



# Spiritual Dimension at the End of Life: A Phenomenological Study from the Caregiver's Perspective

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## Abstract

The lives of healthy and sick people are structured according to a variety of conceptual matrices. One of these matrixes consists of philosophical, spiritual, and religious convictions, being this especially relevant in the process of the end of life. The objective of the study is to understand the meaning that individuals at the end of life and the relatives of such individuals award spiritual and/or religious beliefs through an examination of caregiver narratives. Multicentric study was developed that used a qualitative design and a phenomenological approach. The study was conducted in the autonomous community of Andalusia, specifically in the provinces of Almeria, Malaga, Seville, Granada, and Huelva. The selection method was purposive sampling. Caregivers who had lost a relative in a period between 2 months and 2 years previously and who were not in a process of pathological grieving were selected for inclusion in the study. The method involved five discussion groups and 41 in-depth interviews, with a total of 87 participants. A change of paradigms is necessary in which, among other elements, the focus of palliative care is centered on the ability to address these spiritual needs, and healthcare professionals are trained to assist in the provision of such care. Another important consideration is the inequality of spiritual supported provided by clergy from various religions. At least in the cultural context of the research, Catholic chaplains were the only institutional figures whose presence was assumed necessary by health organizations. However, the cultural and/or religious diversity in the autonomous community in which the study was conducted is increasingly broad and complex. It appears necessary to incorporate a variety of clergies in health units so that all patients may find support, whether in terms of companionship or celebration.

**Keywords** Care · End of life · Spirituality · Religion · Informal caregivers · Phenomenological study

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## Background

The lives of healthy and sick people are structured according to a variety of conceptual matrices whose interrelations constitute the complexity and multidimensionality of human existence (Torralba 2005, p. 361). One such matrix consists of philosophical, spiritual, and religious convictions. Convictions determine the values and meaning that everyone awards his or her life, and in the case of a terminal illness, such convictions hold specific meanings for each individual that link one's fundamental beliefs and the social context (Beger and Luckman 2012, pp. 35–41). Beliefs regarding death have been transformed in relation to historical and cultural evolution from the custom of dying at home under the control of the dying and his or her family to a medicalized death, which primarily occurs in health institutions and under the control of healthcare personnel (Aries 1999, pp. 484–488). Against this backdrop, one could conclude that death has become taboo and that anything related to death has been transformed into an uncomfortable truth that must be shunned (Jankelevich 2002, pp. 35–37). As Jankelevich (2002) states, death has an ecumenical nature; it does not distinguish beliefs and reaches everywhere and everyone (pp. 35–37).

Numerous studies have found that religion and spirituality represent effective defense mechanisms for patients and family caregivers (Sherman et al. 2018). In addition, accepting and discussing spiritual and religious needs have been found to have a highly positive effect on the patient and the patient's family (Hatami-pour et al. 2015). The sick more frequently expresses their physical pain or discomfort than their spiritual suffering (Petee 2012).

Therefore, it seems evident that it is not possible or ethical to provide quality health care during the dying process if that health care does not embrace all aspects of the human person, including spirituality (Rosa et al. 2017). Numerous authors recognize the importance of the spiritual dimension at the end of life (Roze et al. 2018; Kastbom et al. 2017; Renz et al. 2015) as aid in helping the dying individual overcome or mitigate suffering and spiritual pain (Rosa et al. 2017; Rodrigues 2011). Religion and spiritual life seem closely related to health, particularly (but not only) regarding resignation toward disease and life quality, whether during the drawn-out terminal stage of an illness or shorter periods of convalescence (Jim et al. 2015). That is, spiritual well-being, particularly in the sense of finding meaning and peace, is fundamentally related to the ability of patients to continue enjoying life despite high levels of pain and fatigue (Araújo and Olivia 2017; Buonaccorso et al. 2018).

