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Exploration of the Spiritual Expectations of Patients in a Swiss Hemodialysis Center

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Abstract: Background: Whether hemodialysis patients want caregivers to discuss spirituality is poorly studied, especially in Europe. The goal of this qualitative study was to explore the spirituality and spiritual expectations of hemodialysis patients in a Swiss dialysis center. Methods: Semi-structured, qualitative interviews were performed by an experienced sociologist with dialysis patients in the ambulatory dialysis unit of the University Hospital of Lausanne. The interviews included a set of open questions on the role that spirituality plays in patients' lives, in coping with their illness and in the recent COVID-19 epidemic. All interviews were recorded, transcribed, coded and analyzed following the approach of content analysis. Findings: Twenty interviews were performed in 2022. In total, 14/20 patients practiced some form of religion (believers), four were agnostics, and two defined themselves as atheist. The majority (15/20) confirmed that spirituality plays a positive role to preserve hope and to manage the difficulties caused by the disease and its treatment; one out of four wishes to discuss spirituality in the hospital setting. The largest needs are related to social dimensions (isolation, loneliness, need to talk, financial problems). Their level of spirituality has not been impacted by the COVID-19 pandemic. Discussion: In this pilot study, spirituality in a broad sense was important for the majority of the patients, and a quarter of them would like it to be actively addressed by healthcare professionals. They also ask for more attention to social and socio-economic difficulties.

Keywords: hemodialysis; spirituality; religion; mental health; coping; COVID-19

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1. Introduction

Hemodialysis patients face not only physical challenges, but also psychological challenges and distress. Outside the field of nephrology, many researchers have shown that taking the dimension of spirituality into account in the care of patients can contribute to their well-being, as well as to better coping with the difficulties induced by the disease and the treatments [1].

This is, for instance, the case in studies exploring the role of spirituality for people with mental disorders [2] or with chronic pain [3]. Spirituality includes—but is not restricted to—religion. The literature on 'spirituality and nephrology' is limited [4]. Some observational studies focused on the role that spirituality plays in life satisfaction and the quality of life of hemodialysis patients [5], whereas others have suggested that the inclusion of spirituality in the care of patients can help to combat depressive symptoms and improve their quality of life [2]. Most studies on this subject have been conducted in the United States and Canada,

or in populations with a specific religious tradition [6]. Besides these examples, qualitative studies are rare. Whether the same need for giving more space to spirituality exists among hemodialysis patients in a European context remains an open question. The aim of this qualitative study was to explore the spiritual expectations of hemodialysis patients at the Dialysis Center of the University Hospital of Lausanne (CHUV, Switzerland).

2. Materials and Methods

This study was designed by a professional healthcare chaplain (ER), a sociologist (SM) and a clinical nephrologist (MP). The study was conducted using a qualitative socio-anthropological approach according to the COREQ criteria [7]. It used semi-structured interviews that were analyzed following a thematic content analysis approach [8]. The study was performed in accordance with the guidelines of the Declaration of Helsinki and approved by the Ethical Committee of the University Hospital of Lausanne (CER-VD 2019-01942). Each subject received written information about the aim of the study. Written informed consent was obtained from all subjects involved in the study.

2.1. Participants

Research participants were recruited among the patients of the Dialysis Center of Lausanne University Hospital (CHUV, Switzerland). Eligible patients had to be aged $\geq$18 years, have been on hemodialysis for more than 3 months, and speak French. Among the exclusion criteria were refusal to participate and incapacity to give informed consent. The predefined aim was to recruit a total of 20 participants. Recruitment took place over a four-month period, from 1 February 2022 to 31 May 2022. According to protocol, recruitment stopped when 20 patients had been interviewed. The information about the study and the consent form was provided to patients during the dialysis session by the clinical nephrologist (MP). The sociologist who performed the interviews (SM) was introduced to the patients by the clinical nephrologist (MP). Patients were then given a minimum of 24 h to make their decision. Hereafter, the research collaborator (SM) contacted patients by telephone or in person during their next dialysis session to collect their responses. If the patient wished to participate, he/she was asked to bring the signed consent form to the next dialysis session.

2.2. Data Collection

The data were gathered through semi-structured interviews that were recorded with a dedicated device and performed by an experienced sociologist (SM). The 20 interviews took place between February and June 2022. The interviews had an average duration of about 45 min and were conducted in three different types of settings, depending on the wishes and availability of the patients:

- directly at the patient's bedside during dialysis sessions (six interviews).
- in an office located in the building where dialysis is performed (outside the sessions, 11 interviews).
- at the patient's home (outside the sessions, three interviews).

