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Perception of the Quality of Life of People with Kidney Transplants and Transplant Candidates in Mérida, Yucatán, México

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ABSTRACT

Objective: To analyze the perception of quality of life of people with kidney transplants and candidates for kidney transplants treated at the High Specialty Medical Unit of Mérida.

Materials and Methods: Qualitative study with an interpretive phenomenological approach, intentional sampling, the final sample was made up of 11 people with a history of CRF: 7 candidates for kidney transplantation and 4 transplanted. The data was collected through semi-structured interviews carried out during their follow-up consultations, which were analyzed through content analysis.

Results: The categories analyzed were: concept of quality of life with its domains: physical, economic, family and social. Most of the participants stated that quality of life is to be well physically, mentally and emotionally, as well as having all the basic services and not depending on kidney replacement treatments: dialysis or hemodialysis.

Conclusions: A perception of absolute quality of life or free from discomfort is not reached and human responses are still manifested that require care and interventions to reach the maximum level of well-being. The construction of the concept of quality of life includes physical, mental, personal and social elements that are feasible to document and in which to carry out interventions for the benefit of trafficked persons and their families, it is evident that human responses not only obey physiological needs.

Introduction

Chronic kidney disease (CKD) affects around 11% of the population over 20 years of age worldwide, with an increase in incidence in recent years [1]. Peritoneal dialysis, hemodialysis, and kidney transplantation are treatments that have been effective in increasing the life expectancy of people with CKD [1,2]. In the last three decades, the analysis of quality of life has been integrated as an indicator of the evolution of the state of health in patients with CKD to see beyond the number of years of survival. The quality of life is, according to the WHO, "the perception that an individual has of his place in existence, in the context of the culture and value system in which he lives and in relation to his objectives, his expectations, his standards, your concerns. It is a concept that is influenced by the physical health of the subject, their psychological state, their level of independence, their social relationships, as well as their relationship with the environment ". This concept encompasses both objective and subjective aspects that reflect the degree of physical, emotional, social and economic well-being of each individual. The analysis of the quality of life in people with

CKD allows us to understand the impact of the disease and its treatment, to know more about the patients, how they evolve and how they adapt to the organic alteration [3,4].

At present, the analysis of the quality of life in people with CKD seeks to generate evidence, qualitative and quantitative, to facilitate: the process of assessing human needs and the implementation of quality interventions in healthcare sectors [5]. In health sciences, phenomenological research, and those with a qualitative approach in general, generate evidence that serves as a guide to practice that is sensitive to the realities of the people to whom care is directed, their cultural diversity and the contexts in which their lives unfold [6,7]. In studies related to quality of life in transplanted people and candidates for kidney transplantation, the participants manifest as the main human responses: recurrent hospitalizations, uncertainty about the work situation, deterioration of body image, deterioration of sexual functionality, dependence on third parties, stress and guilt [2,8-12]. Specifically, people who are candidates for kidney transplantation show anxiety and depression as the main human responses. Transplants report acute rejections, side effects of medication, and emotional instability; [12-14] immediately, after transplantation, they can perceive liberation with respect to dependence on renal replacement therapy, but as time passes they have to face various adaptation problems: side effects of medications, medical and social complications, among the latter the reincorporation of work, social and family life [12,13,15].

The analysis of quality of life, with its respective components and human responses in patients with a history of CKD is recent. Therefore, the inherent needs of the nursing care process may go unnoticed when directing care for people with these characteristics. Although there are numerous studies that quantitatively address health-related quality of life, [4,16,17] qualitative studies such as this one provide particular evidence to integrate it into the holistic process of the nurse-patient relationship at different levels of care [18,19]. Therefore, the objective of this study is to analyze the perception of quality of life of people with kidney transplants and candidates for kidney transplants treated at the High Specialty Medical Unit of Mérida, to identify related human responses through a phenomenological approach. interpretative.

Methodology

Design

A qualitative study with an interpretive phenomenological approach was carried out. From this design it is possible to understand the experiences and the articulation of similarities and differences in the meanings and human experiences of people with kidney transplants and kidney transplant candidates. Although it is not possible to make generalizations from the results of this study, particular data are achieved with transferability to other populations with similar characteristics [6,7,20]. This article followed the COREQ criteria (Consolidated criteria for reporting qualitative research) to enhance its quality and clarity [21].

Study and Sampling Population

An intentional sampling was carried out, obtaining a final sample was made up of 11 people with a history of CRI: 7 candidates for kidney transplantation and 4 transplants, who received health services at the High Specialty Medical Unit of Mérida (UMAE) of the Mexican Institute of Social Security (IMSS) during the period from November 2019 to February 2020.