The experience of death's proximity can trigger a great personal revolution, an internal turmoil that bears little resemblance to prior experience. Following Cobo-Medina (2000), one can state that the so-called "personal uninstall" affects all dimensions of the individual. In these moments, the dying undergoes what is termed the "final existential crisis". This crisis concerns a search for life's meaning, an appreciation of one's novel life in light of the circumstances. This search for values, which involves reviewing one's life course as if examining it in a mirror, reshapes one's life (Roze et al. 2018). A truly peaceful death requires balance

and reconciliation. For believers, an encounter with the Supreme Being is also highly important, i.e., to search for God, whoever He may be, to meet with Him, and to receive forgiveness and consolation (Renz et al. 2015).

In this sense, within the multidisciplinary healthcare team, the nurse plays a fundamental role because of the relevance of the competences he or she represents in terminal situations (Rejnö and Berg 2015). Nightingale said, “caring for the soul should never be separate from caring for the body. She was very clear that nursing and all healthcare practices are indeed spiritual practices and a human service that bonds us to something greater than ourselves” (Macrae 1995). The key, therefore, is to somehow get away from the focus on the disease and from a clinical–medical view to embrace and honor the mystery of the human soul (Rosa et al. 2017; Wiklund and Wagner 2013).

As care experts, we cannot ignore the spiritual dimension of human life because spirituality promotes resilience or coping and increases quality of life (Guirao-Goris 2013). To be able to foresee the spiritual needs of their patients, healthcare professionals must be aware of and comfortable with the spirituality of the patients (Hold 2017; Sanders 2002). However, recent research confirms a lack of preparation and knowledge in this aspect of palliative care (Kim and Hwang 2014). Similarly, a lack of time and training in the caring relationship hinders healthcare personnel from providing the requisite spiritual care (Pinedo-Velázquez 2011).

Therefore, the influence of beliefs and religious and/or spiritual revelations in the dying process of the terminally ill and their families are factors require careful investigation. This study arises from an awareness that an increase in research in this field and in spiritual aid practices and the application of the outcomes of that research may favor a peaceful death.

## Objective

To understand the meaning that individuals at the end of life and the relatives of such individuals award spiritual and/or religious beliefs through an examination of caregiver narratives.

## Research Design

A multicentric study was developed that used a qualitative design and a phenomenological approach. The phenomenological method aims to understand the phenomena of consciousness and experience to comprehend the reasons and beliefs behind people’s actions (Van Manen 2003). An emergent design whose main feature is flexibility was adopted. This design facilitated combining different elements of the research process interdependently without having to wait until the examination of one element was complete before moving forward to the next one.

The data collection period was from January 2013 to June 2014, and the analysis was conducted from January 2013 to December 2016.

The method involved five discussion groups and 41 in-depth interviews, with a total of 87 participants. Table 1 shows the general sociodemographic characteristics of the study participants.

The number of discussion groups and the number of study participants depended on the desire to include participants proportionally from different areas of the autonomous community of Andalusia and data saturation. The discussions and interviews were performed by research team and nursing professionals who were previously trained and had not been in prior direct contact with the participants. First, the discussion groups and analysis were conducted, which enabled us to establish the most relevant topics for a question script for use during the interviews. The group discussions lasted 60–90 min and were held at various healthcare centers or hospitals. In addition, a second investigator was requested to record any exceptional incident that occurred during the discussions in a notebook. This researcher was unaware of the healthcare status of the participants. Subsequently, interviews were conducted in health centers, care centers, hospital consultation rooms, and the participant's home if travel to a health center was impossible. The interviews lasted 45–60 min. Different narratives that resulted from each approach were recorded in audio format for later transcription and analysis with the informed consent of the participants and their voluntary collaboration.

In the analysis, a phenomenological-hermeneutic-interpretive method was adopted based on Van Manen (2003).

Next, the narratives were transcribed and a comprehensive reading was performed. Then, based on a second reading, most relevant categories were extracted and grouped according to broader dimensions. Finally, the content of each category and dimension was interpreted and described. In the narrative analysis, Atlas.ti 6.0 computer software was used.