Questions were based on an interview guide that was inspired by FICA/SPIR [9] and HOPE [10], two established tools to discuss with patients the role of spirituality in the framework of healthcare systems. The interviews investigated three main themes that were pre-defined: (1) the role that spirituality plays in the patient's life in general, and in relation to their illness; (2) the (lack of) resources for patients to face their illness (coping strategies, social network); (3) the impact of the recent COVID-19 pandemic on their life in general, and more specifically on their spirituality. A summary of the pre-defined interview guide is shown in Table 1.

Table 1. Interview questions.

- Do you have any spirituality, religion, beliefs or interest in existential questions in the broadest sense? If so, which one(s)?
- What place do you attribute to it/ them in your life? What about the context of your illness and treatment?
- What do you hold on to in difficult moments?
- What are your spiritual and/or religious practices? What do they bring you in the context of your illness?
- How are you surrounded? Do you belong to a group that shares your beliefs or activities?
- Has your current state of health brought about any changes in the way you live your spirituality?
- Would you like healthcare professionals to take note of what you've just told me, and if so, how would you like them to take it into account in the future? Within the hospital, whose role do you think it is to be concerned about your expectations, if any?
- How did you experience the confinement and restrictions caused by the COVID-19 pandemic? Has it changed your spiritual and/or religious practices?

2.3. Data Analysis

All interviews were recorded and then transcribed by SM. The first round of analysis led to a first selection of thematic codes to be explored. This selection was completed following an inductive approach. Transcriptions were then coded with Atlas.ti version 22 qualitative analysis software, according to thematic analysis [8].

3. Results

Of the 80 patients treated at the CHUV dialysis center, 28 were excluded because they did not fulfill the inclusion criteria. The study was offered to 27 consecutive patients, of whom 20 agreed to participate. Seven persons declined; reasons were a lack of interest or confidence in the research project, unwillingness to share one's intimacy or family members blocking the process. Interviews were completed without drop-outs in all included patients. As predefined in the protocol, recruitment stopped thereafter.

The mean age of the 20 participants was 62.5 years, and 40% were women (see Table 2 for baseline characteristics). Fourteen defined themselves as believers, four as agnostics and two as atheists. This corresponds to the Swiss average of 65.4% believers, 17.9% agnostics and 15.1% atheists [11]. Among the participants with religious denominations, four were Catholic, six were Protestant, three were Evangelical and two were Muslim.

Table 2. List of participants and their characteristics.

Patient	Age (Years)	Gender	Faith	Religious Affiliation	Vascular Access	Cause of Kidney Disease	Previously Transplanted
1	70	Female	Believer	Catholic	fistula	glomerulonephritis	Yes
2	83	Male	Believer	Evangelical	fistula	hypertension	Yes
3	52	Male	Believer	Catholic	fistula	other	No
4	66	Female	Believer	Protestant	fistula	other	No
5	60	Male	Atheist	None	fistula	diabetes	No
6	68	Male	Believer	Muslim	fistula	glomerulonephritis	No
7	68	Male	Atheist	None	fistula	diabetes	Yes
8	86	Male	Believer	Protestant	fistula	diabetes	No
9	72	Female	Believer	Protestant	fistula	other	No
10	76	Male	Agnostic	Protestant	fistula	diabetes	No
11	66	Male	Believer	Evangelical	fistula	obstructive uropathy	No
12	58	Male	Believer	Protestant	fistula	glomerulonephritis	No
13	69	Female	Believer	Evangelical	fistula	interstitial nephropathy	No
14	66	Female	Believer	Catholic	fistula	hypertension	No
15	78	Female	Believer	Catholic	fistula	obstructive uropathy	No
16	55	Male	Agnostic	None	fistula	glomerulonephritis	Yes
17	31	Male	Agnostic	None	fistula	glomerulonephritis	Yes
18	55	Female	Agnostic	None	catheter	other	No
19	30	Female	Agnostic	Protestant	catheter	congenital malformation	No
20	41	Male	Believer	Muslim	fistula	glomerulonephritis	No

3.1. Importance and Role Played by Spirituality in the Framework of Health and Its Treatment

Whether religious or not, a large majority (15/20) of the participants consider that spirituality helps to better face the difficulties caused by the disease and its treatment.

