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Ethical conflicts and decision making on renal replacement therapy

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Abstract

This article aimed to explore whether healthcare professionals perceive ethical conflicts and issues related to decision making and to highlight the significance of patient involvement in this process. This is a descriptive cross-sectional study, where 63 professionals from four nephrology services in Rio de Janeiro were interviewed. Through analysis using Bardin's technique, two main themes emerged: 1) the decision-making process; and 2) bioethical considerations regarding renal replacement therapy referral. The findings suggest that decision-making is primarily guided by the principles of beneficence and non-maleficence, with an emphasis on improving the clinical condition associated with renal failure. However, there is often a lack of consideration for patient autonomy and participation, and ethical conflicts and decision-making issues may not always be recognized. Paternalistic attitudes remain prevalent and strong within the studied population.

Keywords: Bioethics. Renal insufficiency, chronic. Physician-patient relations.

Resumo

Conflitos éticos e tomada de decisão sobre terapia renal substitutiva

Este artigo teve por objetivo investigar se profissionais de saúde percebem o conflito ético e os problemas relacionados a tomada de decisão, e identificar a importância da participação do usuário nesse processo. Trata-se de estudo transversal descritivo no qual foram entrevistados 63 profissionais atuantes em quatro serviços de nefrologia do Rio de Janeiro. Após análise das entrevistas segundo a técnica de Bardin, emergiram dois eixos: 1) processo de tomada de decisão e 2) bioética no encaminhamento a terapia renal substitutiva. Conclui-se que o processo de tomada de decisão é pautado, em sua maioria, pela beneficência e não maleficência, tentando favorecer a condição clínica relacionada a não funcionamento renal. Porém, muitas vezes, as ações não consideram a autonomia e a participação do usuário, e nem sempre o conflito ético e os problemas relacionados à tomada de decisão são percebidos. O paternalismo ainda é presente e forte na população estudada.

Palavras-chave: Bioética. Insuficiência renal crônica. Relações médico-paciente.

Resumen

Conflictos éticos y toma de decisiones con relación a la terapia de reemplazo renal

El objetivo de este artículo fue investigar si los profesionales de la salud perciben el conflicto ético y los problemas relacionados con la toma de decisiones, e identificar la importancia de la participación del usuario en este proceso. Se trata de un estudio transversal descriptivo en el que se entrevistó a 63 profesionales que trabajan en cuatro servicios de nefrología en Río de Janeiro. Los análisis de las entrevistas según la técnica de Bardin arrojaron dos ejes: 1) proceso de toma de decisiones y 2) bioética en la derivación a terapia de reemplazo renal. Se concluye que el proceso de toma de decisiones se basa, mayoritariamente, en la beneficencia y no maleficencia, tratando de favorecer la condición clínica relacionada con la insuficiencia renal. Sin embargo, a menudo, las acciones no tienen en cuenta la autonomía ni la participación del usuario, y no siempre se perciben el conflicto ético y los problemas relacionados con la toma de decisiones. El paternalismo sigue siendo presente y fuerte en la población analizada.

Palabras clave: Bioética. Insuficiencia renal crónica. Relaciones médico-paciente.

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The choice of renal replacement therapy (RRT) for a patient with advanced chronic kidney disease (CKD) hinges on various factors, including the resources available within the healthcare system. A critical consideration revolves around determining whether the patient will receive periodic clinic visits or have access to self-sufficient home-based treatment. This decision is influenced by factors such as treatment availability and location, household dynamics, familial support, and technical considerations like water quality and access to electricity [1].

Nephrologists face a multifaceted decision-making process in this regard, which may entail navigating ethical conflicts and evaluating clinical, legal, and ethical dimensions unique to each case. Importantly, patients, in collaboration with their healthcare team, may recognize that foregoing any form of RRT is the optimal choice. Even in cases where dialysis is not feasible due to patient preferences or health conditions, dignified care ensuring a high quality of life can be provided through conservative treatment options [2].

