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Autonomy and decision making in chronic kidney disease

Autonomia e tomada de decisão na doença renal crônica

Autonomía y toma de decisiones en enfermedad renal crónica

RESUMO
Objetivo: apresentar as principais evidências encontradas na literatura sobre a autonomia e tomada de decisão dos pacientes com doença renal crônica em tratamento conservador na escolha da terapia renal substitutiva. Método: revisão sistemática da literatura, através da busca nas plataformas Biblioteca Virtual em Saúde, PubMed e SciELO, em português, inglês, francês e espanhol, publicados nos últimos 20 anos. A coleta de dados e seleção dos estudos ocorreu entre março e abril de 2020. Resultados: Foram encontrados 32 estudos. Há consenso na literatura sobre a importância da participação do paciente na tomada de decisão. A oferta de educação e orientação para o autocuidado com avaliação dos objetivos de vida e valores do paciente é primordial para uma escolha autônoma. Conclusão: a discussão é relevante e escassa na literatura. A tomada de decisão compartilhada entre usuário e equipe assistente, quando da instituição de tratamento, deve ser priorizada.
DESCRITORES: Insuficiência Renal Crônica; Autonomia Pessoal; Tomada de Decisão Compartilhada.

ABSTRACT
Objective: to present the main evidence found in the literature on the autonomy and decision-making of patients with chronic kidney disease under conservative treatment in choosing renal replacement therapy. Method: systematic literature review, through a search in the Virtual Health Library, PubMed and SciELO platforms, in Portuguese, English, French and Spanish, published in the last 20 years. Data collection and selection of studies took place between March and April 2020. Results: 32 studies were found. There is consensus in the literature about the importance of patient participation in decision making. The offer of education and guidance for self-care with assessment of the patient's life goals and values is essential for an autonomous choice. Conclusion: the discussion is relevant and scarce in the literature. Shared decision-making between the user and the assistant team, at the treatment institution, should be prioritized.
DESCRIPTORS: Renal Insufficiency, Chronic; Personal Autonomy; Decision Making, Shared.

RESUMEN
Objetivo: presentar las principales evidencias encontradas en la literatura sobre la autonomía y toma de decisiones de los pacientes con enfermedad renal crónica en tratamiento conservador en la elección de la terapia renal sustitutiva. Método: revisión sistemática de la literatura, mediante búsqueda en las plataformas Biblioteca Virtual en Salud, PubMed y SciELO, en portugués, inglés, francés y español, publicada en los últimos 20 años. La recolección de datos y la selección de estudios se llevó a cabo entre marzo y abril de 2020. Resultados: Se encontraron 32 estudios. Existe consenso en la literatura sobre la importancia de la participación del paciente en la toma de decisiones. La oferta de educación y orientación para el autocuidado con evaluación de los objetivos y valores de vida del paciente es fundamental para una elección autónoma. Conclusión: la discusión es relevante y escasa en la literatura. Se debe priorizar la toma de decisiones compartida entre el usuario y el equipo asistente, en la institución de tratamiento.
DESCRIPTORES: Insuficiencia Renal Crónica; Autonomía Personal; Toma de Decisiones Conjuntas.

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INTRODUCTION

Chronic Kidney Disease (CKD) is defined as a reduction in Glomerular Filtration Rate (GFR) or structural damage, present for at least 3 months. When the patient with CKD has a GFR lower than 29 ml/min/1.73m², in stages 4 and 5, he should be referred for multidisciplinary follow-up, with a nephrologist, nurse, nutritionist, psychologist and social worker in conservative treatment. It is up to the team to identify the need for Renal Replacement Therapy (RRT), as early as possible, providing guidance and preparation for the choice of modality, considering the patient's desire and clinical condition. [1-3]

Ordinance 1820/2009 provides that in the Unified Health System (SUS) the patient has the right to choose and refuse treatment, when there are several alternatives. 4 In this sense, it is highlighted that the patient with CKD can choose not to undergo any RRT, and together with the assistant team, define the maintenance of conservative treatment. 5

However, RRT is essential for the maintenance of life. An ethical conflict is then generated: the patient's autonomy and their decision not to undergo RRT are guaranteed, which may lead to a shortening of their life span, but it is supported by Articles XXI and XXII of the Medical Code of Ethics; 6 or life is guaranteed based on the principle of sacredness, supported here, by the duty, in situations of risk of death, to act without the patient's consent. In a patient who is fully capable of deciding, could not performing RRT have its ethical support in the argument of a dignified life/death? 5,7

Assess "the real meaning of a life worth living and who should be given the prerogative to decide on such meaning" 8 it is necessary. The central issue of sacrality versus quality can and should be faced when choosing whether to institute RRT or not, based on the dignity of the human person and on autonomy, and may even be debated by the bioethics of protection by Schramm & Kottow. 9

Chronic Kidney Disease (CKD) is defined as a reduction in Glomerular Filtration Rate (GFR) or structural damage, present for at least 3 months

