


# Understanding the Experience of Spirituality of Patients on the Waiting List for Organ Transplantation

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## ABSTRACT

**Objective:** To understand how the spirituality of adult patients on the waiting list for solid organ transplantation can be experienced. **Materials and methods:** Qualitative study was carried out with adult patients on the waiting list for solid organ transplants who used Facebook—a popular social network on the internet. Data were collected through semi structured interviews, conducted remotely with 8 participants, and analyzed using content analysis. **Results:** Three categories were found that express the experience of spirituality by patients waiting for solid organ transplants, namely: giving meaning to the difficult wait for the transplant, finding the strength to get through the wait, and cultivating good works and gratitude. **Conclusion:** The study made it possible to understand how patients waiting for a solid organ transplant experience their spirituality and how this influences the waiting process for treatment. For these patients, spirituality proved to be a powerful resource for coping with the adversities encountered while waiting for the transplant. We recommend that more studies be carried out to understand the spiritual experience better and seek to establish intervention strategies in this context.

Descriptors: Transplantations; Spirituality; Nursing; Tissue and Organ Procurement; Qualitative Research.

## *Compreendendo a Vivência de Espiritualidade de Pacientes em Fila de Espera para Transplante de Órgãos*

## RESUMO

**Objetivo:** Compreender como a espiritualidade dos pacientes adultos, que estão na fila única de espera para transplantes de órgãos sólidos, pode ser vivenciada. **Materiais e métodos:** Estudo qualitativo, realizado com pacientes adultos em lista de espera para transplante de órgãos sólidos que utilizavam o Facebook – popular rede social da internet. Os dados foram coletados por meio de entrevistas semiestruturadas, realizadas remotamente com 8 participantes, e analisados por meio de análise de conteúdo. **Resultados:** Foram encontradas três categorias que expressam a vivência da espiritualidade pelos pacientes que aguardam por transplante de órgãos sólidos, sendo elas: dando sentido à difícil espera pelo transplante; encontrando forças para atravessar a espera; e cultivando boas obras e gratidão. **Conclusão:** O estudo possibilitou compreender de que forma os pacientes que aguardam por um transplante de órgão sólido vivenciam sua espiritualidade e como esta influencia o processo de espera pelo tratamento. Para esses pacientes, a espiritualidade revelou-se como poderoso recurso de enfrentamento às adversidades encontradas durante o aguardo pelo transplante. Recomendamos que mais estudos sejam feitos, com o intuito de melhor compreender a vivência espiritual e buscando estabelecer estratégias de intervenção neste contexto.

Descritores: Transplante; Espiritualidade; Enfermagem; Obtenção de tecidos e órgãos; Pesquisa qualitativa.

## INTRODUCTION

Solid organ transplantation is a safe and effective treatment option to improve the quality and perspective of life for people of any age with end-stage irreversible chronic disease. Transplants are a significant advance for science, health systems and society. They are recognized as a curative therapeutic option for numerous diseases—that affect the kidneys, pancreas, liver, heart, lungs, and intestine.<sup>1</sup>

The transplant program in Brazil stands out, among other things, for the donor rate growth and the number of transplants performed in recent years. But, although the number of transplants has increased over the years, the scarcity of organs continues to be one of the biggest obstacles for transplant teams throughout the country because the demand for transplants has been increasing at a greater rate than the number of donations, leading to longer waiting lists.<sup>2</sup> According to the estimate made by the Brazilian Organ Transplant Association, between January and September 2021, there were 28,389 patients in need of a solid organ transplant - among them kidney, liver, heart, lung and pancreas—but only 5,141 transplants were performed—thus extending the waiting time for a transplant.<sup>3</sup>

This prolonged waiting period significantly impacts the patient's life and well-being, affecting the likelihood of recovery or response to transplantation, the nature and extent of sequelae, and impacting the lives of the family members involved. The worst situation occurs when, besides being extended, the deadlines are unpredictable.<sup>4</sup>