Several factors could complicate the decision-making process, including the expectation that the doctor will direct the choice of treatment, which the patient may perceive as the best option for their case. Moreover, there is a financial incentive to pursue RRT, as funding from the Unified Health System (SUS) for clinics relies on procedures performed on each patient, with many services owned by doctors overseeing patient care and guidance on available modalities. Additionally, inadequate training among professionals to handle the possibility of forgoing treatment and accepting end-of-life care reinforces paternalistic tendencies among healthcare providers, contrary to patient autonomy and decision-making [2].

Ordinance 1,675/2018 [3] of the Ministry of Health mandates that the patient be the focal point of the decision-making process regarding the type of RRT to undergo. Participating in this process entails making informed choices based on clinical health conditions and available treatments within the SUS, aligned with the patient's preferences. It is recognized that education and support from professionals, provided before decision-making, can facilitate the choice of modalities that align with the patient's lifestyle, including those conducive to home-based care or offering a better quality of life [1,3-5].

From this standpoint, the study aims to underscore the significance of patient involvement in the decision-making process concerning the initiation of RRT as perceived by professionals It also endeavors to examine whether professionals tasked with deciding on the implementation of RRT recognize the ethical conflicts and issues associated with decision-making.

Method

This cross-sectional, descriptive study with a qualitative approach involved interviewing professionals working in conservative CKD treatment outpatient clinics across four nephrology specialist training services in Rio de Janeiro. Following recommendations, all 65 team members, comprising doctors, nutritionists, nurses, psychologists, and social workers, were invited to participate, with invitations sent via email or telephone provided by heads of service. The research objectives and participation details were explained, and interviews were scheduled based on professionals' preferences and availability upon acceptance.

Two professionals on vacation during data collection were excluded, resulting in 63 interviews conducted in total; of those, 61 were conducted in person at restricted locations within the respective services to ensure confidentiality, while two were conducted via the Google Meet platform. Prior to any statement, participants were required to read, agree, and sign a free and informed consent form.

The interviews, conducted between March and September 2022, adhered to a structured script focused on various aspects of the decision-making process for establishing RRT. Topics included whether the decision-making process was individual or team-based, the professionals involved, how treatment modalities were communicated to patients, and whether professionals believed this to be within their professional competence. Additionally, professionals were asked about their views on whether patients could choose the best modality for themselves and the rationale behind such choices.

Each interview, averaging five minutes, was audio-recorded and later transcribed in full, coded with the letter "I" followed by an occurrence number, and subjected to content analysis through Bardin's method[6] without software assistance. The statements were then aggregated, synthesized, and categorized based on similarity and repetition, ultimately resulting in emergent topics. Data saturation was not pursued as the intention was to interview all professionals within the teams of the four services.

Ethical principles were strictly adhered to throughout the research process[7]. This work is an excerpt from the doctoral thesis *Implicações bioéticas na escolha da terapia renal substitutiva: o olhar do profissional de saúde*[8].

Results

In data analysis, a total of 191 meaning units (MU) and 2,429 registration units (RU) were identified. RUs were then clustered based on similarity, and the primary findings were summarized in Table 1 under two theme axes: 1) decision-making process and 2) bioethics concerning RRT.

