Ethical Aspects In Choosing Renal Replacement Therapy: An Integrative Review

Aspectos Éticos na Escolha da Terapia Renal Substitutiva: Uma Revisão Integrativa

Aspectos Éticos En La Elección de La Terapia de Reemplazo Renal: Una Revisión Integradora

RESUMO
O objeto do presente estudo trata as questões éticas concernentes às terapias de substituição renal. Idealmente, as decisões terapêuticas deveriam ser tomadas pelo usuário, com apoio da equipe multidisciplinar, tendo na enfermagem um ponto de integração nesse contexto. Ao se respeitar o princípio da autonomia, o usuário, esclarecido, teria capacidade de optar por qual o melhor tratamento para atender suas necessidades. Entretanto, o paternalismo presente nas decisões da equipe de saúde por julgar saber o que é melhor ao paciente, somado ao subfinanciamento das terapias renais substitutivas acarretam a má comunicação e não esclarecimento das opções terapêuticas ao paciente, que tem seus destinos determinados pelos profissionais de saúde. Trata-se de uma revisão integrativa. A busca nas bases de dados foi realizada na Biblioteca Virtual em Saúde (BVS) e Pubmed (via MEDLINE). O tratamento dialítico não está disponível para todos os pacientes que necessitam dela, configurando-se como um grave problema de saúde pública global, afetando tanto os pacientes renais crônicos quanto os com injúria renal aguda (IRA), principalmente nos países de terceiro mundo e os países em desenvolvimento. Devido à alta prevalência da DRC, altos custos e inequidade ao acesso às TRS, questões éticas sempre foram parte intrínseca da história da nefrologia e seu desenvolvimento. No ano de 2010, foram contabilizadas cerca de 2,3 a 7,1 milhões de óbitos de pessoas com doença renal terminal sem acesso a diálise. Uma tentativa de superar esses entraves é a decisão compartilhada, através de uma comunicação clara que esclareça e informe ao indivíduo e família as opções terapêuticas disponíveis, seus riscos, benefícios e disponibilidade, para que assim o cuidado seja centrado no paciente-família e estes sejam capazes de escolher e consentir pela TRS escolhida.
DESCRITORES: Autonomia; Ética; Bioética; Terapia de Substituição Renal.

ABSTRACT
The aim of this study is to address ethical issues related to renal replacement therapies. Ideally, therapeutic decisions should be made by the user, with the support of a multidisciplinary team, with nursing as a point of integration in this context. By respecting the principle of autonomy, the user, once informed, would be able to choose the best treatment to meet his/her needs. However, the paternalism present in the decisions of the health team, which believes that they know what is best for the patient, combined with the underfunding of renal replacement therapies, leads to poor communication and lack of clarification of therapeutic options to the patient, whose fate is determined by health professionals. This is an integrative review. The search in the databases was carried out in the Virtual Health Library (VHL) and Pubmed (via MEDLINE). Dialysis treatment is not available to all patients who need it, and is a serious global public health problem, affecting both chronic kidney disease patients and those with acute kidney injury (AKI), especially in third world and developing countries. Due to the high prevalence of CKD, high costs and inequitable access to RRT, ethical issues have always been an intrinsic part of the history of nephrology and its development. In 2010, approximately 2.3 to 7.1 million deaths of people with end-stage renal disease without access to dialysis were recorded. One attempt to overcome these obstacles is shared decision-making, through clear communication that clarifies and informs the individual and family of the available therapeutic options, their risks, benefits and availability, so that care is centered on the patient and family and they are able to choose and consent to the chosen RRT.
DESCRIPTORS: Autonomy; Ethics; Bioethics; Renal Replacement Therapy.

