

EVALUATION OF QUALITY OF LIFE RELATED TO HEALTH AMONG PATIENTS WITH CHRONIC KIDNEY DISEASE TREATED FOR CHARITY ORGANIZATION IN WILLOW, BRAZIL

AVALIAÇÃO DA QUALIDADE DE VIDA RELACIONADA À SAÚDE ENTRE PACIENTES COM DOENÇA RENAL CRÔNICA ATENDIDOS POR ORGANIZAÇÃO BENEFICENTES EM SALGUEIRO, BRASIL

EVALUACIÓN DE LA CALIDAD DE VIDA RELACIONADA CON LA SALUD ENTRE PACIENTES CON ENFERMEDAD RENAL CRÓNICA SERVIDOS POR LA ORGANIZACIÓN BENEFICIOSA EN SALGUEIRO, BRASIL

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ABSTRACT

Objective: This study aims to assess the health-related quality of life (HRQoL) of patients with chronic kidney disease (CKD) at a charity in Salgueiro, Brazil, in order to support the design of public policies that improve the quality of life. **Method:** Methodologically, it is a descriptive quantitative study, with a prospective transversal cohort approach. The instrument used was the Health Utilities Index (HUI), in which patients on hemodialysis self-evaluated and had their health status assessed by the responsible physicians. **Theoretical basis:** There are few studies evaluating the impact of medical treatment on the HRQoL of patients in Brazil, mainly in relation to CKD. In this way, this study was based on several works that approach the subject, such as Romão Junior (2004), Furlong et al. (2001), Rodrigues (2011), Del Nero (2002), Sesso et al. (2016), Carvalho (2012) and Melo et al. (2000). **Results:** The results showed that the majority of patients and doctors considered that the treatment impaired health-related quality of life. **Conclusions/contributions:** The results of the research suggest that managers of basic public health policies can launch measures that aim to make the community aware of the problems that most cause CKD, such as hypertension and diabetes.

Keywords: Health-related quality of life; Chronic kidney disease; Health Utilities Index.

RESUMO

Objetivo: Este trabalho tem por objetivo avaliar a qualidade de vida relacionada à saúde (QVRS) de pacientes com renal crônica (DRC) em uma instituição de caridade em Salgueiro, Brasil, a fim de apoiar o desenho de políticas públicas que melhorem a qualidade de vida. **Método:** Metodologicamente, trata-se de um estudo quantitativo descritivo, com abordagem de coorte prospectiva transversal. O instrumento utilizado foi o Health Utilities Index, no qual os pacientes em hemodiálise se auto-avaliaram e tiveram seu estado de saúde avaliado pelos médicos responsáveis. **Fundamentação teórica:** Existem poucos estudos avaliando o impacto do tratamento médico na QVRS de pacientes no Brasil, principalmente em relação à DRC. Desta maneira, este estudo foi baseado em vários trabalhos que abordam o assunto, como Romão Junior (2004), Furlong et al. (2001), Rodrigues (2011), Del Nero (2002), Sesso et al. (2016), Carvalho (2012) e Melo et al. (2000). **Resultados:** Os resultados mostraram que a maioria dos pacientes e médicos considerou que o tratamento prejudicou a qualidade de vida relacionada à saúde. **Conclusões/contribuições:** Os resultados da pesquisa sugerem que os gestores de políticas públicas básicas de saúde podem lançar medidas que visam conscientizar a comunidade sobre os problemas que mais causam DRC, como hipertensão e diabetes.

Palavras-chave: Qualidade de vida relacionada à saúde; Doença renal crônica; Índice de Utilitários de Saúde.

RESUMEN

Objetivo: Este estudio tiene como objetivo evaluar la calidad de vida relacionada con la salud (CVRS) de pacientes con enfermedad renal crónica (ERC) en una organización benéfica en Salgueiro, Brasil, con el fin de apoyar el diseño de políticas públicas que mejoren la calidad de vida. **Método:** Metodológicamente, es un estudio cuantitativo descriptivo, con un enfoque prospectivo de cohorte transversal. El instrumento utilizado fue el Health Utilities Index (HUI), en el cual los pacientes en hemodiálisis se autoevaluaron y los médicos responsables evaluaron su estado de salud. **Base teórica:** existen pocos estudios que evalúen el impacto del tratamiento médico en la CVRS de los pacientes en Brasil, principalmente en relación con la ERC. De esta manera, este estudio se basó en varios trabajos que abordan el tema, como Romão Junior (2004), Furlong et al. (2001), Rodrigues (2011), Del Nero (2002), Sesso et al. (2016), Carvalho (2012) y Melo et al. (2000). **Resultados:** Los resultados mostraron que la mayoría de los pacientes y médicos consideraban que el tratamiento perjudicaba la calidad de vida relacionada con la salud. **Conclusiones / contribuciones:** Los resultados de la investigación sugieren que los administradores de políticas básicas de salud pública pueden lanzar medidas que tengan como objetivo concienciar a la comunidad sobre los problemas que más causan ERC, como la hipertensión y la diabetes.

Palabras clave: calidad de vida relacionada con la salud; Enfermedad renal crónica; Índice de servicios de salud.

INTRODUCTION

Over the past decades, the growth in the incidence of noncommunicable – or chronic – diseases have become a public health problem worldwide. It is also a huge concern in Brazil since, according to the Brazilian Institute of Geography and Statistics (IBGE) and the Brazilian Ministry of Health, noncommunicable diseases (NCDs) account for more than 70% of the causes of death in the country. Population aging reduced the number of communicable diseases and increased the number of noncommunicable diseases (BARROS et al., 2003). An NCD is a change in health that remains in an individual for a long period of time and may display periods of significant improvement or worsening over time (ALMEIDA et al., 2002).

Among the NCDs that affect the Brazilian population, the number of chronic kidney disease (CKD) patients has increased, becoming a serious public health problem. According to Barros et al. (2003), the prevalence of CKD, that is, the number of ill people, across Brazilian macroregions is of 4.23% in Central West region, the higher in the country, whereas the South, Southeast, North and Northeast regions present, respectively, 2.97%, 2.76%, 2.10% and 2.01%. These data were obtained from the Brazilian National Household Sample Survey (PNAD) using a probabilistic sample of the population. The incidence of new CKD patients increases about 8% per year, with 112,004 undergoing dialysis in 2014 (ROMÃO JUNIOR, 2004; SESSO et al., 2016).

According to Romão Junior (2004), CKD consists of a progressive and irreversible loss of kidney functions (glomerular, tubular and endocrine) in which, in its most advanced stage, the kidneys cannot maintain the constancy of the internal environment of the patient. When kidneys lose their functions, the patient starts renal replacement therapy (RRT) and enters the waiting list for kidney transplantation.