For the validity analysis, contrasting through methodological and subject triangulation was used to control the heterogeneity biases of the data and those stemming from the diverse views of the informants.

## Participants and Research Context

The study participants were primarily family caregivers who had recently suffered the loss of a beloved relative and had been firsthand witnesses of their relative's experience and circumstances. The study was conducted in the autonomous community of Andalusia, specifically in the provinces of Almería, Málaga, Sevilla, Granada, and Huelva. The selection method used was purposive sampling. Caregivers who had lost a relative in a period between 2 months and 2 years ago and who were not in a process of pathological grieving were selected for inclusion in the study. Caregivers who did not meet these criteria were excluded. To locate potential informants, participation in the research was requested from those who had lost a relative. Subsequently, the caregiver was informed of the inclusion and exclusion criteria. Feedback was exchanged between the researchers and nursing professionals regarding the coordination and selection of study participants (See Table 1).

**Table 1** Sociodemographic variables

	Gender		Relationship			Death place				
	Man	Woman	Spouse	Son	Father/mother	Others	Home	Hospital	Public road	Other
Discussion group <i>n</i> =40	6	34	7	25	1	7	18	19	2	1
Interviews <i>n</i> =41	5	36	12	19	2	8	17	23	1	0

## Ethical Considerations

This study adopts the seven research ethical criteria for qualitative research established by Enmanuel and Enmanuel (1999) and adapted by Barrio-Cantalejo and Simón-Lorda (2006): social value, scientific validity, favorable risk–benefit ratio, informed consent, respect for the participants, independent evaluation, and equitable subject selection.

During the project development, the main ethical question involved the selection of the participants and informants. From the researcher's perspective, when gathering knowledge regarding the experience of individuals at the end of life, it is best to do so in collaboration with the actual protagonists of such experiences. In this case, we respected the vulnerability of our subjects, and although truthful, firsthand information was valued, and the importance of collecting such information was weighed against the importance of protecting the vulnerability of those who were dying. Therefore, another type of informant was required who without being the actual dying protagonist could act as a first-order witness and who, expanding the knowledge field, could provide the personal background required to enhance the narratives.

It was important to preserve the confidentiality and privacy of the participants. Therefore, we followed the recommendations of the Research Ethics Committees of the various Andalusian provinces, who examined the project. Potential informants were contacted through case management nurses (CMNs). Based on advice provided by the research team, these nurses selected individuals who could be good informants and could provide information regarding different ways of dying in Andalusia. The CMNs requested the informants' permission for the research team to contact them by telephone to arrange an appointment, either for an interview or to participate in a discussion group. Only if permission was granted and under the conditions of confidentiality, privacy and voluntary participation did the contact process begin.

Finally, among the inclusion/exclusion criteria considered was the initial shock that grieving individuals experience. Therefore, informants whose relatives had died during the preceding 2 months were excluded. In addition, to avoid reviving unresolved or pathological conflicts, any potential informant whose relative had died more than 2 years previously was excluded. On several occasions, it was necessary to reject an informant with a wealth of information on the death experience.

Another ethical consideration that was carefully adhered to throughout the development of the project was that no harm would be caused to any interviewee or discussant. In this regard, the active listening and validation of the informant were ensured. To this end, all researchers underwent accredited training on grief and grief management support groups. In all cases, the participants acknowledged that they felt welcomed and listened to, and in some cases, the participant considered the research participation therapeutic.

The research team obtained the appropriate permits from various research ethics committees of all the provinces in which the study was performed (code: S0362). At all times and regardless of research technique, informed consent was obtained from the subjects, and confidentiality and anonymity were maintained. In addition, the participants were informed in advance of the study's objective, and the bioethical

principles of the Helsinki Declaration were fulfilled. Similarly, the data obtained from various narratives was treated in a manner that complied with current regulations regarding the protection of personal data. Once the study was complete, the recordings were archived in the documentary collection of qualitative materials Memories Archives of the Index Foundation. After seven to 10 years from the completion of the investigation, the original material will be destroyed.

