

# Religion in the treatment of chronic kidney disease: a comparison between doctors and patients

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## Abstract

Chronic kidney disease is a disease with high morbidity and mortality. The daily life of affected patients includes negative feelings, fear of prognosis, disability, and economic dependence, as well as challenges related to changes in self-image. Religion and spirituality can be important resources in dealing with these difficulties. To test this hypothesis a qualitative, descriptive study was undertaken at the Hospital das Clínicas Samuel Libânio, Pouso Alegre/MG, in order to verify from the point of view of both doctors and patients if they believe that religion influences the treatment of the disease. For doctors, religion represents a strength and a comfort when facing any disease. Patients, however, identify religion with the hope that they will get better. While the significance of religion in their lives was different between the groups, both agreed that it represents a beneficial factor in the life of patients, providing relief, support and optimism.

**Keywords:** Religion. Renal insufficiency, chronic. Qualitative research. Quality of life. Bioethics.

## Resumo

### Religião no tratamento da doença renal crônica: comparação entre médicos e pacientes

A insuficiência renal crônica é uma doença de elevada morbimortalidade. O cotidiano dos pacientes acometidos reveste-se de sentimentos negativos, medo do prognóstico, incapacidade, dependência econômica, além daqueles relacionados à alteração da autoimagem. A religião e a espiritualidade podem ser recursos importantes para lidar com essas dificuldades. Para verificar essa hipótese, realizou-se no Hospital das Clínicas Samuel Libânio de Pouso Alegre/MG estudo qualitativo descritivo, objetivando avaliar, do ponto de vista do médico e do paciente, em que medida a religião influi no tratamento da doença. Para os médicos, a religião representa força e conforto no enfrentamento de qualquer doença. Já os pacientes, depositam na religião a esperança de que irão melhorar. O significado da religião em suas vidas foi distinto entre os dois grupos analisados; entretanto, ambos concordam que a religião configura um fator benéfico na vida do paciente, propiciando alívio, suporte e otimismo.

**Palavras-chave:** Religião. Insuficiência renal crônica. Pesquisa qualitativa. Qualidade de vida. Bioética.

## Resumen

### Religión en el tratamiento de la enfermedad renal crónica: una comparación entre médicos y pacientes

La insuficiencia renal crónica es una enfermedad con una elevada morbilidad y mortalidad. La vida diaria de los pacientes afectados es de sentimientos negativos, el miedo ante el pronóstico, la incapacidad, la dependencia económica, además de aquello relacionado con el cambio de imagen de sí mismo. La religión y la espiritualidad pueden ser recursos importantes para hacer frente a estas dificultades. Para comprobar esta hipótesis, se llevó a cabo en el Hospital das Clínicas Samuel Libânio, de Pouso Alegre/MG un estudio cualitativo, descriptivo, con el fin de verificar, desde el punto de vista del médico y del paciente en qué medida la religión influye en el tratamiento de la enfermedad. Para los médicos, la religión representa fuerza y bienestar para hacer frente a cualquier enfermedad. Los pacientes, por su parte, depositan en la religión la esperanza de que van a mejorar. El significado de la religión en sus vidas fue diferente en los dos grupos analizados, sin embargo, ambos coinciden en que ésta configura un factor beneficioso en la vida del paciente, proporcionando apoyo, alivio y optimismo.

**Palabras-clave:** Religión. Insuficiencia renal crónica. Investigación cualitativa. Calidad de vida. Bioética.

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Chronic kidney failure is a disease with high morbidity and mortality rates. It is characterized by a progressive decline in renal function and by its chronicity, which leads to physical, social and emotional limitations, which significantly affect the quality of life of patients. In "The epidemiology and prevention of chronic kidney disease in Brazil," Sesso <sup>1</sup> warns that the incidence and prevalence of advanced stages of the disease have increased both in Brazil and worldwide.

The available treatment options for the disease achieve only partial replacement of renal function, relieving symptoms and preserving life, although none are curative <sup>2</sup>. In addition, the therapeutic process is difficult and painful, which, although essential for maintaining the life of the chronic kidney disease sufferer, makes his or her daily routine and eating habits extremely challenging, as well as causing changes in physical and emotional integrity, among other aspects of life.

Such experiences involve significant changes in social and family life, and can end up triggering dependency on social care and a loss of autonomy <sup>3</sup>. In general, patients report increasing physical limitations, provoked by fatigue and constant pain which prevents them from performing certain tasks <sup>4</sup>. Daily contact with these patients can reveal the expression of negative feelings, such as anxiety, insecurity, panic, depression, discouragement, a feeling of being attached to the dialysis machine, fear related to the limitations resulting from their situation, the effects of the disease and the changes in how they live and how they are as people, with possible changes in quality of life <sup>5</sup>.

