## Spirituality and religion / religiosity: the perceptions of people with chronic kidney disease under hemodialytic treatment

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#### **ABSTRACT**

**Objective:** to describe the perceptions of people undergoing hemodialysis treatment on spirituality/ religion/ religiosity. **Method:** this is a descriptive study with a qualitative approach. Twenty-eight chronic renal patients undergoing hemodialysis treatment were interviewed in two hemodialysis units of hospitals in the state of Mato Grosso do Sul between April and June, 2022. **Results:** the data showed that, in the sociodemographic characterization, the majority were female, married, and retired; Catholic and Evangelical religions prevailed. From the interviewees' statements, two categories emerged: perceptions about spirituality, faith, and religion; spirituality in coping with the disease. **Final considerations:** the analysis of testimonies showed positive perceptions in the use of spirituality/religiousness as a method of coping with the adversities experienced during hemodialysis treatment. With these findings, we emphasize the importance of implementing spiritual care in the systematization of nursing care in order to provide relief from the suffering of patients with chronic kidney disease.

**Descriptors:** Qualitative research, Adult health, Chronic disease, Nursing, Religion and medicine.

### INTRODUCTION

Chronic kidney disease (CKD) is the negative consequence of various chronic non-communicable diseases, especially high blood pressure and diabetes mellitus<sup>1</sup>. According to data collected in the last Brazilian dialysis census conducted in 2020, there are approximately 144,776 people on dialysis in Brazil (a variation of  $\pm$  5% = 137,527 to 152,038), 3.6% higher than in July 2019<sup>2</sup>. The 2020 incidence rate was 209 pmp (per million population), higher than that of Latin America (159 pmp) and Europe (122 pmp) in 2018 and lower than that of the United States (370 pmp) in 2017<sup>2</sup>.

Hemodialysis, one of the modalities of dialysis treatment, is the most used method in Brazil with 92.6% of people who undergo this treatment<sup>2-3</sup>. Even though hemodialysis prolongs life expectancy, it leads to various physical, emotional, social, and spiritual issues<sup>4</sup>. Given this scenario, the need to establish coping strategies can

be perceived, such as spirituality and religiosity, which can be strategies that help deal with the disease and its complications<sup>4</sup>. Religious/spiritual coping has contributed to good health outcomes, greater social support, and lower rates of emotional imbalances. It favors a better coexistence with a determined condition<sup>5-6</sup>.

In this way, the scientific community, especially health scientists, has, in recent years, increasingly explored spirituality and its help in the treatment of various diseases. For many people, spirituality, sacredness, and religiosity represent a meaningful approach to managing stress and the difficulties of everyday life. Some researchers believe that spirituality has the ability to help individuals overcome hardship, illness, and even comfort from death<sup>7</sup>.

However, religion can be understood through rituals or symbolisms, which determine how people have contact with the divine and the sacred. The execution of these rituals is what we call religiosity. Religiosity and Spirituality are

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important elements, since religious/spiritual beliefs and practices have been shown to be relevant in coping with the most diverse situations of health imbalance<sup>8,9</sup>.

Therefore, it is worth emphasizing the need to increasingly know the spiritual care demands of these people. Health professionals who work in the hemodialysis service can seek support for the beliefs of these people and provide a welcoming environment to the exercising of their faith and spirituality<sup>10</sup>. With this, and in order to further explore the perception of spirituality and religiosity in people undergoing hemodialysis treatment, this study aimed to know the perceptions of people on hemodialysis treatment about spirituality/religion/religiosity.

### **METHOD**

This study is a piece of research with a qualitative approach using Hsieh and Shannon's targeted content analysis<sup>11</sup>. Considering that the scientific production comes from the area of Nursing in Brazil, we elected as a study guide the instrument Consolidated criteria for reporting qualitative research (COREQ)<sup>12</sup>.

The research took place in two hemodialysis units in two hospitals in a state in the Midwest of Brazil: one regional reference hospital of low and medium complexity in the interior of the state, composed of a team with two nephrologists and nursing staff divided into shifts; and a university hospital of a capital city, which is a state reference in infectious diseases and highly complex procedures in the treatment of people with infectious diseases, renal therapy, diagnosis, cardiovascular surgery, hemodialysis, and neurology, as well as high-risk pregnancy, urology, treatment with tomography, and lithotripsy linked to the Unified Health System (SUS). The hemodialysis unit is formed by a multidisciplinary team (nephrologists, nurses, nursing technician, nutritionist, psychologist).