The uncertainties arising from this unpredictability hinder the planning of the lives of patients and their families, the performance of the health system, and the functioning of the productive system where these patients perform work activities.<sup>4</sup> For this reason, patients acquire different feelings and reactions when they are on the transplant waiting list, such as hope, anxiety, freedom, ambivalence, fear, guilt, and faith.<sup>5</sup>

Faced with these feelings and reactions, patients adopt different behaviors, which, we believe, can be influenced by their spirituality since it is one of the factors that determine the individual's opinions and attitudes, influencing their way of caring or being cared for.<sup>6</sup> Spirituality encompasses the search for personal well-being, psychological, spiritual, and personal relationships.<sup>7</sup>

In a previous study, we investigated the scientific production of the last decade regarding the relationship between religion and spirituality in the context of organ transplantation.<sup>8</sup> The results obtained showed that the literature already describes spiritual experiences and perspectives on the process of organ donation and transplantation; highlights the influence of religion and spirituality on decision-making when facing the process of donation and transplantation; and shows initial data pointing to religion/spirituality as a variable that influences the patient and caregiver in the disease and transplantation.

Although the findings of this review already show the influence of spirituality on patients in the context of organ donation and transplantation, we realized that studies exploring the spiritual dimension in patients waiting for solid organ transplantation still need to be made available in Brazil. Thus, the objective of the present study was to understand how adult patients on the single waiting list for solid organ transplantation experience their spirituality.

## METHODS

### Type of study

This is a qualitative study because it considers the experience from the point of view of those who live it.

### Place where the research was conducted

The research data were collected via the web, through the dissemination of the research through Facebook, a popular social network on the internet, which has a group called “Pre- and Post-Transplanted from Brazil”, whose members are adult Brazilians who are on the waiting list for solid organ transplantation. The research disclosure was made through an explanatory text about who the researcher was and the study's objective, accompanied by invitation to participate in the project.

### Population and sample

The study population of interest was adult patients on the single waiting list for solid organ transplantation who used the social internet networks. The inclusion criteria were: patients who were enrolled on the single line for solid organ transplantation, aged 18 years or older. The exclusion criteria were: medical conditions that prevented the patient from participating in an interview.

The participants were recruited using the snowball sampling technique, in which the first interviewees refer the next ones and these, in turn, refer others, and so on—until the proposed goal is reached (saturation point).

## Data collection

For data collection, an instrument consisting of sociodemographic data was used to characterize the participants, followed by a semi-structured interview, which was guided by the following questions: “How do you experience spirituality in your life?” and “What role does spirituality play in your experience of waiting for a transplant?”

The interviews were conducted remotely, through Google Meet and Skype platforms, and by video call through WhatsApp, according to the participants’ preference, with an average duration of 15 minutes.

The meetings were recorded, later converted to digital audio and submitted for download to a local electronic device. Any and all records were deleted from any virtual platform, shared environment, or *cloud*. Afterward, the interviews were transcribed by the interviewer to avoid the loss of significant data.

## Data analysis

The data were analyzed using the content analysis technique proposed by Laurence Bardin, who foresees three fundamental phases for content analysis: pre-analysis, exploration of the material, and treatment of the results—inference and interpretation.<sup>9</sup> In the pre-analysis phase, the interviews were transcribed, and a floating reading was performed. The coding, classification, and categorization procedures were adopted in the second phase of material exploration. In the third phase, results treatment, inference and interpretation of the data were performed.

## Ethical aspects

The research only began after approval by the Research Ethics Committee of the State University of Campinas, according to CNS Resolution No. 466/12, process no. 4.730.191 and CAAE: 42741721.1.0000.5404. In addition, data collection was only performed after the participant’s consent by signing the Informed Consent Form, which was sent through Google Forms and had, as a form of signature record, the option “I have read and agree to participate in the research” and “I do not agree to participate in the research.”