The patient with CKD must be encouraged by professionals to make a decision. However, after evaluating the clinical and cognitive conditions that may be affected by diseases such as CKD, identifying the patient's capacity for self-government and the ability to make decisions, exercising autonomy. In the identification of prejudice in decision-making, the support of a legal representative is imperative, considering the Brazilian legal system. Autonomy can be represented by signing a consent form containing information about the treatments offered and the choice, which must be attached to the medical record. 2,10-14

We discussed autonomy, without, however, conceptualizing it. Autonomy here is conceived as: the individual's ability to decide about his/her life; respect for individuals who seek self-fulfillment; achieve goals through personal preferences and choices. There is autonomy as long as the actions do not affect or harm other people's lives. Autonomous actions must not be controlled/limited, including by professionals. 15

Commonly, professionals recommend treatments based on clinical and laboratory evaluation, perpetuating paternalism. It can be difficult to assess the individual's ability to decide on therapy, as in the Brazilian population with CKD there is a prevalence of advanced age and low education, which makes it difficult to understand the guidelines provided. Can it be said then that there is autonomy? Several conditions influence decision making. However, we should not consider incapable patients a priori. It is important to make them informed, ensuring the humanization of care. 12,15-17

From these points, the concern of this work arises, which aims to present the main evidence found in the literature on the autonomy and decision-making of patients with CKD undergoing conservative treatment in choosing the RRT, in order to

substantiate discussions about comprehensiveness in the care of patients with CKD.

METHODS

This is a systematic literature review following the PRISMA protocol, 18 formulated from the acronym PICO (Population: Patients with CKD under conservative treatment; Intervention: Decision making in choosing the RRT; Comparison: none in this study; and Outcomes: Autonomy) that defined the research question: "Patients with CKD in conservative treatment have autonomy in decision-making for RRT?".

The research consists of texts available in full and free of charge on the platforms of the Virtual Health Library (VHL) and The Scientific Electronic Library Online (SciELO) and on the basis of the US National Library of Medicine and National Institutes of Health (PubMed) in the languages Portuguese, English, French and Spanish, published in the last 20 years (between 2000 and 2019), found by combinations of descriptors: "Chronic Kidney Failure" AND "Personal Autonomy" AND "Decision Making" (Key 1); "Chronic Kidney Failure" AND "Personal Autonomy" (Key 2); "Chronic Renal Failure" AND "Decision Making" (Key 3) and the respective terms in Portuguese for national bases. Exclusion criteria were to be a systematic or integrative review and not address the proposed theme.

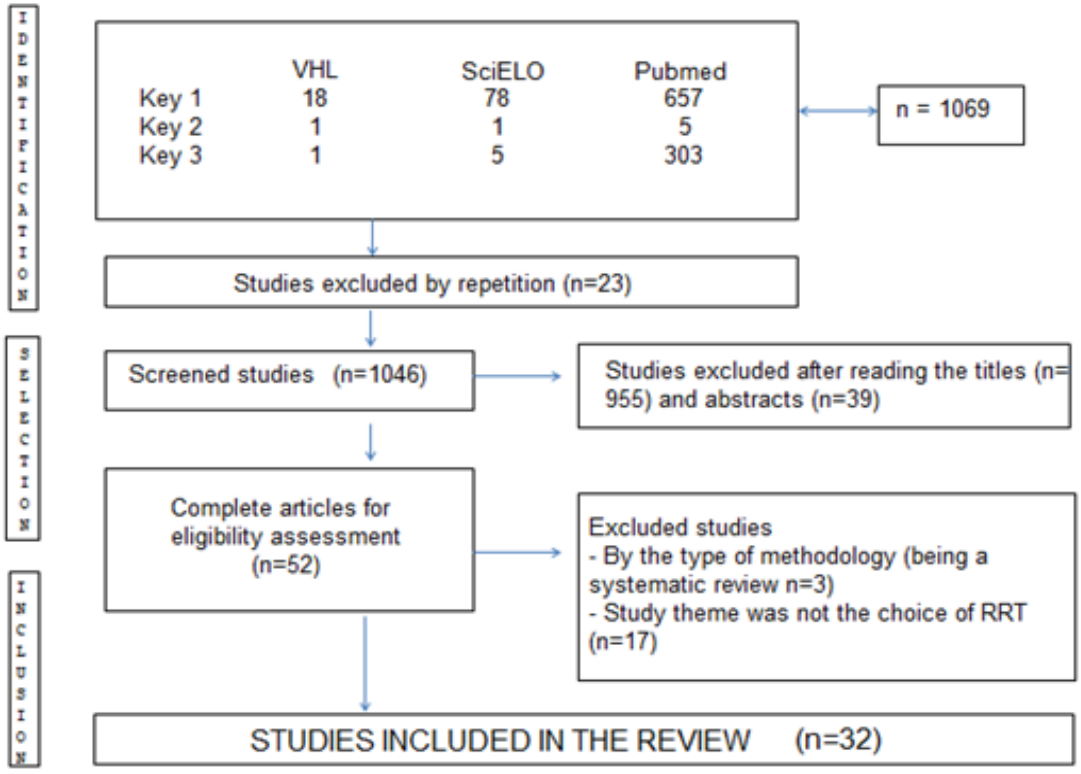
Data collection and selection of studies took place between March and April 2020, by 2 reviewers. 1069 studies were found. After the evaluation, shown in Figure 1, 32 articles were adequate for the purpose of the study.

