

# Renouncement of renal replacement therapy: withdrawal and refusal

Renúncia à terapia renal substitutiva: descontinuação e sonegação

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## ABSTRACT

Renouncement of renal replacement therapy (RRT) is a medical dilemma. This review covers the concept, the magnitude, the prognosis, and discusses strategies and management approaches about this subject in patients with CKD and AKI. Evidence suggests that refusal is more frequent and carries a more guarded prognosis than withdrawal of RRT. When RRT is not expected to be beneficial in terms of survival or quality of life, conservative treatment and palliative care are alternatives. We review the historical evolution of guidelines about renouncement of RRT and palliative care, and highlight the absence of specific recommendations in Brazil. However renouncement of RRT may be ethically and legally accepted in Brazil, as the right to a dignified death. Longer life expectancy, economic pressures, and greater awareness will require a more detailed discussion about indications and sustainable use of RRT, and possibly the elaboration of national guidelines.

**Keywords:** dialysis; renal dialysis; palliative care; bioethics; acute kidney injury; renal replacement therapy; geriatrics; medical futility; withholding treatment; kidney failure, chronic.

## RESUMO

A renúncia à terapia renal substitutiva (TRS) é um dilema. Essa revisão aborda o conceito, magnitude, prognóstico, estratégias e condutas sobre o tema, em pacientes com doença renal crônica e com injúria renal aguda. Evidências indicam ser a recusa mais comum e de prognóstico mais incerto do que a suspensão da TRS. Quando a TRS não agrega sobrevida ou qualidade de vida, o tratamento conservador com cuidados paliativos pode ser uma alternativa. A evolução das diretrizes sobre a renúncia à TRS e a instituição de cuidados paliativos é revista, com ressalva à ausência de tais recomendações no Brasil. Em certos casos, a renúncia à TRS pode ter sustentação ética e legal no país, amparada pelo direito à morte digna. A maior expectativa de vida e pressões econômicas exigem maior discussão sobre indicações e uso sustentável da TRS, demandando maior conscientização e, possivelmente, a elaboração de diretrizes nacionais sobre o tema.

**Palavras-chave:** diálise; diálise renal; cuidados paliativos; bioética; lesão renal aguda; terapia de substituição renal; geriatria; futilidade médica; suspensão de tratamento; insuficiência renal crônica.

## INTRODUCTION

Chronic kidney disease (CKD) is a global public health issue.<sup>1</sup> Many factors have contributed to the increase in the number of individuals diagnosed with CKD, including the evident association between CKD and poverty and unhealthy living conditions; the growing incidence of the main underlying causes of the disease,

namely diabetes and hypertension; and, paradoxically, the greater availability of diagnostic methods and increased awareness of physicians and the general public over CKD.

In this context, when the glomerular filtration rate (GFR) of individuals with CKD decreases to critical levels, the disease enters a pathophysiological progression pattern that almost inevitably leads to added

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functional impairment. While many patients die prematurely from a wide array of causes,<sup>2</sup> as a rule individuals with the disease for prolonged periods of time progress to kidney failure.

Aging is one of the main risk factors for CKD, diabetes, and hypertension. As the number of elderly individuals grows, significant increases are expected to occur in the ranks of patients diagnosed with CKD or significant comorbidities, along with referrals to renal replacement therapy (RRT).

In developed nations, the analysis of time trends of incident dialysis patients has shown that the number of elderly individuals in this group is growing at higher rates.<sup>3</sup> This finding gains weight when the clinical outcomes of elderly patients on RRT are considered. In a significant number of cases, the introduction of RRT is accompanied by spiraling distress, loss of independence, functional impairment, and decreased survival.<sup>4-7</sup>

In Brazil, differently from other emerging countries, patients are offered dialysis and referred to RRT without much debate. However, given that circumstances in developed nations may very well manifest in Brazil,<sup>8</sup> it is quite likely that the number of individuals on RRT in the country will increase substantially, including frail elderly subjects with an extensive list of comorbidities.