Table 1. Categories emerged from Bardin's content analysis

DECISION-MAKING PROCESS	The responsible for making the decision to start RRT 26 RU (1.07%)	Reported assessments reflect a scenario where decision-making in clinical settings is predominantly driven by medical professionals, either individually or in consultation with the medical team, particularly in the case of residents: "*But in the office, the decision is usually mine* [physician]" (I4). That indicates a lack of emphasis on team participation or discussion. Notably, only three professionals acknowledged the importance of patient involvement: "*Though I've never decided for any patient*" (I25). "*But, ultimately, the decision is always theirs* [patient]" (I28). "*It's always a joint decision... it's never just ours*" (I56). These statements underscore a prevalent paternalistic approach within healthcare services.
	Driving force behind decision-making 73 RU (3%)	Reports indicate that the decision-making process is primarily guided by clinical and laboratory parameters: "*Yes, actually, from a medical standpoint, our assessments are pretty objective. There's nothing subjective about it; we've already established criteria for that*" (I27). "*But it's not just about hitting a certain number that automatically subjects a patient to dialysis. It's more about the overall clinical context they're in*" (I4). "*That magic clearance number below 10 for all patients and below 15 for children and diabetics isn't always used*" (I21). Social, economic, and treatment feasibility concerns, cognition and familial support, the stage of CKD, glomerular filtration rate (GFR) and its deterioration, age, the timing of onset, and how it is "coped with," patient confidence, experiencing symptoms, and urgency were identified as factors requiring evaluation. Regarding peritoneal dialysis (PD) suitability, individuals with vascular access difficulties or significant cardiac conditions were noted.
	Reasons/indications/ symptoms for starting RRT 48 RU (1.97%)	The following criteria were outlined to guide decision-making: deterioration in clearance/drop in GFR (<10 or stage 5), loss of appetite and difficulty eating, nausea and vomiting, weight loss and muscle wasting, hypervolemia and edema, fatigue and tiredness, malnutrition, worsening sleep quality, itching, hypoalbuminemia, hyperkalemia, proteinuria, elevated parathyroid hormone levels or bone mineral disorders, uremic symptoms, hypertension, congestion, reduced urine output, signs of acidosis, anemia, and sarcopenia. These criteria can be categorized as either urgent or elective. It is important to note that patients exhibit varying tolerance to these changes, calling for individual assessment: "*But he shouldn't be entirely asymptomatic, nor should he be severely symptomatic... After considering the laboratory test results, you will determine that it's time for the patient to initiate therapy*" (I10).

continues...

Table 1. Continuation

DECISION-MAKING PROCESS	Shared decision-making 67 RU (2.75%)	When queried about the decision-making process, the majority of professionals clearly prioritize respecting the patient's autonomy and emphasize the importance of their involvement: 19 indicated that it involved the medical professional and the patient directly, while 4 mentioned it was shared between professionals, patients, and family. A nutritionist and two psychologists noted their involvement in the decision-making process with the patient. Unfortunately, instances of disregard for patient autonomy were reported: six professionals stated that decisions were made solely between doctors (particularly between the resident and the preceptorship/staff); six decisions made in team discussions or meetings without considering patient participation; four mentioned decisions were made between the doctor and a family member, without mentioning the patient; and one professional reported making the decision on their own. "*Typically, we are the ones to decide to initiate therapy, I usually do it in consultation with the* staff, *and then we inform the patient*" (I43). There was a lack of acknowledgment of the full team's involvement in this process, as noted by two professionals who were expected to participate: the doctor, nurse, psychologist, and patient. "*And the doctor invites the multidisciplinary professional to contribute at a stage where the decision has already been made and the plan is already established, do you see?*" (I15).
	Can the patient choose the best RRT modality? 98 RU (4.03%)	49 professionals responded affirmatively, indicating that patients not only can but should have the right to participate in decision-making processes. Two professionals noted that it depends particularly on the patient's sociocultural background, level of understanding, and guidance, as long as there are no formal medical or nursing contraindications to any therapy. Seven indicated that patient participation should be possible, but it is not a common practice in care settings: "*It's not that they can't! It's just not recommended most of the time* [laughs]" (I31). "*At times, patients might have a say. But often, they already have a clinical picture, you know?*" (I35). Three professionals did not explicitly state whether patients are allowed to participate: "*I believe they lack the understanding, you know, of these modalities*" (I40). It's important to highlight that guiding and fostering patient autonomy is the professional's responsibility. Two professionals indicated that it is not the patient's right to make the choice: "*No. Most of them do hemodialysis; they don't opt for it*" (I45).
	Professionals' approach to patient choice. 25 RU (1.02%)	Outlines what treatment options are feasible (either due to clinical contraindications or space availability), while also respecting the patient's choice regarding which therapy they would rather undergo, within the constraints, and avoids steering the patient towards any specific therapy. The patient can choose their preferred modality but cannot opt out of treatment altogether. In terms of respecting autonomy and its deprivation: "*And we acknowledge their condition, as long as it aligns with medical rationale, you know?* [...] *So, as long as the patient is alert and coherent, we do not force hemodialysis onto anyone who refuses it*" (I55). "*If the situation arises, say, during my shift* [laughs], *and I'm tasked with initiating dialysis for a patient, they'll receive dialysis*" (I4).

continues...