Data Collection

The data were collected through semi-structured interviews conducted during their follow-up consultations. Interviews lasted 30 to 40 minutes, were recorded in audio format and field notes were taken. Table 1 presents the questions asked during the semi-structured interviews.

Table 1: Questions from the semi-structured interviews.

Candidates for Kidney Transplantation	With Kidney Transplant
1. According to your culture, what is quality of life for you? 2. Based on this definition, what changes in your life have you noticed due to the problem you present? 3. What do you think might change in your life after the transplant? 4. Tell me, how has your family relationship influenced that quality of life according to the concept you gave me? 5. Tell me, how has this waiting process influenced your family, friends and / or neighbors? 6. How do you think your mood with your family and friends has changed because of the waiting process? 7. From the day you were told that you would need a transplant, how has your life been up to today?	1. According to your culture What is quality of life for you? 2. Based on this definition, was there any change in your quality of life before and / or after the transplant? 3. Mention all the aspects of your life that are important to you that could be affected by the transplant. 4. Tell me, how has your family relationship influenced that quality of life? 5. Tell us about the influence the transplant has and / or had on your relationships with friends, neighbors, and acquaintances. 6. Are you happy with the change that the transplant has brought about in your relationships with friends, neighbors, and acquaintances? 7. From the day of the transplant until today, how has your life been?

Ethical Considerations

The study respects the ethical principles: beneficence, non-maleficence, justice and autonomy. The study research protocol, with folio R-2018-785-129, was approved by the ethics committee of the High Specialty Medical Unit of the Mexican Institute of Social Security. The testimonies presented herein are referenced with codes to safeguard the identity of the participants.

Information Processing

The semi-structured interviews were transcribed verbatim and then analyzed through content analysis. This analysis process consisted of:

1) Coding the data and establishing a data index;

2) Categorize data content into meaningful categories; and

3) Determine the issues related, in this case human responses, with the previously defined categories. [7,22]. In the results section, tables are presented that allow the visualization of the analysis categories delimited in table 2 based on Urzúa and Caqueo [23], the human responses within the categories and, finally, the testimonies of the participants; all of the above accompanied by an interpretive narrative.

Table 2: Categories for grouping and analysis of qualitative data.

Category	Definition
Quality of life	Perception that an individual has of his place in existence, in the context of the culture and the value system in which he lives and in relation to his objectives, his expectations, his norms, his concerns.
*Physical	Referred to the state of physical health of the student to be evaluated, such as the subject of sleep, their diet, the appropriate use or not of free time, the suffering or not of any disease that threatens to prostrate the person
*Economic	Regarding the acquisition of food, accommodation, comfort and socioeconomic status of the person, as well as their income and economic security. It also refers to skills and abilities that could provide training opportunities for personal growth.
*Family	Referred to in valuable relationships with the family, as well as friendships, social interactions with acquaintances or classmates; without neglecting the quality and satisfaction associated with
*Emotional	the interpersonal relationships.

Note: *Categories of the concept of quality of life from Urzúa and Caqueo

Quality Criteria

Once the transcription of the interviews was completed, the 11 participants were asked to verify that the interpreted information was correct. Also the protocol related to the organization of the data, the detailed and meticulous description of the selection of the sample and the context in which the study is carried out, facilitate the possibility of transfer and reproducibility of the same under similar conditions, providing this otherwise qualitative quality criterion.

Results

Participant Characteristics

The years of age resulted with a median of 37 (mean 39) and SD = 13 in the 11 participants. In people who were candidates to receive KT, the median was 37 (mean 41) and in those with KT it was 35.7 years (mean 41), respectively. In this last group, two people were 6 months or less after having received RT, one was 1 year old and one person was 10 years after receiving this treatment. Table 3 shows that the majority of the total sample was made up of men who worked as employees.

Table 3: Sociodemographic characteristics of the 11 participants included in the study.

Sociodemographic Variables		Children(n=4)		TR Candidates (n=7)	
		n (%)			
Male gender	Male gender	3	-75	4	-57
Feminine	Feminine	1	-25	3	-43
Job	Housewife	-	-	1	-14
	job	3	-75	4	-57
	Housewife	1	-25	2	-29

Quality

Once the transcription of the interviews was completed, the 11 participants were asked to verify that the interpreted information was correct. Also the protocol related to the organization of the data, the detailed and meticulous description of the selection of the sample and the context in which the study is carried out, facilitate the possibility of transfer and reproducibility of the same under similar conditions, providing this otherwise qualitative quality criterion.

