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# End Stage Kidney Disease: A Brief Review on the Quality of Life and Death Anxiety Among Patients

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Abstract: Purpose: Chronic kidney disease is an ailment with complete loss of kidney function. Due to chronic illness, the patients' Quality of Life gets affected significantly. In addition, it may cause mental health issues and death anxiety. The burden of care experienced by the relatives is enormous. They may require counselling and emotional therapy. The main aim of this study was to collect information about an existing topic on chronic kidney disease. This may be useful for patient and caregiver education on reducing death anxiety. Objective: The objective of this particular research paper was to offer a good and thorough explanation of quality of life, and death anxiety among chronic kidney disease patients. The main objective was to review select literature related to terminally ill patients suffering from chronic kidney disease. Design/Methodology/Approach: The information used here are from several credible authoritative results of few clinical studies which were used mainly from journal articles. A secondary source of data has been used. Finding/Result: The results from reviewing several literatures showed most of the patients had poor quality of life. Family members experienced burden of care. Most Chronic kidney disease patients had mild, to severe level of Death Anxiety. Originality/Value: All of the clinical information was collected from trustworthy, scientific sources and was logically organized in this paper. It is presumed that this paper will be useful not only to medical staff but also the relatives of the patient.

Keywords: Chronic kidney disease, mental health, death anxiety, quality of life.

#### 1. Introduction

Chronic Kidney Disease (CKD) is also known as End Stage Renal Disease in its final stage when the patients continue to have renal impairment for more than 3 months. Classifications according to eGFR are stage 1 to stage 5 and End Stage Renal Disease (ESRD) [1]. A persistent abnormality of the kidneys lasting more than 3 months where the estimated glomerular filtration rate is less than 60 ml/min/1.73 m2 or albuminuria of ≥30 mg per 24 hours is another way of defining CKD [2]. In CKD stages 4 and 5, the ability to maintain fluid balance is diminished leading to rapid sodium load and becoming more apparent. The recommended sodium intake for CKD patients is less than 2 gm per day only [3]. Early identification of CKD is the key to improving the treatment modalities. Awarenesseducation and identification of risk factors need to be implemented to improve the outcome [4]. Patients with CKD are more prone to frequent complications [5]. The main treatment plan is to prevent CKD population by guiding and educating them to be alerted to risk factors of CKD as the treatment of CKD is quite challenging once reaches above stage 3 [6]. The global prevalence of CKD is 11 to 13%. It has a higher prevalence in meta-analysis observational studies using highquality studies [7]. The global burden of CKD is approximately 10% and it is predicted to be 5 of the most common causes of death by 2040. Every year in India it is estimated that more than 100,000 new patients enter renal replacement therapy. Though there is no precise relationship between anxiety and haemodialysis, the Indian study showed the prevalence of anxiety and depression at 28% and 61.3% respectively. Once the dialysis has been initiated the fear of dependency increases as they must spend at least 4 hours hooked to the machine. Quality of Life (QOL) gets affected significantly due to this reason [8]. The global prevalence of 9.1% is Chronic Kidney Disease (CKD) and has an estimated 700 million people with a major risk of premature death. It is also estimated about 4.6% of deaths annually are due to renal impairment. The risk of hospitalization and mortality rate is higher in CKD patients due to the chronic symptoms and the QOL is also affected [9]. Death anxiety is one of the anxieties where the person is afraid of dying of death or his loved ones [10]. The study by Igra Mushtaque et al showed that ESRD patients suffer from death anxiety which is negatively proportional to their quality of life and affects their illness acceptance among CKD patients [11]. CKD patients are more prone to psychological disorders mainly anxiety and depression [12]. The quality of life decreases in all stages of CKD patients [13].