According to the Census carried out by the Brazilian Society of Nephrology (SBN) in 2016, an estimated 122,825 patients undergo dialysis and the dialysis prevalence and incidence rates will keep growing. According to data from DataSUS, only in 2009 the Brazilian Ministry of Health invested R\$1.6 billion in hemodialysis services provided by the Brazilian Unified Health System (SUS). In this context, evaluating the health-related quality of life (HRQOL) of CKD patients is necessary for managers and policymakers to make decisions that improve quality of life during treatment (SESSO et al., 2016).

When patients are diagnosed with CKD, they are either sent to renal replacement therapy (RRT) or to kidney transplantation. Dialysis¹ aims to replace kidney function totally or partially, filtering blood, removing toxins from the body and correcting metabolism. There are two main dialysis techniques: peritoneal dialysis and hemodialysis. The goals of RRTs are to ensure the survival and to improve the quality of life of patients while they wait for kidney transplantation, which is the most cost-effective measure against CKD (MELO et al., 2000).

According to the World Health Organization (WHO), quality of life (QOL) is the physical, mental and social well-being, not merely the absence of disease (WHOQOL GROUP et al. 1995; ZIMMERMANN, 2016). The HRQOL concept arises from the QOL concept, and measuring it is a key health topic (FERREIRA; SILVA, 2002).

Based on these concepts, this study aims to evaluate the HRQOL of CKD patients undergoing treatment in a specialized charitable organization in the municipality of Salgueiro, in the state of Pernambuco, Brazil, in order to support public policies aimed at improving health services.

We measured the HRQOL of CKD patients using the Health Utilities Index (HUI) questionnaire elaborated, applied and validated by the McMaster University Department of Clinical Epidemiology & Biostatistics. It is a generic instrument that consists of two systems, HUI2 and HUI3, which together form a single questionnaire. Two types of questionnaires are applied, one for the patient who will self-assess and other for people other than the subjects themselves (FURLONG et al., 2003).

¹ According to Melo et al. (2000, p.111), dialysis is “a blood filtering process based on the transportation of solutes, ions and substances through a semipermeable membrane to a liquid whose composition is carefully controlled”.

LITERATURE REVIEW

Socioeconomic determinants of health

In the constitution of Brazil, Art. 196 says that “health is the right of all and the duty of the State”. The Law ensures health as a right, which promotes welfare and social justice. It is understood that every individual should be guaranteed equal and universal access to health promotion, protection and recovery services. However, there are health inequities that compromise health care for the population

Analyzing the concept of health determined by the World Health Organization (WHO) since 1946, it is observed that the health of an individual is complex, dynamic and multidimensional, as it conceptualizes with the complete state of physical, mental and social well-being. It is noted that health is influenced by several factors, such as social, economic, cultural, behavioral and other factors that impact the health of individuals more than factors related to medicine (CARRAPATO et al., 2017). Carvalho (2012), states that addressing social determinants means understanding the value that health has for a society but admits that it depends on actions that are not always related to health.

It has been known for some time that health is determined by the living and working conditions of individuals, and it is clear that the distribution of health is not random, since not all individuals have the same risk of dying or acquiring a disease or illness. This difference is due to the fact that people live in different social conditions, with different living and working conditions (PELLEGRINI, 2007).

There are several types of social determinants, one of which is behavioral, such as a preference for dieting or exercise. But for this to happen, it is necessary for other factors to happen, such as access to healthy food and leisure spaces for exercising. Other factors are living conditions, for example, if the place of residence is unhealthy or several people live in the same environment, if they have drinking water and a basic sanitation system. Other factors that make up the social determinants of health are access to education, transportation, as well as human relationships that assist in health recovery. Therefore, all of this makes up the determinants of health that influence the health conditions of the population, and they can be modified through public policies that improve conditions for people to live with more quality and equity (PELLIGRINI, 2007).

According to Carvalho, (2012) and Campos et al., (2010) the determinants of health can be divided into three broad categories, being the social, economic and environmental determinants, but in this study only the first two determinants will be taken into account. Social determinants are linked to education, culture, living and working conditions, lifestyle, gender, health-related behaviors, degree of social inclusion, ethnicity, age. The economic determinants, on the other hand, are related to the country's economic performance, income, situations of employment, housing, occupation. For Godoy et al., (2005) chronic kidney disease affects the behavior of economic agents in the labor market. For this reason, due to the high cost of IRC treatment that economists are interested in studying such behavior.

The relationship between the state of health and the socioeconomic level of a population has long been debated. Some authors criticize that inequalities are the result of globalization, which brings different cultures and economies closer together, narrowing the barriers for the circulation of goods and people. Although some countries are concerned about inequality, their actions to end inequality are insufficient (ILO, 2011).

Economic determinants are often associated with health-related behaviors, in which the individual's income may or may not be responsible for some attitudes, checking which individuals are more likely to maintain longevity, compared to another individual with lower income. This determinant is related to the country's economic performance, income, employment, housing and occupation situations (SOUZA et al., 2013).

Health Economics

Among the discussions about the best way to allocate resources destined to health, the impacts that a disease can cause in the economic scenario, as well as the impact that economic development has on health, came the Health Economy (DEL NERO, 2002). The study of this new theme is relevant in defining new or updating public policies, as well as in the distribution of health services to the population. To achieve a good distribution of health services, it is necessary to apply economics principles in the health sector.

It is a great challenge to establish harmony between economics professionals and health professionals, since both have different views on health care. Economists defend the ethics of the common and social good, on the other hand, health professionals are based on individualistic ethics, which says that health is priceless and that every effort is valid.

Therefore, Health Economics is a recent area that seeks to help managers and other health policy makers to allocate resources in a rational way, install assistance with cost-effectiveness, enhance the benefit of resources destined to health, above all, to provide quality medicine to patients (VIANNA; MESQUITA 2003).

The origin of Health Economics was through the application of economic instruments to both strategic and operational issues in the health sector, combining the two approaches. Although health economics is a recent discipline, there is research and older studies on the living conditions of populations and their implications for health, in which they seek to relate socioeconomic factors and health indicators.

According to the thinking of Del Nero (1995), health economics has two types of theoretical foundation, one broad and the other applied, more linked to its field of action. In the broad theoretical basis, the concepts used are traditional economics, such as the government budget; deficits and public debt; demand and service offerings; the economic evaluation of projects, with the analysis of benefits and costs, efficiency, effectiveness, effectiveness and utility, etc. Applied concepts related to the field of health economics, on the other hand, are associated with the role of health services in the economic system; study of health indicators and levels correlated to economic variables; the cost-benefit, cost-effectiveness and cost-utility analysis of specific goods or services; among the others.