The sample consisted of people undergoing hemodialysis treatment in hemodialysis units in two cities in a state in the Midwest of Brazil. The inclusion criteria were: be 18 years old or older; be on hemodialysis treatment; be able to adequately

dialogue with the questions during the application of the questionnaire (subjective evaluation of the researchers); be more than three months on hemodialysis treatment. Initially, all people on hemodialysis who met the inclusion criteria were invited. The final sample was comprised of 28 people.

Data collection took place between the months of April and June, 2022, through semi-structured interviews, containing a guiding question "Tell me how you experienced spirituality/ religion / religiosity since the beginning of hemodialysis treatment". The meetings took place during the hemodialysis sessions. This moment was chosen because most of the patients did not live in the city of the units, thus protecting them from concerns about the scheduling of the sessions or how to return home; after the sessions, the patients were debilitated.

The interviews were conducted with a pocket digital recorder and an Android mobile phone application after the signing of the Informed Consent Form (ICF) and the Term of Grant of use of Image and/or Voice for Scientific and Academic Purposes, therefore transcribed in full. To maintain the anonymity of the subjects, the letter P and the sequence of numbers 1 to 28 were used to characterize each person.

Data analysis took place in three stages according to the premises of Hsieh and Shannon's targeted content analysis<sup>11</sup>: for the first stage, a floating reading was performed to identify and quantify the words or content of the text, with word repetition being highlighted to understand the contextual use of them, identifying the main themes present in people's speech. In the second stage, notes of first impressions, thoughts, and a pre-analysis of the interview were collected through the process of pre-coding or keywords. The pre-codes or keywords emerged from an in-depth reading carried out in each of the interviews. In the third stage, the interviews were pre-coded and a reading of the pre-codes and regrouped was carried out. In this regrouping, we analyzed and reevaluated emerging categories that expressed the perceptions of the subjects about spirituality and religion/religiosity in their experiences as a chronic renal patient on hemodialysis.

The research was approved under Ruling No. 5,247,122 of 02/16/2022 of the Research Ethics Committee of Universidade Federal do Mato Grosso do Sul.

### **RESULTS**

On the characterization of the people who participated in this study, we highlight: 18 were female and 10 were male, with ages ranging from 23 to 82 years, average age of 44 years, predominantly married. The duration of the hemodialysis treatment ranged from three months to fifteen years. Regarding schooling, the majority reported having four to eight years of education and 16 of the people were retired. There was a prevalence of Catholics and Evangelicals. One interviewee declared himself a spiritist. No other religions were declared. After analyzing the data of the interviews, two categories emerged: perceptions about spirituality, faith, and religion; and spirituality in coping with the disease.

# Perceptions about spirituality, faith and religion.

Based on what was said, we realized that, when the patients were asked about spirituality, religion, and faith, they brought up a unique meaning for all these concepts, which they perceived in a very subjective way. Some lines stood out and refer to the lack of a reflection on spirituality in their lives.

"Good question. I never thought about it, I never thought about it" (P5)
"A happy person. Are you talking about a person who believes in God?" (P4)

However, the definitions of faith involve believing in subjectivity, in the omnipotence of God. It means to believe in something that transcends lived reality and to hope and expect a better future.

"Faith, believing, believing in any goal very strongly." (P20)

"Faith is all that you will one day succeed, right! To God nothing is impossible." (P24)

"It's believing in God, it's trusting in people." (Q26)

"Faith is something that belongs to us, it is believing, believing in what you are doing, believing in it" (P7)

The narratives suggest faith as purpose, optimism, belief in God and oneself. In turn, God was perceived as a protector, a support, and as deliverer from evil. Faith involves deep beliefs of the self, in what is perceived as truth for each person. The meaning of faith is evidenced in the trust in a Supreme Being, God and Jesus Christ, and in the possibility of representing protection, resilience, and in the enthusiasm in daily life in the fight against the disease and in the continuity of their existence.

"You believe in God, Jesus Christ, trust in him and he delivers you from all evil, helps you and protects you, that is faith." (P4)

"Well, my faith, it's God! Everything that drives people's lives is God, right?" (P16)

"The faith I have is God. I meet only with himself!" (P21)

However, as was already mentioned, spirituality and religion/religiosity differ from each other, mainly in relation to their practice. The relevance of individuality in religious expression is reported by them in the statements below. They emphasize the importance of religion/religiosity in bringing clarity to their doubts and emphasize the unification of all in God.