We sought to understand the main findings in the literature regarding the choice of RRT by users who are still under conservative treatment, correlating and comparing, whenever possible, the results of the studies. The research was not submitted to the Research Ethics Committee as it is a secondary data analysis. The authenticity of the authors' ideas was maintained.

RESULTS

Of the 32 studies included, only one is Brazilian. None specifically deal with the autonomy of the patient with CKD in the process of choosing the RRT. There is a consensus on the importance of the participation of patients with CKD in decision-making, which must occur through education and guidance for self-care, with assessment of life goals and values. The literature points to the sharing of the decision-making process between patients, family members and the assistant team. We pre-

Figure 1 - PRISMA: Flowchart of artcile selection



Source: Campos, TS; Gomes, AP; 2021.

Table 1. Main characteristics of the selected articles in the systematic review

Authors/ Year	Title / Method	Main Results/Conclusion
Shukla AM, Easom A, Singh M, Pandey R, Rotaru D, Wen X, Shah SV / 2017 [42]	The impact of education on chronic kidney disease patients' plans to initiate dialysis with self-care dialysis: a randomized trial. / Randomized clinical trial	Of the patients, 82,1% intend to start home dialysis thinking about self-care (after receiving intervention) and 50% (without intervention). Education favors self-care.
Bezerra CIL, Silva BC, Elias RM / 2018 [43]	Governing therapy choices: power/knowledge in the treatment of progressive renal failure. / Reflective essay	It describes the struggle between the professional's power and the individual's right to choose RRT. Nurses are essential to assist in choosing RRT.
Campbell-Crofts S, Stewart G / 2018 [44]	Decision Making around Dialysis Options. / Cross-sectional study with a control group	Decision-making should be facilitated by professionals: simple language, neutral terms, avoiding opinion and explaining "positive" and "negative" points of the RRT.
Chen N-H, Lin Y-P, Liang S-Y, Tung H-H, Tsay S-L, Wang T-J / 2018 [45]	Patient INformation about Options for Treatment (PINOT): a prospective national study of information given to incident CKD Stage 5 patients. / Multicenter national prospective study	Most Australian patients were informed of treatment options prior to onset, but at an advanced stage of CKD. Education and support prior to decision making can help in choosing transplantation and home dialysis
Friberg IO, Mårtensson L, Haraldsson, B, Krantz G, Määttä S, Järbrink K / 2018 [46]	Factors influencing patient choice of dialysis versus conservative care to treat end-stage kidney disease. / Exploratory descriptive research	More likely to choose dialysis: day treatment, available transport and increased life expectancy. Remains conservative: increases hospital visits and travel restrictions
Ladin K, Pandya RA, Kannam A, Loke R, Oskoui T, Perrone RD, Meyer KB, Weiner DE, Wong JB / 2018 [47]	How to Select among Dialysis Options. / Reflective essay	Making the decision: improves adherence and results; makes you understand and accept complications better.
Malkina A, Tuot DS / 2018 [48]	Choosing dialysis modality: decision making in a chronic illness context / Qualitative study	Patients understand that the choice of RRT is theirs. Alertness: only when symptomatic. Decision: to undergo dialysis or not; and no, choose the best RRT.
Scott J, Owen-Smith A, Tonkin-Crine S, Rayner H, Roderick P, Okamoto I, Leydon G, Caskey F, Methven S / 2018 [49]	Shared decision making and patient involvement in choosing home therapies. / Reflective essay	Shared decision-making improves the quality of treatment and ensures attention to psychosocial and clinical needs
Teso AD, Moutet AL Lefuel P, Seigneux S, Golay A, Martin P-Y / 2019 [50]	The patient perspective and physician 's role in making decisions on instituting dialysis. / Randomized clinical trial	Consider: benefits and burden of RRT, patient behavior and support network. Dialysis seen as standard therapy prevents understanding of the other options.
Lam DY, O'Hare AM, Vig EK / 2013 [28]	Decisions About Dialysis Initiation in the Elderly. / Case report	Elderly (80 years old): undergoing RRT or palliative care. Decision: dialogue with the family and autonomy
Murray MA, Bissonnette J, Kryworuchko J, Gifford W, Calverley S / 2013 [29]	Whose Choice Is It? Shared Decision Making in Nephrology. / Reflective essay	Describes principles of shared decision making. Health systems need to innovate communication to ensure patient decision support.
Porter E, Watson D, Bargman JM / 2013 [30]	Education for patients with progressive CKD and acute-start dialysis. / Reflective essay	It presents educational and psychological strategies to help support CKD patients, especially when starting dialysis in an emergency.