Health Economics is being used to equip doctors and managers for the decision-making process, since it is fundamental that we decide what, for whom, how much, at what cost and what benefit the action is causing to society as one all. This analysis is essential because resources are limited and there is inequality in access to health care, among others (VIANNA; MESQUITA 2003).

In an economic analysis, costs must be assessed, and these are divided into direct costs and indirect costs. The difference between both is that direct costs are directly linked to the costs of interventions, such as hospitalizations, medication, tests and others. Indirect costs, on the other hand, are related to the loss of productivity, either because of the inability to perform an activity or due to early death, because of the time spent on treatments, consultations and hospitalizations. (VIANNA; MESQUITA 2003).

The SUS faces challenges common to universal health systems, with regard to the security of financial sustainability. The system's difficulties are due to poor management of resources and insufficient funding, which cause losses in the quality and access to health services. In addition to these factors, the aging of the population, the development of new technologies, the shift from infectious epidemiologies, to chronic, infectious-parasitic and other diseases caused by violence, impact the public budget (BRASIL, 2012).

Faced with this scenario, health system managers and technicians need instruments that help in the efficient allocation of resources. Health Economics enters as a field of knowledge that can assist in more firm decisions about the sources and destinations of resources.

Chronic kidney disease

According to Romão Junior (2004), chronic kidney disease consists of kidney damage and progressive and irreversible loss of kidney function (glomerular, tubular and endocrine). In its most advanced phase, it is called the terminal phase of chronic renal failure (CRF), in which the kidneys are unable to maintain the normality of the patient's internal environment. According to Bastos et al., (2004), diabetes mellitus and hypertension are the two main causes of chronic kidney disease and are directly associated with overweight or obesity.

The kidneys have the function of filtering the blood, eliminating waste, toxins and excess fluids in the form of urine. It is also responsible for the release of some hormones in the body, such as the production of red blood cells, bone metabolism, for the regulation of some chemical elements, such as calcium, sodium, phosphorus and potassium (MORSCH; VERONESE, 2011).

Romão Junior (2004) divides chronic kidney disease (CKD) into six functional stages, in accordance with the patient's level of renal function, being relevant for clinical, conceptual, epidemiological and didactic effects. It can be presented from the following table.

Among the symptoms that patients experience with the progression of kidney failure can be cited easy tiredness, fatigue, nausea, vomiting, swelling, fluid retention in the body, reduced urine volume, anemia, hypertension, muscle spasms and cramps, coma and mental confusion. As a result of these symptoms, the patient begins to change his routine, reducing the workday, lower salary rates, early exit from the labor market, with early retirement (GODOY et al., 2007; MELO et al., 2000).

According to Melo et al. (2000) dialysis can be explained as a sage filtration process, which is carefully controlled through an impermeable membrane that takes ions, solutes and substances into another liquid. Treatment through RRT aims to improve patient survival and provide an improvement in the patient's quality of life.

The most common modality is hemodialysis, in which the blood filtration procedure is performed by a dialyzer equipment, also known as "artificial kidney". Through two ducts, the patient's blood flows through a first duct, which takes the blood to receive an ion bath dissolved in treated water inside the dialyzer, removing impurities from the blood so that it, through another duct is returned to the patient's body (MELO et al. 2000).

The increased involvement of kidney disease can cause socioeconomic implications in a country, given the increased spending on renal replacement therapy (AMARAL, 2016; CHERCHIGLIA et al., 2010). According to data from Datasus, only in 2009 did the Ministry of Health invest R \$ 1.6 billion in hemodialysis services through the Unified Health System (SUS). Estimates made by companies that provide hemodialysis services reveal that a hemodialysis session aggregating the entire set of expenses with used material, human resources, facilities and equipment costs around R\$ 142.99, totaling an estimated annual expenditure by SUS of R\$ 2.2 billion in 2014, according to SBN (SANTOS; MOURA, 2014).

These expenses with IRC treatment impact public coffers, in addition to causing socioeconomic changes in the lives of patients and their families. SUS does not spend only on hemodialysis sessions, since the care of patients with renal failure includes medication, hospitalization when necessary and access to kidney transplantation (CRUZ, 2014).

From the patient's point of view, his daily life is totally modified, suffering from changes in his physical, psychological and social state. Hemodialysis such as CRF can cause symptoms such as vomiting, pain in the fistula, headaches or headache, weight loss and in women it can also reduce menstruation (AMARAL, 2016). In addition, it can cause a reduction in family income, since part of the income will be available for indirect treatment costs. All of these factors influence the quality of life of patients.

The patient will be unable to perform daily activities that require greater effort and pain caused by the disease and treatment. In addition, time will be limited as treatment requires a large part of the patient's time, hampering activities such as travel and long-term work. Many have an early exit from the labor market, impacting their financial lives. The family also suffers from the impact of time and financial,

due to the greater dedication given to the patient, and in many cases, it is necessary to quit work to care for the patient (AMARAL, 2016; FRÁGUAS et al., 2008).

Kidney disease can affect the financially responsible person of the family, which will affect the entire family structure. Even in cases where kidney failure affects another individual, the person in charge feels obliged to quit his job or reduce the hours worked to dedicate himself to the relative. This financial impact can affect housing, food, leisure and other factors that are directly linked to income.

Chronic end-stage renal disease affects the quality of life of patients and family members, as well as being responsible for a significant portion of resources destined to health (MOURA et al., 2006). For this reason, assessing the quality of life related to the health of chronic kidney patients is interesting for decision making aimed at generating less impact on the economy.

Health-related quality of life

As indicated by the World Health Organization (WHO), health is not defined only as a state of absence of disease, but as a state of complete physical, mental and social well-being. From this definition, it is possible to perceive the formation of a new, less restricted model, in which biological, psychological and social factors are composed for the search for health. We can see that the center of this new model is not only in the disease, but also in the context in which the individual is inserted. Therefore, using as a health indicator only the prevalence or incidence of diseases becomes insufficient to understand the health of the population (ZIMMERMANN, 2016).

There was an epidemiological transition, as Zimmermann (2016) reported in his work that the epidemiological transition occurred because before the biggest causes of deaths were from infectious diseases, and today the main causes of death are caused by non-communicable or chronic diseases. The focus of attention shifted from acute diseases that are eminently lethal to chronic diseases that weaken the individual for a long time. Thus, conventional epidemiological indicators have become insufficient to measure health.