This observation underlines the difficulties inherent to establishing limits and parameters for the acceptance of dialysis, notably among elderly patients with slim chances of attaining functional recovery to a level that would allow them to survive for a relatively short period with minimal quality of life.

Individuals with CKD or acute kidney injury (AKI) may renounce dialysis by either discontinuing or simply never starting treatment in situations in which dialysis has been indicated based on traditionally accepted criteria.

Nephrologists are often faced with the dilemma of withholding or withdrawing dialysis. These decisions, at times construed as failure on the part of physicians to inform their patients of the ensuing risks, are complex and must be analyzed individually. The entanglement of technical, ethical, legal, cultural, and economic issues present in this dilemma still fills the

minds of practitioners of Nephrology with questions and doubt.

## WITHDRAWING DIALYSIS

In developed nations, withdrawal from dialysis accounts for 15-22% of the deaths of patients on RRT<sup>9-13</sup> and ranks as the second or third more frequent causes of death among patients with failing kidneys.<sup>9,12,14</sup> In the USA, some 36,000 deaths of patients on RRT (17%) were preceded by discontinuation of maintenance dialysis between 1995 and 1999.<sup>15</sup>

These rates, however, vary geographically, indicating the existence of cultural diversity and variances in medical practice in different areas of the country. For example, 28% of the deaths in RRT settings recorded in 2002 in New England occurred after withdrawing dialysis, a significantly larger proportion than in other parts of the nation.<sup>16</sup> Depictions of this issue in Brazil are rare in the literature. One might assume, however, that social, cultural, and economic factors in effect in Brazil produce lower rates than the ones observed in more developed nations.

Evidence indicates that patients on dialysis in Brazil and other countries are at higher risk for suicide.<sup>17-20</sup> Since it may be viewed as a form of suicide, patients choosing to discontinue dialysis must be assessed by a psychiatrist to rule out cases of potentially treatable depression.

A study on suicide among individuals on dialysis concluded that withdrawal from dialysis and suicide were strongly associated with time on dialysis, although the risk patterns of both outcomes were different. Risk of suicide was greater within the first three months of dialysis and decreased consistently with time. RRT discontinuation was higher within the first year of treatment and decreased considerably afterwards.

Various patient characteristics have been independently associated with suicide and withdrawal from dialysis, though the order of magnitude of these associations varied between the two outcomes. Older age and recent hospitalization were stronger predictors of RRT discontinuation, while being Caucasian or Asian, alcohol or drug abuse, and hospitalization due to mental illness were stronger predictors of suicide.<sup>17</sup>

Where practiced, discussions on withdrawing dialysis are initiated by patients with intact decision-making capacity in 42-56% of the cases.<sup>21,22</sup> When the patient lacks decision-making capacity, the discussion is initiated by the patient's family (10-42%) or the physician in charge (30-62%).<sup>21,22</sup> The wishes of patients with intact decision-making capacity to discontinue RRT are granted in 88-92% of the cases.<sup>21,23</sup>

The prognosis is, inexorably, death after a short period of time. Patients tend to live for six to eight days after making the decision.<sup>24-26</sup> A multinational retrospective study with 8,615 patients from 308 dialysis centers published in 2002 reported that fewer than 5% of the patients survived for more than 30 days after the discontinuation of RRT.<sup>25</sup>

### WITHHOLDING DIALYSIS

Refusal to start dialysis, understood as withholding RRT in situations of kidney failure, is a frequent event. Differently from withdrawal from dialysis, prognosis is more uncertain. A survey with 161 nephrologists in the USA found that 89% had withheld dialysis at least once in the previous year, and 31% had withheld dialysis more than six patients within the same time period.<sup>21</sup> When compared to the decision of discontinuing maintenance dialysis, 81% said they had done it at least once the previous year and only 9% had done it more than six times.