Schell, JO, O'Hare AM / 2013[31]	Illness trajectories and their relevance to the care of adults with kidney disease. / Reflective essay	Knowing gravity drives risk of future events. Individual assessment aids discussion of realistic predictions and decisions.
Harwood L, Clark AM / 2014[32]	Dialysis modality decision-making for older adults with chronic kidney disease. / Qualitative study	Professional and family support leads to the choice of home dialysis. Elderly people influence the decision: values, health status, gender, knowledge, experience, belief, available resources, lifestyle.
Schell JO, Cohen RA / 2014 [33]	A Communication Framework for Dialysis Decision-Making for Frail Elderly Patients. / Experience report	Discusses the best treatment strategy in frail older adults with CKD and benefits of starting dialysis. Clinician can recommend targeted treatment plan
Erlang AS, Nielsen IH, Hansen HO, Finderup J / 2015 [34]	Patients' experiences of involvement in choice of dialysis mode. / Qualitative study	Patient is a significant part of the decision. They tend to put off choices for being asymptomatic. Professional advice alters the experience.
Jayanti A, Neuvonen M, Wearden A, Morris J, Foden P, Paul B, Mitra S and BASIC-HHD study group / 2015 [35]	Healthcare decision-making in end stage renal disease-patient preferences and clinical correlates. / Exploratory descriptive study	Patients prefer to receive information; but do not become active by receiving it. Understanding the individual factors related to the decision provides an assessment of needs and preferences.
Seah AS, Tan F, Srinivas S, Wu HY, Griva K / 2015 [36]	Opting out of dialysis – Exploring patients' decisions to forego dialysis in favour of conservative non-dialytic management for end-stage renal disease. / Qualitative study - semi-structured interviews	Participants report the factors that led them to choose conservative treatment. All took ownership of their decision despite advice to the contrary and were satisfied with the decision and current condition. Highlights factors that determine the decision.
Dahlerus C, Quinn M, Messersmith E, Lachance L, Subramanian L, Perry E, Cole J, Zhao J, Lee C, McCall M, Paulson L, Tentori F / 2016 [37]	Patient Perspectives on the Choice of Dialysis Modality: Results from the Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT) Study. / Cross-sectional study	They understand the choice is not theirs: 47% in Hemodialysis (HD); only 3% in Peritoneal Dialysis (PD). The limited role perceived in the choice of RRT shows the need for interventions for shared decision-making.
Moist LM, Al-Jaishi AA / 2016 [38]	Preparation of the Dialysis Access in Stages 4 and 5 CKD. / Reflective essay	Target RRT based on GFR, risk of complications and access to services; Team: support decision.
Pereira E, Chemin J, Menegatti CL, Riella MC / 2016 [39]	Choice of dialysis method - clinical and psychosocial variables related to treatmen / Exploratory descriptive research	The choice of RRT was an exclusively medical decision in 76,3%. PD was considered the best RRT related to quality of life, clinical and psychosocial well-being
Noble H, Brazil K, Burn A, Hallahan S, Normand C, Roderick P, Thompson C, Maxwell P, Yaqoob M / 2017[40]	Clinician views of patient decisional conflict when deciding between dialysis and conservative management: Qualitative findings from the PAlliative Care in chronic Kidney disease (PACKS) study. / Qualitative and interpretive study	Themes identified: frequent change of opinion of patients regarding treatment options; mandatory inclusion of physicians in decision-making (which retains information so as not to cause concern to the patient); complexity of decision making that reveals medical opinions.
Piccoli GB, Sofronie AC, Coindre JP / 2017 [41]	The strange case of Mr. H. Starting dialysis at 90 years of age: clinical choices impact on ethical decisions. / Case report	Elderly (90 years old) = initiation of dialysis = principialist analysis: no RRT restriction (justice); Balance of beneficence and non-maleficence; Final decision of the elderly (autonomy).

Shukla AM, Easom A, Singh M, Pandey R, Rotaru D, Wen X, Shah SV / 2017 [42]	Effects of a comprehensive predialysis education program on the home dialysis Therapies: a retrospective cohort study. / Retrospective and qualitative descriptive study	Pre-dialysis education increases choice for home therapy. Discuss: location, structure and kidney function; CKD and stages; types of RRT and when to start (include transplant and conservative); Lifestyle; is there a better RRT?
Bezerra CIL, Silva BC, Elias RM / 2018 [43]	Decision-making process in the pre-dialysis CKD patients: do anxiety, stress and depression matter? / Prospective study	Depression, anxiety and stress in the final stages of CKD are not related to the choice of RRT; these symptoms abate after starting dialysis.
Campbell-Crofts S, Stewart G / 2018 [44]	How perceived feelings of "wellness" influence the decision-making of people with predialysis chronic kidney disease. / Qualitative exploratory descriptive	Do I need RRT? Which one is "right" for me? When should I start? Responses were impacted by well-being, belief in RRT not needed, person-centered care, and pre-dialysis education.
Chen N-H, Lin Y-P, Liang S-Y, Tung H-H, Tsay S-L, Wang T-J / 2018 [45]	Conflict when making decisions about dialysis modality. / Cross-sectional correlational study	RRT decision: related to values. Those who do not receive pre-dialysis education have less self-efficacy and conflict in the decision.
Friberg IO, Mårtensson L, Haraldsson, B, Krantz G, Määttä S, Järbrink K / 2018 [46]	Patients' Perceptions and Factors Affecting Dialysis Modality Decisions. / Cross-sectional study	Those who receive pre-dialysis education from 3 or more professionals are more likely to have home dialysis. Less likely with older age and living close to the clinic.
Ladin K, Pandya RA, Kannam A, Loke R, Oskoui T, Perrone RD, Meyer KB, Weiner DE, Wong JB / 2018 [47]	Discussing Conservative Management of Older Patients With CKD: An Interview Study of Nephrologists. / Qualitative study	North American nephrologists who advise the elderly about RRT should present conservative treatment as a treatment modality and envision this possibility without the burden of moral distress.
Malkina A, Tuot DS / 2018 [48]	Role of telehealth in renal replacement therapy education. / Literature review	Suggests technology-assisted education on RRT options for geographically isolated and/or clinically fragile patients
Scott J, Owen-Smith A, Tonkin-Crine S, Rayner H, Roderick P, Okamoto I, Leydon G, Caskey F, Methven S / 2018 [49]	Decision-making for people with dementia and advanced kidney disease: a secondary qualitative analysis of interviews from the Conservative Kidney Management Assessment of Practice Patterns Study. / Qualitative study	The prevalence of cognitive alterations among people with CKD is high. In the UK, dialysis is started and continued by individuals with dementia and services must be tailored to meet the needs of this population.
Teso AD, Moutet AL Lefuel P, Seigneux S, Golay A, Martin P-Y / 2019 [50]	How to adapt an educational offer to the specificities of patients with chronic renal failure? / Experience report	Awareness of chronicity, being asymptomatic, feeling of control over life and being active in care favors the assessment of therapeutic options, acceptance and resilience for autonomous choice.