A study conducted by the Universidade Federal do Rio Grande do Sul (UFRGS) in 2011, entitled "Perceptions and changes in the quality of life of patients undergoing hemodialysis" <sup>6</sup> found changes in the quality of life of those suffering from this disease, as can be seen in the words of one of the participants of the study: *"I had a very intense, physically active life; I was a physical education teacher. So it was a very complicated experience, I was going to the gym, going to dance class, it was my life, it was my greatest achievement (...) now I find myself kind of useless, sometimes I'm at home, I have too much free time and at the same time, I cannot find anything that occupies me and makes me feel happy (...) for me, it was very complicated, all of a sudden you feel weak because of the anemia, and you're not able to do lots of things you used to do, you're trapped in a machine to survive"* <sup>6</sup>.

Patients with chronic kidney disease must adapt not only to the disease and its treatment,

but also to numerous physiological, psychosocial and spiritual problems arising from the condition. In this difficult environment, many cling to faith and religion as a source of support and relief from their suffering. Religion and spirituality are becoming more and more important in health care, as they are commonly perceived as a way to give meaning to life and provide hope and a way to find peace in the midst of serious events such as chronic illness <sup>7</sup>.

Today, an association between greater religiosity or spirituality of patients and greater general well-being has been found in cases of mental illness <sup>8</sup>; lower prevalence of depression <sup>9</sup>, drug abuse and suicide <sup>11-10</sup>; a better quality of life <sup>12-14</sup>; a more appropriate way to deal with a disease (coping) <sup>15</sup>; lower mortality <sup>16,17</sup>; less time spent in hospital <sup>18</sup>; and better immune system functioning <sup>19</sup>. With so many benefits, it is important to evaluate the relationship with religion and spirituality in dialysis patients.

### State of the art

The September 2007 edition of the European journal *Nephrology Dialysis Transplantation* took as its central theme the relationship between spirituality, quality of life and dialysis patients. The editorial states that the *relationship between spirituality and various quality of life domains is certainly worth exploring in more detail...since it has been difficult to positively impact on the quality of life of ESRD patients*. The editorial finishes by asking: *Would it not seem reasonable then to further explore the role of spirituality in helping to support, guide and coordinate the care of these patients?* <sup>20</sup> Another study demonstrated that in patients with end-stage renal disease, perception of the importance of religious faith was associated with adapting to changes caused by the disease, and was directly linked to behavior and inversely related to alienation or spiritual suffering <sup>21</sup>.

Religion has brought comfort to relatives, as well as being a form of support, as the religious community encourages involvement among its members by facilitating the sharing of experiences. Religion also promotes social interaction and support between the family and other members of society <sup>22</sup>. It can therefore be seen that in addition to the patient, religious association and spirituality is also beneficial to family members living with the disease carrier.

Another important aspect to be considered is the importance given by doctors and health profes-

sionals to the knowledge and encouragement of the spiritual practice of the patient in order to improve their quality of life. In 2006, a study conducted in the United States<sup>23</sup> warned that patients expect health-care professionals (doctors, nurses) to ask them about their spirituality, and utilize spiritual resources in their care. When the subject of spirituality was raised by a chaplain with dialysis unit patients under his pastoral care, there was an overall improvement in team performance and in responses to the spiritual concerns of patients.

It is necessary, therefore, that health professionals, especially doctors and nurses who are treating a patient, understand not only the meaning of spirituality and religion for that patient, but also the extent to which significant events such as chronic kidney disease may influence how they deal with this experience, so that, in clinical practice, concerns about aspects of spirituality can genuinely form part of holistic care<sup>24</sup>.

Everyone has their own life story. The relationship between health professionals and a sick individual is, above all, interpersonal by nature. In the contact between the two, stories intersect, connect, and overlap. At times, professionals and patients build a new, living history together. It is in this context that the spirituality that is constructed makes a difference<sup>25</sup>.

Religion and spirituality are undeniably of significant relevance in the treatment of chronic kidney disease, whether it is for patients or to family and friends who live with the chronic pain caused by the disease. It is for health professionals in general, and the doctors and nurses who closely follow these patients in particular, to value this relationship and stimulate their patients' reflection on the subject.

The aim of this study was to understand the importance that doctors at the Hospital das Clinicas Samuel Libânio, in Pouso Alegre, Minas Gerais, and their patients attribute to religion and spirituality, as well as identifying how they relate the same to the treatment of chronic kidney disease in this specific context.