## Results

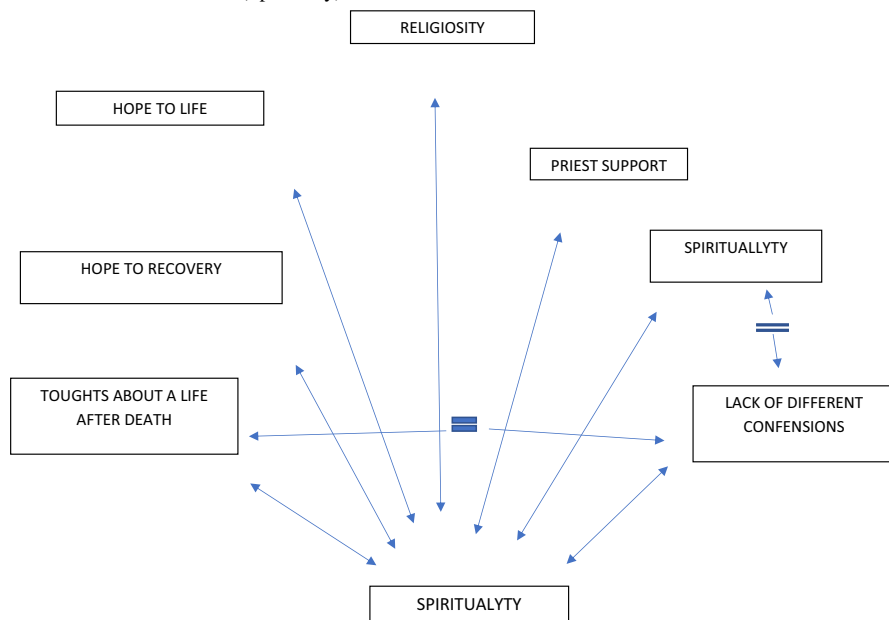
Caregiver's narratives about spirituality were differentiated into two main blocks: those that refer to the meaning of spirituality for the patients they accompanied and those related to their own perception of spirituality based on their personal experience as caregivers. Both visions are important when attempting to understand the spiritual process that is lived in the terminal illness in the family unit; to deepen each one, however, we present separately both perceptions (See Table 2).

### Spiritually According to End-of-Life Patients

#### Spiritually Reduced to Christian Dimensions

This research was development in an environment that continues to be primarily influenced by Christianity, and it is strengthened by many religious

**Table 2** Net codes Atlas Ti (Spirituality)



popular experiences (e.g., festivities and celebrations). Therefore, it is logical that most spiritual narratives referred to the Christian God. Such a belief was occasionally expressed in the form of religious images, whose presence was essential for psychological security at certain points of the disease.

“He always carried his crucifix and his chain; yes indeed, yes indeed, he could not be without it. If he went through a surgery or something, he said, indeed, where is my Christ? Indeed, for him, his Virgin from here of the Angel and his Christ. (E2)

The accompanying figure of the spiritual dimension (religious at this moment) is centered on that of the Christian priest. In the discourse, no signs of other professional interventions are found regarding spiritual support; however, the strangeness of the informants of this situation does not appear either. It seems accepted that only religious leaders are responsible for the religious expression of the spiritual dimension.

“...but, he chatted with the priest, they spoke several times, and said ‘Well, we talk about my things, about my people’”. (E5)

A: Did she ask you for a priest?

