Support:

Having supportive family and friends helps subjects feel better about their kidney disease. They talk to their loved ones about how they're feeling, and this support makes them feel happier and more positive. Knowing that their family is there for them gives them strength to deal with their illness. Subjects RH and TV were very much connected with the family and that emotional support help them cope the situation. All the subjects KP, AA, and JA also get support from their family and friends too. Although emotional support seems very much needed in the coping strategies of all the subjects who has a high quality of life.

3. Positive Reframing:

Clients who think positively about their kidney disease see it as a chance to learn and grow. They focus on the good things in life, like spending time with loved ones or trying new activities. Instead of feeling sad or worried, they see their illness as a way to become stronger and more resilient. All 5 of them reframed their thought pattern to a positive one. Subject TV said being positive helps him to be fine all the time. Subject AA found it difficult to be positive but once he reframed his negative thoughts it helped him to improve his quality of life. RH, KP, JA also have a positive impact in the quality of life by reframing their thoughts and situations.

4. Planning:

Making plans to manage their kidney disease helps clients stay on track with their treatment. They write down when to take their medication, what foods to eat, and when to see their doctor. This helps them feel more organized and prepared to deal with their illness. Subject TV has a very detailed plan of his life and treatment. He plans for the transplantation soon and increase the quality of his life.

All other subjects RH, KP, JA, AA, says that planning about future may give them sadness in future. Therefore, focusing on the present seems accurate for them.

5. Humour:

Some clients use humour to cope with their kidney disease. They find funny things to laugh about, even when they're feeling down. Laughing helps them feel better and forget about their worries for a while. It's like a medicine that makes them feel happier and more relaxed. Subjects TV, JA, AA said that humour has positive impact on their quality of life. Comic movies, comedy television shows, humorous conversations with friends and family too helps the subjects to lead a healthy life.

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For subjects KP and RH, humour doesn't really help them to improve their standard of living. Majority uses humour as a coping strategy.

6. Acceptance of Health Condition:

Clients who accept their kidney disease understand their condition and take steps to manage it. They don't let it stop them from living their lives. Instead, they focus on what they can do to stay healthy, like following their treatment plan and making healthy lifestyle choices. The hardest thing for all the subjects were to accept their health condition. But of all the responses acceptance seems to be the most important coping strategy for a good quality of life.

Subject TV tried to escape the reality at the beginning but later on there was no any option other than to accept the health condition. And that made positive impact on his life. Subject RH also accepts the reality also his physical condition and lead a healthy lifestyle with proper medication and food. Subjects AA and KP took the longest time to accept the physical condition. Subject JA accepted the reality and changed her lifestyle to a healthy one. It was observed that accepting the physical condition seems to be an important aspect of the overall quality of life.

7.Spirituality:

For many clients, spirituality is a positive coping strategy. It provides them with a sense of purpose and meaning, helping them find comfort and peace in their beliefs. Prayer, meditation, or involvement in religious communities can help them feel connected and supported, easing their emotional burden and providing strength to face their illness.

Subjects JA, TV was very much influenced by spirituality. They said that their belief in God made them handle their situation. Spiritual belief and spiritual activities positively impacted their quality of life. For subject RH there seems no positive or negative impact created.

But for subjects AA and KP their situation took away their faith indeed. They were religious before knowing their illness. But knowing about the illness created a thought that God abandoned them.

8. Distraction:

Doing things that take their mind off their kidney disease helps clients feel less stressed. They might do hobbies they enjoy, spend time with friends, or focus on work or school. This helps them relax and feel more positive about life, even when things are tough. All 5 of the subjects do this coping strategy to increase their quality of life.

9. Avoidance/Denial:

Some clients try to ignore their kidney disease or pretend it's not serious. They might avoid thinking about it or refuse to talk about it with others. This can make it harder for them to get the help they need and lead to more problems in the long run. At the earlier stage, before accepting the physical condition denial was used to cope the situation. None of the subjects are currently using denial as a mean to cope the situation.