## RESULTS

The study was conducted with eight participants, most of whom were men ( $n = 6$ ). As for the organs to be transplanted, four participants were waiting for kidney transplantation, while the other four were waiting for lung transplantation. As for the waiting period for a transplant, the participant who joined the list the longest has been waiting for eight years, while the one who joined more recently has been waiting for two months. As for the religion of the participants, the majority called themselves Catholic ( $n = 3$ ), but Evangelical, Spiritualist, and Christian participants with no defined denomination were also interviewed. Table 1 presents a summary of the sociodemographic data collected.

**Table 1: Sociodemographic data.**

Age	Gender	Marital status	Education	Religion	Organ to be transplanted	Time of disease diagnosis	Time in waiting list
52	F	Single	Complete College degree	Spiritist	Kidney	10 years	8 years
62	M	Married	Complete High School + Technical	Catholic	Lung	8 years	2 years
51	F	Married	High school completed	Protestant	Lung	20 years	5 months
36	M	Single	High school completed	Christian without a defined religion	Kidney	4 years	3 years
47	M	Married	High school completed	Catholic	Lung	7 years	2 months
24	M	Single	Complete College degree	Catholic	Lung	8 years	5 months
45	M	Single	Up to 7th grade	Christian without a defined religion	Kidney	25 years (initial) 4 years (need for retransplant)	3 years
33	M	Single	High school completed	Evangelical	Kidney	9 years	2 years

The analysis of the interviews allowed the identification of three categories that express the experience of spirituality by patients waiting for solid organ transplantation: giving meaning to the difficult wait for transplantation; finding strength to go through the wait; and cultivating good deeds and gratitude.

## Making sense of the difficult wait for a transplant

Waiting for a transplant causes many repercussions in the patients, including feelings of anguish, fear and anxiety. Because of this, the participants find spirituality an important resource to give meaning to this period.

When reflecting on spirituality, the participants refer to subjects such as death, life, and its different situations, attributing to God's designs the meaning for all the events in their lives, highlighting the feeling of belonging to God and the conviction that the experience of the disease and the wait for the transplant are consistent with His purpose for their lives.

*My living belongs to God because if I am alive, it is with God, and if I close my eyes, it is also with God. [...] If the best of all that I say doesn't happen, which would be for me to live, it is because my time has come for me to leave, but I leave with God because I believe that at all times, He is with me. So, I have this peace, this firmness (Participant 3).*

*If God didn't want me alive, He didn't need to put any disease in my path, He would have already taken me. [...] So I see that I am alive, regardless of whether I get the transplant or not, it is because God still wants me on this plane here. The moment I don't want to, I'll go for any other reason (Participant 2).*

In this way, even if they do not fully understand, they abide by the will they believe to be beyond their control. In this sense, the participants allow us to apprehend that spirituality helps to have tenacity in waiting because it is something to be experienced by designs transcendent to their will—and not as a situation of punishment or injustice or a condition without a solution.

*I don't see this disease as a burden, I think it's something I have to go through. [...] I don't face it with that weight of suffering, of poor thing (Participant 1).*

*Because I have the disease, I don't blame anyone either [...]. It is not God punishing me, it is life taking a toll on me for smoking too much (Participant 2).*

Moreover, the contemplation of the process of getting sick, through the lens of spirituality, transformed the participants' view of life, its meanings, priorities, and the best way to live, helping them face the waiting process with more serenity.

*After I got sick, I enjoyed life more and valued things more (Participant 4).*

*In the old days, I couldn't accept being sick and giving up everything I liked, what I love to do [...]. So, this [faith and also antidepressant medication] helps me a lot. Today I accept myself the way I am, calm, that I need this lung, I need this transplant, I need it so that I can live, prolong my life, even knowing all the benefits and risks, so today I am with my mind very calm, you know? (Participant 6).*

And, just as spirituality influenced the transformation of the patients' view when facing the process of getting sick, being sick and waiting for transplantation also acted as a factor to strengthen the spirituality of these participants.