Death anxiety is multi-dimensional and difficult to explain the concept; it includes negative thoughts and emotions along with fear of dying [14]. Until the last couple of hundred years, modern scientific discoveries made an impact on health and mortality around the world, people were stuck with religious priests to know about death and dying. They also considered that talking about death is taboo [15]. Freud is the first person to discuss death anxiety; he stated that death anxiety could be due to unresolved conflicts during childhood. It is a real and basic fear of death. Not surprisingly, fear of death anxiety is more common in hypochondriac patients. Concern about death anxiety is often the principal reason people fear serious and chronic illness [16]. Psychological issues have a greater

influence on receiving treatment, following the compliancy of diet and fluid restriction including regular dialysis [17]. Hudson et al. conducted a study on psychological distress which is most common among CKD/ESRD patients and the plan was to perform interventions whether pharmacological or nonpharmacological which are tailored to treat the distress of specific features presented by the client [18]. The prevalence of depression and anxiety was investigated by Yan Meng who concluded that 55.1% suffered from depression, whereas 25.9% suffered from anxiety in North China. The main causes were low income, co-morbidities, and pruritis [19]. The fear of dying sets in due to the frustration of knowing that there is no cure for this ailment [20]. "Quality of life" has no definition as such; it is just used to describe the health status with the performance of activities of daily living physically, psychologically, and socially [21]. Mental health and Death Anxiety in CKD Patients revealed that mental health had a positive relationship with the fear of death [22]. Death anxiety is a death consciousness or fear of death which is also a notion and mostly used to theorize apprehension [23]. Most CKD patients are facing a financial crisis and due to the long-term expenses ahead of their treatment and knowing that there is no cure; they are undergoing an enormous level of stress, depression, and anxiety [24]. There is a significant correlation between socio-demographic variables as well as clinical variables affecting QOL among CKD patients. It is easy to treat patients when health professionals have a better understanding of these variables [25]. Stress and death anxiety go hand in hand and the QOL is affected to great extent among CKD patients [26]. CKD patients are vulnerable to stress. Depression and poor sleep quality, especially among the elderly, and women undergoing dialysis are extensively studied [27].

This research is aimed at measuring the levels of death anxiety among CKD patients. Though there are different stages in CKD from stage 1 to 5 and end-stage renal disease, the first three stages require only medications, and renal replacement therapies (RRT) will be required by the last two stages [1]. Many psychological issues have been raising concerns among CKD patients [17]. Among all the mental issues death anxiety has been given very less importance and there are very few studies on death anxiety among CKD patients, though it is a terminal disease when compared to cancer. Appropriate screening of mental health and staging at the primary stage will help healthcare professionals in treating CKD patients better. As per most of the studies, many patients suffer from some or other mental health issues after diagnosis of CKD. Financial status and social support play a major role in the outcome of CKD patients too [2]. Mental health is not of any importance in any physical disorders including CKD.

However, the amount of stress, depression, and anxiety will always make the prognosis worsen. The involvement of Psychologists and counseling is the need of the hour, especially in chronic illnesses such as CKD. Death anxiety is the core fear of death after the diagnosis, as they realize that there is no cure and the complications while receiving treatment as well as the restrictions on diet and fluids. Clients feel devastated as most patients presume that the initiation of dialysis is the end of their

life. To come out of this taboo they need counselors to provide emotional support consistently to alleviate the fear of death. Good few studies were conducted on anxiety and depression among CKD patients. But there are only an enumerable number of studies on death anxiety carried out among CKD patients. Assessing their mental health in the primary stage would be more beneficial to the health care professionals in treating the patients and can improve their psychological well-being. It is advisable to counsel the family members too. The primary assessment of psychological issues will assist in treating them in their early stages and will improve their QOL.

#### 2. Related Research Work

Google search engine has been used in this review of literature in the table below from 2018 to 2022. The key words used in search engine are, anxiety, depression, CKD, QOL, and death anxiety.

#### A. CKD and Mental Well-being

Shdaifat E. A. (2022) [28] in this study he concluded that CKD/ESRD patients, though they have renal replacement therapies (RRT) in their last stage, they suffer a lot of mental issues such as anxiety, depression, stress, insomnia, and so on. This in turn affects the QOL of the patient. This cross-sectional study from Saudi Arabia was conducted on CKD patients on haemo-dialysis (HD), peritoneal dialysis (PD) &Transplant patients to determine the association between emotional status and QOL. This study improves awareness and understanding of the QOL of CKD/ESRD patients undergoing renal replacement therapies (RRT) and identifies the needs of vulnerable clients.

Um-e-Kalsoom, Khan, et al (2020) [29] in their study, the results concluded that CKD patients suffer from anxiety, depression, and poor QOL. The longer the dialysis treatment among CKD patients has negative effects on them. It is advisable to treat mental health problems as early as possible to improve the QOL among them. They insisted on improving social support for the client and family. They suggested that early initiation of dialysis treatment reduces psychological issues.