There is great diversity in the role attributed to spirituality by the participants in relation to their illness and treatment. Three main trends can be distinguished.

Seven patients consider that spirituality does not play any role regarding their illness and treatment. These patients rely fully on medical treatment, which is seen as the only source of safeguard. The family often represents a crucial source of comfort for these people.

Nine participants rely on spirituality to help them cope with their situation. Their spirituality allows them to make sense of what they are going through and brings them serenity. It is also a way to express gratitude. This is, for example, the case of patient 13, who asks "God for blessing for the dialysis" and expresses her gratitude to God by stating:

> "I bless God that there are still nurses (. . .) I bless that these machines exist (. . .) I bless God that dialysis is common."

For these patients, spirituality is a source of appeasement which is distinct and parallel to the medical dimension.

A third group of four patients not only rely on spirituality as a coping resource but also consider that medicine and divine action are intimately connected. Their confidence is based on the belief that their treatment depends on God's will and that the healthcare team is guided by God's hand. This is illustrated in particular by the following words of patient 2:

> "When I go to the dialysis center, I recommend my day to God through prayer. The work that is done in dialysis to purify my blood: I know that it is God who gives the doctor this understanding, this intelligence. Medicine is an instrument of God. And sometimes I pray for the doctors."

Patient 11 considers that "it is the Lord who gives knowledge to the healthcare team and gives them the strength to fight for the patients, to make them better". According to him, divine support for medical teams can be increased through prayer.

3.2. Coping Strategies: What Helps Patients Face Illness

Four main trends emerge in the way patients cope with hardship: While eight of them (a) build mostly on the support of their relatives, eight other patients (b) rely mostly on their beliefs and/or faith. Those who have grown up with the disease (2/20) (c) manage to put it into perspective by describing their situation as normal, having never experienced anything else. Finally, two patients (d) manage to relativize their illness experience in relation to worse illness situations experienced by others.

Almost half of the study participants (eight patients) specifically mention the importance of support from family and/or friends They explain that they want to stay alive for their loved ones, as in the case of patient 3 who states:

> "It's not for me [that I struggle]. It's for my family. It's for my children. You know, I'm suffering a lot but I'm not alone. And so I have to stay here. I am a warrior."

Patient 18 explains that she has taken information about assisted suicide but has not resorted to it "at the last moment". She explains having changed her mind thanks to the presence of her children which "boosts her a bit" and convinced her not "to let herself go".

For eight patients, faith and spirituality play a central role. By linking their experience of illness to their faith, they achieve acceptance mechanisms (coping strategies) [10]. This is the case of patient 15, who states:

> "When you believe in something, it helps a lot to bear the disease. Coming to dialysis three times a week is not always fun. I leave my husband alone. We can't travel anymore. But I tell myself that I am lucky to be able to live anyhow. There is a good God who helps us."

For four patients, faith in God contributes to their emotional regulation. This is the case of patient 2, who states that he knows "that he is not alone" and considers his illness as "a test that is part of his vocation". His faith leads him not to be "without hope and not to be disoriented". He feels "loved by God", who "supports and encourages him".

Among the research participants, two have grown up with health problems and sometimes had to resort to dialysis before adulthood. They both mention that having struggled for years with the disease strengthens the ability to resist difficulties.

According to patient 16, it is more complicated for "someone of a certain age" to begin dialysis than for someone who started as a child. He explains: "after a while, you say to yourself, this is it. When that's all you've known, that's normal". Growing up with the disease confers a deep experience of it and a form of mental mastery, which is transformed into resilience.

In a different register, two patients manage to better accept their situation by relating their health problems to difficulties experienced by others. A particularly striking example is that of patient 17, who has a family member with cystic fibrosis. This leads him to relativize his own health problems.

Patient 16 also puts his own situation into perspective compared to others who are experiencing worse. He recalls the mental process that led him to gradually overcome the feeling of injustice:

> "With time passing by, you become resigned. The first few years, I said to myself, 'Why me?' Afterwards, you hear about people who have heart problems. Either they get a transplant right away or they die. There is no alternative. (. . .) At some point, you put it into perspective. It's not fair but I didn't get the worst of it."

3.3. Social Network and Spiritual Community

The participants range from people seeing their relatives on a daily basis to individuals living in great loneliness, sometimes only interrupted by interactions during dialysis sessions.