With the change of focus to chronic diseases, the attention that was given to the cure of an infectious disease is transferred to mitigate the damage that it can cause in people's daily activities. The purpose of health care is focused in this context on quality of life, that is, on the well-being of individuals, instead of just increasing the number of days of life.

Defining health-related quality of life is not an easy task. The term health-related quality of life (HRQoL) is due to the fact that when studying quality of life, it restricts only the influences of diseases and conditions. However, it is interpreted that health is only one among several factors that can affect the quality of life of individuals. According to Patrick and Erickson (1993) the definition of HRQoL can be the value attributed to the continuation of life, altered by impairments, functional states, perceptions and social opportunities that are influenced by diseases, injuries, treatments or policies.

The main form of assessing HRQoL is self-assessment questionnaires. However, the use for elderly people can be hampered by difficulty of interpretation by them. In cases where patients cannot participate in the assessment of HRQoL, the assessment by a third party (proxy-report) may be essential or the only source to carry out the research. However, the caregiver's stress and tiredness must be taken into account.

Although there is no understanding between the definitions of QOL, some characteristics are in agreement among some researchers (WHO, 1995):

1. It is subjective and objective, since it is associated with subjective aspects such as satisfaction with its goods and objective aspects such as the availability of material goods, making it possible to evaluate under the individual's conception whenever feasible.
2. It is considered multidimensional, since it is common to several cultures: the physical view shows the individual's perception in relation to his physical state; in the psychological it reveals the individual's perception of his cognitive and affective state and the social one shows the individual's perception regarding his interpersonal and social relationships

in his life. The WHO also inserted the spiritual dimension, which represents the individual's perception of the meaning of life or even the beliefs that idealize and qualify the experiences.

3. Covers the individual's perception of positive and negative dimensions, such as mobility and contentment, and fatigue and dependence on drugs, respectively.

Various instruments have been developed to assess the health-related quality of life of individuals affected by illnesses or other problems that impact their health. Therefore, knowing the characteristics of the instruments before application is essential to be adequate for the purpose of the research.

In the last decades, some studies were carried out with the aim of evaluating the quality of life related to the health of individuals, using the Health Utilities Index as an assessment tool, developed by the Epidemiology and Biostatistics group at Mc Master University (FURLONG et al., 2001). As an example, the study by RODRIGUES (2011) and CUNHA et al., (2012), deals with children's health. The HUI is one of the most used for the HRQoL assessment with children, as it is possible that the intermediary will answer for them, if they are too sick to respond or are below the allowed age.

The article by Cunha et al., (2012) aimed to evaluate the health-related quality of life (HRQoL) of children surviving discharge from pediatric intensive care, obtaining the data through the questionnaire Health Utilities Index Mark 3 (HUI3), applied to a representative of the child, parent or guardian. It was applied in two moments, one pre-admission and the other after months. A high number of cases were found to have scores close to 1 (perfect health status) and only 9 to 7% of cases, at pre-admission and at follow-up, respectively, had negative scores. Although HRQoL is globally similar in the two assessments, they were differentiated on an individual basis. The conclusion reached was that children with low HRQoL before admission (severe disability) can benefit from pediatric intensive care, as many of these children improved HRQoL compared to their pre-admission status.

Rodrigues' research (2011) aimed to evaluate the quality of life of adolescents diagnosed with malignant neoplasms, that is, with cancer, during treatment, at Hospital das Clínicas, Federal University of Minas Gerais (UFMG) in October 2007 to July 2010, using HUI2 and HUI3. The study pointed out that from the perspective of patients, caregivers and physicians it considered that there was an impairment of HRQoL, but that there was also an improvement over time. Among the attributes that make up the global HRQoL score, pain was the attribute most affected by both the perception of patients and their caregivers and doctors, and there was an improvement when comparing the two moments of the assessment. Still in the assessment of the global HRQoL scores, it revealed a tendency for physicians to attribute lower scores to their patients, and the study did not show a statistically significant relationship when associated with age, sex, family income, caregiver's education, number of residents in the household and diagnosis.

Still on the work of Rodrigues (2011), the correlation between the global HRQoL scores according to HUI2, revealed a high correlation between the patient and his caregiver both in the first moment (T1) and in the second moment (T2) and a moderate correlation between the patient and his doctor at the first moment and none at the second moment. T2 also showed a moderate correlation between the patient's caregiver and doctor. Regarding HUI3, we observed that at T1 there was a high correlation of the global HRQoL scores between the patient and his caregiver and between the patient and his doctor and a moderate correlation between the caregiver and the doctor. In T2, the correlation remained high only between the patient and his caregiver.

Other researches were also developed with the same objective of evaluating HRQoL, however, they used other methods and different instruments for data collection. As an example, we have the studies by Teixeira et al., (2014); Lopes et al., (2014) and Silva et al., (2017). The article by Teixeira et al., (2014) aimed to determine the survival rate; characterizing the epidemiological and clinical profile; to identify comorbidities and variables associated with the survival of patients undergoing hemodialysis in a university hospital. The data collected were analyzed using Cox regression, presenting the main results: the average age was 48.09 years, the monthly family income and the level of education were reduced by most of the participants. if the main comorbidity associated with chronic end-stage renal failure, followed by diabetes mellitus. The factors that significantly compromised patient survival were advanced age at the

beginning of therapy, hemoglobin and albumin, with an overall survival rate of 84.71% and 63.32% in one and five years, respectively.

The article by Lopes et al., (2014) aimed to assess the health-related quality of life of chronic renal patients on dialysis, using the Subject Characterization Instrument and the Kidney Disease Quality of Life- Short Form. As a result, the research showed impairment in the physical function domains, work situation and physical functioning. The cognitive function, social support and sexual function obtained the best perceptions.

The study by Silva et al, (2017) aimed to describe the sociodemographic and clinical laboratory profile of patients with CKD on hemodialysis, using the individual interview method for data collection. The results achieved were: the median age was 59 years; most of the 102 patients were men (65.7%); married (59.8%) and with an income of up to one salary (53.9%). The most frequent etiology was SAH (40.6%), followed by DM (14.9%). SUS served 94.1%, the median time on hemodialysis was 36 months and the median use of drugs was five. Hematocrit, hemoglobin and HDL were decreased. Phosphorus, urea and creatinine were increased.

METHODOLOGY

This study is classified as a descriptive research. According to Gil (2006), descriptive research uses standardized techniques for data collection and aim to study characteristics of a group or to establish relations between variables. In descriptive research there is no interference of the researcher; the facts are only observed, recorded, analyzed, classified, and interpreted (Andrade, 2006).