The mental health of CKD patients is affected to an extent that some of the clients even don't want to continue further treatment. Most of our patients are in denial to commence dialysis as they think it is going to be the end of their life. This area needs more awareness to make them understand that the dialysis procedure is going to replace the job of the kidneys thereby improving the QOL. Unfortunately, or fortunately when the kidneys completely fail, we have an option to treat them and prolong their life through dialysis. If we consider the advantage of extending the life and improving the QOL, some clients are more vulnerable due to the expenses and the pain they need to go through for the life. Some patients stop getting dialysis out of frustration or due to the lack of social/financial support. These patients need counseling and education regarding the importance of continuing treatment and compliance with medication and dialysis.

Table 1 Literature survey

Serial No./Year	Field of Research	Focus	Outcome	References
1/2022	QOL, Depression and anxiety in CKD patients undergoing RRT	Need for studying the QOL of CKD patients and association between emotional statuses along with improvement measures.	Progress in awareness about the disease. Understanding the concept of QOL and identified the vulnerable clients.	Shdaifat E. A. [28]
2/2022	Acceptance of illness by the CKD patients and the effect of death anxiety	The CKD population suffered more of mental health problems when compared to the common population. Assessing for mental health issues at the earliest.	Implemented the assessment of CKD patients by health care workers for mental health issues.	Mushtaque, I et al. [11]
3/2021	Assessment of death anxiety among CKD patients	Evaluation of QOL and the effects of death anxiety in deterioration of same.	Majority of patients suffered from severe death anxiety and every CKD patient was a culprit for some or the other mental health issues.	Ghiasi Z, et al. [10]
4/2021	Mental health, social support and death anxiety among CKD patients	Relationship between mental health and perceived social support enhancement of QOL by reducing the death anxiety among CKD patients.	Social support constructs improved mental health and reduction in death anxiety in patients with chronic kidney failure.	Khodarahimi, S. et al [22]
5/2021	CKD and living experiences	CKD is a challenging disease due to its chronic nature. It hits the client financially & socially thereby affecting their mental health. The feeling of dependency is the worst part of it.	Every CKD patient needs social and psychological support and same need to be implemented in the CKD settings.	Tadesse H, et al. [1]
6/2020	Anxiety and depression among CKD patients	The prevalence of anxiety and depression and measurement of the severity of same.	Family & social support decreased the prevalence of anxiety and depression on haemo-dialysis patients. However, in the long run due to the financial burden and dependence on family/friends, the patients suffered more with psychological issues.	Gadia, P. [8]
7/2020	Commencement of haemo- dialysis and impact on well-being of CKD patients.	Role of Social support in improving the mental well-being and QOL	All the CKD patients suffered from anxiety, depression and there is marked deterioration in QOL. With social support and dialysis, the mental well-being has improved along with QOL in this study.	Um-e- Kalsoom, Khan et al. [29]
8/2019	Relationship between Quality Of Life, Psychological Stress and Death Anxiety and impact of death anxiety and stress on quality of life	Evaluation of QOL, mental stress and death anxiety among CKD post renal transplant patients.	Stress significantly positively correlated with Death Anxiety & patients with higher level of stress also have higher level of death anxiety.  These two together deeply affect the quality of life.	Perveen N. [26].
9/2019	Psycho-social aspects of patients undergoing haemodialysis	Finding out the relationship between socio- demographic details and psychosocial problems of the dialysis patients. Suggestions and measures to bring positive psychosocial health among the respondents.	The present study reveals, the majority of CKD/ Dialysis patients are facing a major financial crisis due to the huge anticipated expenses to meet their treatment requirements. They are undergoing unexplainable pain and stress during their treatment.	M. C. Sandhyarani et al [24].
10/2018	Anxiety and depression in patients with end-stage renal disease: impact and management challenges	The prevalence of anxiety and depression among CKD patients is a concern but there are not many extensive studies when compared to other similar chronic illnesses namely cancer and cardiac disease. This study reveals the contributing factors for development of anxiety and depression.	Studies show the significant relationship between CKD with anxiety and depression.	Goh ZS et al. [12].