"It's very important. It is important for us to have a religion, to stay close to God. It's important." (P26)

"It is what makes you good no matter what your religion, Catholic spiritist, something that makes you good that ends up filling something inside." (P5) "I understand that everyone has their own religion, but as I like mine,

everyone has their own. I think religion really shouldn't exist, because God is one." (P2)

"Religion is good. It can be any, it's good, but hard, not having any. But any religion that a person seeks is good, right? I always liked being in church." (P25)

Negative feelings were demonstrated when asked about the exercise of religion/religiosity. During hemodialysis treatment, bodily changes and physical symptoms occur, making it a challenge to go to church or worship. The act of attending a religious institution is no longer essential, causing damage to their social life.

"I pray at home. So, at first, I was ashamed because of my arm and I had to put a band so as not to have contamination for me, one day we were right in the middle of COVID. Then I was taking care of myself, things were going, it was going, I didn't go to church anymore, because where I went, I had to put that thing and then everyone was staring, you know?" (P14)

"When I don't go to mass, I watch it on TV at home. Some days it is not good for you to go, but every Sunday, I watch it on television." (P21)

"When I could, now I fell this dizziness. Sometimes Saturday, Sunday, you can't go straight. I do not do anything to say, I have a dizziness at home. I can't do anything." (P11)

"I live in Estrela Dalva, but near my house there are times when I'm not good, you know, I get bad. Tuesday I was bad all day until nighttime, I got better the next day. The next day I woke up still kind of bad. So sometimes I go, sometimes I don't." (P3)

### Spirituality in coping with illness

Situations of pain and suffering make the human being face many difficulties and have to make difficult decisions. The uncertainties make them,

in the search for relief and resilience, revive their faith. In the patients' discourse there were many references to the connection with God as a source of inner peace. They describe that the establishment of this intimacy with God made them find lightness in the harsh changes that had occurred and even made them feel renewed and brought significant improvements in their health condition.

"After I started praying every night to sleep and to get up, I saw that it seems that our lives change. I think we have to have a religion. You seem to have more peace at home. My health seems to be improving a lot." (P16)

"Praying, praying, talking to God, asking him to bless us, to free us from the danger of bad things. I was too sick, it was good for me, he renewed me and now I'm better." (P7)

Belief in God and faith were cited as important in the management of coping with the diversity of the disease and treatment. They often feel depressed, despairing, or afraid. Therefore, they pointed to the belief in God as being the strength and courage for their survival and the support to deal with the constant presence of their finitude.

"Like, sometimes when I'm at rock bottom, I ask God to help me, to give me strength. ... And I believe the faith that gives me strength so sometimes when I'm down, I pray, I pray. " (P22) "It helped me a lot for having brought me here, it gave me strength to continue, it was faith, faith in God. I think it would be different if I didn't have a faith, a religion, if I didn't have a faith in Jesus the person gets lost. With Faith no, you know that you are supported by God and you go forward and God gives you strength. In the name of Jesus." (P4)

"Everything is difficult for us and if you don't have faith in God, you can't overcome it.". (P9)

"Because then we are not afraid, we are not. We trust and cheer up that

there are people that when they say that they have to treat a kidney problem, that they have to dialyze, they despair, they cry." (P17)

There are diseases that change people's lives and make them struggle to stay alive, such as chronic kidney disease. This raises several questions about why and what for the disease affects them. In the narrative below, the person comes to the conclusion, during their reflections, that the reason for the suffering that afflicts them is the fact God is testing them, testing their faith and hope.

"I believe that God has given me this one more trial to see how far my faith goes, how far my hope goes. Got it? It's not like that. My mother was very devout. Today she's no longer with us. So, what she passed on to us was this. Don't lose hope, have faith. She had great faith in Our Lady of Aparecida." (P14)

However, others have found, in adversity, the purpose of their lives, change in behavior and in relationships with others, self-acceptance, and a glimpse to something beyond all their pain.