Table 1. Continuation

DECISION-MAKING PROCESS	Professional recommends RRT – for patients they deem eligible 20 RU (0.82%)	Professionals indicate that they often recommend modalities they believe to be the best, appropriate, or indicated for the patient: “*We share our perspectives, you know?* [...] *of course, we discuss what would optimize the patient’s well-being, including their quality of life*” (I26). “*We consistently advise them towards what we perceive to be the optimal course of action*” (I28). “*I try to suggest the most suitable technique, the most effective approach for the patient*” (I47). “*I also offer my insight, suggesting what I believe to be the most suitable method, and then convey that to them*” (I59). “*If a patient is eligible for PD, I typically recommend PD initially*” (I13). “*This way, there are two options, but I would still have to say, ‘Look, you have these options, but this one is more suitable, understand?’* [...] *Essentially, we steer the patient towards hemodialysis*” (I24). “[If there are] *challenges with peritoneal dialysis therapy, we don’t involve the patient in the decision-making; instead, we recommend hemodialysis*” (I37). However, there is also recognition of a concern with this approach, a classic paternalistic tendency prevalent in professional practice: “*We often hold onto the belief that we’ve made the right decision, see?” Like... I did the best I could, right?*” (I49).
	Family participation in decision-making 41 RU (1.68%)	The importance of family participation was mentioned: “*Yes, when we reach this stage... often, we even have a family member present, you know? Whether it’s a son, daughter, father, mother, or sibling, in essence, someone close*” (I63). “*And they always want their family there. We consistently ask to involve a family member whenever patients have a low* clearance. “*Yeah... the guy is completely dependent; 40 years old, still... He already comes with his family, because it’s helpful to explain to the family together that we think it’s beneficial for the family to participate somewhat in this* [process]*...*” (I60). “*So, I called the wife... I called the children in. They refused it, like... ‘No, no, we’re not doing it!’* [...]*, remember what I said, there will come a time when things go downhill; a moment* [when] *he has an emergency, and they will still tell you what you are going to do, you have to think about that, see?*” (I25).
	Team support in the decision-making process 23 RU (0.94%)	The team’s involvement included eight professionals (if needed, psychologists assist, nurses participate), and when required, professionals communicate with each other to provide assistance or converse with the patient. However, one interviewee stated that they do not engage in any processes, and another mentioned a split among professionals, emphasizing that this support might not be adequate, as indicated in the following statement: “*And, when it’s already decided, when it’s settled and encounters some resistance from the family, there’s some difficulty with the family’s understanding, their acceptance, you know? It’s at this point that the multidisciplinary professional is invited to step in*” (I15).