The limitations of this study, however, included: only nephrologists from six States in New England were enrolled; and 73% of the contacted nephrologists answered the survey.<sup>21</sup> Apparently, withholding dialysis was more common than withdrawing dialysis, as also described in another study.<sup>22</sup>

### ELDERLY PATIENTS AND THE DECISION TO START DIALYSIS

The number of elderly individuals on dialysis has grown substantially. According to the Brazilian Society of Nephrology (SBN), only 25% of incident dialysis patients were 65 years and older in 2006.<sup>27</sup> In 2010, the proportion had grown to 30.7%.<sup>28</sup> The prevalence of elderly individuals on RRT is also increasing, albeit more slowly. The 2014 SBN Dialysis Census reported the highest prevalence of patients aged 65 and older ever on RRT: 32.5%.<sup>29</sup> Patients aged 80 and older accounted for 4.6% of all individuals on RRT.

This trend has also been confirmed in the USA, where the elderly make up the fastest-growing segment of the population on dialysis.<sup>13</sup> In absolute numbers, the number of patients aged 80 years and older in the USA grew from 7,054 in 1996 to 13,577 in 2003.<sup>3</sup> In Europe, the number of incident patients aged 75 and older grew from 20% to 29% in Wales and from 18% to 23% in England between 1998 and 2004.<sup>30</sup>

Although old age is not a contraindication for dialysis, morbidity and mortality are more significant in elderly than in younger individuals on RRT. Fifty-nine percent of the patients starting dialysis at 75 years of age and older die within a year and 43% within two years in the USA;<sup>31</sup> and 71% and 54% in European countries, respectively.<sup>32</sup> However, more than 10% of these individuals die within the first three months of dialysis.<sup>32,33</sup> Therefore, in recent years the discussions on alternative non-dialysis therapies for elderly individuals with CKD and kidney failure have been expanded.

In 2015, in order to promote multidisciplinary care and foster shared decision-making, an algorithm was developed to assess the risk of early death of incident dialysis patients aged 75 and older, defined as death occurring within three months of the start of dialysis. A scale built around eight clinical variables and one workup variable ranging from 0-25 points was thus developed to categorize patients into three groups based on their risk of death. This tool enabled the individualization of care and allowed patients to have more say in the choice of RRT or palliative care.<sup>34</sup>

Effective decision-making does not involve solely the process leading to a decision, but also the establishment of a clear plan once a decision has been made. For example, a 30- or 60-day dialysis trial run might be useful in certain contexts, particularly when doubt persists. Patients have to be clinically monitored throughout the process, until a decision to renounce or accept dialysis is made.<sup>35</sup>

Individuals choosing RRT - for a limited period of time or not - must be informed of the possibility of opting for palliative care in the future. The choice for conservative management has to be accompanied by meticulous patient follow-up. Ideally, treatment should be offered in institutions capable of providing geriatric and palliative care, a combination virtually

inexistent in Brazil. In either case, the natural history of the disease requires strict cooperation between nephrology and geriatric or palliative care teams, so that patients and their families are provided with the best possible outcome.<sup>36</sup>

### CONSERVATIVE MANAGEMENT VERSUS DIALYSIS

Studies on elderly populations have shown minor differences in survival between conservative management and dialysis, particularly in individuals with extensive comorbidities.<sup>37</sup> A prospective study published in 2003 enrolling 44 individuals looked into patient survival counting from the start of dialysis. The mean survival time of patients on dialysis was 8.3 months, a non-significant difference when compared to the 6.3 months for which patients offered conservative managed survived.<sup>38</sup> A more recent retrospective study conducted in the United Kingdom with individuals aged 75 years and older found minimal benefit in survival in a comparison between dialysis and conservative management (mean 19.6 *vs.* 18.0 months).<sup>39</sup> The same study reported that the difference in survival ceased to exist in individuals with multiple comorbidities, particularly patients with ischemic heart disease.

Other studies indicated patients offered dialysis survived for longer, although a more thorough methodological review might help explain some of the reported results. A study carried out in a large kidney care center in France analyzed the outcomes of 144 pre-selected incident patients aged 80 years and older with GFR below 10 ml/min treated by a multidisciplinary care team between 1989 and 2000, offered RRT or conservative management.<sup>40</sup>

The authors reported a significant difference in survival in favor of individuals offered dialysis (28.9 *vs.* 8.9 months,  $p < 0.0001$ ). But the study was clearly biased. Six of the 43 individuals not offered dialysis had been selected for RRT but refused treatment. The other 37 were never offered RRT by the multidisciplinary team for reasons that included late referral to the kidney care center, social isolation, low functional capacity, and *diabetes mellitus*. The marked difference in survival was explained by the selection of patients for dialysis or conservative management.