DOI: https://doi.org/10.36489/saudecoletiva.2025v15i92p14199-14205

RESUMEN

El objeto de este estudio aborda las cuestiones éticas relacionadas con las terapias de sustitución renal. Idealmente, las decisiones terapéuticas deberían ser tomadas por el usuario, con el apoyo del equipo multidisciplinario, teniendo en la enfermería un punto de integración en este contexto. Al respetar el principio de autonomía, el usuario, informado, tendría la capacidad de optar por el mejor tratamiento para satisfacer sus necesidades. Sin embargo, el paternalismo presente en las decisiones del equipo de salud, al considerar que sabe lo que es mejor para el paciente, junto con el financiamiento insuficiente de las terapias renales sustitutivas, da lugar a una mala comunicación y falta de claridad sobre las opciones terapéuticas para el paciente, que ve su destino determinado por los profesionales de salud. Este es un estudio de revisión integrativa. La búsqueda en las bases de datos se realizó en la Biblioteca Virtual en Salud (BVS) y Pubmed (a través de MEDLINE). El tratamiento dialítico no está disponible para todos los pacientes que lo necesitan, lo que constituye un grave problema de salud pública global, afectando tanto a pacientes con insuficiencia renal crónica como a aquellos con lesión renal aguda (IRA), especialmente en los países del tercer mundo y en los países en desarrollo. Debido a la alta prevalencia de la Enfermedad Renal Crónica (ERC), los altos costos y la inequidad en el acceso a las TRS, las cuestiones éticas siempre han sido una parte intrínseca de la historia de la nefrología y su desarrollo. En 2010, se contabilizaron entre 2,3 y 7,1 millones de muertes de personas con enfermedad renal terminal sin acceso a diálisis. Un intento de superar estos obstáculos es la toma de decisiones compartidas, a través de una comunicación clara que informe al individuo y a su familia sobre las opciones terapéuticas disponibles, sus riesgos, beneficios y disponibilidad, para que así la atención esté centrada en el paciente y su familia, y ellos sean capaces de elegir y consentir la TRS seleccionada.

DESCRIPTORES: Autonomía; Ética; Bioética; Terapia de Sustitución Renal.

RECEIVED: 12/26/2024 **APPROVED:** 01/05/2025

How to cite this artilce: Debelian ACM, Ferreira LSA, Macêdo MLG, Cristiane Maria Amorim Costa, Spezani BOD.Ethical Aspects In Choosing Renal Replacement Therapy: An Integrative Review. Saúde Coletiva (Edição Brasileira) [Internet]. 2025 [acesso ano mês dia];15(92):14199-14205. Disponível em: DOI: 10.36489/saudecoletiva.2025v15i92p14199-14205

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DOI: https://doi.org/10.36489/saudecoletiva.2025v15i92p14199-14205

INTRODUCTION

The aim of this study is to address ethical issues related to renal replacement therapy. Ideally, therapeutic decisions should be made by the user, with the support of a multidisciplinary team, with nursing as a point of integration in this context, ensuring all the necessary clarification for decision-making. By respecting the principle of autonomy, the user, once informed, would be able to choose the best treatment to meet his or her needs.

Autonomy is defined as the freedom of choice of the human being. It is related to the responsibility of the human being and the freedom to make choices based on one's own concepts of morality.[1]

Chronic kidney disease (CKD) is defined as decreased kidney function, with estimated glomerular filtration rate adjusted for body surface area (eGFR/1.73 m2) <60 ml/min, or kidney damage that persists for at least 3 months. When the patient reaches stage IV (pre-dialysis), renal replacement therapies (RRT) should be presented and chosen by the individual, together with the multidisciplinary team. Among the RRTs are hemodialysis, peritoneal dialysis and kidney transplantation.[2]

Brazil is one of the countries with the most dialysis patients in the world, and the country that performs the most transplants.[3] According to the 2022 Brazilian Dialysis Census, the estimated total number of patients was 153,831 dialysis patients, with 80.3% of treatments financed by the Unified Health System (SUS).[4]

According to Ferraz[5], "possibly no other medical specialty has suffered as much from the impacts of the moral dilemmas arising from progressive scientific technological advances as Nephrology". The impact of this advent, especially of kidney transplantation, was discussed by Jonsen[6], in what he called the "Divine Committee".