10. Substance Use:

Using drugs or alcohol to cope with kidney disease can make things worse. It might seem like it helps them feel better for a short time, but in the end, it can cause more health problems and make their kidney disease harder to manage. None of the subjects use

substance for coping their physical difficulties. Only AA used alcohol as a mean to cope the situation earlier. At present he doesn't use alcohol. All others keep themselves away from alcohol and drugs for a healthy living.

11. Disengagement:

Some clients disengage from their kidney disease, avoiding thinking or talking about it. They may withdraw from social activities or stop following their treatment plan. This can lead to feelings of isolation and make it harder for them to manage their illness effectively. Subject TV travels alone to avoid situations. Subject KP keep away himself from social functions like marriage, burial etc. He avoids situations of facing other people. Subject JA also wish to be inside her room all the time. Subjects AA and RH still engage with their existing social activities.

This research shows that using good coping strategies can really help people with kidney disease feel better. Subjects like RH, TV, KP, AA, and JA got better at handling their health by using positive ways to deal with their disease, such as actively managing their health, getting support from friends and family, and finding comfort in their beliefs. These methods helped them not only with their physical symptoms but also made them stronger emotionally. On the other hand, negative strategies like ignoring the problem or using alcohol made things worse. This research highlights how important it is to support kidney disease patients in finding and using good ways to cope with their illness.

SUMMARY AND CONCLUSION

The study aimed to understand the coping strategies employed by chronic kidney disease (CKD) patients below the age of 30 with a high quality of life in Kerala. Conducted using a sequential explanatory design, the research involved 16 participants selected via snowball sampling from various places. Due to the sensitive nature of the topic and the relatively young age of the participants, many patients were initially reluctant to participate, resulting in a challenging recruitment process. However, through snowball sampling and the assistance of healthcare professionals, 16 participants were eventually recruited. Out of these, only five participants exhibited a high quality of life despite their condition. The study focused on exploring the coping mechanisms of these individuals in dealing with the challenges of CKD. Structured interviews were then conducted with the five participants identified as having a high quality of life, delving into their coping strategies and experiences. The interviews were designed to elicit detailed responses and insights into the participants' coping mechanisms. Additionally, the study considered demographic factors such as age, gender, and socioeconomic background to provide a comprehensive understanding of the coping strategies in this population. Through this study, the research aimed to shed light on effective coping strategies among young CKD patients below the age of 30 with a high quality of life, offering valuable insights for both healthcare professionals and patients alike.

Major Findings

This study looked at how young people with chronic kidney disease (CKD) cope with their illness and found some important details:

- **Positive Coping:** Young CKD patients who have a good quality of life use positive ways to cope. They rely on support from family and friends, stay positive, and accept their health condition.
- **Age and Quality of Life:** Older patients seem to have a better quality of life compared to younger ones.

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- Importance of Support: Having emotional support from loved ones is really important for CKD patients. It helps them handle their illness and live well.
- Clients with high quality of life generally have lower symptom scores and moderate to high physical and mental health scores.
- Despite perceiving a burden from kidney disease, they manage symptoms well and have effective coping strategies.
- Good support systems, both medical and personal, may contribute to their higher quality of life.
- Areas for improvement may include addressing specific physical health challenges and providing additional support where needed, particularly in managing the impact of the disease on daily life.

Implications of the Study

These findings have important implications for healthcare and research:

- Healthcare: Doctors and nurses should focus on helping CKD patients use positive coping methods to feel better.
- Education: Patients should learn about these coping strategies so they can manage their illness better.
- Support: Health services should offer support to help young CKD patients cope better with their illness.
- Mental health support: Counselling and other sessions would help the CKD patients to improve their quality of life.

Limitations of the Study

However, this study has some limitations:

- Small Sample Size: Due to the less availability of samples, the number of people in the study was small, so we can't be sure if the findings apply to all CKD patients.
- Short Study Time: Patients were looked at one point in time, so coping could change over time.
- Self-Report Bias: Sometimes people might not give accurate answers about themselves, which could have affected results.
- Less willingness: Many were not willing to participate in the study.
- Lack of early diagnosis: Many of the subjects diagnosed their physical condition in the later stages.