Another retrospective study carried out in England in 2010 collected data from 844 patients and reported mean survival times of 67.1 months in the group offered dialysis and only 21.2 months in the group provided conservative management ( $p < 0.001$ ).

However, the group offered conservative management was significantly older ( $p < 0.001$ ), with a mean age of 77.5 years *vs.* 58.5 in the group offered dialysis, and 68.4% *vs.* 11.2% of the patients were 75 and older. Comorbidities were a lesser factor among patients in the RRT group (17.3% *vs.* 49.7% with a high comorbidity score,  $p < 0.001$ ). Indeed, as the analysis was refined with the aid of a Cox proportional hazard model adjusted for age, diabetes, and comorbidity scores, differences in survival of patients aged 75 and older between dialysis and conservative management were no longer elicited.<sup>41</sup>

Another British study published in 2009 looked into survival in a prospective cohort of 202 patients with GFR below 30 ml/min and ages greater than 70 years.<sup>42</sup> The authors reported better survival (37.8 *vs.* 13.9 months,  $p < 0.01$ ) for individuals offered RRT in relation to what they referred to as patients offered “maximum conservative management.” Not surprisingly, the subjects offered conservative management were older (81.6 *vs.* 76.4 years,  $p < 0.001$ ).

It should be noted that patients on RRT spent a greater proportion of the time for which they survived in hospital. For example, the 112 patients treated exclusively with hemodialysis spent 47.5% of their surviving days (173 days per patient per year) either hospitalized, on dialysis, in medical visits or being driven to dialysis. Patients offered conservative management spent only 4.3% of their surviving days in similar situations (16 days per patient per year).

### GUIDELINES

Accounts indicate that Hippocrates suggested that patients “overwhelmed” by their diseases should not be treated, since in such cases treatment is ineffective.<sup>43,44</sup> Though there have been discussions of situations in which RRT might be inappropriate,<sup>10,45</sup> the first attempt to set out a specific guideline on the topic in nephrology was published just over 20 years ago.<sup>46</sup>

In what was described explicitly as a personal opinion, Lowance suggested in 1993 that patients and their families should be advised not to initiate dialysis or undergo kidney transplantation in five situations: 1. Advanced physical or chronological age with life expectancy of less than two years; 2. Dementia with irreversible cognitive disorder; 3. Life expectancy below two years due to severe coexisting conditions (diabetes, heart disease, vasculopathy, cancer or other systemic diseases); 4. Coexisting diseases in which

prolonging life through RRT, even if life expectancy is greater than two years, causes untreatable pain or suffering; and 5. Individuals with chemical dependency (who should remain on dialysis until they are able to overcome the dependency and comply with a treatment scheme to support their grafts).<sup>46</sup>

A year later, Canadian authors proposed an improved set of guidelines, in their words open to discussion and review, in which combinations of morbidity and CKD prompted physicians to discuss the possibility of turning RRT down with patients and their families.<sup>47</sup> The two guidelines mentioned above stated that the responsibility of physicians transcended a merely objective presentation of the treatment options.<sup>46, 47</sup>

Though mindful of patient autonomy, the authors understood it was the physician's duty to discuss the best course of action for each patient. Admittedly, this approach may be interpreted differently in different cultures. For example, the Canadian authors alluded to the potentially less contentious nature of their patients vis-à-vis their American counterparts.<sup>46, 47</sup>

An "Emerging Consensus" document was published in 1998 to sum up the common elements in the four guidelines published until then.<sup>46-49</sup> The new consensus document set out five situations in which RRT should not be indicated: individuals with non-renal terminal disease, permanently unconscious patients and individuals unable to interact, non-cooperative individuals, and patients with a history of refusing to undergo dialysis.<sup>50</sup>

In 1999, the *Renal Physicians Association* (RPA) and the *American Society of Nephrology* (ASN) combined their efforts to develop a set of guidelines to inform the decision of initiating or discontinuing RRT.<sup>51</sup> The group convened religious leaders, bioethics experts, dialysis patients, nurses, and physicians.