*The fact that I am in the pretransplant phase has not changed what I believed, I tell you, it's even the opposite, it has even strengthened what I believed (Participant 2).*

*I think that after I got sick, I became more religious (Participant 5).*

## **Finding the strength to get through the wait**

In addition to attributing meaning to the waiting period, the study participants also revealed that the experience of this dimension provides strength to face this process, using spiritual practices to tolerate and go through the waiting time.

Throughout the interviews, the participants brought reports that indicate faith and spirituality as important sources of encouragement and strength to face the long waiting period, stating that these concepts are configured as powerful resources responsible for keeping them on their feet during this difficult time.

*My faith keeps me upright and lifts me up (Participant 6).*

*Spirituality strengthens me to face all of this (Participant 1).*

*If I did not have this faith, this communion, it would be more difficult today (Participant 3).*

The respondents also found strength through hope in God, with the confidence that this higher being is taking care of everything; therefore, they feel impetus and firmness to face the waiting.

*Hope, I think [spirituality] helps to have hope. You always believe that there is something greater, do you understand? Because the doctors themselves say that they go a certain way, that there is no way they can do more than that, and we have to stick to what we believe, right? You have to hold on to God. (Participant 5).*

Although spirituality can provide firmness, encouragement and hope to the participants, in many moments, these patients are or have been afflicted by feelings of anxiety and anguish and, in view of this, another attribute associated with the experience of spirituality is the achievement of calmness in the face of difficult moments—peace in the face of the storm.

*I think it makes me calmer, it makes me calmer to know that while we are living, there is a being there that programmed all of life, that there is a superior being, a God, right, who is in charge. So, it reassures me (Participant 2).*

Through spiritual practices, the concrete and tangible realization of the actions that express spiritual beliefs and values, respondents find a reason to follow and a willingness to face the arduous wait. In this sense, all participants associated their religious practices with spiritual ones, evidencing the interrelation between the two concepts.

*Faith, I think, is the first step. When I'm down, I try to protect myself more, I try to meditate more, I try to do everything so that I don't offend someone or mistreat someone because of this treatment—which is not easy; I try to protect myself by meditating a lot, the Bible, praise, preaching, something that will enlighten me a lot, a social project... These things make me very happy (Participant 8).*

*I talk to God in gospel music [...] [I feel] a very good relief, a lightness so that I can face life with more lightness (Participant 7).*

## Cultivating good deeds and gratitude

Living spirituality during periods of uncertainty and suffering also pushes participants to look outward to the other or God. In this sense, even amidst the turbulences of the illness and the course of treatment, they find comfort in seeing reasons to be thankful to God.

*So, I thank God for all my history of struggle and many wonderful deliverances (Participant 4).*

In addition to cultivating gratitude, the participants are encouraged to look at their fellow human beings and somehow seek to help them through difficult times. As they share their journey with people facing similar circumstances or other suffering situations, they realize that they are, in so doing, helping others—which renews their strength and gives them reasons to go on.

*You practicing good is how you practice your spiritual the best you can (Participant 2).*

*I fight every moment, every second, I tell my story to other people so that they can move on and so that they cannot give up. [...] I helped many people through my story, and many people got out of depression because of my story and my testimony; now, I speak and give my testimony because I try to help others (Participant 6).*

## DISCUSSION

Spirituality has received increasing emphasis as an important dimension of health care. Its association with a better quality of life has become evident,<sup>10</sup> fewer depressive symptoms, and <sup>11</sup> shorter hospitalization time<sup>12</sup> and as a coping strategy.<sup>13</sup>

But while the consistent body of scientific work already developed in this area is notable, only some articles deal with the relationship of spirituality, transplantation, and organ donation. In a previous literature review study<sup>8</sup>, we found only 12 articles that addressed the topic, but none with a focus on understanding how patients on the transplant waiting list experience their spirituality, especially in the South American context—highlighting the unpublished results obtained in the present research, as well as the need to conduct further work in this context.