At the beginning of renal replacement therapy, the treatment was not capable of absorbing all patients. The divine committee was established to decide which patients would be absorbed and the eligibility criteria. Since its creation, the development of renal replacement therapies has provided patients with an extension and quality of life, however, it is clear that in the early days there was an impact due to moral dilemmas.

Due to the greater demand than supply of RRT for CKD patients, developing countries face a shortage of resources, using utilitarian policies as an instrument to manage this scenario.[5]

Utilitarian practices consist of actions for collective, not individual, benefits. These practices are synonymous with equality, after all, their actions are designed and planned with the aim of positively impacting the greatest number of people.[5]

However, the paternalism present in the decisions of the health team, who believe they know what is best for the patient, combined with the underfunding of renal replacement therapies, leads to poor communication and lack of clarification of therapeutic options to the patient, whose fate is determined by health professionals.[7,8]

Professionals must respect patients' autonomy when making decisions, understanding that technical knowledge and autonomy must go hand in hand to ensure ethical principles are met.

The National Policy for Patients with Kidney Disease (PNPDR - Política Nacional ao Portador de Doença Renal), in its second article, states that coverage for patients with kidney disease must be expanded, ensuring universality, comprehensiveness and equity, as well as social control and access to different types of RRT.[9]

Although patients have the right to choose RRT, the number of people with CKD increases every year due to demographic changes experienced in recent years with increased longevity and, consequently, an increase in chronic non-communicable diseases (NCDs). This change impacts the Brazilian health system, since the demand for RRT is greater than the supply, making it difficult to implement the principles of the PNPDR and the SUS, of universality, comprehensiveness and equity.[3]

Thus, the present study aims to discuss the ethical conflicts surrounding renal replacement therapies in the scientific literature.

The relevance of the research lies in the ethical precepts of the profession, where patients must be assured autonomy so that they can choose the best therapy for their reality.

The medical-centered training of health professionals, associated with the lack of ethical discussions during graduation and the paternalistic attitude of professionals, hinders and hinders the communication and clarification of RRT options to users, so that they can choose freely as guaranteed by law.

The study contributes to research as it increases scientific production focused on the topic, to teaching by raising debates about the ethical aspects in choosing RRT and to assistance by subsidizing the practices developed by health professionals.

METHOD

This is an integrative review, which according to Souza, Silva and Carvalho[10] is conducted in order to identify, analyze and synthesize the results of existing research on the same subject, contributing to the quality of care provided, based on evidence. To this end, the six steps described by the same authors will be adopted: 1- Elaboration of the guiding question; 2- Search or sampling in the literature; 3- Data collection; 4- Critical analysis of the included studies; 5- Discussion of the results; 6- Presentation of the integrative review.

To meet the study objective, the PICo strategy was adopted to formulate the guiding question, where P is patient, I is intervention and Co is context. Finally, the study question is: What are the ethical conflicts, indicated in the scientific literature, in the daily work in renal replacement therapy in adult patient units?

The search in the databases was carried out in the Virtual Health Library (BVS) and Pubmed (via MEDLINE) using the DeCS/MeSH descriptors and their alternative terms, translated here: Renal Replacement Therapy, Ethics, Nursing Ethics, Medical Ethics, Professional Ethics, Bioethics, Dialysis, Peritoneal Dialysis and Hemodialysis, combined with the Boolean operators AND and OR, presented in the table below.