In light of new evidence, the RPA revised and updated the guidelines in 2010 (Table 1).<sup>52</sup> The updates included a new model to predict the risk of death within the first six months of hemodialysis (available at <http://touchcalc.com/calculators/sq>), which considers five variables: age, serum albumin levels, presence of dementia and peripheral vascular disease, and the answer to a "surprise question."<sup>53</sup> This last item, designed to be answered by the patient's physician, was developed within the context of palliative care and consists of the following question: "Would you

be surprised if this patient died within the next 12 months?"<sup>54</sup>

The revised document of the RPA currently in effect also includes additional consideration to the propriety of offering RRT to very old patients affected by severe comorbidities or cognitive disorders. The decision-making and caregiving processes have now incorporated concerns related to barriers to communication between healthcare teams and patients and their families, respect for previous patient choices and advance healthcare directives, and the recognition of the importance of incapacitating and intolerable symptoms such as pain and nausea, invariably underdiagnosed and undertreated.<sup>52</sup>

### INTENSIVE CARE AND AKI

The elevated death rate of critically ill patients submitted to RRT indicates the probably futile nature of providing renal support in a significant number of cases.<sup>55</sup> Advance directives for the discontinuation of dialysis may also be upheld in the context of patients with AKI on intensive care. In fact, the more recent recommendations of the RPA/ASN make reference to patients with AKI and CKD.<sup>56</sup>

Nonetheless, a few important differences must be considered. For example, the two scenarios entail different possibilities for shared decision-making. The decisions made by patients with CKD in need of dialysis usually stem from the relationship developed with their families and nephrologists throughout the long period of time for which the disease progressed.

The central role nephrologists play while providing care to patients with CKD contrasts with the often secondary role they assume when treating critically ill individuals with AKI.<sup>55</sup> In these situations, the decision to discontinue dialysis is not related solely to RRT, as it encompasses the discontinuation of a series of other therapeutic interventions.

Discussing the withdrawal of dialysis alone in patients on intensive care and multiple organ support therapy is pointless. In this group of patients, the perception of futility of care and the choice of curtailing the aggressiveness of therapeutic and diagnostic measures do not always lead to immediate discontinuation of all modes of life support.

In other cultures, discontinuation of life support is implemented gradually, and dialysis is usually among the first to be suspended. Nutrition, hydration, and mechanical ventilation are often the last to