"This has changed me, you know? I started to see the world differently, to know people. I began to be humbler, to have more empathy for people, for the elders. I didn't have it." (P19) "Yes, that was decisive because I went into depression, I was depressed for a long time. And if I wasn't or if I hadn't heard that voice, it would say, "you came here because you have a goal, you didn't come here in vain." I don't think I would have ever gotten out of where I was. Only those who have been depressed know what it is." (P8) "Yes. Because until then I was angry. I was very angry about this. Then I studied the Bible. Then I attended courses. Then I understood that God has nothing to do with being sick, with me being sick, there I understood." (P27)

### DISCUSSION

Our study reveals the perceptions about faith, spirituality, and religion for people with CKD undergoing hemodialysis treatment. The results showed that faith was synonymous with believing, hope, purpose, optimism. And they chose faith as a protective factor. Corroborating our study, we highlight a survey with family members of psychoactive substance abusers, which presented the beliefs that led to improvements in positive and optimistic perspectives in the circumstances experienced by people at that time. Religiosity and religious practices by family members proved to be important in the acquisition of strength and courage to face the adverse and challenging situations experienced with those dependent on the consumption of psychoactive substances. In addition to perceiving perseverance, persistence, hope, faith, religiosity, and trust, they were considered as positive forces to face and overcome the difficulties arising from the lived context<sup>13</sup>.

About religion, the people who were part of this study reported having found that being close to God filled inner gaps they might have and this brought them satisfaction. However, attending religious institutions becomes difficult, as mentioned in the narratives, due to changes in image as well as physical limitations, with some being dependent on their families, which damaged their social lives. This was demonstrated in a cross-sectional study conducted with 161 patients from two kidney replacement therapy centers, which aimed to investigate the association between levels of religiosity/spirituality and happiness in patients with chronic kidney disease on hemodialysis and determine whether this possible association is mediated totally or partially by the sense of coherence. In this study, there was no association between happiness and religiosity. The authors attribute this finding to the greater difficulty that this public has in participating in religious meetings due to their physical limitations. Because of that, they turn to personal and private religiosity, that is, living their religiosity in the intimacy of their home as a way of coping with setbacks14.

Dialysis treatment brings with it several issues to people's social lives due to physical

demands and long hours on dialysis. In addition, commuting to the dialysis center and post-dialysis fatigue end up leaving them with low energy to participate in social activities<sup>15</sup> and attend religious institutions, making it difficult to express their belief.

People mentioned feelings such as fear, despair, depression related to the difficulties faced since the beginning of treatment. Thus, seeing their lives transformed by the disease made them seek coping strategies such as spirituality/religion/religiosity. In a qualitative study with 20 Pakistani people with chronic liver disease, they reported that, in the face of the complications of the disease, they restored their relationship with God and other religious practices to overcome their challenges. They also used prayer to divert their attention from the pain and to try and understand the adverse effects of the disease. Another subject that came up highlighted the connection between healing and visiting shrines to pray for healing purposes, this gave them hope<sup>16</sup>.

The routine of maintaining a connection with God through prayers showed that people felt more strengthened, supported, able to get back on their feet to fight for their survival. This was also evidenced in another study, in which 85% of the 1039 patients hospitalized for acute coronary syndrome claimed to obtain strength and comfort in religion<sup>17</sup>.

They also reported that, from the moment they instituted spirituality/religiosity in their lives, this provided changes in behavior and in the relationship with other people as well as self-acceptance. A qualitative study, with a phenomenological approach, which interviewed 14 people, highlighted that spirituality, for most of them, was a powerful force and an "enabling motivator". The meaning of suffering, the finitude of life, and the increase in spirituality have led to personal transformation, altering perceptions and behaviors towards oneself and others. This experience of change influenced the sense of identity and instigated thinking, feeling, and doing. This resulted in a transformation, which led to a change of character, direction, and loving actions and caring attitudes18.

Spiritual care has been shown to be significant as a coping strategy in health interventions,

thus providing us with a basis to incorporate spiritual/religious interventions in the nursing process of people undergoing dialysis treatment, with the aim of promoting positive coping and improving their quality of life.

### **FINAL CONSIDERATIONS**

This study revealed that spirituality/religiosity can lead to behavioral changes, interpersonal relationships, and self-acceptance. Therefore, as it is inherent to the nursing professional to provide care to the patient in its entirety, it is worth including spiritual care in the systematization of nursing care in order to relieve their suffering, considering the individual experience of each human being.

These findings provide subsidies for health professionals working in dialysis services to address the spiritual/religious needs of patients.

Because this is a qualitative sample and that important information was collected in a single interview, we cannot affirm or generalize the results for the entire population with ESRD undergoing hemodialysis treatment.

New research is suggested, from this study, in other services to explore the ways in which people with chronic diseases with severe comorbidities use spirituality/religiosity/religion to cope with the difficulties imposed by the disease and to subsidize the construction of nursing care protocols, securing the implementation of the spiritual approach in care. New discussions and studies can be addressed in similar audiences and in different cultures, expanding knowledge and supporting science in the construction of effective interventions in the dimension of spirituality.

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