Suggestions For Future Research

To improve our understanding in this area, future research could:

- Long-Term Studies: Follow CKD patients over a longer time to see how their coping strategies change.
- Interventions: Test ways to help CKD patients cope better and improve their quality of life.
- In depth studies: Talk to patients in more detail to understand their experiences better.
- Age Factor: Look more closely at how age affects coping and quality of life in CKD patients.
- By doing more research in these areas, we can help CKD patients live better lives and manage their illness more effectively.

REFERENCES

- Abraham, S., Venu, A., Ramachandran, A., Chandran, P. M., & Raman, S. (2012). Assessment of quality of life in patients on hemodialysis and the impact of counseling. *Saudi Journal of Kidney Diseases and Transplantation*, 23(5), 953-957.
- Al Salmi, I., Kamble, P., Lazarus, E. R., D'Souza, M. S., Al Maimani, Y., & Hannawi, S. (2021). Kidney disease-specific quality of life among patients on hemodialysis. *International journal of nephrology*, 2021.
- Anandraj, J., Subramanian, S., Parameswaran, S., & Kar, S. S. (2020). Quality of Life and its Associated Factors among Patients Undergoing Dialysis in a Tertiary Care Hospital, Puducherry, South India-A Cross-Sectional Analytical Study. *J Urol Ren Dis*, 5(5), 1189.
- Anvar Ibrahim, A. P., Gwalani, M., & Koorankot, J. (2023). Effectiveness of Cognitive behaviour therapy in treating generalised anxiety disorder of patient with chronic kidney disease– A clinical case study research. *Journal of Korean Academy of Psychiatric and Mental Health Nursing*, 5(4), 386-393.
- Broers NJH, Martens RJH, Canaud B, et al. (2018) Health-related quality of life in end stage renal disease patients: the effects of starting dialysis in the first year after the transition period. *International Urology and Nephrology* 50: 1131–1142.
- Chitra Devi, R. (2018). Defensive coping and quality of life in chronic kidney disease patient in a tertiary care centre: A cross-sectional study (Doctoral dissertation, Thanjavur Medical College, Thanjavur).
- Fradelos, E. C., Alikari, V., Tsaras, K., Papathanasiou, I. V., Tzavella, F., Papagiannis, D., & Zyga, S. (2021). The effect of spirituality in quality of life of hemodialysis patients. *Journal of Religion and Health*, 1-12.
- Global Burden of Disease study 2015 Mortality and Causes of Death Collaborators, Global, regional and national life expectancy, all - cause mortality, and causes specific mortality for 249 causes of death, 1980- 2015: a systematic analysis for the Global Burden of Disease Study 2015(2016). *Lancet* 2016 388: 1459 -1544.
- Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017, (2020) *Lancet London England* 395: 709–733.
- Hemodialysis | NIDDK (2018) National Institute of Diabetes and Digestive and Kidney diseases. Available from: <https://www.niddk.nih.gov/health-information/kidneydisease/kidney-failure/hemodialysis> (Accessed 15 May 2020).
- Hussien, H., Apetrii, M., & Covic, A. (2021). Health-related quality of life in patients with chronic kidney disease. *Expert Review of Pharmacoeconomics & outcomes Research*, 21(1), 43-54.
- Jacob, S. R., Kannan, S., Raveendran, R., & Wilson, T. (2020). Quality of life in chronic kidney disease: a community perspective using world health organization quality of life: BREF questionnaire. *International Journal of Community Medicine and Public Health*, 7(10), 4105.
- Jadhav, S. T., Lee, P., & D'souza, C. V. (2018). Effectiveness of prehemodialysis preparatory program on improving coping among chronic kidney disease patients. *Saudi Journal of Kidney Diseases and Transplantation*, 29(6), 1342-1349.
- Jith, A., Sreekumar, K., & Venkateswaran, C. (2018). To assess anxiety and depression in patients undergoing maintenance haemodialysis in a tertiary care hospital in Kerala. *Amrita J Med*, 14(2), 1-44.
- Kombilath D, (2018) kidney disease grips Kerala; Number of patients keep increasing Mathrubhumi. 29 April 2018 [Online] Available:<https://english.mathrubhumi.com/health/health-news/kidney-Disease-grips-kerala-number-of-patients-keep-increasing-kidney-patients-in-Kerala.1.2775932> [Accessed 8 Jan 2019].
- Kunwar, D., Kunwar, R., Shrestha, B., Amatya, R., & Risal, A. (2020). Depression and quality of life among the chronic kidney disease patients.
- Manju, L., & Joseph, J. (2024). Health-related quality of life among patients undergoing hemodialysis in a tertiary center in South Kerala. *Clinical Epidemiology and Global Health*, 101547.
- Mathews, T. G. (2023). A Study on Perceived Social Support among Hemodialysis Patients in Kerala. *Mental Health and Well-being—New Paradigms*, 1.