## Method

Considering the nature of this study, a qualitative exploratory research approach was chosen, adopting as a methodological reference social representation theory (SRT). SRT is extremely useful for health studies as it brings together subjective aspects from an area and synthesizes them into

common ideas. In order to discover and describe the importance of religion in treating chronic kidney disease, under the framework of social representation, the discourse of the collective subject method (DCS) was used, as it allows the study of this phenomenon.

An exploratory survey is conducted in an area in which the subject is relatively unexplored, and there is therefore little accumulated and systematized knowledge. It is, in fact, the first stage in a wider investigation. As it represents a survey, it does not involve assumptions which, however, may arise during or at the end of the study<sup>26</sup>.

Individual interviews with two semi-structured questions were carried out, preceded by the signing a free and informed consent form (FICF), as required by Resolution 466/2012 of the National Health Council, which addresses research involving human subjects. In addition, this regulation also guided the ethical issues of the study, which were presented by the investigators to the research subjects<sup>27</sup>.

The survey, conducted from December 1 2013 to October 1 2014, involved ten doctors and ten patients with chronic kidney disease at the Hospital das Clinicas Samuel Libânio. The interviews sought to identify the meaning and importance of religion in the treatment of chronic kidney disease. Each interview was recorded and then transcribed for analysis.

The results, based on DSC (written in the first person singular), revealed key expressions (KEP) with the same central ideas (CI) and the same anchor (AC), strictly obeying the order of the following steps:

- 1st) Literal transcription of answers, after repeated listening to the recordings and a clear understanding of the general idea and discourse contained within.
- 2nd) Overall Reading of the responses of each of the respondents, followed by a separate reading of all the answers to the question being analyzed.
- 3rd) Transcribing of the answers to Question 1, with the KEP being marked in italics and underlined to indicate the CI, representing a description, and not an interpretation of the KEP. Same procedure performed for all other questions.
- 4th) individual transcribing of each central idea and their respective KEP.
- 5th) Extraction of the theme of each of the questions, collating their respective CIs of the subjects (represented by the number of respondents) and frequencies of ideas into tables.

6th) Finally, the separate construction from the DSC of each central idea with its respective KEP.

## Results

In terms of the religious profile of the ten interviewed chronic kidney disease patients on dialysis at the Hospital das Clínicas Samuel Libânio, 80% said they were Catholic and 20% said they were Protestant. The average time since being diagnosed with the disease among the interviewed patients was 6.7 years, while the average dialysis treatment time was 3.9 years.

**Table 1.** Religious profile of chronic kidney disease patients, time since diagnosis and treatment time – Hospital das Clínicas Samuel Libânio (Pouso Alegre/MG)

Patient	Religion	Time since diagnosis (years)	Time of dialysis treatment (years)
1	Catholic	3	3
2	Catholic	6	1
3	Catholic	2	2
4	Catholic	17	15
5	Catholic	1	1
6	Catholic	20	6
7	Protestant	2	1
8	Protestant	5	5
9	Catholic	10	4
10	Catholic	1	1

All the health professionals were medical doctors who had graduated between one and 30 years ago, and three had ten or more years of education. As for religious belief, 50% said they were Catholic; 20%, agnostic; 20% Spiritualist; and 10%, Protestant.

When doctors were asked “*What does religion mean to you in your life?*” 50% of the answers contained the following central idea: *Faith, not religion, is what matters.* The prevalent keywords in the CSD were “*faith,*” “*God,*” “*ritual,*” “*dogmas,*” “*churches,*” “*spirituality,*” “*strength,*” “*soul,*” “*belief,*” as can be seen in the following extract from DSC 1:

*“Faith, not the name of a religion, is what elevates us to God. I believe in God’s mercy toward humans, independent of rituals, dogmas and churches. (...) In my life, spirituality has a greater magnitude than religion, and it is on that which I base my actions and which forms my character. (...) Religion in my life means to have faith, to believe that there is a*

*higher power guiding us, blessing, illuminating each decision we take, protecting us from evil in everyday life. (...) Religion is not important, because only God changes your soul and saves you. (...) Religion is one way of exercising faith, one way of expressing belief”.*

The second central idea, identified by another 50% of respondents, was that *Religion is an essential factor in life.* The set of keywords related this were “*essential,*” “*important,*” “*protection,*” “*fundamental,*” “*spiritual,*” “*strength*”. This idea relates to the following section of DSC 2:

*“I believe that religion is an essential factor in preserving mental health. When we belong to a group, whatever it is, it releases a sense of importance and protection of our subconscious. (...) Religion is a fundamental part of my life, because it helps me to develop my spiritual side. (...) Something that gives us strength to tackle the difficulties we face. (...) A strength to support us. (...) It’s something more, a place where patients can leave their pain and sufferings”.*

When patients were asked the same question - “*What does religion mean to you in your life?*” the central idea in 30% of answers was: *Faith in God.* The keywords associated with this were “*faith,*” “*basis,*” “*God,*” “*nothing*”. DSC 3 illustrates this choice of terms:

*“Faith in God. (...) Without faith, we can achieve nothing, right? Faith is the basis of everything, it goes beyond the doctors and everything else. (...) We have to have a lot of faith in God, right? Because without faith in God, nothing can be done”.*

Another central idea that appeared often in the discourse of the participating patients was *Means everything,* which corresponded to 70% of the answers, as noted by the keywords identified, “*everything,*” “*I became,*” “*nothing,*” “*religious,*” “*content,*” “*happy*”. The following DSC 4 explains such terms:

*“It’s everything, without religion we are nothing, I believe strongly in religion. (...) I was born and raised in a religious environment, my father was Catholic, that’s where I got it from, right? And I became religious. (...) It means everything. A person who isn’t religious is nothing. Thank God. (...) God is very good for us, you know. I’ve been religious for 20 years, I am very content and happy. (...) Religion, to me, means everything, because without God we are nothing”.*



Among the doctors evaluated, it was observed that 50% valued faith in God, placing it above religion. For them, religion is just different forms of exercising faith. The other half considered religion to be the primary factor in people's lives. There was agreement between these results in relation to patients, as 30% of the latter believed that the meaning of religion is faith in God, while 70% reported that religion meant everything in their lives. It can be seen, therefore, that this group of respondents, both doctors and patients, valued belief in God, considering it important in their lives.

In answer to the question *"If someone asked you about the importance of religion in treating chronic kidney disease, what would you say,"* the answers of 60% of doctors contained the following central idea: *It represents strength and comfort.* The set of keywords was made up of *"bearable", "comfort", "acceptance", "positive", "comfort", "optimistic", "strength"*, as is shown in DSC 5:

*"Faith makes a burden more bearable for the suffering. (...) Through religion, I believe that these patients find great comfort and a sense of transcendentalism, which gives them a new perspective on the disease itself, leading to greater acceptance and a positive impact on their own survival. (...) I would say that religion can serve as a comfort to these patients, capable of making them optimistic. (...) One more strength. Faith helps a lot".*

Another central idea, identified in the discourse of 40% of doctors, was *Help in any disease.* This corresponded to the keywords *"any," "bearable", "treatment", "similar"*, reproduced in DSC 6 below:

*"Faith helps cure any disease. (...) In chronic kidney disease, as with any disease, faith makes the burden more bearable for the sufferer. (...) Religion is of great importance in medical treatment, once patients find religion (and do not just say they do) they tend to be more optimistic, accept treatment and follow it correctly. (...) Religion, in my opinion, has a similar importance for all diseases. Of course you notice a heavier reliance on religion in more stigmatizing diseases such as cancer, degenerative diseases etc..."*

When patients were asked the same question, *"If someone asked you about the importance of religion in treating chronic kidney disease, what would you say?"*, the following key words and expressions were identified: *"cure", "get better", "grace", "above", "I'll get improve", "get out of here", "courage"*. These terms are summarized in the central

idea of 90% of speeches, *Hope that I will get better*, as can be seen in DSC 7 below:

*"I think it's very important for the cure for my illness. (...) I still have faith I'll get better. (...) I pray a lot, and thanks to God it looks like I'll find grace. (...) I have faith, I believe that God is above the doctors. I'll improve. I'm going to get out of here. I do not want to stay because I have my family to look after. Think positive, have faith. (...) It gives us more courage, more enthusiasm to face each day. (...)"*

In terms of difficulty, one patient interviewed (10%) said they "didn't know how to answer" the questions from the researchers, a response representing the *corpus* of DSC 8: *"I don't know how to answer you."* It is important to remember, however, that this statement may mean that the patient does not know the answer to the question, but may also indicate that he considers his future a mystery.

In assessing the relevance of religion in treating chronic kidney disease, it was found that both groups, doctors and patients, consider it very important in the evolution and prognosis of the disease. Among doctors, it became clear that they attach to religious belief a capacity to strengthen patients in the daily fight against the disease, and provide more comfort regarding the negative effects it has on quality of life. However, 40% of doctors highlighted the extent of the value of religion, which included, favorably and equally, the course of all diseases, and was not exclusive to chronic kidney disease. Among the patients, 90% saw religion as a healing factor and hoped for a positive outcome to their disease. They believed that God was greater than their illnesses and that, when putting their trust in him, there was a greater prospect of a cure.