Quality of Life: Perception in People who are Candidates for Kidney Transplantation

Table 3 shows the interpretations related to the categories: concept of quality of life with their respective domains: physical, economic, family and social, then the identified human responses are presented. Most of the participants stated that quality of life is to be well physically, mentally and emotionally, as well as having all the basic services and not depending on kidney replacement treatments: dialysis or hemodialysis. In the physical domain, people highlight discomforts, pain and discomfort related to the procedures of renal replacement therapies or of the body itself: chronic or bone pain, for example. These human responses largely condition the inability to enter the labor field. In the economic domain, the participants report that they are unable to carry out the activities of any job due to physical disability, and therefore, they consider that their monetary income from a trade or job is limited, scarce or nil. In addition, they highlighted that the economic resources are focused on financing the management of one's own health: laboratory tests, transportation, extraordinary treatments, medical appointments and consultations, among others; These efforts are complicated precisely by the lack of monetary inputs. In the family domain, people identify the importance of the support, attention and understanding that they receive, received and expect to receive from their family in the ups and downs related to their state of health and well-being. In this regard, some express feelings of feeling a burden for their relatives due to the extra activities that the latter carry out in health care, which generates tension and uncertainty. However, the interviewees expressed the motivation generated by their family environment: mothers, children and grandchildren, among other ties, drive the desire to want to get out of their problem and be patients while waiting for the transplant.

In the emotional domain, each of the people interviewed expressed their affectation at different points that leads them to present low self-esteem: fear, frustration, depression, sadness and uncertainty are some of the emotions they expressed in their testimonies. Participants follow a continuous coping process, because not every day they feel with all the energy and motivation to continue with daily life. The emotional perception of the interviewees was reflected in their features during the interviews, points were touched that led them to tears, they expressed how difficult it is to live with a dysfunctional organ, the uncertainty before latent complications that can even lead them to lose life (Table 4).

Table 4: Quality of life: perception of kidney transplant candidates.

Categories	Interpreted Human Responses	Testimonials n=7
Quality of life concept	Independence: physical, economic and social / Physical and mental well-being	1. It is to be healthy, to be well of mind and basically, the most important thing is to be physically and mentally healthy in order to be well. 2. It is living with dignity, both in terms of health, nutrition and, in itself, having good health. 3. Not to depend on any medical treatment, to be able to be free of consultations. 4. It is the way we live, the way I am living, how I carry my food, the house, how I pay for electricity, rent, water.
*Physical	Pain and discomfort	1. Physical pain, bone pain. I have been with kidney failure for eleven years. 2. Dialysis is painful and uncomfortable.
*Economic	Inability for labor insertion	3. I can no longer work. 4. Difficult because of medical appointments and outings. 5. A lot of travel, treatment, appointment and diet expenses. 6. Job opportunities, I can't take them. 7. I was earning well and now the pension is not enough.
*Familiar	Perception of "being a severe burden" for family members	1. They accompany me to medical sessions and appointments. There is always someone with me, the support of the family is the most important thing. 2. Sorry to be a burden. They understand how long I can't be at home. 3. If I didn't have my family, I would have already left. I feel like it's tiring for them. 4. The stress in patients who are unsuccessful in their first transplant and are now waiting again is remarkable. When I relapsed they turned their attention back to me. 5. I would be alone without my children, absolutely alone.
*Emotional	Low self-esteem	1. I adapted. Moments of depression. Sad because I did not see the possibility of improving. If it arrives (the transplant) it is good if not, then there is fear. 2. It is frustrating not knowing what will happen, if the transplant can come and if I can be suitable for it to be achieved or I will no longer be there. My children depend on my strength so I try to be strong. 3. You feel like you can't anymore. 4. You feel that the world is ending, that there is no other way to have a quality of life.

Note: *Categories of the concept of quality of life from Urzúa and Caqueo.

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Quality of Life: Perception in People with Kidney Transplantation

Table 5 shows that most of the participants consider that quality of life involves physical, environmental and personal well-being as components. For one of the interviewees it means no longer depending on external factors to maintain life; another considered that the longer he can extend his life the better for its quality, he considered that discomforts are companions of life. In the physical domain, the interviewees expressed the freedom to carry out various activities and eat food without affecting their quality of life. They expressed that they can move and travel without thinking about the need to carry too many supplies related to their treatment. They also stated that they can eat food without causing discomfort or altering their clinical parameters, especially water, which was previously restricted. In the economic domain, the participants report that they have time and autonomy to build opportunities for insertion to trades, jobs and professional or educational training. One case mentioned that the ability to acquire economic resources improves their quality of life, another participant refers that they can work freely without thinking about the times of any kidney therapy, finally, one case reports that they returned to normal by taking fully these opportunities than before approached discreetly.