DOI: https://doi.org/10.36489/saudecoletiva.2025v15i92p14199-14205

Quadro 1. Estratégia de Busca na Base de Dados

Database	Strategy
BVS	("Terapia de Substituição Renal") OR (diálise) OR ("Diálise Peritoneal") OR (hemodiálise) AND ((ética) OR ("Ética em Enfermagem") OR ("Ética Médica") OR ("Bioética") OR (ética profissional)) AND NOT (covid-19) AND (fulltext:("1" OR "1" OR "1") AND la:("en" OR "pt" OR "es")) AND (year_cluster: [2018 TO 2022])
Pubmed	(("Renal Replacement Therapy"[All Fields] OR ("dialysance"[All Fields] OR "dialysances"[All Fields] OR "dialysation"[All Fields] OR "dialysator"[All Fields] OR "dialysators"[All Fields] OR "dialyse"[All Fields] OR "dialysed"[All Fields] OR "dialyser"[All Fields] OR "dialysers"[All Fields] OR "dialysing"[All Fields] OR "dialysis solutions"[Pharmacological Action] OR "dialysis solutions"[MeSH Terms] OR ("dialysis"[All Fields] AND "solutions"[All Fields]) OR "dialysis solutions"[All Fields] OR "dialysate"[All Fields] OR "dialysates"[All Fields] OR "dialyzate"[All Fields] OR "dialyzates"[All Fields] OR "dialysis"[MeSH Terms] OR "dialysis"[All Fields] OR "dialyses"[All Fields] OR "dialyzability"[All Fields] OR "dialyzable"[All Fields] OR "dialyzation"[All Fields] OR "dialyze"[All Fields] OR "dialyzed"[All Fields] OR "dialyzer"[All Fields] OR "dialyzer s"[All Fields] OR "dialyzers"[All Fields] OR "dialyzing"[All Fields] OR "renal dialysis"[MeSH Terms] OR ("renal"[All Fields] AND "dialysis"[All Fields]) OR "renal dialysis"[All Fields]) OR "Peritoneal Dialysis"[All Fields] OR ("haemodialysis"[All Fields] OR "renal dialysis"[MeSH Terms] OR ("renal"[All Fields] AND "dialysis"[All Fields]) OR "renal dialysis"[All Fields] OR "hemodialysis"[All Fields])) AND ("ethic s"[All Fields] OR "ethicality"[All Fields] OR "ethically"[All Fields] OR "ethics"[MeSH Terms] OR "ethics"[All Fields] OR "ethic"[All Fields] OR "ethics"[MeSH Subheading] OR "morals"[MeSH Terms] OR "morals"[All Fields] OR "ethical"[All Fields] OR "Nursing Ethics"[All Fields] OR "Medical Ethics"[All Fields] OR "Professional Ethics"[All Fields] OR ("bioethical"[All Fields] OR "bioethics"[MeSH Terms] OR "bioethics"[All Fields] OR "bioethic"[All Fields])) AND ("loattrfull text"[Filter] AND 2018/01/01:2022/12/31[Date - Publication] AND ("english"[Language] OR "portuguese"[Language] OR "spanish"[Language]))) AND ((fft[Filter]) AND (2018:2022[pdat]) AND (english[Filter] OR portuguese[Filter] OR spanish[Filter]))

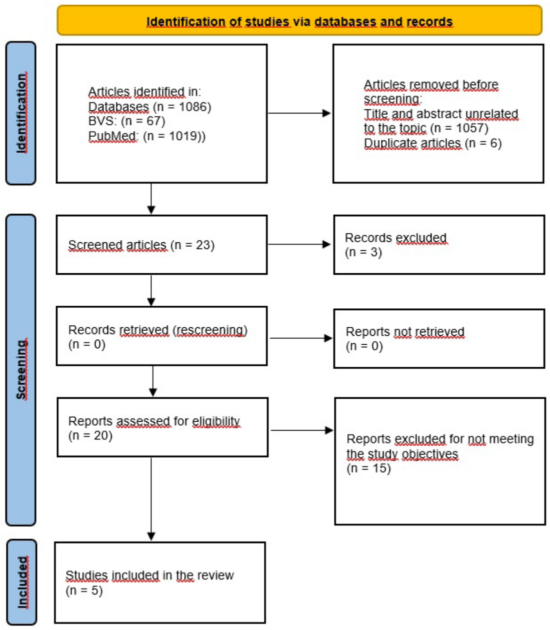
The time frame used was 2018 to 2022, and full articles in English, Portuguese and Spanish were included, excluding duplicates.

The Main Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart was used to present the selected articles, respecting the inclusion and exclusion criteria mentioned.