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Table 1. Continuation

BIOETHICS IN REFERRAL TO RRT	Experience of bioethical dilemmas in professional practice 108 RU (4.44%)	There is difficulty in identifying the experience of bioethical issues among professionals. "*But I never had an actual problem that ended up, I don't know, at the ombudsman's office or something like that. Not ever*" (I3). 21 professionals report having never experienced a bioethical issue; 5 admitted to having the experience, but don't remember how it went. Among those who reported having had issues, the most frequent was the patient's refusal to undergo dialysis, cited by 19 professionals. Some of the issues mentioned include: a patient arriving in emergency dialysis when consent is not obtainable; maintaining dialysis when it results in more suffering than quality of life; issues with the transplant process; non-adherence to treatment; refusal of transfusion by Jehovah's Witnesses; conflicts with professional colleagues; blaming the doctor for patient complications; medication causing side effects with refusal [by the doctor] to change it; health professionals discouraging patients regarding RRT; conducting research; industry interests; requests for a biopsy to justify abortion; concealing of patient diagnosis; decisions regarding nutrition at the end of life; withholding treatment from a patient; and two professionals mentioned there too many problems, to the point they cannot be listed.
	How do professionals incorporate bioethics into their actions and decision-making? 43 RU (1.77%)	The importance of respect for autonomy was reinforced: "*Because firstly, when you present it to the patient, explaining the modalities, and allowing them to somewhat have this knowledge, you know?, you are treating them bioethically*" (I1). However, there is concern about initiating RRT urgently because, according to professionals, it is challenging to promote and respect the patient's autonomy at this time: "*I say: look, when he gets sick, he's going to be taken to the hospital unconscious, and there, no one will ask if he's willing to start dialysis or not*" (I4). This statement symbolizes a breach of autonomy by failing to consider and respect the patient's wishes, instead prioritizing beneficence—proceeding with the procedure to save the patient's life: "*And one actually had an emergency; he arrived at the hospital unconscious and needed immediate admission but couldn't... because I thought that by refusing to put him on dialysis in an emergency, I would be denying assistance, incurring negligence, that sort of thing*" (I13). Another significant aspect reported is the constraints imposed by the healthcare system, which give rise to ethical challenges that professionals must address: "*We also need to learn how to adeptly navigate the system's limitations and strive to deliver optimal care for each patient case by case, wouldn't you agree?*" (I32).
	Difficulty accessing PD 40 RU (1.64%)	Professionals consistently report the persistent lack of vacancies for PD, underscoring the imperative to assess distributive justice: Referral to this therapy and the implantation of a Tenckhoff catheter pose significant challenges. The prolonged waiting time for the access to reach maturity emerges as a decisive factor in decision-making. This issue persists across Rio de Janeiro. Notably, not all facilities where interviews were conducted offer a PD program, and, among those that do, inserting new patients is challenging due to full capacity. A significant concern highlighted is the lack of awareness among many patients regarding the existence of this RRT. Professionals refrain from discussing it, fearing that expressing interest might result in referrals unavailability: "*Right now, peritoneal dialysis isn't even an option for them*" (I18). "*To be honest, we almost disregard PD. It's not at the forefront of our minds because there are limited facilities that provide it... Our institution doesn't offer PD, and within the public health system, we encounter significant challenges... Moreover, the environment* [in] *which we operate doesn't facilitate access to PD either*" (I24).

continues...

Table 1. Continuation

BIOETHICS IN REFERRAL TO RRT	The patient's right to refuse 29 RU (1.19%)	Professionals emphasized that patients may opt against RRT or decline any form of treatment, as RRT is a specific intervention. It is within the patient's rights to choose conservative treatment. In transplantation, the donor can refuse, and so can the recipient. It is a mutual prerogative! Healthcare providers cannot compel patients to undergo RRT. *"There have been instances where patients were been recommended for treatment, we made the referral, but the patient declined it entirely and left"* (I44). *"It does have an impact because there are patients who decline to initiate renal therapy, despite us explaining its benefits and that their kidneys are no longer functional… The patient won't show up at the outpatient clinic, refuses to commence treatment, and subsequently disappears. Consequently, we're left unaware of their fate"* (I45). *"There are patients who decline hemodialysis even when referred… And what can we do besides accepting the patient's choice, right? We can't force anyone"* (I57).
	The difference between youth and senior advising 27 RU (1.11%)	There is a moral consideration evident in the statements, highlighting the variance in treatment approaches, particularly regarding age: *"So, I don't typically recommend transplantation for very elderly patients. For younger patients, I emphasize transplantation alongside hemodialysis and peritoneal dialysis, aiming at their recovery and societal reintegration. With elderly patients, I recommend peritoneal dialysis, hemodialysis, and have even suggested palliative care"* (I9). Naturally, clinical indications must also be taken into account. There is a need to rethink statements such as the ones below: *"And then, depending on the patient's age, I'll discuss… for older patients with multiple comorbidities, I typically present four options, right?… However, for certain age groups, I may not broach the topic of transplantation at all, focusing instead on the main three options. I usually prefer to engage in discussions regarding transplantation with patients up to 60 years old, or perhaps up to 70 if they don't have significant comorbidities… So, I typically discuss both hemodialysis and peritoneal dialysis with them"* (I26). It is important to emphasize that a contraindication for a particular treatment modality does not prevent the professional from informing the patient about its existence. Additionally, it is crucial to underscore that acceptance of treatment options is not solely determined by age; rather, it is influenced by various factors. *"We often exercise more caution with older patients, while with younger patients, we're inclined to initiate treatment earlier… Elderly patients with well-established family support, and who may have hypertension or diabetes, tend to be more easily resignated. Younger patients can be more challenging, I think it doesn't need an explanation"* (I60).