In addition, regarding its temporal approach, the research is a cross-sectional study, which, according to Hair Jr. et al. (2005) are descriptive studies in which data are collected at a point in time and then statistically synthesized. Since they are made from a sample that represents a population or a population subset, these studies must be rigorous with representativeness. Therefore, patients undergoing hemodialysis in this organization in Salgueiro were approached only in a single moment.

Regarding the nature of the data, we used the quantitative method, which treats information by means of statistical techniques and uses modalities of quantified data collection (Richardson et al., 1999). In order to obtain the results, we used descriptive statistics, standard deviation, mean, mode, correlation coefficient, and minimum and maximum values.

As for the research technique, the prospective cohort approach was chosen. A cohort is a group of individuals that share common characteristics, constituting a sample that must be monitored for a certain period (from the present to the future). Cohort studies are widely used in health sciences (Gil, 2006).

The technique used for data collection was the questionnaire, which is an ordered series of questions whose answers, unlike in an interview, must be written down (Gerhardt & Silveira, 2009). Because it aims to collect data on opinions, feelings, beliefs, expectations, interests and situations experienced by an individual, the questionnaire is the most appropriate instrument for self-assessment among CKD patients.

The questionnaire was elaborated with objective questions, printed and distributed among patients and physicians. The data collected were kept confidential, exposing only the information necessary for the conclusion of the research. After applying the questionnaires, the data were organized and analyzed using statistical methods that allow verifying relations between phenomena and obtaining generalizations about their nature, occurrence and meaning (Marconi; Lakatos, 2009).

The patients were approached while they were connected to the machine because they were immediately sent to the hemodialysis room when they arrived at the unit and spent 3 to 4 hours dialyzing. The questionnaire was applied only by the researcher herself between July and August 2018. In some cases, it was necessary for the researcher to read and mark the answers, since many patients were illiterate,

others had difficulties to read or see, were in an uncomfortable position to read or could not move their arms because of the fistula.

The questionnaire was completed only after clarification, agreement to participate in the study and signing of the free and informed consent form. It was answered according to the experiences of the patient in the week prior to its application. All questionnaires were checked upon delivery in order to avoid data loss by both patient and physician.

We used the Health Utilities Index (HUI) questionnaire, an instrument used to evaluate QOL elaborated and validated by the McMaster University Department of Clinical Epidemiology & Biostatistics (Furlong et al., 2001). HUI2 and HUI3 are preference-based generic systems used to describe health status and HRQOL (Horsman et al., 2003; Shimoda et al., 2005).

The HUI is a family of questionnaires composed of three distinct evaluation systems, with the latter two complementing each other: HUI Mark 1 (HUI1), HUI Mark 2 (HUI2), and HUI Mark 3 (HUI3). Together, HUI1 and HUI2 describe 1,000,000 unique health states. HUI3 is intended for primary analyses and has a descriptive system more detailed than that of HUI2, population norms available, and full structural independence. HUI2 offers distinct and independent attributes such as emotions, self-care, and fertility (Horsman et al., 2003).

Health status classification systems were elaborated to relate directly to preference-based scoring models based on the multi-attribute utility theory. The HUI provides descriptive measures in the health profile and HRQOL scores, on a generic scale, being applicable to almost everyone. It can be used to calculate the quality-adjusted life years (QALYs) for cost-utility analyses.

The HUI questionnaire is standardized and is available in two types – the self-report one, in which the subject self-assesses, and the proxy-report one, in which other individual assesses the health status of the subject. In addition, it is responsive to changes in health status, enabling long-term assessment and measurement of the effect of the treatment or other factors. Questionnaires answered by third parties are necessary when the subject is unable to answer by themselves because of their age or mental or physical disability.

There are four key components of each HUI system: a health-status classification system, preference-based scores, data collection questionnaires, and coding algorithms for deriving HUI variables from responses to the questionnaires.

The HUI2 classification systems have 7 attributes: sensation, mobility, emotion, cognition, self-care, pain and fertility, each with 3 to 5 levels that describe 24,000 unique health states. In this study, fertility will take value 1, for it will not be assessed. The HUI3 classification system has 8 attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain, each with 5 to 6 levels that describe 972,000 unique health states.

The HRQOL attribute scores depict abilities deriving from utility functions (Torrance et al., 1996; Fenny et al., 2002; Horsman, 2003). Single-attribute scores vary on a scale in which worst level has a score of 0.00 and the best level has a score of 1.00. Multi-attribute scores are defined on a scale in which 0.00 is dead and 1.00 is perfect health. The classification systems allow for negative scores of HRQOL that represent health states worse than dead.

The data collected for the research were transformed into scores using algorithms already established in the questionnaire. After assigning all levels and values to each attribute, the HRQOL was calculated using the expression below, where b corresponds to the comprehensive functional score:

$$\text{HUI3u} = 1.371 \times (b1 \times b2 \times b3 \times b4 \times b5 \times b6 \times b7 \times b8) - 0.371$$

$$\text{HUI2u} = 1.06 \times (b1 \times b2 \times b3 \times b4 \times b5 \times b6 \times b7) - 0.06$$

We also applied a questionnaire that obtained demographic and socioeconomic data from each respondent. The variables were: age, gender (masculine or feminine), schooling, household monthly income, and household size.

We compared the scores obtained for each category of the study using the nonparametric tests of Wilcoxon (Mann-Whitney), Kruskal-Wallis and the t-test. The Wilcoxon test intends to compare measures of central tendency of two independent samples of equal size. The Kruskal-Wallis test is an

extension of the Wilcoxon test that allows for comparing between three or more samples or populations. The t-test is used to compare matched or independent samples. The data were organized, tabulated and statistically analyzed using Microsoft Excel 2010 and Stata 13.

The research was carried out at a charitable organization in the municipality of Salgueiro, Brazil, a reference in the Central Hinterland of the state of Pernambuco in the treatment of CKD patients. The city started providing the service to the population in 2009, attending up to 120 patients per month ever since.

According to their official website, the unit has 20 propulsion machines and a state-of-the-art hemodialysis water treatment system. The unit attends people from 18 different cities. The goal is to improve the care provided to the population of the state, reducing the suffering of Unified Health System (SUS) users, CKD mortality and out-of-home expenditures on treatment, given that patients used to travel more than 90 miles in search of treatment.

The organization works in the areas of medical-social assistance, teaching, research and community outreach. It is a reference in technical research and training in human resources for health services for national and international organizations, either governmental or non-governmental.