Table 5: Quality of life: perception of kidney transplants.

Components	Human responses	Testimonials n=4
Quality of life concept	Physical, environmental and personal well-being	1. Way to improve the environment and own life. 2. No setback, everything in order, all laboratories fine 3. Lead daily life without depending on visits to the hospital or medications, without episodes of depression. 4. Survival in years, lengthening. Maybe there will be deterioration, but you do not depend on machines.
*Physical	Physical and nutritional autonomy	1. The problem was in many aspects: physical, moral, nutritional, now it is normal. The labs have been successful. 2. I am on a new diet and with my medications my levels have been good. 3. I can eat more things, enjoy myself, and drink more water. I am no longer agitated, the anemia is completely gone. I hope to play sports; I can travel without depending on dialysis bags. 4. I go for a walk whenever I want, I urinate more, I drink more water.
*Economic	Physical and nutritional autonomy	1. I no longer have to go to the hospital every week for hemodialysis, I only go for consultation. 2. I can work tending the family store, do more activities and walk better. 3.. I never stopped working and studying, I finished high school and career. I walk quite a bit. I can attend to the business we have. I was back to normal. 4.. More possibilities to study, seek better quality of life and personal improvement. I can move to work
*Family	Perception of "being a moderate burden" for family members	1. It is less the burden for them, help is needed, they give you motivation. I used to see them go out of their way for visits to the hospital.
*Emotional	Confidence and emotional balance	1. My son told me that he donated to me and I said no, he was going to be unarmed. I feel like it's one less burden, I feel happier.

Note: *Categories of the concept of quality of life from Urzúa and Caqueo

In the family domain, the perception and feelings of being considered a burden for their families has decreased along with the amount of care related to kidney replacement therapies from which transplant participants are already exempt; People mentioned that despite the constant support of their relatives there was a physical distancing seeking to reduce the cross-infection of infections, a situation that has recently ended and they can share more time and experiences together. In the emotional domain, confidence and emotional balance were interpreted in the participants. Two people mentioned that they feel they have a new opportunity in life, to restart it and have new experiences that they previously did not consider possible. Two people mentioned the need to have confidence and know how to take the advice of health personnel: doctors and nurses. Finally, a participant described that he was overwhelmed by living a few days in isolation after his transplant, necessary to prevent infections, but at the same time accepting that it is necessary to improve his quality of life.

Discussion

The quality of life of people with a history of kidney disease is affected from the first clinical manifestations, QoL in this sector has shown deficiencies, low levels or areas of opportunity compared to the rest of the population [24]. Physical, environmental and personal well-being are part of the conception of quality of life in people with kidney disease, whether they have been transplanted or not. In the early stages of the disease, a series of negative perceptions of the disease and its immediate and intermediate quality of life are experienced that, ultimately, can influence their coping actions, these perceptions can trigger anxiety, depression, coping, autonomy, self-esteem and accelerated progression of the disease [25]. In the identification of human responses in patients with chronic kidney disease, the main physiological risks related to this pathology have been highlighted. Farias et. to the. point out the overestimation of human biological responses and those related to complications by the nursing staff who provide care to patients with nephropathies in a renal center. Among 24 diagnostic labels identified, the most frequent were "risk of infection", "excess fluid volume", "hypothermia", among others whose main domains were located in Safety / Protection and Activity / Rest, on the other hand, " low situational self-esteem "was ranked 16th in frequency [26] corresponding to the Self-perception domain in the NANDA-I [18]. The above shows what Spilogon et. to the. (2018) points out as an area of opportunity in the nursing process since it has the flexibility and openness to consider the perceptions and preferences of the user, in this case of the patient with nephropathies [27].