**TABLE 1** 2010 GUIDELINES OF THE RENAL PHYSICIANS ASSOCIATION AND THE AMERICAN SOCIETY OF NEPHROLOGY.<sup>47</sup>

Establishing a shared decision-making process
Recommendation 1
Develop a patient-physician relationship that promotes shared decision-making.
Informing patients
Recommendation 2
Fully explain the diagnosis, prognosis, and all treatment options to patients with AKI, CKD stages 4 and 5 or established kidney failure
Recommendation 3
Provide patients with AKI, CKD stage 5 or established renal failure specific prognostic estimates concerning their global condition.
Facilitating advanced healthcare directives
Recommendation 4
Establish an advanced care plan.
Making the decision to withhold or withdraw dialysis
Recommendation 5*
If appropriate, withhold dialysis for patients with AKI, CKD stage 5 or established renal failure meeting the following criteria:
<ul style="list-style-type: none"> <li>• Patient with decision-making capacity who, being fully informed and making voluntary choices, refuses dialysis or requests that dialysis be discontinued.</li> <li>• Patient who no longer possesses decision-making capacity who has previously indicated refusal of dialysis in an oral or written advance directive.</li> <li>• Patient who no longer possesses decision-making capacity and whose properly appointed legal agent refuses dialysis or requests that it be discontinued.</li> <li>• Patient with irreversible, profound neurologic impairment such that he/she lacks signs of thought, sensation, purposeful behavior, and awareness of self and environment.</li> </ul>
Recommendation 6
Consider not initiating or withdrawing dialysis for patients with AKI, CKD stage 5 or established renal failure who have very poor prognosis or whose medical condition precludes the safe administration of dialysis. This category includes patients in the following situations:
<ul style="list-style-type: none"> <li>• Medical condition that precludes the technical process of dialysis for lack of cooperation (e.g.: patients with advanced dementia who pull out the dialysis needles) or clinical instability (e.g.: severe hypotension).</li> <li>• Non-renal terminal disease (except for individuals who may benefit from dialysis and decide to be treated)</li> <li>• CKD stage 5, age &gt; 75 years, presenting two or more significant criteria for poor prognosis (see Recommendations 2 and 3): 1) when the answer to the surprise question is no (see text); 2) high comorbidity score 3) significant functional disorder (e.g.: Karnofsky performance scale index &lt; 40) and 4) severe chronic malnutrition (e.g.: serum albumin &lt; 2.5g/dl).</li> </ul>
Resolving conflicts over decisions concerning dialysis
Recommendation 7
Consider offering dialysis for a limited trial period when patients with uncertain prognoses need dialysis but consensus has not been reached as to when to start treatment.
Recommendation 8
Establish a systematic approach to resolve conflicts arising from decisions concerning dialysis when disagreement exists regarding when to start or whether to continue dialysis.
Providing effective palliative care
Recommendation 9
In order to improve patient-centered outcomes, offer palliative care and interventions to all patients with AKI, CKD or established renal failure suffering with the burden of renal disease.
Recommendation 10
Use a systematic approach to inform patients of their diagnoses, prognoses, treatment options, and care goals.

\* Clinical treatment, including palliative care, is an integral component of the decision to discontinue dialysis for patients with AKI, CKD or established renal failure. The healthcare team in charge must strive to provide patients with comfort and quality of life, either directly or through referral to palliative or hospice care for terminally ill patients (see Recommendation 9).

be removed.<sup>57</sup> The pattern of treatment withdrawal is less evident in Brazil, since the removal of all support measures customarily occurs only in cases of brain death. Therefore, the decision to discontinue dialysis often reflects a transition to palliative care and the cessation of additional attempts to recover the patient.

Nephrologists are often called to give opinions on the propriety of RRT and on the maintenance of other therapeutic measures. In the absence of national guidelines, the authors of this paper recommend that the decision over dialysis discontinuation be made jointly with the unanimous agreement of the entire team, the involvement of the patient's family, and under the tutelage of the physician in charge of the patient.

### ETHICAL AND LEGAL ASPECTS

Medical work is grounded on two moral pillars: maintenance of life and relief from suffering. In most cases the two complete - and not compete with - each other. In 1978, Beauchamp and Childress identified the four guiding principles of bioethics and moral life: autonomy, justice, beneficence, and nonmaleficence.<sup>58</sup> It is the job of the physician in discussions on what to do in cases of advanced renal disease to use the principle of beneficence to assess whether the patient can still recover and define possible beneficial interventions.

Topics that once were the object of unilateral decisions by physicians have gained new shades under the auspices of bioethics, with ramifications into patient autonomy. It has been discussed that the choice to start or discontinue RRT is not solely the responsibility of physicians. Nonetheless, patient autonomy is more easily accepted when all the patient wants is to start RRT. A much taller order is to let the patient's right to refuse treatment prevail, particularly when the consequence, albeit not immediate, is death.

Similarly, the principles of nonmaleficence and beneficence must be in equilibrium. When the progression of the disease drives away the possibility of cure or control, the principle of nonmaleficence must be applied to give way to measures devised to mitigate patient pain and suffering.

However it is not uncommon, even in Brazilian society, for patients and their families to have trouble coming to terms with the progression of disease and the inevitability of death. Reluctance in accepting this fate may lead to dysthanasia, i.e., insistence in keeping all possible therapeutic interventions, unreasonably

prolonging the patient's life while causing additional suffering to a profoundly debilitated individual.