Fonte: Campos, TS; Gomes, AP; 2021.

sent below a summary of the publications found.

DISCUSSION

Ethics is essential to health practice and respect for the patient's autonomy is present in the codes of ethics of the professions. Everyone must have the exercise of their autonomy largely guaranteed and the information must be presented, making possible the full exercise of the capacity to choose. Ethical discussions related to nephrology are frequent and focus on maintaining or withdrawing dialysis. The dialogues about the choice of RRT, however, are little debated. 20,26

The involvement of patients in decision making reflects their preferences and values. The implementation of education strategies allows for empowerment, enables the choice of the RRT modality; optimizes participation in decision making; in addition to increasing the choice for residential therapies, such as PD. Making the information within the reach of the patient understandable favors the understanding of the influence of RRT in life, and makes choices suitable for those who will perform it. [19,21-22,26,33,35-36,42] During care in conservative treatment, nurses can play a key role in education for choosing RRT and can thus act with a holistic and differentiated view, favoring the development of professional autonomy. 20,51

The process of knowledge construction is growing and must be started at the same time as the disease is discovered, since the clinical evolution is dynamic in CKD and

the focus must be on quality of life and not on the method of treatment.25,34. It is important to start sharing information in the early stages of CKD, helping the patient to understand the positive and negative points of each modality, until the beginning of the RRT, strengthening their autonomy and the ability to express their opinion in their care plan. 50 In the United Kingdom, a study with 458 patients, 39,7% in pre-dialysis and the others in HD, showed that young people find it easier to make decisions and that the elderly want to receive more information, even though they do not actively participate in the choice. 35 It should also be noted that it is not just information for the sake of information, but the quality and the way in which the professional presents it. Autonomy may or may not be valued so that the decision is actually clarified and shared. 20

Professionals are paramount in helping patients to make better choices. However, its role is to advise treatment options, providing information for the individual decision. In this sense, it is important to promote the autonomous decision, even if it conflicts with the beneficence or non-maleficence that the professional believes to be applying. 28,40 We emphasize that RRT can be essential for the maintenance of life and that, even so, there is the possibility of denying its institution. It will be up to the professional, in view of this choice he disagrees with, to exercise his right to conscientious objection and refer the patient to a colleague capable of offering such care.

The only Brazilian study identified that the choice of dialysis modality was the exclusive decision of physicians in 76,3% of the 220 cases evaluated; in 17,8% the decision was made jointly by patients and the medical team; and 5,9% the decision involved only a family member or patient, with no participation of the assistant physician. 39 In Washington, of patients who started HD, 47% believed that the modality decision was not theirs; in PD only 3% had the same report. Those who chose it did it for fear of complications that other RRT could offer, especially infection. 37

It is noteworthy that the joint decision process is ideal: multidisciplinary team and patient; and in cases unable to decide: family member or legal representative will do it. Therefore, it is important to routinely implement educational strategies to support patients as they approach RRT. Professionals must pay attention to individuality, learning barriers, beliefs and understanding about their condition, considering the support network, as the education process can take time. [24,26,40]

It is not recommended to only send leaflets or informational materials. It takes joint work, offering support and following the stages of readiness for change that can interfere with decision-making, innovating in communication with the inclusion of technologies. 24,29-30 In 2005, 82,1% of patients who received 2 sessions of guidance on choosing RRT intended to start home dialysis. In the group that received the standard treatment, without guidance, only 50% had the same choice. 19