PD: peritoneal dialysis; CKD: chronic kidney disease; HD: hemodialysis; GFR: glomerular filtration rate; RRT: renal replacement therapy; UR: registration unit

Based on Bardin's content analysis, categories also emerged that identified bioethical principles according to the principlist theory of Beauchamp and Childress[9] in a very clear and evident manner. These categories reinforce the notion that work is carried out based on the provision of care aimed at benefiting health and avoiding unnecessary harm, as well as providing fair and equal care.

Additionally, there is a strong emphasis on autonomy, highlighting the importance of patient involvement in the decision-making process regarding the establishment of RRT. Conversely, there was also evidence of disregard for the patient's autonomy, particularly concerning family involvement in decision-making, indicating the need to further underscore the role of this principle, as it may not be readily apparent to all, as anticipated[9] (Table 2).

Table 2. Clear identification of the principles according to the principlist theory emerging from Bardin's content analysis

Beneficence – The healthcare professional emphasizes their role in offering guidance to help patients comprehend both the disease and its treatment. 10 RU (0.41%)	The professional demonstrates their commitment to offering guidance and furnishing the requisite information to ensure the patient comprehends their role effectively: “*We clarify this matter... at least I do, right? [...] And we also explain—at least I try—the process related to the waiting list for deceased donors [...] we, or at least I, make an effort to communicate and engage with the peritoneal dialysis (DP) staff*” (I14). “*So, I believe that having these mechanisms, you know, where everything is laid out on the table, based on what the patient brings forth, while also being open to input from others in a way that, if I don't listen, I'll simply state what it is. I think this is what it is about, making an offer*” (I16). “*I think this matters, that ethics comes into play here... It's about your dedication to the patient*” (I17). “*So... we have to make an effort to convey the information*” (I28). “*And then, that really helps, they express their emotions through this service, they mention that... wow... the level of experience they got*” (I34).
Non-maleficence – Waiting until the patient's case worsens before starting RRT 5 RU (0.20%)	Despite emerging only briefly in a few statements, the professionals' apprehension about preventing the deterioration of the patient's condition is palpable. There's a consensus on the necessity of initiating RRT early to mitigate potential complications: “*You're not going to abandon the patient; he's too uremic to be included in a dialysis program*” (I10). “*And here, the outpatients are even better clinically, because obviously, it's much preferable to initiate dialysis when the patient is healthy and strong, right?*” (I17). “*So that the transition process to renal replacement therapy can be as non-urgent as possible, it's also less traumatic for the patient, don't you agree?*” (I37).
Justice – How to treat patients 3 RU (0.12%)	It is evident that attention is tailored to individual needs and specificities, with a consistent effort to distribute care equitably: “*All patients are equal, see?” So, each patient must be treated equally [...] whether they have insurance, they are covered by SUS, or they are privately insured, they are all patients and should be treated the same, right?* (I17).
Justice – Resource distribution 2 RU (0.08%)	It is an endeavor to ensure equal access to resources, as evidenced by the principle of distributive justice: “*So, I always have to advocate for the institution to find means to provide patient care, because I can't do it alone. I don't think it's fair, it's not what the patient deserves, you know? I can't take it, and neither can the patient*” (I24). “*Ensuring justice, particularly in terms of resource allocation, is crucial*” (I63).
Autonomy – Respect for patient autonomy 15 RU (0.61%)	Autonomy was represented by respect for the patient's right to refuse to undergo RRT: “*I've had patients who expressed their decision not to undergo dialysis, and they followed through with that decision until their passing [...]. We truly lack the authority to intervene, to make decisions for the patient*” (I4). “*It was their decision, a rational one; they weren't uremic when they made it, and they've always been clear about it: that they didn't consent to any dialysis*” (I25). “*We cannot adopt a paternalistic approach, right? We must respect the person [...] patient's autonomy, right?” Their ability to shape their own life*” (I28). “*And there are many who disagree and refuse to initiate treatment, and ultimately, you can't push them, right? You can provide clarification and present the best options, but there's no way to force them*” (I45). “*For instance, when a patient who is cognizant declines renal replacement therapy, that's always challenging for us, you know? It's a patient whose autonomy we must respect, right?*” (I50). “*We make every effort to convey the risks, right? Ultimately, we respect the patient's opinions and desires*” (I56). “*We offer guidance, and provide comprehensive information about the potential consequences if the patient declines hemodialysis, but there are no means to compel a lucid and rational patient*” (I57). “*We recommended it again, but she... insisted on not undergoing dialysis... She didn't want to. We respected her decision by acknowledging 'it's alright. It's your call.' It was clear*” (I63).

continues...