In our study, we verified that the participants find spirituality an important resource to give meaning to the waiting period for transplantation, relating spirituality to death, to life and its different situations, and attributing to God's designs the meaning for all the events of their lives. Similar results were found in two separate surveys conducted with patients diagnosed with leukemia undergoing hematopoietic cell transfusion, in which participants said they found meaning for their cancer in spirituality, as well as having their perceptions about death, life, and health affected by spirituality. The experience of illness can also bring strengthened faith in God and greater confidence in religious and spiritual activities, results that can be related to the findings of our study.<sup>14,15</sup>

The spiritual experience of patients on the transplant waiting list has proven to be an important resource to help them find the strength to get through the wait, to gain courage and firmness, calm and hope. Spiritual and religious beliefs have been described as important in adapting to the disease situation, proving to be a valuable resource for relieving pain and suffering.<sup>16</sup> The literature has shown an association of spirituality with the level of happiness, as well as positively correlating beliefs of hope and optimism.<sup>17,18</sup>

In this regard, a survey conducted with liver transplant candidates indicated that the greater the patients' religious and spiritual expression, the better the emotional function and the less the patients' concern about transplant-related issues.<sup>19</sup> We can infer that the body of literature is growing in pointing out that healthcare professionals should not neglect spiritual care as a fundamental integral of their caregiving actions.

Brazilian studies that investigated religion and spirituality in cancer patients also showed similar results, with both assuming an important role in coping with chemotherapy, helping to deal with palliative care, and proving to be a strategy to reduce anxiety.<sup>20-22</sup> Research with patients with lung disease indicates that religion and spirituality are associated with better mental health and emotional well-being, helping to cope better with the disease.<sup>23</sup> An integrative review on the benefits of spirituality in chronic renal failure patients, conducted from a survey of 26 studies, also brought, as a result, a category that highlights the benefits of spirituality/religion as a coping modality.<sup>24</sup>

Spirituality also presented itself as an avenue of encouragement and help to others. Participants reported spiritual comfort in sharing their experiences with others and practicing good works. Finding a higher purpose for living, a purpose for everything that happens, and being empowered by beliefs that transcend what can be understood propel patients to extend and offer the strength they have received to others.<sup>25,26</sup>

Gratitude, in turn, is the response of a mindset that recognizes blessings even during tribulations. People who consistently demonstrate gratitude in their lives tend to have better emotional performance and lower levels of stress and anger—evidencing the spiritual outcome that practices like these bring about.<sup>27</sup>

Considering this, we need to ask ourselves if health professionals have been adequately trained to access the spiritual dimension of patients since the content on this topic is scarce in the national curricula, emphasizing spirituality only in situations of death and dying. However, we understand that such a position needs to be revised to cover individuals throughout their life cycle and thus provide adequate care—not only at the end of life but also in situations of chronic illness and other contexts.<sup>25</sup>

## CONCLUSION

The study made it possible to understand how patients waiting for a solid organ transplant experience their spirituality and how this experience influences the process of waiting for treatment. For these patients, spirituality was a powerful resource for coping with the adversities encountered while waiting for the transplant.

Given the results found, there is a need for new studies that seek to expand the knowledge about the experience of spirituality in patients with chronic diseases and who are waiting for a transplant. It is also necessary to understand how health professionals have perceived and, above all, offered spiritual care and to understand spiritual experiences in other sociocultural situations. These are new directions of research that will contribute to the deepening of knowledge on the subject, which may point to paths of intervention and best practices of spiritual care.

## CONFLICT OF INTEREST

Nothing to declare.

## AUTHORS' CONTRIBUTION

Substantive scientific and intellectual contributions to the study: Rosa MS and Mendes-Castillo ANC; Conception and design: Rosa MS and Mendes-Castillo ANC; Data analysis and interpretation: Rosa MS and Mendes-Castillo ANC; Article writing: Rosa MS; Critical review: Mendes-Castillo AMC; Final approval: Rosa MS and Mendes-Castillo ANC.

## AVAILABILITY OF RESEARCH DATA

All data were generated or analyzed in this study.

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