Fifteen of the research participants are either well cared for or cared for, whether by a close family or close friends. Their environment plays a central role in their emotional regulation and mental stability. Some of them have the possibility of having even more social contacts but limit them. They want to avoid being a burden to their loved ones at all costs and are reluctant to contact them or to ask for help. This is, for example, the case of patient 5, who explains:

> "Each [of my children] has his job, is married. They come maybe once a week on Sunday. I am well surrounded with family and even friends. I wouldn't like to give them any more burdens, to explain my problems to them. I would like them to live a normal life (. . .) I don't like to worry about my health. I try to bear it myself."

The study shows that five of the research participants are socially very isolated. They have either broken contact with their families or they rarely see them.

For some, dialysis sessions represent rare moments of social interaction. In contrast with the majority of patients for whom dialysis sessions are a constraint, they experience these fixed weekly moments rather positively as they represent a kind of valve to their drift of social isolation.

3.4. Impact of the Evolution of the Patient's Health Condition and the COVID-19 Pandemic on Life and Spirituality

Some participants describe their illness, and in particular the start of dialysis, as an existential crisis that has led to changes in their beliefs or spiritual practices. This is the case of patient 8, who states: "You know, dialysis, you are hanging on a thread. If they cut the thread, you don't have long to live. And that makes you think."

Yet only a few participants consider that the evolution of their health condition has greatly impacted their spiritual practice. This is the case of patient 12, who describes this evolution as follows:

> "(the illness) made me increase my prayer life even more. Being sick, living on medication for life. For those who don't have faith in God, it is worrying and that makes the problem even worse. I live away from worries because I know that he [God] wanted me to be sick. It is nature and I accept it."

With regard to the COVID-19 pandemic, the research participants generally did not experience it as something dramatic; for them, dialysis sessions continued to take place, and their daily lives were only partially affected. As patient 3 stated: "I have a disease that can kill me every day for the last ten years. Do you really think I'm going to bother being afraid of COVID?"

They view their experience of illness as something that makes them stronger and more resilient in the face of this new threat.

3.5. Need for Spiritual Support and Other Concerns

The need for spiritual support is not the most urgent or important requirement for patients, even for those patients who have a spiritual practice. Most patients (15/20) do not wish to discuss the topic of spirituality in the hospital setting. Moreover, patients with a spiritual practice generally want to keep this dimension in the private sphere.

The topic of spirituality is often described as difficult to discuss in the hospital setting. Seven participants mention that the frequent rotation of healthcare workers and their lack of time raises barriers to talking about spirituality and adds additional stress.

Some patients mention a "taboo" on the subject. Patient 3 describes the situation as follows:

> "I think everybody is a bit scared of death here. You know, if anyone is on the verge of death, it's us. I've had a sword of Damocles hanging over my head for ten years. I can snap from one day to the next like that [snaps fingers]. We live with a sword of Damocles hanging over our heads. We don't know how to talk about it."

Some patients mention that stopping treatment is also a topic that is difficult to speak about with the medical team. This issue, for example, comes out in the testimony of patient 2, who wishes to have the opportunity to express himself more about his apprehension about the end of life:

> "I remember once I said [to myself] I can't take it anymore. I want to go away. Yes, I admit it. I had doubts. So I think that if there was a possibility to express it, then people would use it. We have to feel that it is possible [to express such ideas and emotions]."

The most important and/or urgent needs are mainly related to social (isolation, loneliness, need to talk) or economic (financial problems, life limitations due to low income) dimensions.

This idea is found, for example, in patient 3, who considers that dialysis patients would benefit from moral support but that their most urgent need is on another level:

> "Most people who are on dialysis have no money. Most people on dialysis used to have an active life and they don't have an active life anymore. They are people who suffer. Do you think they have a place for God? They don't have time to think about that."

Continuing, patient 3 suggests that "more than listening" or spiritual support, it is "social support" that patients need most. It is to be able to count on the presence of "someone who can talk with you about everyday problems". He expands on his own case:

> "I'm lucky, I have friends but there are people here who are alone. You know, they are silent here. Silence kills. I'm not a silent person, it's not my character. If it's not right I'll tell you. But silence kills people."

4. Discussion

The majority of participants in this study (15 out of 20) consider that spirituality can play a positive role in coping with their kidney disease and its treatment. However, most prefer to keep it in a private setting, whereas one out of four participants expressed the desire to speak about their spirituality with caregivers. There is a general wish for more attention to their everyday socioeconomic problems.