Another conflict arises in this case, since the decision to prolong life causes additional suffering to the patient and violates the principle of nonmaleficence.<sup>59</sup> In other situations, based on scientific knowledge and on the impacts over the quantity and quality of life of the individual in question and despite the will of the family or the patient, it may be understood as a right of the physician to deny futile treatment.<sup>59</sup>

Brazil lacks specific legislation on the matter.<sup>60</sup> The Federal Constitution of 1988 provides some legal basis for withdrawal decisions concerning treatments such as dialysis. Article 1 Item III sets "human dignity" as one of the guiding principles, and Article 5 Item II states that "nobody can be forced to perform or cease to perform treatment unless the Law provides otherwise."<sup>61</sup>

Resolution n° 1805/2006 of the Federal Board of Medicine (CFM) dictates: "In the end stages of severe incurable diseases, the physician may limit or discontinue procedures and treatments to prolong the life of the patient. The patient must receive integral care and all the needed measures to mitigate the symptoms that cause him/her to suffer, in strict compliance with the will of the patient or his/her legal representatives."<sup>62</sup>

The CFM resolution is in agreement with the guidelines of the World Medical Association, the European Council, the European Court of Human Rights (ECHR), and the United Nations Educational, Scientific and Cultural Organization (UNESCO). It has also followed the legal framework adopted in other nations, such as Spain, Switzerland, France, Belgium, the United Kingdom, Italy, Canada, the USA, Mexico, Uruguay, Sweden, and the Netherlands.<sup>63</sup>

However, Resolution n° 1805/2006 was challenged by the Federal Prosecution Office (MPF).<sup>64</sup> The long petition made reference to orthothanasia as an unreasonable homicidal resource in clear violation of the Federal Constitution, whose purpose was "the mere desire to give men the possibility of making a decision that never belonged to them."<sup>64</sup> In 2007 the Resolution was revoked in a preliminary decision, following the recommendation of the Federal Prosecution Office.

Despite the unfavorable preliminary decision, therapeutic obstinacy was also disavowed in the 2009 Code of Medical Ethics.<sup>65</sup> Autonomy was given significant attention in the new code. Item XXI in the chapter

on Fundamental Principles sets out that “the physician will accept the choices of the patients related to diagnostic and therapeutic procedures when suitable and in scientifically recognized situations.”

Dysthanasia, with patient suffering without possibility of improvement or cure, was also mentioned. Item XXII in chapter I determines that “in irreversible and end-stage clinical scenarios, the physician must avoid unnecessary diagnostic and therapeutic procedures and provide patients with proper palliative care.”

After three years of intense discussion, the CFM appealed the decision supporting the original opinion of the Federal Prosecution Office.<sup>66</sup> Judgment was rendered in December of 2010 in favor of the reinstatement of Resolution n° 1805/2006. The Judge understood that the Resolution did not violate the Law as it regulated the possibility of limiting or suspending procedures designed to prolong the lives of patients with terminal incurable diseases.<sup>67</sup> Two years later, CFM Resolution n° 1995/2012 allowed patients to manifest their will in the form of advanced healthcare directives.<sup>68</sup>

Despite the guiding principles of the Federal Constitution and the CFM, there is no specific legislation covering practices connected to palliative care and orthothanasia. The latter term means “good or right death,” and may be understood as not artificially prolonging one’s life to thus avoid suffering and dysthanasia.<sup>69</sup>

Although the Brazilian Penal Code makes no reference to orthothanasia, lawyers and physicians have found legal bearings to perform it. Current interpretation indicates that discontinuing treatment is not a crime as long as the patient cannot benefit from the treatment and the treatment is understood as therapeutic obstinacy. Given the number of bills of law being discussed, until decided otherwise the contraindication or indication of treatment is a medical decision discussed with patients and their families, for the preservation of dignity at the end of life.<sup>70</sup>

It is important that physicians understand the opinion of patients and their families in regards to their beliefs and religious faith. But in spite of religion, patient dignity at the end of life is the chief concern in medical conduct. Comfort and relief through palliative care must not be understood as disrespect for the

human condition or religion, but rather as a means to soothe the transition between life and death.<sup>71</sup>