According to Fernandes (1994), charities operate in a public space, but are private organizations. In this space, the government, the market and the third sector also operate, with the latter being object of controversy. Even private, they see their responsibility of developing society and solving issues that the government fails to. Thus, they seek to improve QOL in the society, not profits.

The participants were picked in different days of the week in order to achieve temporal representativeness; however, there were only two nephrologists in the dialysis center.

The inclusion criterion was being a CKD patient attended by the charitable organization in Salgueiro between July and August 2018. Parameters such as age, gender and income were not considered. The exclusion criterion was being an already kidney-transplanted patient, that is, a patient that has already quit dialysis.

RESULTS AND DISCUSSION

The charitable organization in Salgueiro can attend up to 120 patients; however, during the application of the questionnaires, only 117 patients were being treated at the unit. It was possible to reach a sample of 60 patients. However, due to the absence of most caregivers during the hemodialysis session, this category of participants was removed from the scope of the study. It was possible, though, to collect data from the physicians' assessment.

The gender distribution of 117 patients was as follows: 70 (59.8%) of the male gender and 47 (40.2%) of the female gender. The sample inherits such characteristics, with 35 patients (58.4%) of the male gender and 25 (41.6%) of the female gender.

A similar distribution was found by the 2016 Brazilian Chronic Dialysis Census, which estimated that, out of the 122,825 patients on dialysis, 57% were male. Also, Teixeira et al. (2014), which aimed to determine survival among patients on hemodialysis in a university hospital, presented this same gender distribution, with 90 (55.56%) male patients and 72 (44.44%) female patients. A similar division among patients was also found by Lopes et al. (2014), whose goal was to evaluate the HRQOL of 101 CKD patients on dialysis, with 69 (68.32%) patients of the male gender and 32 (31.68%) of the female gender.

Instrument and time for completion of the questionnaire

During the development of this research, we noticed that the HUI questionnaire is a generic instrument that can be applied to several diseases and has already been translated to Brazilian Portuguese, validated and used with adult patients on dialysis (Horsman et al., 2003). Hence, the HUI is the most appropriate instrument in this scope. Another important condition for choosing it was the existence of a

validated version in Portuguese for the proxy-report questionnaire, which is the only way of evaluating HRQOL when the patient is unable to respond.

There was a low rate of invalid data in this study, since the researcher verified the questionnaires upon receiving. The presence of the researcher during the application was useful to resolve potential doubts as well as to help patients that were either illiterate or had reading or writing disabilities. In addition, it was possible to obtain important information that was not foreseen in the methodology and enriched the discussion.

Since the HUI is a generic instrument, some difficulties were identified regarding issues that were not related to the clinical context. For example, question 15 in both self-assessment and third-party assessment questionnaires asks “Which of the following sentences best describes the pain or discomfort experienced by the individual in the last week?”. We noticed that there were gaps, since there were patients who experienced pain that did not interrupt their activities and did not use controlled substances, but who needed medical prescription.

During the application of the questionnaire, we did not calculate the time spent by participants to fill them. This happened because most patients asked the applicator to read the questionnaire due to visual problems, postural difficulties, illiteracy or reading difficulties. In addition, it was necessary to interrupt the application in some moments due to the necessity to check blood pressure or to remake the dressings.

Socio-demographic data

To analyze age, it was necessary to remove from the sample a patient who was not able to report neither their age nor their year of birth, resulting in 59 valid cases. The age of the patients by the time of the application of the questionnaires ranged from 20 to 80, with an average of 48 years, median of 47 and standard deviation of 14.429, what shows a great dispersion and indicates a very age-heterogeneous sample.

To analyze income, one answer was not considered because the patient was not able to report theirs, resulting in 59 valid cases. The household monthly income ranged from 0 to 8 minimum wages with an average of 1.55, median of 1.0 and standard deviation of 1.30, showing little dispersion. Household size ranged from 1 to 13 people with an average of 3.55, median of 3.0 and an elevated standard deviation of approximately 2.42.

Regarding the years of schooling of the patient, it ranged from 0 to 16, which stand for illiteracy and undergraduate degree, respectively. The average was of 7.19 years and the median, 6.25. In this feature, a high standard deviation of 4.47 was found, indicating an elevated degree of dispersion in the data. The median explains why many patients had difficulties reading and understanding the questionnaire.

The present research had results very similar to those of Silva et al. (2017), which aimed to depict the socio-demographic, clinic and laboratorial profile of patients on hemodialysis, finding also a higher proportion of male patients, poorly educated and with low income. CKD may reduce household income due to either the patient’s early exit from the labor market because of treatment needs and/or to the breadwinner’s exit from the labor market to dedicate time to the patient’s recovery (Amaral, 2016; Fráguas et al., 2008).

The data showed that the population studied consisted of young people and predominantly adults. One of the most evident characteristics regarding age was that the patients were in full economically active age, burdening pensions with early retirements and reducing the number of professionals in the labor market, affecting individual and household income (Teixeira et al., 2009; Barbosa et al., 2006).

Hence, the sample is reasonably homogeneous regarding income. This may be associated with the type of organization considered, with the location of the organization and/or to the illness, in which the population is mostly poor, as demonstrated by the median of household monthly income of 1.0 minimum

wage. A larger sample, with more diverse socio-economic conditions and organizations, may be necessary to evaluate whether income is important to assess HRQOL.

HRQOL assessment: evaluation of attributes affected according to the categories of study participants

In the self-assessment, according to HUI3, 32 patients (53.4%) presented up to two attributes affected. According to HUI2, 32 patients (53.4%) also presented up to two attributes affected (Table 1). We considered “affected” only the moderate and severe levels, following the HUI algorithm. According to HUI3, only one patient presented 7 out of the 8 potentially affected attributes. In HUI2, five patients presented 5 out of the 6 potentially affected attributes.

Table 1 – Absolute frequency of patient distribution by the number of attributes affected in the self-assessment according to HUI3 and HUI2

Number of attributes affected	HUI3	HUI2
0	5	4
1	10	16
2	17	16
3	12	10
4	11	9
5	4	5
6	0	0
7	1	NA
8	0	NA

Subtitle: NA - not applicable.

Source: The authors (2021).

In the assessment made by the physicians, according to HUI3, 39 patients (65%) had up to two attributes affected. According to HUI2, 40 patients (66.7%) also had up to two attributes affected (Table 2).

In the comparison between the physicians’ answers and the self-assessment, despite having more positive scores, the physicians classified – according to HUI3 – three patients with 7 out of the 8 potentially affected attributes, whereas only one patient presented 7 attributes affected. The same happened in HUI2 – no patient present 6 out of the 6 potentially affected attributes in their self-assessment, but the physicians evaluated five patients with 6 attributes affected.