B: Yes, I mean... most recently, when the priest came, already...I mean, it was twice ... the day before she died, and the day she died, she asked for him again in the morning.... Yes, she was... every time she was admitted, he went to give her communion... because she was, as I said, a strong believer.... She was not pious, she was a believer... really. (E3)

In the context of the Christian faith, discourses emerged that suggest that the non-acceptance of the ecclesial institution can nevertheless accommodate a deep belief in the Christian God and/or the values that form the basis of various religions, such as love, solidarity, or justice. This ambivalence between the adherence to the embodied values of the Christian God and the discrepancy with the structure that sustains the ecclesial institution was recorded in the informants’ experiences.

Even in such cases in which the absence of a bond with a religious institution and/or an aversion to such institutions is apparent, in the final moments of life, the approach of and a relationship with clergy may be accepted within the context of an intimate, comprehensive conversation that helps connect with the life story

He was a believer in a very strange way. He did not believe in the church [or] in the priesthood, but strongly believed in doing good, the right thing, the unfair things that his parents did weren’t fair, and he was the rebellious son because he always told the truth, except he was not a good speaker. (E8)

Several narratives included complaints regarding the lack of spiritual support from representatives of various religious communities for patients of different religions and their caregivers. In the study areas, the right of spiritual accompaniment is recognized in the law of April 8, 2010. However, there is only one Catholic Church-State agreement that provides for resident priests in health institutions.



Real support, no. Here he comes... there he goes... a healer comes in, a priest, and since I am raised on the Bible, I am a Jehovah's Witness, and, well, I am just not...considered... Sure, because to me at the time he realized I was a Jehovah's Witness... since I study it, he did not even approach me and just asked her my name, and that was it... And then, there was my mother... my mother had her eyes open still and could speak; she could communicate. My mother was still speaking and still communicating, but this man, no.... (E1)

### **Believing in God and in a Life After Death is a Support and Source of Hope**

The caregivers expressed that believing in God was an important support during the course of the disease and the dying process. In addition to the family and health professionals involved, this belief represented a resource for sustaining hope in life and a foundation on which the experience of illness was based.

A: Yes, he was a real believer

B: Do you think that it helped?

A: Yes of course, like [it helped] me. He was a real believer. (E2)

It was common to hear from sick individuals at the end of their lives expressions that suggested that they believed in life after death. One could even hear a positive assessment of and desire to embrace the “other life” as the progress of the disease and physical deterioration combined to deprive a meaning of existence.

When he said goodbye to me, he said that he was going to be more useful up there than here, that here he did nothing. (E8)

He didn't go out much in his wheelchair, and, well, in the last months of his life, he would ask God to take him away. When he said he wanted God to take him, it meant he believed in God. (E11)

### **Spiritual Experience of Caregivers After the Death of their Relatives**

#### **Reductionism from Spiritual to the Religious: An Anthropomorphism View of the Christian God**

The discourses obtained through the interviews show that the identification of the spiritual dimension of Christian religious expression is common for both patients and caregivers according to the latter. The Christian God is prescribed with anthropomorphic functions (listening, carrying, and so on); believers expect God to perform as though he were human. It is lived by caregivers, like a giving up experience, when these functions have not occurred with regard to themselves or their relatives.

I suppose yes, because he wanted to go now, and He brought him. What has happened that God waited so long to listen him? (E11)

For the caregivers, a positive religious experience during the dying process could change their approach to events and help them find, despite the suffering and pain, reasons for gratitude.

... to thank God for seeing that he has had a good... death, within what I have experienced so far in Torre Cárdenas (hospital), a good death then, and praising God. (E2)

### **Believing in Changes After Experiencing the Loss of a Relative**

Two reactions were noted to questions regarding maintaining individual faith during the grieving process after the relative's death. Certain caregivers stated that they maintained their beliefs and that these beliefs aided them on their way through life. Other caregivers found that the loss experience entailed a rupture with their previously practiced faith. Such a change was explained as a feeling that God did not provide them what they or their relatives required:

I was a believer at that time. Now, I only believe in myself. I do not believe in anything or anyone. I only believe in myself and in the day-to-day. I spent all night praying because I wanted my husband to die that night. (E8)