# B. Death Anxiety

Ghiasi Z et al (2021) [10] conducted a study on CKD patients to find out the levels of Death Anxiety and evaluation of Quality of Life (QOL). They wanted to get an idea of how the renal staff can recognize vulnerable patients and treat them accordingly. They also investigated the predictors of death anxiety and QOL. The results concluded that 60.4% of patients suffered from high levels of death anxiety. 70% of patients had lower or moderate QOL. The effects of personality traits on death anxiety were also investigated in this study.

Taghipour, B et al, (2017) [30] in their research of the relationship between spiritual health and death anxiety among

haemo-dialysis patients, found out that there was a significant relationship between religious beliefs and spiritual intelligence, gender as well as economic status, and death anxiety. This study also concluded the significant relationship between spiritual health and quality of life. Enhancement of spirituality proved to promote health and reduction in death anxiety.

Iverach L. et al, (2014) [31] Death Anxiety is a basic fear due to plenty of underlying psychological conditions. Death Anxiety is a trans-diagnostic construct and treating it may improve the efficacy in treating other many ranges of psychological disorders. In this article, they examined the role of Existential Psychology and Terror Management Theory (TMT) in trying to understand death anxiety. The severity of

death anxiety was measured as well as the non-clinical and clinical treatment trials along with the evidence of research assessments were studied. Death Anxiety is a significantly serious issue both clinically and theoretically, it is a basic fear at the core including anxiety, hypochondrias, depressive disorder, and panic disorder. Death Anxiety is a therapeutic issue, at the unconscious level; it can impact significantly daily functioning.

Death Anxiety is one thing nobody wants to talk about. It is a tradition not to talk about death especially in India as it is considered as ominous. But all we need to make CKD patients understand that we need to live a quality life until we die. When we collected the questionnaire for death anxiety measurements, few of our clients were not happy to disclose their feelings about dying. Death is an inevitable journey for all living beings. Some or other day certainly we will attain death. The frustration and pain will make CKD patients exhibit anger toward life.

#### C. Quality of Life

Mushtaque et al, (2022) CKD/ESRD patients were suffering from more mental health issues when compared to the general population. The Quality of Life (QOL) was affected enormously and the elderly with less education as well as lower economic status were the culprits. Their suggestions to healthcare workers are to keep this in mind while treating the patients. However, they also stressed the need for assessing the mental health and QOL of CKD/ESRD including any other chronic/terminally ill patients [11].

Gerasimoula, K. et al, (2015), [25] found a relationship between age and education in the QOL of CKD patients who are receiving dialysis. With education, the patients were compliant in receiving treatment along with higher income due to their better education they showed improvement in the QOL. The understanding of the important factors affecting the QOL needs to be investigated further for better interventional strategies so that a tailored individualized treatment could be offered.

QOL among CKD patients is poor according to most of the above-mentioned studies. What can be done to improve the QOL among these patients? It is a million-dollar question. As the chronic illness has left the client to suffer mentally, physically, socially, and financially, the amount of stress the client goes through is unable to imagine. This area needs further research, and more research was done on cancer patients we need furthermore studies on CKD patients to boost their confidence and improve their QOL. The major age group affected by this disease is the elderly but children and young adults are not an exception.

#### 3. Need for the Study/Research Gap

The reviewed articles are mostly from Iran and Indonesia, and there are not many studies about Death Anxiety in India. Hence this study has been selected to introduce measuring Death Anxiety in the Dialysis department. The current study is to evaluate and measure the levels of Death Anxiety among CKD patients. In any chronic disease, psychological issues flare up due to the long-lasting pain and the diagnosis has no curative

treatment. Temporary treatment like dialysis in CKD patients is transitory as it gives one-day relief and again must schedule the time for dialysis the next day. Self-loathing and frustration will build up due to the lifetime alternate-day dialysis. The researcher mainly considers the CKD part, however, the psychological issues, patients are facing go unnoticed. Through this study, Researcher would like to implement the strategy of regular assessment of the mental health of CKD patients who are on regular hemo-dialysis. The plan is to implement the required psychological counseling and if required consult a psychiatrist for treatment. The main purpose of this study is to assess for death anxiety and give priority to mental health and start treatment for the sufferers concurrently along with CKD treatment.