Table 2 – Frequency of patient distribution by number of attributes affected in HUI3 and HUI2 according to physicians

Number of attributes affected	HUI3	HUI2
0	13	16
1	11	11
2	15	13
3	7	9
4	6	5
5	4	1
6	1	5
7	3	NA
8	0	NA

Subtitle: NA – not applicable.

Source: The authors (2021).

Regarding the number of attributes affected, we noticed that most patients had up to two attributes affected, similarly to Rodrigues (2011), who evaluated HRQOL in adolescents on cancer

treatment. In this study, in the individualized assessment of the attributes that constitute the global HRQOL scores, cognition was the most affected attribute in the patients' point of view (Table 3) and pain according to the physicians (Table 4), and both were the most affected attributes considering the two categories of participants together. In both HUI3 and HUI2, cognition is assessed by questions I1 and I2, which relate to the patient's ability to recall things, think and solve everyday problems. On the other hand, pain is evaluated in HUI3 in question 8, that approaches to which extent pain has impaired the activities performed by the patient; and in HUI2 by question I5, which evaluates pain referring to the type of medicine used to relieve it.

Cognition is one of the attributes that are usually affected in CKD patients, since, according to Condé et al. (2010), "they are users of polypharmacies and present comorbidities such as diabetes and hypertension". Pain may be caused by complications of the disease, as Godoy et al. (2012) mention in their study that symptoms experienced by patients as CKD advances are fatigue, nausea, vomiting, swelling, fluid retention, smaller amounts of urine, anemia, hypertension, muscle spasms and cramps, coma, mental confusion and others.

Table 3 – Dysfunctional attributes in the patient's point of view

System	Attribute affected	N (%)
HUI3	Cognition	28 (46.7)
	Pain	14 (23.3)
HUI2	Pain	14 (23.3)
	Cognition	12 (20.0)

Source: The authors (2021).

Table 4 – Dysfunctional attributes in the physician's point of view

System	Attribute affected	N = 60
HUI3	Pain	18 (30.0)
	Cognition	13 (21.7)
HUI2	Pain	16 (26.7)
	Cognition	5 (8.3)
	Sensation	5 (8.3)

Source: The authors (2021).

Evaluation of the global HRQOL score according to socio-demographic variables

The Wilcoxon test and the t-test were used to evaluate the association between the HRQOL global score and the socio-demographic data. The first aims to compare whether the measures of position of two samples are equal when the samples are dependent. The second evaluates if there is a significant difference between the means of two samples. For this analysis, we considered only 59 valid cases, since one patient was not able to report some socio-demographic data.

To evaluate the association between global HRQOL scores and age, the patients were split into two groups: 1) patients whose age is equal or inferior to the median age of the entire group, that is, 47 years; 2) patients older than 47 years. The result indicated that the medians are not statistically different and that the means are relatively close for both HUI2 and HUI3 from patients and physicians. In the evaluation of the association between the HRQOL score with gender, we did not notice a statistically significant difference for both HUI2 and HUI3 from patients and physicians.

To evaluate the association between the global HRQOL score and household monthly income, the patients were split into two groups: 1) patients whose household income is equal or inferior to 1 minimum wage, which is the median; 2) patients whose household income is greater than 1 minimum wage. The results indicated that the medians are not statistically different for both HUI2 and HUI3 from

patients and physicians. Income may have not affected the HRQOL evaluation since the sample was homogeneous regarding it.

To evaluate the association between the global HRQOL score and the household size, the patients were split into two groups: 1) patients with up to 3 residents at home (the median household size); 2) patients with more than 3 residents at home. In this case, we also did not verify statistically significant differences for both HUI2 and HUI3 from patients and physicians.

In the evaluation of the association between schooling and the HRQOL score, patients were split into two groups: 1) patients who had up to 6.25 years of schooling (the median years of schooling); 2) patients who had more than 6.25 years of schooling. The results for both HUI2 and HUI3 from patients and physicians showed that the medians are not statistically different.

In summary, since the p-value of the samples for all the associations were higher than 0.05, the results were not statistically significant, showing that the socio-demographic conditions do not affect the evaluation of the HRQOL of CKD patients on dialysis significantly. Hence, there is no sufficient evidence to reject the null hypothesis.

Evaluation of the global HRQOL score according to the categories of participants

In the evaluation of patients according to the HUI3, 50 health states were identified. The global HRQOL scores according to the HUI3 ranged from negative (-0.371; -0.341; -0.237; -0.132; -0.114; -0.097; -0.078; -0.048 and -0.036), which represent a status worse than dead, to 1.00, which is perfect health. Only five patients considered their health perfect according to HUI3.

The negative scores that were reported by patients classified as severe the impairment of the attributes vision, ambulation, pain and cognition. The states worse than dead can be interpreted as if the patient were already dead due to so many restrictions and the lifelong machine dependence, making them not able to perform all the activities they would like to.

In the evaluation of patients, according to HUI2, 42 health states were identified. Only four patients considered their health perfect. The global HRQOL scores ranged from -0.06 to 1.00, with nine patients having assigned negative scores. The negative scores classified as severe or moderate the impairment of sensation, mobility, pain and emotion.

In the evaluation made by physicians, according to HUI3, 36 health states were identified. Thirteen patients had their health considered perfect by the physicians. The global HRQOL scores ranged from negative (-0.371, -0.271, 0.183, -0.124, -0.089, -0.065) to 1.00. The negative scores classified as severe or moderate the impairment of vision, ambulation, cognition, dexterity and pain.

In the evaluation made by physicians, according to HUI2, 28 health states were identified. The physicians considered perfect the health status of sixteen patients. The global HRQOL scores, according to HUI2, ranged from -0.06 to 1.00. Only three patients had negative scores, showing that the physicians considered the health status of the patients better than the patients themselves.

In the evaluation of the global HRQOL score, there was not significant difference between patient and physician. In both, the difference was the same, with the median being, for HUI3 and HUI3 respectively, 0.52 and 0.63 in the self-assessment and 0.70 and 0.81 in the physician's assessment (Table 5).

Table 5 – Global HRQOL scores according to the categories of participants

CATEGORY	HUI	Median	Minimum	Maximum
Patient	HUI3	0.52	-0.371	1
	HUI2	0.63	-0.06	1
Physician	HUI3	0.70	-0.371	1
	HUI2	0.81	-0.06	1

Source: The authors (2021).