The education process using resources such as phone calls, social media, apps and websites enables discussion among patients, family members and professionals, according to 87,9% HD patients in the USA, 55,6% in New Zealand and 13,9% in Hong Kong. In the latter, 81,3% perform PD, an index related to the offer of education and the possibility of choosing RRT. 48 However, in Brazil, we emphasize that CKD mostly affects people with low education and socioeconomic status and, therefore, it is necessary to be careful with the use of technologies, which may not reach everyone. 16

People with greater difficulty in making decisions, did not receive pre-dialysis education, have less knowledge and report a lack of professional support, and this can negatively influence the process. When the conflict related to the decision is great, it can result in disappointment or regret with the choice. 45

Many physicians identify elderly people with cognitive impairment, associated comorbidities and no social support as unfeasible to decide. It is important to discuss the possibility of advance will directives, which favor the patient's previously stated desire, and this strategy can benefit many, as the prevalence of cognitive impairment among patients with CKD is high. Depression, anxiety and stress, common in CKD, do not seem to influence the choice of RRT. [11,43,49]

Potential benefits and burdens of instituting dialysis in frail elderly people is a frequently presented discussion. Benefits are described as the possibility of prolonging life; relief from symptoms such as fatigue, weight loss and appetite; improved sleep and quality of life; ability to perform activities that provide joy and satisfaction; social relationships and strengthening of bonds in dialysis; and support from other people undergoing the same treatment. 23,33,38 The burden is described as: difficulties, failures and complications with access to RRT; time spent on daily treatment; dependence on transport to perform therapy; increased hospitalizations and health complications; and symptoms after the procedure, such as fatigue and pain. 33 It is essential to carefully analyze the benefits and burdens of potential options, considering the behaviors related to the patient's health and their support network. The options must be clear, offering freedom of choice, 27 according to local reality, which may not offer all RRT due to lack of vacancies or services.

Family influence in decision-making is described as a negative factor, as the patient can choose appropriate modalities for their support network and not the one they would like. The autonomous decision is driven by the value and context of an individual's life and is usually influenced by commitment; current health status; presence of symptoms and associated comorbidities; knowledge about the modalities; values, beliefs, preferences, lifestyle, related to the extension of life with quality; past experiences, especially with family and friends who underwent RRT; and available resources, considering support for treatment maintenance. Studies show that professional and family support was the greatest determinant for the selection of home modality. [32,35-36,38,44-46]

Adequate information can improve the decision-making process. Many are highly likely to die before starting dialysis and are

not informed about it. The generalized view of dialysis as standard therapy prevents the guidance of patients who should understand treatment options and adapt to life or accept the possibility of death. 27 Studies discuss the possibility of treatment refusal, especially for the elderly. It is important to present the permanence in conservative treatment as a possibility, which should not be identified as palliative care, but as a care that causes less suffering. 36,47 An interesting report was the case of an elderly person (90 years old), needing to start dialysis, presented through principlism. Dialysis was made available without restriction, applying justice. The final decision on whether or not to start RRT was left to the elderly person (respect for autonomy). However, their choice depended on the balance between beneficence and non-maleficence (quality of life vs. complications caused by the treatment). The decision to start dialysis was maintained while the assistance ensured her well-being. 41

It is necessary to expand this discussion, as the number of people who need to start RRT is growing and need to be prepared to deal with the changes that will occur. The healthcare team must support the patient and be a balance point for decision making, providing information about risks and benefits, always paying attention to the preferences of patients with CKD. 31,38,52

CONCLUSION

The studies point to the need for a shared decision, with the presentation of all existing treatment possibilities. Some publications guide how physicians should act, indicating the best treatment according to the best scientific evidence, providing guidance on the advantages and disadvantages of each available option, enabling informed and autonomous choices. It should be stressed that even without the intention of harming the patient's autonomy, at this time, many professionals make choices without taking into account individual capacity and sharing, after all, the patient is the owner of their own life. In contrast, patients listen to professional positions and opt for modalities that they do not know well. The choice is personal and driven by an individual's value and life context. Due to lack of knowledge, many still follow only the professional indication.

A shortage of Brazilian publications was identified and a gap in the discussion of the performance of the multidisciplinary team in this context; there is only a presentation of the role of the physician in the shared decision-making process. Another important and unidentified point is about the possibility of changing therapy over time, a reality that needs to be shared with the patient. In this sense, patients with CKD do not become hostage to choice when it does not meet their expectations.

We concluded that it is a complex topic and needs to be discussed. It is necessary to consider and reflect on the autonomy and prioritization of this practice in the care of renal patients undergoing conservative treatment, especially in Brazil.

REFERENCES

1. Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. Kidney Int (Suppl) 2013;3:1-150.

2. Brasil. Ministério da Saúde. Portaria nº 389, de 13 de março de 2014. Define os critérios para a organização da linha de cuidado da Pessoa com Doença Renal Crônica (DRC) e institui incentivo financeiro de custeio destinado ao cuidado ambulatorial pré-dialítico. Brasilia, p. 14. 13 mar 2014.