The search in the databases returned 1086 articles, of which 29 articles were selected by title and abstract and 6 were excluded due to duplication, totaling 23 articles in an initial selection. Due to eligibility, after reading them in full, 18 articles were excluded because they did not meet the objectives of this study, and 5 articles were included in the study.

The details of the selection of articles are presented in Figure 1

Figure 1. PRISMA 2020 Flowchart for Database Searches



Source: PAGE, Matthew J et al.[11]

After completing the search for articles, they were analyzed using the data collection instrument validated by Ursi and Galvão 12 adapted, containing: title, authors, year, objective, results and implications, which includes conclusions and recommendations. Data analysis was conducted by adapting the synoptic table prepared by the same authors, including the name of the research, authors, results and recommendations/conclusions. The data were discussed and presented descriptively.

RESULTS AND DISCUSSION

The five articles were analyzed based on the table described below.

DOI: https://doi.org/10.36489/saudecoletiva.2025v15i92p14199-14205

Table 2 . Main findings on ethical issues in Renal Replacement Therapy

Research title	Authors	Results	Recommendations /Conclusions
Chronic Kidney Disease: The Complex History of the Organization of Long-Term Care and Bioethics. Why Now, More Than Ever, Action is Needed	Versino; Piccoli[13]	The global burden of kidney disease is growing, driven by complex interactions, and treatment is fraught with environmental and socioeconomic disparities. We need universal health coverage to ensure effective screening, prevention and early treatment of CKD. It requires the involvement of all relevant stakeholders and the finding of alternative financing strategies to promote equal access to care.	There is a need for action, and action starts with awareness. This is why we feel that this special issue will be welcome as a means of strengthening the links between clinical nephrologists, economists and policy makers.
The current and future landscape of dialysis	Himmelfarb et al.[14]	There is an urgent need to develop new dialysis approaches and modalities that are cost-effective, accessible, and deliver better patient outcomes. Nephrology researchers are increasingly engaging with patients to determine their priorities. The overarching message of this engagement is that while patients value longevity, reducing symptom burden and achieving maximum functional and social rehabilitation are prioritized. In response, patients, payers, regulators, and health systems are increasingly demanding improved value, which can only occur through true patient-centered innovation that supports high-quality, high-value care.	Substantial efforts are underway to support the necessary transformative changes. These efforts need to be catalyzed, promoted and fostered through international collaboration and harmonization.
Consenting for Dialysis or Its Alternative: Systematic Process Is Needed	Li; Brown[15]	Consent is not just a legal requirement. It is a willingness by nephrologists to adhere to ethical standards and show respect for patients and their families. It is also a process that can reduce the burden of moral distress as expectations of dialysis outcomes become realistic from the outset. Providing informed consent to start dialysis means that our patients are making an informed choice.	It is imperative that the nephrology community improves informed consent in accordance with legal and ethical standards, and we propose two ways to achieve this. First, information should be both written and verbal, provided by a multidisciplinary team, and should include all aspects prescribed by law, including how the treatment affects a person's life and the alternatives available. Second, a dialysis consent form should be signed to capture this shared decision-making process.
Introduction: Ethical Issues in Nephrology	Luyckx[16]	It points out that socioeconomic and structural factors are associated with the risk of CKD, and it is these same factors that hinder access to RRT. Given that not all therapies are available, the issue of patient autonomy in choosing treatment can be discussed. Individuals with CKD must be informed and informed about the therapeutic modalities, their risks and benefits. In addition, the lack of resources and financing hinders the availability of RRT, which imposes moral suffering on the professional when offering these therapies to the patient.	It is necessary to discuss and debate in order to find acceptable solutions to ethical issues and dilemmas in the area of nephrology.

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		In addition to issues of affordability of dialysis services, the initiation of treatment can have disastrous consequences for the entire family unit, which is magnified in collectivist societies. Various cost-cutting measures may also have to be used, which raises moral dilemmas for health care professionals.	While the physician's duty is primarily to the well-being of the patient, the socioeconomic realities that govern the well-being of entire family units cannot be entirely removed from the decision-making equation.