## 4. Objective

To review selected literature related to terminally ill patients suffering from chronic kidney disease.

#### 5. Methodology

Secondary source of data was obtained using Google scholar.

#### A. Severity of Death Anxiety Measurement

As discussed earlier, death anxiety is the fear of dying, in CKD patients it is due to the chronic feature of the disease. Once diagnosed it just progresses to the final stage which is known as end-stage renal disease and the sad part is no complete cure, just to prolong life with expected complications. As there is not much improvement even after starting dialysis in these patients, except to watch for temporary complications/symptoms and treat them accordingly. This leaves the patients under complete dependency and most of them fear dying sooner. This fear sets in and especially if there is no family support they end up having more complications and are prone to frequent hospitalizations.

# B. ABCD Analysis

ABCD analysis is taken as a research methodology here. The advantages of measuring death anxiety among CKD patients will benefit in treating their anxiety issues and sorting the problems at the earliest. The constraints being talking about death and most of the patients are fearful and do not want to voice their concerns as such. Disadvantages observed are the frustration among CKD patients and the deterioration of QOL due to this disease.

Advantages: Measurement of general anxiety is done regularly on CKD patients; however, death anxiety measurement is not done regularly. Once the death anxiety is measured, it will be classified into three categories of mild, moderate and severe levels of death anxiety. According to the levels they will be directed to Psychologists or Psychiatrists. Then implementation of treatment follows.

Benefits: The benefits after implementation of treatment are mainly the reduction in hospitalization. Once the patients know what to expect in life after the diagnosis, they slowly tend to adapt to the routine of having dialysis on alternate days, and fluid and diet restrictions. Understanding the disease outcome

and further knowledge about the complications plays an important role here.

Constraints: Death anxiety is not an interesting subject nor anyone would like to discuss it unless you are a mental health professional. Getting their opinion about death anxiety is hard work, especially in India people won't open up and some consider talking about it is going to kill them sooner. Some of the families did restrict researcher from talking to their clients and getting their opinion about death anxiety.

*Disadvantages:* Once death anxiety is measured, if the levels fall in the severe category, the availability of treatment option is less.

#### 6. Discussion

The Quality of Life (QOL) was affected enormously and the elderly with less education as well as lower economic status suffered immensely. A study by Taghipour (2017) from Iran concluded that the Death Anxiety experienced by haemodialysis patients was more than average. Patients suffering from most chronic illnesses do suffer from Death Anxiety. Their study also proved the significant relationship between gender and Death Anxiety [30]. Relaxation techniques and counselling could help to improve the quality of life as well as reduce death anxiety.

## 7. Scope for Further Research

This study is conducted on CKD patients mainly to assess psychological issues specifically Death Anxiety. It is a need of the hour to address the mental health of CKD patients, and eventually promote their QOL. The psychological issues will be hidden due to financial or social reasons and people are not open discussing them. Introducing the mandatory system of initial and regular psychological assessments will assist in improving the QOL of CKD patients. Any non-pharmacological interventions to improve their Death Anxiety are the required area of the study.

#### 8. Conclusion

The patients on haemo-dialysis are certainly suffering from Death Anxiety. The level of death anxiety is moderate among almost every client as per the secondary data. Due to the deterioration of physical health despite dialysis, most of the patients lose hope and whoever is getting accustomed to the new routine of diet and fluid restrictions and hooking to the dialysis machine for four hours three times a week will try to maintain quality. Social support and financial support play crucial roles in maintaining the QOL of these patients. They need continuous education about the disease itself and the complications along with reassurance to be compliant with treatment.

The continuous counseling by the dialysis unit staff and fellow patients is a motivation to continue treatment and follow the diet restrictions as per guidelines. Getting to discuss the outcome and other plans of treatment in the dialysis department such as kidney transplantation and encouragement by the staff was very much appreciated by the patients.

#### 9. Suggestions

This area of measuring Death Anxiety is uncommon among CKD patients. Implementing this in the institutions where chronic patients are treated and educating the health care providers will assist in the evaluation of psychological issues such as Death Anxiety and will treat the issues as needed. The ultimate solution for improving the QOL of CKD patients is maintaining their mental well-being. Implementation of training for dialysis unit staff to give simple counseling methods along with listening to their problems would be beneficial to improve the QOL of these patients.

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