Correlation of the global HRQOL score between patient and physician

The evaluation of the correlation of the global HRQOL scores according to HUI3 showed a moderate correlation of global scores between patient and physician ($R = 0.421$; $p\text{-value} = 0.008$). Regarding HUI2, we observed a moderate correlation between the global HRQOL scores between patient and physician, albeit inferior to that of HUI3 ($R = 0.419$; $p\text{-value} = 0.008$) (Table 6).

The evaluation of the correlation of global HRQOL scores for both HUI3 and HUI2 showed a moderated correlation between patient and physician. However, there was a greater propensity among physicians to assign more positive scores than the patients themselves. The patients could assign negative scores because of the change in QOL, due to the anxiety caused by the treatment and to dealing with a chronic disease, as well as difficulties in mobility, working and performing everyday activities (Lopes et al., 2014; Terra, 2010).

Table 6 – Correlation of global HRQOL scores between patient and physician according to HUI2 and HUI3

Category	HUI	Median	Minimum	Maximum	R	P Spearman
Patient	HUI3	0.52	-0.371	1.00	0.421	0.008
Physician	HUI3	0.70	-0.371	1.00		
Patient	HUI2	0.63	-0.06	1.00	0.419	0.008
Physician	HUI2	0.81	-0.06	1.00		

Source: The authors (2021).

General health status assessment according to patient and physician

Question 16 evaluates the global health status, asking how the patient and the physician assess the health status of the patient, with the answer ranging from excellent to poor. The general health status of the patients was considered “regular” by most patients, with 50% of the sample classifying it like this. On the other hand, the physicians considered “good” the health status of most patients (71.7%) (Table 7).

Table 7 – Assessment of the general health status of patients

CATEGORY	HEALTH STATUS	N	%
Patient	Excellent	1	1.7%
	Very good	7	11.7%
	Good	13	21.7%
	Regular	30	50.0%
	Poor	9	15.0%
	Total*	60	100.0%
Physician	Excellent	0	0.0%
	Very good	7	11.7%
	Good	43	71.7%
	Regular	10	16.7%
	Poor	0	0.0%
	Total*	60	100.0%

Source: The authors (2021).

Correlation of the general health status assessment between patient and physician

The general health status assessment of the patient showed a moderate correlation between the patient and their physician ($R = 0.26$; p -value: 0.044) (Table 8). There was also a greater propensity among physicians to assign more positive scores than the patients themselves.

Table 8 I– Correlation of the general health status between the patient’s and the physician’s assessment

HEALTH STATUS	PATIENT		PHYSICIAN		R	P Spearman
	N	%	N	%		
Excellent	1	1.7%	0	0.0%	0.26	0.044
Very good	7	11.7%	7	11.7%		
Good	13	21.7%	43	71.7%		
Regular	30	50.0%	10	16.7%		
Poor	9	15.0%	0	0.0%		
Total	60	100%	60	100.0%		

Source: The authors (2021).

Thus, it is relevant that the physician is aware of the patient’s self-assessment of their health status. A good understanding between patient and physician can contribute to good medical practices and greater chances of adherence to the treatment and the daily care necessary to avoid the aggravation of the disease. Dialogue and discussion about aspects of the disease, the treatment and how the patient feels may be the best way to maintain agreement between the parties.

CONCLUSION

It is noteworthy that CKD is considered a public health problem, as the number of cases increase each year and so does the life expectancy of the population. Hence, it is necessary to identify the impact of CKD and its therapies on the HRQOL, and which factors affect the health status of the individuals such as social, economic, cultural and behavioral factors.

Thus, this study aimed at assessing the HRQOL of patients on hemodialysis, using a generic instrument that allows for both self-assessment and third-party assessment – in this case, physicians. Then, the answers from both groups of participants are compared. The main purpose of the study is to support future studies and public policies that improve the living conditions of this population through the development of more equitable actions to reduce the incidence of the disease.

In order to achieve our goal, the study was split into three specific goals. The first one, which aimed to evaluate the health status to monitor treatment in order to support public policies that propose the improvement of the living conditions of patients was attained, since the HUI questionnaire assessed the health status of patients and can be applied in the future with the same patients to check if their health status improved or worsened. However, a more qualitative and documentary research will be needed to obtain more detailed information and support more appropriate public policies.

The second goal, regarding the comparison between QOL scores and the socio-demographic variables was attained through the nonparametric Wilcoxon and t tests, using Stata 13. From the tests, we verified that the sample did not show statistically different medians, revealing that socio-demographic conditions do not affect significantly the QOL assessment of the patients participating in the study.

The final goal, which intended to analyze the correlation of the QOL assessment of CKD patients between the patient and the physician was attained using the Spearman correlation coefficient, using Stata 13. A moderate correlation between patient and physician was verified, as well as a greater propensity among physicians to assign more positive scores than the patients themselves.

This study makes it possible for future investigations to be developed with the same patients, what can contribute to understand the influence of the disease and its therapies on HRQOL. The use of

other instruments to evaluate the HRQOL of CKD patients can also be pointed out, since the instrument used does not comprehend all the aspects of the subject. An indication for future works is the use of the specific instrument Kidney Disease Quality of Life-Short Form (KDQOL-SF), which collects, in a single instrument, socio-demographic and clinical conditions data, already validated in Brazil.

Regarding the limitations of the work, we verified that the instrument limited some questions raised by the researchers during the study. Thus, we believe that the use of other instruments such as interviews and observations would add other information to this study and could punctuate other public policies. In addition, we suggest that studies of this nature be carried out in other organizations in order to broaden the perspective.

Since the incidence of CKD grows about 8% per year, basic health public policies could launch measure that aim to raise awareness in the community with respect to problems that most cause CKD, namely hypertension and diabetes. Such measures can reduce incidence rates. The HRQOL evaluation of CKD patients on treatment in a charitable organization in Salgueiro, Pernambuco, Brazil showed that most patients and physicians considered that QOL worsened, given that many assigned negative scores in this research,

The research also showed that in the individualized evaluation of the attributes that constitute the global HRQOL score, pain and cognition were the most affected attributes in both patient's and physician's assessment. It was also possible to detect a propensity among physicians to assign greater scores to their patients as well as a propensity among patients to assess their health status negatively.

The evaluation of the correlation of global HRQOL scores in both HUI2 and HUI3 showed a moderate correlation between patient and physician. In the evaluation of the global HRQOL scores with the socio-demographic data, no statistically significant differences were demonstrated. The results must not be generalized since it is a specific disease, but they can be compared with other studies that follow the same research line, as well as the methodology can be applied to assess the HRQOL of individuals affected by other diseases.

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