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- Mikula, P., Nagyova, I., Krokavcova, M., Vitkova, M., Rosenberger, J., Szilasiova, J. & van Dijk, J. P. (2014). Coping and its importance for quality of life in patients with multiple sclerosis. *Disability and Rehabilitation*, 36(9), 732-736.
- Nagarathnam, M., Latheef, S. A. A., & Sivakumar, V. (2021). Factors influencing scales of burden, coping mechanisms, and quality of life in caregivers of hemodialysis patients in Andhra Pradesh, India. *Indian Journal of Palliative Care*, 27(1), 62.
- Nagarathnam M, Sivakumar V, Latheef SAA, et al. (2019) Burden, coping mechanisms, and quality of life among caregivers of hemodialysis and peritoneal dialysis undergoing and renal transplant patients. *Indian Journal of Psychiatry* 61: 380– 388.
- Nayana, S. A., Balasubramanian, T., Nathaliya, P. M., Hussain, P. N., Salim, K. M., & Lubab, P. M. (2017). A cross-sectional study on assessment of health-related quality of life among end stage renal disease patients undergoing hemodialysis. *Clinical Epidemiology and Global Health*, 5(3), 148-153.
- Nelson, V., Gopalakrishnan, S., Rakesh, P. S., Simon, S., Babu, V., & Vikraman, V. (2016). Depression among dialysis patients. *Age*, 15(35), 6.
- Pandey, R. K., Arya, T. V. S., Kumar, A., & Yadav, A. (2017). Effects of 6 months yoga program on renal functions and quality of life in patients suffering from chronic kidney disease. *International journal of yoga*, 10(1), 3-8.
- Parekh, A. J., & Ravindra, H. N. (2020). Systematic Review on Quality of Life of Patients with Chronic Kidney Disease.
- Peritoneal Dialysis | NIDDK(2018) National Institute of Diabetes and Digestive and Kidney diseases .Available from: <https://www.niddk.nih.gov/healthinformation/kidney-disease/kidney-failure/peritoneal-dialysis> (Accessed 11 May 2020).
- Raval, K., & Mathur, K. (2015). Quality of life in patients undergoing kidney dialysis. *Indian Journal of Positive Psychology*, 6(4).
- Ravindran, A., Sunny, A., Kunnath, R. P., & Divakaran, B. (2020). Assessment of quality of life among end-stage renal disease patients undergoing maintenance hemodialysis. *Indian journal of palliative care*, 26(1), 47.
- Saini, H. K., & Sumeriya, N. K. (2017). Depression & Coping strategies among Chronic Kidney Disease Patients undergoing Hemodialysis in Punjab. *Journal of Advanced Medical and Dental Sciences Research*, 5(10), 93-95.
- Thenmozhi, P. (2018). Quality of life of patients undergoing hemodialysis. *Asian J Pharm Clin Res*, 11(4), 219-223.
- Veerappan, I., Arvind, R. M., & Ilayabharthi, V. (2012). Predictors of quality of life of hemodialysis patients in India. *Indian journal of nephrology*, 22(1), 18-25.

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Conflict of Interest

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