Table 2. Continuation

Disrespect for patient autonomy 2 RU (0.08%)	It is evident that at times, information is withheld from the patient at the request of their family members: *"And often in the ward, too, the diagnosis is hidden, because the family doesn't want them to know... The patient doesn't know what is happening to them. It's cruel. It's underestimating the other's strength, you know?"* (I29). *"They didn't acknowledge the patient's autonomy. The family wanted one thing, but the patient... the patient had a different opinion at the time, see?"* (I63).

SUS: Unified Health System; RRT: renal replacement therapy; UR: registration unit

In the interviews, it was also noted that professionals encounter challenges in identifying ethical conflicts and consistently strive to minimize harm and promote patient welfare. However, there is a strong sense of moral obligation toward meeting patients' needs, to the extent that one participant expresses confidence in the "righteousness" of their actions. A shared morality is apparent, and professionals feel exempt from ethical repercussions, even in situations where outcomes deviate from expectations:

> *"Because the proper technique won't inflict harm. Are there complications? Certainly! But they fall within the bounds of the technique, and I won't always achieve 100% success in a procedure" (I24).*

Discussion

The presentation of news regarding the necessity for therapy must be carefully orchestrated by professionals to enhance comprehension and alleviate challenges in accepting treatment. Communicating news regarding incurable illnesses demands sensitivity and necessitates training for the involved professionals to exhibit greater confidence, fostering shared decision-making [10].

Consequently, this process should entail determining the patient's perception of quality of life, with health professionals refraining from dictating values, attitudes, and information regarding the patient's health condition—crucial criteria for decision-making. Through this approach, it becomes feasible to acknowledge the necessity, heed the individual's desires, and safeguard their privacy, offering support by acknowledging spiritual, social, and psychological needs to confront the changes imposed by the situation [11,12].

Despite the evident importance of this collaborative process, health professionals often find themselves ill-equipped or apprehensive about engaging in dialogue with patients and participating in the decision-making process concerning dialysis.

In a study assessing the awareness of 676 patients (ranging from stages 3 to 5 and undergoing conservative treatment) regarding various RRT modalities, 43% indicated a lack of familiarity with HD, 57% with PD, and 66% with transplantation. When questioned about their understanding of the disease, one in three admitted to having limited or no knowledge about their CKD and its treatment options. It was also evident that attending consultations with a nephrologist before initiating RRT does not ensure a better understanding of RRT options [13].

An experiment conducted in Spain involved training nurses, physicians, nutritionists, and psychologists specializing in nephrology, who assist patients in RRT decision-making, to actively participate in the decision-making process. During the training, they honed their skills and confidence through instruction in communicating challenging news and understanding bioethical principles and concepts. The 36 trained professionals reported increased confidence and acknowledged their lack of preparedness for discussions about the RRT selection process in their foundational training [14].

This training contributed to enhancing the shared decision-making process in nephrology units in Spain. Consequently, teamwork, bioethics, and effective communication skills emerged as pivotal elements for a successful scenario [14]. Considering this, it might be important to contemplate preparing Brazilian professionals with these techniques to convey information more effectively to their teams.

A Brazilian study interviewing 75 professionals working in municipalities in Minas Gerais, comprising 26.7% doctors, 32% nurses, and 41.3% nursing technicians, revealed that HD was the RRT modality most frequently recommended by doctors, amounting for over 90% of cases, while less than 10% would advocate for PD as their primary choice. The authors suggest that the low percentage of patients undergoing home RRT could be attributed to inadequate information provided by healthcare professionals [15].

Notably, these statistics align closely with those found in this study, which, while not specifying the proportion of professionals advocating for HD, indicated a predominant preference for this modality among most practitioners, underscoring a significant structural concern regarding PD.