## Discussion

It was observed that for doctors, the meaning of the word health goes beyond the physical state of the patient, and also includes psychological factors such as religion, which was considered to be highly relevant. Some extracts from the interviews explain this fact: *"Our stability is based on three elements: the emotional the spiritual and the physical. If one of these is in poor condition, it reflects on the others, and destabilizes us emotionally, which is significant for chronic kidney disease."* This feeling is consistent with the trend found in recent studies<sup>28,29</sup> which emphasizes the importance of considering cultural and psychosocial characteristics as determinants of indi-

vidual and group behavior in the medical clinic, which can facilitate coping with the disease, adherence to treatment and the search for a better quality of life<sup>30</sup>.

The idea of accepting and stimulating religion as a way to encourage the patient to cope with their illness and its everyday consequences and to safeguard a dimension of their human rights, is also compatible with the perspective of health adopted by the World Health Organization (WHO), which includes not only the absence of disease, but a more complete state of physical, mental and social well-being<sup>31</sup>.

The terms “faith”, “religion” and “spirituality” are often used interchangeably, but their meanings are not the same<sup>32</sup>. In this study an awareness of this distinction among the doctors interviewed was noted, as half said that faith is important, but not religion. Spirituality and religion can strengthen families by contributing to the formation of their beliefs and values, encourage healthy behavior and practices, stimulate social interaction, promote recreation and help in coping with crises and transitions of life<sup>22</sup>. It was found that both groups of participants, doctors and patients, agreed with this idea, expressing their confidence in the potential of religion and spirituality to help people, by providing them and their families with ways of dealing with the disease on a daily basis. For patients, believing that they can rely on spiritual forces brings feelings of comfort.

As a result, incentivizing of religion and spirituality has been one of the strategies adopted by health professionals in coping with terminal illnesses<sup>33</sup>. In this study, there was clear recognition of its potential by 60% of responding doctors, who said that religion represents strength and comfort for patients, facilitating the acceptance of the disease and the limitations it imposes. For hemodialysis patients, research shows that the followers of a religious belief have a higher quality of life, survival rates, satisfaction with life and medical care, adherence to treatment, ability to work and to deal with the symptoms of kidney disease, than non-religious patients<sup>34</sup>. Among respondents, 70% reported that religion means “everything” in their lives, as shown in this passage: “*God is very good for us, you know. I have been religious for 20 years, I am very happy and content*” (Patient 7)).

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In 2006, a systematic review of literature was carried out, which included articles on the spiritual perspective of adult patients with terminal illnesses. The study covered a 40 year period, and began in 1966<sup>35</sup>. Based on a sample of 11 articles, collectively representing the data of 217 adults, it found that feelings of alienation were an important aspect of spiritual suffering. A “sense of spiritual emptiness” is described as a secondary defining characteristic<sup>36</sup>. Among the patients interviewed in this study, there was no such sense of spiritual emptiness, except for one patient who could not answer. On the contrary, most were emphatic when explaining how religion is significant in their lives.

As previously described by Borges, the initiation of hemodialysis is a critical time for most patients facing the irreversibility of the disease and, in some ways, the impossibility of a cure by traditional medicine<sup>37</sup>. Accordingly, Loyola states that an illness that a doctor cannot cure can be interpreted as a disease with a spiritual background, and can therefore be treated in this as the cause, by exceeding medical expertise, must lie in the field of religion<sup>38</sup>. The same idea was expressed by 90% of patients in this study, who, when asked about the importance of religion in treating chronic kidney disease, answered: “*I hope that I will get better.*” This clearly demonstrates the relevance of spirituality and religion in the course of this disease, as they are accumulators of hope, and make the life of each patient more dignified and comfortable.

## Final considerations

The individual significance of religion was divergent among both physicians and patients, as some saw it as essential in their lives, while others considered only faith in God to be important. Both groups generally agreed, however, on the relevance of religion in treating chronic kidney disease. The study indicated that among the group studied, it was indeed considered – both by doctors and by patients – as a significant and important element of the evolution of chronic kidney disease, given its ability to bring comfort, support, strength and hope of improvement to the lives of patients.

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#### Participation of the authors

Eli Ávila Souza Júnior and Diego Da Silva Vanoni Trombini participated in the planning of the study, its development and the preparation of the text; Augusto Castelli Von participated as an orienter of these stages and Adriana Rodrigues dos Anjos Mendonça participated as a coordinator.

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