Several studies have shown that dialysis patients are subject to many stressors. Their quality of life is also lower than that of patients with other types of chronic diseases [12]. Nevertheless, as stated by Finkelstein FO et al., "few studies have looked at specific treatment strategies to improve the symptoms of these patients" [13]. As far as Switzerland is concerned, to our knowledge, no study has investigated the potential role of spirituality in this context.

Previous studies suggest that taking the spiritual dimension into account is potentially beneficial in many cases. As observed by Tanyi and Werner, patients' spirituality helped them "in their coping and adjusting to ESKD [=end stage kidney disease] and HD [=hemodialysis] treatment" [14]. Pilger C et al. suggested that healthcare teams should take spirituality into consideration more often as a way to improve patients' quality of life [15].

Our study shows that faith and spirituality play a central role for a part of the participants (8/20). Half of these patients achieve acceptance mechanisms (coping strategies). Spirituality contributes significantly to their emotional regulation, for example by limiting their fear and anger. This percentage is in line with the population survey performed in 2019 by the Swiss Federal Office of Public Health, reporting that 44% of the Swiss population considered that spirituality played an important role during illness [11].

The difficulty that arises is that spirituality is seen as "largely a private matter", as the majority (15/20) did not wish to speak about spirituality with caregivers in the dialysis ward. Similar results were seen in a previous study on quality of life (including private matters such as emotional wellbeing and sexual life) in Swiss dialysis patients and the perception of nurses [12]. In a different context, a Swiss study that included 209 patients with chronic pain reported that more than 60% wanted to address spiritual aspects in their treatment [3]. Hence, there may be a tension between getting the patient to speak about their intimacy while respecting it in the busy dialysis unit, where privacy is an issue. According to Monod-Zorzi, entering patients' spiritual intimacy requires a careful and clear approach, which must be carried out by a person with the skills and dedicated time to do so [16].

At the level of care, we observed that the rotation of caregivers induces additional stress in a significant proportion of patients and potentially weakens the bond of trust between patients and caregivers, which is key to discussing their intimacy. In accordance with Deal and Glassey [17] and Bornet MA et al. [18], we observed that this is further increased by the medical team's lack of available time to exchange with patients on non-technical matters. This may be an incentive to provide more time in the work schedules

of caregivers for this essential exchange, or to more frequently involve other persons such as social workers. Alternatively, the presence of a person not categorized as a medical staff member may be an interesting option [19]. This person could also address patients' wider socio-psycho-economic issues [20]. This could also be a way to lighten the burden of informal caregivers such as family and friends, who are at increased risk of physical and psychological stress because of their caregiving role for dialysis patients [21]. We believe that there is a need for more studies to better characterize the socio-economic and psychological problems of the fragile dialysis population, and to investigate the different ways to address this issue.

This study has certain limitations. It is a qualitative exploratory study which does not aim to be representative for the entire Swiss dialysis population. Patients on peritoneal dialysis were not included in this study. Finally, the number of nephrology patients is limited and concerns a single center (CHUV). However, despite the limited number of participants, data saturation occurred. Several major themes emerged, and similar patterns were identified.

5. Conclusions

Taken together, this study aimed at understanding patients' needs regarding spiritual support in a Swiss hemodialysis center. Most patients, whether affiliated to a religion or not, emphasized the important role that spirituality can play in accepting their illness, maintaining hope and coping with the consequences of the disease. This sheds light on the potential of spiritual resources for producing sense and hope in this framework. This result also encourages further research on how to integrate this resource for empowering the patients. However, the need for spiritual support is not among the research participants' most urgent needs. Nevertheless, patients that wish to address spirituality should be given this opportunity, considering the positive impact this resource may have on their wellbeing.

We also observed that neither the evolution of the patients' health nor the COVID-19 epidemic decisively influenced the level of religiosity or the relationship to spirituality of the participants of the study. Research participants' most important and/or urgent needs are related to the social dimension (loneliness, need to talk) and to socio-economic aspects (financial problems, life limitations due to a low income and high auxiliary costs). These socio-economic dimensions, and how to address them, are largely unexplored in dialysis patients and need more attention in future studies.

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Data Availability Statement: The datasets used and analyzed during the current study are available from the corresponding author on reasonable request. In order to protect patients' privacy, available data include the minimal dataset that is needed to replicate the findings of the article. Fully transcribed interviews are not available.

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