3. Brasil. Ministério da Saúde. Secretaria de Atenção à Saúde. Departamento de Atenção Especializada e Temática. Diretrizes Clínicas para o Cuidado ao paciente com Doença Renal Crônica – DRC no Sistema Único de Saúde. Brasília, pp. 37. 9 mai 2014

4. Brasil. Ministério da Saúde. Portaria nº 1.820, de 13 de agosto de 2009. Dispõe sobre os direitos e deveres dos usuários da saúde. Brasilia, pp. Brasília, pp. 6. 13 ago 2009

5. Moura Neto JA, Moura AFDS, Suassuna JHR. Renouncement of renal replacement therapy: withdrawal and refusal. J. Bras. Nefrol, 2017;39(3):312-22.

6. Brasil. Conselho Federal de Medicina. Resolução Nº 22, de 17 de setembro de 2018. Código de Ética Médica. Brasília, pp. 110. 27 set 2018.

7. Villas-Bôas ME. A ortotanásia e o Direito Penal brasileiro. Rev Bioét, 2008; 16:61-83.

8. Siqueira-Batista R, Schramm FR. Conversações sobre a "boa morte": o debate bioético acerca da eutanásia. Cadernos de Saúde Pública, 2005; 21 (1):111-9.

9. Schramm FR, Kottow M. Principios bioéticos en salud pública: limitaciones y propuestas. Cad Saúde Pública, 2001; 17: 949-56.

10. Brasil. Conselho Nacional de Saúde. Ministério da Saúde. Resolução n° 466, de 12 de dezembro de 2012. Aprovar as seguintes diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. Brasília, pp. 12. 12 dez 2012.

11. Matta SM, Matos MJ, Kummer AM, Barbosa IG, Teixeira AL, Silva ACS. Alterações cognitivas na doença renal crônica: uma atualização. J Bras Nefrol, 2014; 36(2):241-245.

12. Ugarte ON, Acioly MA. The principle of autonomy in Brazil: one needs to discuss it. Rev. Col. Bras. Cir, 2014;41(5):274-7.

13. Brasil. Código Civil: Lei nº 10.406, de 10 de janeiro de 2002. Brasília, pp. 194. 11 jan 2002. [Disponível: http://www.planalto.gov.br/ccivil_03/leis/2002/L10406compilada.htm Acessado 08 junho 2021.

14. Brasil. Lei Brasileira de Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência): Lei nº 13.146, de 6 de julho de 2015. Brasília, pp. 31. 6 jul 2015.

15. Beauchamp TL, Childress JF. Princípios de ética biomédica. São Paulo: Loyola; 2002.

16. AguiarLK,PradoRR,GazzinelliA,MaltaDC. Fatores associados à doença renal crônica: inquérito epidemiológico da Pesquisa Nacional de Saúde. Rev Bras Epid, 2020; 23.

17. Rego S, Gomes AP, Siqueira-Batista R. Bioética e humanização como temas transversais na formação médica. Rev Bras Educ Med, 2008; 32(4): 482-91.

18. Galvão TF, Pansani TSA, HarradD. Principais itens para relatar Revisões sistemáticas e Meta-análises: A recomendação PRISMA. Epidemiol. Serv. Saúde, 2015;24(2):335-42.

REFERENCES

19. Manns BJ, Taub K, Vanderstraeten C, Jones H, Mills C, Visser M, et al. The impact of education on chronic kidney disease patients' plans to initiate dialysis with self-care dialysis: a randomized trial. Kidney Int, 2005;68(4):1777-83.

20. Holmes D, Perron AM, Savoie M. Governing therapy choices: power/knowledge in the treatment of progressive renal failure. Philos Ethics Humanit Med, 2006;1:12.

21. Mooney A. Decision Making around Dialysis Options. Cont Nephrol, 2009;163: 257-60.

22. Morton RL, Howard K, Webster AC, Snelling P. Patient INformation about Options for Treatment (PINOT): a prospective national study of information given to incident CKD Stage 5 patients. Nephrol Dial Transplant, 2011;26(4):1266-74.

23. Morton RL, Snelling P, Webster AC, Rose J, Masterson R, JohnsonDWet al. Factors inluencing patient choice of dialysis versus conservative care to treat end-stage kidney disease. Canadian Medical Association or its licensors, 2012;184(5):277-83.

24. Mooney A. How to Select among Dialysis Options. Cont Nephrol, 2012;178: 278-83.

25. Winterbottom A, Bekker HL, Conner M, Mooney A. Choosing dialysis modality: decision making in a chronic illness context. Health Expectations, 2012;17: 710-23.

26. Johansson L. Shared decision making and patient involvement in choosing home therapies. Journal of Renal Care, 2013;39(Suppl. 1):9-15.

27. Kurella TM, Periyakoil VS. The patient perspective and physician's role in making decisions on instituting dialysis. Nephrol Dial Transplant, 2013;28(11):2663-66.

28. Lam DY, O'Hare AM, Vig EK. Decisions About Dialysis Initiation in the Elderly. Journal of Pain and Symptom Management, 2013;46 (2):298-302.

29. Murray MA, Bissonnette J, Kryworuchko J, Gifford W, Calverley S. Whose Choice Is It? Shared Decision Making in Nephrology Care. Seminars in dialysis, 2013; 26(2): 169-74.