In the emotional category, low self-esteem was detected in the participants with CKD without transplantation, and it is that a patient with CKD has recognition and esteem needs, therefore the people in charge of their care should promote favorable behaviors in coping with the pathology and adherence to treatment, avoiding judging and repressing the failures of our human condition [28]. In contrast, the participants who had received a kidney transplant showed confidence and emotional balance, something that could be considered normal after receiving the expected transplant according to Tucker et. to the [29]. From a quantitative approach, Rocha et. to the. point out that the higher the quality of life, the better the self-esteem assessment of people with chronic kidney disease after transplantation [30]. In the economic category, while people who had not received a kidney transplant conceived the inability to enter the job market among their perception of quality of life, those who had received a kidney transplant indicated more time and autonomy to build job and academic opportunities. Reports indicate that chronic kidney disease patients face many barriers to staying or joining the workforce after starting dialysis: few opportunities, lack of financial resources to invest, fatigue and other symptoms of kidney failure, potential loss of disability benefits or medical follow-up, dialysis programming and employer biases. The social perception that CKD patients cannot work completes a vicious cycle of low job expectations [25,31].

In the family category, the perception of "being a burden" for family members influences is an important component in the perception of the quality of life of people with and without kidney transplantation. The evidence indicates that family members of patients with a history of kidney disease manifest sleep interruptions, depression, anxiety, among other disorders associated with unforeseen responsibilities related to the treatment and logistics of their relatives; they must also deal with insufficient information, medication regimen and accompany periodic hospitalizations [32]. The NANDA International classifies problems in plausible diagnostic labels of interventions focused on promoting the health of individuals, the family. and community, we can cite: Risk of fatigue of the caregiver role, Tiredness of the caregiver role, Dysfunctional family processes, Willingness to improve family processes, among others [18]. In the physical category, participants without kidney transplantation identified pain and discomfort as a condition for quality of life, a common and often severe manifestation in various populations with CKD; with prevalence's of 40% to 60%, it constitutes a strong imperative to establish the management of chronic pain as a clinical and research priority [33]. In this regard, the labels acute and chronic pain are available in the NANDA-I [18]. Although pain and physical limitation decrease after a kidney transplant, it is important to mention that the physical and nutritional autonomy indicated by the present participants can generate an excess of confidence and the acquisition of unhealthy practices. Regulated physical training by physiotherapy specialists appears to be safe in kidney transplant recipients and is associated with better quality of life and exercise capacity [34]. With regard to diet, the Mediterranean and DASH (Dietary Approaches to Stop Hypertension) diets have been shown to be the most beneficial dietary patterns for the population after kidney transplantation by focusing on less meat and food while increasing the intake of fresh foods and plant-based options [35]. Knowledge and awareness in the kidney transplant population should be a cornerstone of therapy and an integral part of nursing responsibilities.

Therefore, nurses must educate patients about self-care behaviors and remind them of the dangerous complications of abandoning them [28]. In the participants who had not received a kidney transplant, there was an expectation of receiving a kidney transplant to improve their quality of life and, from there, improve their quality of life. In this regard, we can mention the benefits in anticipation of receiving a kidney transplant mentioned by Santos et. to the. who in a group of people with Brazilian kidney disease detected that patients who were not waiting for a transplant had a risk of poor quality of life, mainly in the emotional and physical aspects; those who were not awaiting transplantation died more frequently in the following 12 months [36]. However, betting on kidney transplantation to improve the quality of life in patients with kidney disease is not entirely recommended, in this regard we can cite the studies by Schulz et. to the. and Smith et. to the. published in 2014 and 2019, [29,37] who reported that before transplantation, patients can overestimate the gains in quality of life without finding significant improvements in it after being transplanted. Kidney transplantation is not a guarantee of improvement in quality of life in all patients with kidney disease. In the present study, those people who had received kidney transplantation did not consider an absolute improvement in their quality of life. The literature indicates that kidney transplants can provide dramatic improvements in quality of life and health status, however, the effects on the improvement are not universal and patients live in constant uncertainty as they are aware of the probability of kidney dysfunction Graft [29]. There are samples that have indicated that the expectation about the functionality or rejection of the graft generates greater fear and uncertainty than death itself [38]. The results on the perception of quality of life in people receiving renal replacement therapy support the trend of the last decade focused on the analysis of this category beyond just assessing life expectancy [39]. Among the limitations of the present, the risk of bias due to the same interpretive approach and the inability to generalize the results to the study population stands out. To compensate for the above, criteria of methodological rigor were followed and from a particular context a search for generalities was made, reinforcing the results with respect to other studies (twenty-one).

Conclusion

In transplant patients, a perception of absolute quality of life or free from discomfort is not reached and human responses are still manifested that require care and interventions to achieve the maximum level of well-being. The construction of the concept of quality of life includes physical, mental, personal and social elements that are feasible to document and in which to carry out interventions for the benefit of trafficked persons and their families, it is evident that human responses not only obey physiological needs.

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