Source: Authors, 2022.

Dialysis treatment is not available to all patients who need it due to scarcity of resources, constituting a serious global public health problem, affecting both chronic kidney disease patients and those with acute kidney injury (AKI), mainly in third world countries and developing countries. Due to the high prevalence of CKD, high costs and inequitable access to RRT, ethical issues have always been an intrinsic part of the history of nephrology and its development. In 2010, approximately 2.3 to 7.1 million deaths of people with end-stage renal disease without access to dialysis were recorded. [13]

Difficulties in accessing and choosing RRT independently are also associated with factors such as socioeconomic conditions, gender, and race or ethnicity, as well as the level of socioeconomic development of the region in which the individual lives.

Even when dialysis is reimbursed, a lack of individual financial resources can limit access to care. Furthermore, without necessarily being perceived as such, the provision of dialysis can be influenced by the financial interests of dialysis providers or nephrologists, for example, influencing whether a patient receives dialysis in-center or at home, or resulting in dialysis patients not being referred for transplant or conservative treatment. The most widely used RRT in the world is HD, which can be justified by the patient's lack of knowledge about the existence of other therapeutic modalities, since they were not given a choice. [12,16]

The best way to overcome these barriers is shared decision-making, which allows the patient to choose therapies based on evidence-based knowledge promoted by the multidisciplinary healthcare team. [14] In this context, consent at the start of dialysis is a way to reinforce respect for patient autonomy, shared decision-making and patient-centred care. Informed consent encompasses both the physician's duty to inform patients about the nature, risks and benefits of possible treatments and, subsequently, the right of competent persons to make decisions about their health care. [15]

Autonomous action or choice has three fundamental elements which are intentionality, understanding and the absence of controlling influence.[17]

The elements of understanding and the absence of controlling influence may undergo some variations and yet the action may still be considered autonomous according to the theory by principles:

> The first of the three conditions of autonomy—intentionality—is not a matter of degree: acts are either intentional or unintentional. However, acts may satisfy the conditions of understanding and absence of controlling influence to greater or lesser degrees. For example, understanding may be more or less complete; threats may be more or less severe; and mental illness may be more or less controlling. [...] Acts, therefore, may be autonomous by degrees, depending on whether they satisfy these two conditions of understanding and voluntariness to varying degrees. A continuum of understanding and lack of control runs from complete understanding and being entirely in control to complete absence of relevant understanding and being entirely in control. Cutoff points on these continuums are necessary for the classification of an action as autonomous or nonautonomous. The lines between adequate and inadequate degrees of understanding and degrees of control must be determined in light of specific decision-making goals in a particular context, such as deciding whether to have surgery, choosing a college to attend, and hiring a new employee. [17]

The importance of clarification and consent is not only necessary for choosing a RRT method, but also for not choosing one. Most patients with end-stage renal disease are elderly, frail and have multiple comorbidities. Sometimes, undergoing dialysis treatment can bring more risks than benefits and this should be communicated to the individual and family, so that together with the multidisciplinary team they can decide whether or not to pursue a therapy. [15]

CONCLUSION

Access to and choice of renal replacement therapy is affected by a series of macro socioeconomic and micro socioeconomic factors, in addition to being costly to the health system, which culminates in utilitarian policies by governments to provide and access renal replacement therapy treatments, to the detriment of equal access.

The lack of universality in the provision of dialysis services can cause moral distress, because they do not allow for an autonomous decision by the user in choosing the therapy, which would be the morally acceptable conduct.

One attempt to overcome these obstacles is shared decision-making, through clear communication that clarifies and informs the individual and family of the available therapeutic options, their risks, benefits and availability, so that care is centered on the patient and family and they are able to choose and consent to the chosen RRT. Finally, it is essential that nurses are aligned with this knowledge so that they can associate practical knowledge with respect for patient autonomy.

DOI: https://doi.org/10.36489/saudecoletiva.2025v15i92p14199-14205

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