Several caregivers deeply desired an assurance that the afterlife would enable them to reunite with a loved one:

I hope so. I would love it if there was something else so one day I could see my mother again for real, but I'm not sure of that. My body says no; my heart says yes. But since I don't know, I can't say anything more. (E4)

### **Discussion**

Generally, in accordance with the analyzed results, we conclude that spirituality is a needed dimension among patients and their caregivers during the end-of-life process. This spiritual dimension primarily includes the belief in the Catholic God based on values and the hope of finding life after death. As indicated by the opinions of the patients expressed in this and other studies, patients who suffer less and feel better use strategies to cope with their illness and give meaning to their lives (Moreira et al. 2017; González-Barón et al. 2005). People with spiritual beliefs experience less intense pain (Christian et al. 2018); specifically, the level of suffering of patients in spiritual palliative care decreases at the end of life (Rufino-Castro 2015)

Various studies highlight the positive effect of the presence of clergy as a spiritual support (Balboni et al. 2013; Ferrell et al. 2008). Any type of spiritual support or practice can generate hope and help individuals express their feelings (Simão-Miranda et al. 2017; Ando et al. 2009; Herth 2000), for example using rituals and ritual-like acts (Van der Weegen et al. 2019), by promoting the resilience capacity

(Barreto et al. 2015). Thus, investing in spiritual care may benefit patient well-being and reduce suffering.

However, several informants noted inequities between the attention provided by clergy to Catholics and that provided to those who of non-Catholic faiths. Spiritual support provided by healthcare professionals, such as nurses, assistants, or doctors, was not identified in any narrative. Studies on cancer patients have also identified the absence of such care. Only 16% of cancer patients claim that they were visited by personnel responsible for spiritual care (Rosa et al. 2017).

Various studies note the absence of such spiritual support despite its potential importance in the death experience (Moestrup and Hvidt 2016). It “is not a priority in the care of the studied patients. The spiritual component could be perceived as an area of less relevance to the patients’ health than the physiological or social areas” (Van der Weele et al. 2017).

As noted at the beginning of this article, it was difficult to find access to the intimate experience of death by the terminally ill and their families (Keall et al. 2014). In the collected narratives, we found few references to this experience. Thus, one must simply accept this difficulty as a research limitation, one which strongly contrasts with the critical importance of spiritual beliefs to cope with illness and death and the subsequent grief of the caregivers (Swinton et al. 2017; Gall et al. 2009).

On the other hand, as a research line for the future, we believe it necessary to include religious leaders to investigate the spiritual dimension of palliative care. They serve as additional firsthand witnesses of the dying process, and their experience can help to guide healthcare institutions in developing spiritual care.

## Conclusions

Therefore, a change of paradigm is necessary in which, among other elements, the focus of palliative care is centered on the ability to address these spiritual needs, and healthcare professionals are trained to assist in the provision of such care.

Another important consideration is the importance given to the priest because he is the only person qualified to perform spiritual accompaniment. In the cultural context of this research, Catholic chaplains were the only institutional figures whose presence was assumed to be necessary by healthcare organizations. However, the cultural and/or religious diversity in the autonomous community in which the study was conducted is increasingly broad and complex. It appears necessary to incorporate a variety of clergies in health units so that all patients may find support, whether in the terms of companionship or celebration (Cheraghi et al. 2014).

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## Compliance with Ethical Standards

**Conflicts of interest** All authors declare that there are no conflicts of interest in this investigation.

**Ethical Statement** The research has obtained all relevant reports and authorizations from the respective research ethics committees of Andalusia.

**Informed Consent** The participants were informed verbally and in writing of the purpose of the study, obtaining their written informed consent in a document designed for that purpose. During the investigation, the confidentiality and anonymity of the participants have been maintained, respecting the bioethical principles of the Declaration of Helsinki. The data of the speeches have been guarded and protected, complying with the regulations in force in our country regarding the official protection of personal data (Organic Law 15/1999).

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