To comprehensively understand decision-making processes, three key elements warrant observation: 1) patient factors (personal values and life circumstances, autonomy, and emotional responses); 2) educational factors (information assimilated by the patient, suitable timing for information provisioning, and resources utilized for guidance); and 3) support systems (interactions with the healthcare team and assistance from family and friends). These elements must be investigated and evaluated by healthcare professionals involved in the RRT selection process to facilitate informed and shared decision-making [16].

It is important to note that an ill-considered decision can significantly impact patient satisfaction with the treatment. An evaluation of negative sentiments associated with treatment reveals that 17.7% experience insecurity, 18.6% feel fear, 21.8% report anxiety, 13.2% express anger, and 29.1% experience discomfort during RRT. The study underscores that the behaviors exhibited during the decision-making process have repercussions that resonate differently among patients and their caregiving team [17].

Moreover, it is crucial to highlight the escalating frequency of patients declining or discontinuing treatment, whether in the early stages of dialysis or as part of their established routine. Healthcare professionals tasked with patient care grapple with ethical conflicts, encompassing considerations of the patient's right to a dignified death and navigating religious, philosophical, and legal perspectives on the essence of life and death, autonomy, and the end of life [18].

However, there is often a sense of "discomfort" among the healthcare team when refraining from initiating any RRT for the patient. Consequently, there is a perceived "need" to deploy all available technological interventions to extend life, often at the behest of the physician or family, which can result in dysthanasia. Dialysis is frequently employed for this purpose, giving professionals a false sense of being able to provide optimal care to their patients, even though they recognize that its inclusion would minimally impact the outcome and the inevitability of the patient's condition [11].

This is often the case with elderly patients. Among the participants in this study, moral considerations related to this issue were particularly pronounced, especially when providing care to both young and older individuals.

Most physicians recognize the significance of their role in aiding patients in making informed decisions to mitigate harm, thereby upholding the principle of beneficence. However, grappling with the understanding that their primary responsibility lies in advising on treatment options, evaluating pertinent information for individual decision-making, fostering autonomy, and respecting patient choices—even if they diverge from beneficence or non-maleficence—can be challenging. Healthcare professionals are trained to present treatment possibilities based on their clinical judgment, yet many find it challenging to accept patient decisions that deviate from their assessment of the optimal course of action [19,20].

Balon [21] posits that when beneficence is prioritized over autonomy, it underscores a paternalistic approach in medical practice, wherein the physician believes that recommending treatment based on their expertise is ideal for the patient. Moreover, healthcare professionals often struggle to perceive patients as fully autonomous, recognizing that no individual is entirely free from external influences that shape their decision-making process. This challenge is magnified in the context of illness, where constraints limit the ability to maintain autonomy as before.

Additionally, the traditional perception of the healthcare professional or caregiver as a paternalistic figure, wielding the power to make decisions on behalf of the patient, is increasingly seen as outdated. Consequently, there is considerable debate surrounding the imperative to eschew paternalistic actions, whether it involves providing simple advice and informing patients about available treatments for their health condition or intervening to prevent what may be perceived as self-inflicted harm when patients opt not to prolong life or treatment [21,22].

Final considerations

The decision-making process for professionals is predominantly guided by the principles of beneficence and non-maleficence, aiming to improve the clinical condition associated with renal failure. However, these actions often overlook the patient's autonomy, involvement, and the potentially life-limiting nature of the treatment. Unfortunately, the ethical conflicts and decision-making challenges are not always recognized by the professionals responsible for establishing RRT.

While the importance of patient participation in the decision-making process for initiating RRT was emphasized, this involvement has not consistently materialized given difficulties in accessing all RRT modalities within the healthcare system (such as entitlement to the transplant queue only after the commencement of hemodialysis or peritoneal dialysis, preemptive transplantation only for living donors, and insufficient vacancies for PD). In essence, despite frequent references to patient rights, they are often not adequately informed or invited to participate in this process.

Paternalism remains prevalent and robust within the studied population, indicating a need for reconsideration. Professional training institutions must prioritize education that fosters ethical awareness, encompassing both theoretical and practical aspects. By doing so, the impact of this approach would extend to all settings where nephrology care is provided, as these professionals often continue their practice in diverse healthcare environments following specialization.

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