Orthothanasia and euthanasia have to be properly distinguished. While the first refers to not using futile or excessive treatment to prolong patient suffering, euthanasia presupposes the active or passive abbreviation or interruption of life. However, the decision to withhold treatment, refuse or discontinue futile life support should not be equated with euthanasia, but with good medical practice.<sup>70</sup>

When orthothanasia is performed with discipline and appropriateness, assisted suicide and euthanasia lose a great deal of their meaning. Since orthothanasia is a mediating procedure that produces consensus from different opinions on the matter, a few points must be discussed jointly between society and the medical and legal communities.

They are: consent to limitation of treatment; palliative care and pain management; the work of hospital bioethics committees; healthcare worker education; and education of the population.<sup>63</sup> Orthothanasia is currently thought to meet the principles of bioethics and find support in law,<sup>71</sup> and is claimed to represent a means to attain death with dignity and an extension of the principle of human dignity.<sup>69</sup>

## CONSERVATIVE MANAGEMENT AND PALLIATIVE CARE

Nondialytic treatment of CKD also includes the proper management of anemia, fluid and electrolyte balance (potassium, calcium, and phosphorus), acidosis, and blood pressure. Recent evidence suggests that adequate nutritional support may reduce symptoms and increase survival.<sup>72</sup> Individualized symptom care and early introduction of palliative care are relevant in improving quality of life.<sup>73-75</sup>

According to the definition of the World Health Organization (WHO) of 1990 updated in 2012, palliative care comprises the efforts made by multidisciplinary teams to improve the quality of life of patients and families faced with life-threatening diseases through prevention and relief of suffering.

It requires the early identification, assessment, and management of pain and other issues of a physical, psychosocial or spiritual nature.<sup>76</sup> Palliative care should be ideally initiated at the time the disease has been diagnosed and applied as the disease progresses (CKD, in our case).<sup>77</sup>



## PERSPECTIVES

The growing number of individuals on dialysis, the increases in life expectancy, and the economic pressures arising from the expenditures with RRT and new treatments will certainly encourage more discussion on the indications and sustainable use of dialytic therapies.

Few nephrologists have been formally trained on ethics. A survey conducted in the USA revealed that only 9% of nephrologists had undergone formal training on ethics.<sup>78</sup> Brazil is lagging behind in this area. The growing judicialization of healthcare, the lack of training on bioethics among medical personnel, and the economics of healthcare in the country may help explain the current state of affairs.

In Brazil, RRT is primarily funded by the government (84%), mainly through the Sistema Único de Saúde; the remainder is paid for by health insurance companies.<sup>79</sup> Neither of the contexts produce direct financial pressure on patients and their families, so there is little stimulus for anyone to discuss the actual need of therapy. In this context, the eventual inaction of families and medical teams may allow the continuity of futile therapies and the perpetuation of patient suffering.

The growth of health insurance plans with co-payment in Brazil may encourage discussions on the matter. Following the lead of the RPA and the ASN, nephrologists and their representative institutions should work more actively in the production of protocols and guidelines suitable to the Brazilian medical and legal realities.

## CONCLUSION

In a scenario characterized by the aging of the population, increased prevalence of chronic conditions, and ongoing development of technologies to artificially support life, it is no surprise that discussions on withholding or withdrawing dialysis will occur more frequently, with effects on the practice of nephrology and on the development of guidelines and regulation on the access to dialysis.

Existing RRT technologies offer little or no advantage in terms of survival and quality of life to patients facing multiple comorbidities and/or advanced age. In this context, conservative management with early introduction of multidisciplinary palliative care becomes a viable alternative.

Orthothanasia currently finds support in law and ethics, and should be more disseminated as part of good medical practice. Discussions must be intensified in order to increase levels of awareness among nephrologists and help develop national guidelines on the matter. The alignment between knowledge, principles of bioethics, and patient and family participation in the decision-making process will enhance the safety of medical conduct, lessen legal risks, offer improved emotional protection to families and health-care workers, and preserve patient dignity.

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