30. Porter E, Watson D, Bargman JM. Education for patients with progressive CKD and acute-start dialysis. Adv Chronic Kidney Dis, 2013;20(4):302-10.

31. Schell JO, O'Hare AM. Illness trajectories and their relevance to the care of adults with kidney disease. Curr Opin Nephrol Hypertens, 2013;22(3):316-24.

32. Harwood L, ClarkAM. Dialysis modality decision-making for older adults with chronic kidney disease. Journal of Clinical Nursing, 2014; 23: 3378-90.

33. Schell JO, Cohen RA. A Communication Framework for Dialysis Decision-Making for Frail Elderly Patients. Clin J Am Soc Nephrol, 2014;9(11):2014-21.

34. Erlang AS, Nielsen IH, Hansen HO, Finderup J. Patients experiences of involvement in choice of dialysis mode. Journal of Renal Care, 2015;41(4):260-7.

35. Jayanti A, Neuvonen M, Wearden A, MorrisJ,Foden P, Paul B et al. Healthcare decision-making in end stage renal disease-patient preferences and clinical correlates. BMC Nephrol, 2015;16:189.

36. Seah AS, Tan F, Srinivas S, Wu HY, Griva K. Opting out of dialysis – Exploring patients' decisions to forego dialysis in favour of conservative non-dialytic management for end-stage renal disease. Health Expect, 2015;18(5):1018-29.

37. Dahlerus C, Quinn M, Messersmith E, LachanceL, SubramanianL, Perry E et al. Patient Perspectives on the Choice of Dialysis Modality: Results From the Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT) Study. Am J Kidney Dis, 2016;68(6):901-10.

38. Moist LM, Al-Jaishi AA. Preparation of the Dialysis Access in Stages 4 and 5 CKD. Adv Chronic Kidney Dis., 2016; 23(4):270-275.

39. Pereira E, Chemin J, Menegatti CL, Riella MC. Escolha do método dialítico - variáveis clínicas e psicossociais relacionadas ao tratamento. J Bras Nefrol, 2016; 38(2):215-24.

40. Noble H, Brazil K, Burn A, Hallahan S, Normand C, Roderick P et al. Clinician views of patient decisional conflict when deciding between dialysis and conservative management: Qualitative findings from the PAIliative Care in chronic kidney disease (PACKS) study. Palliative Medicine, 2017; 31 (10): 921-31.

41. Piccoli GB, Sofronie AC, Coindre JP. The strange case of Mr. H. Starting dialysis at 90 years of age: clinical choices impact on ethical decisions. BMC Med Ethics, 2017; 18(1):61.

42. Shukla AM, Easom A, SinghM, Pandey R, RotaruD, WenX et al. Effects of a comprehensive predialysis education program on the home dialysis therapies: a retrospective cohort study. Perit Dial Int., 2017;37(5):542-7. 43. Bezerra CIL, SilvaBC, Elias RM. Decision-making process in the pre-dialysis CKD patients: do anxiety, stress and depression matter?. BMC Nephrol, 2018;19(1):98.

44. Campbell-Crofts S, Stewart G. How perceived feelings of "wellness" influence the decision-making of people with predialysis chronic kidney disease. J Clin Nurs, 2018; 27(7-8):1561-71.

45. ChenN-H, LIN Y-P, LIANG S-Y, TungH-H, TsayS-L, WangT-J. Conflict when making decisions about dialysis modality.J Clin Nurs, 2018; 27(1-2):138-46.

46. Friberg IO, Mårtensson L, Haraldsson B, Krantz G, Määttä S, Järbrink K. Patients' Perceptions and Factors Affecting Dialysis Modality Decisions. Perit Dial Int., 2018; 38(5):334-42.

47. Ladin K, Pandya R, KannamA, Loke R, Oskoui T, Perrone RD et al. Discussing Conservative Management with Older Patients With CK D: An Interview Study of Nephrologists. American Journal of Kidney Diseases, 2018;71(5): 627-35.

48. Malkina A, Tuot DS. Role of telehealth in renal replacement therapy education. Semin Dial, 2018; 31(2):129-34.

49. Scott J, Owen-Smith A, Tonkin-Crine S, RaynerH,RoderickP,Okamotolet al. Decision-making for people with dementia and advanced kidney disease: a secondary qualitative analysis of interviews from the Conservative Kidney Management Assessment of Practice Patterns Study.BMJ Open, 2018; 8:e022385.

50. Teso AD, Moutet AL, Lefuel P, Seigneux S, Golay A, Martin P-Y. Comment adapter une offre éducative aux spécificités des patients atteints dínsuffisance rénale chronique? Nephrologie & Therapeutique, 2019;15: 193-200.

51. Oliveira NC, Peçanha TBA, Fonseca CSG. Desafios enfrentados pelos enfermeiros para garantir sua autonomia no cenário de alta complexidade. Saúde Coletiva (Barueri), 2020; 9(50), 1842–1850.

52. Sousa CND, Araújo DAM, Sousa WGS, Lemos MHS, Rocha NRA, Negreiros ALB. Percepção de portadores de doença renal crônica sobre o tratamento hemodialítico. Saúde Coletiva (Barueri), 2021; 11(64), 5594–5603.