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“Oh, yeah, I’m getting closer to god”: spirituality and religiousness of family caregivers of cancer patients undergoing palliative care

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Abstract

Purpose Within the cancer palliative care setting, where both patients and family caregivers (FCs) undergo a transition from the end of curative treatment to palliative therapy, spirituality and religiousness (S/R) may be a strategy to help the patients and FCs better cope with the disease, in addition to exerting a positive impact on symptoms, particularly emotional symptoms. The present study aimed to understand how S/R influence FCs of cancer patients undergoing palliative care.

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Methods This study was an exploratory and descriptive qualitative study. The qualitative approach to the data was based on Bardin’s content analysis technique. The consolidated criteria for reporting qualitative research (COREQ-32) was used in the description of the results. Thirty FCs of individuals with advanced cancer undergoing palliative care were included.

Results Analysis of the FCs’ narratives indicated that the FCs considered that religiousness and faith in God or a Supreme Being provide them with the strength to cope with the suffering associated with the care of relatives with advanced cancer. Many FCs emphasized that talking about God was somehow comforting and made them feel at peace with themselves. Four categories were identified in the FCs’ narratives: (1) increase in faith and closeness to God becomes stronger, (2) rethink life issues, (3) negative interference in the extrinsic religiosity, and (4) quest for religiousness to gain strength or support. A conceptual framework was developed.

Conclusions The results of the present study indicated that S/R are a coping strategy frequently used by FCs of individuals with advanced cancer. The perceptions of the FCs interviewed in the present study corresponded to the four distinct categories related to spirituality and religiousness.

Keywords Palliative care · Cancer · Family caregivers · Spirituality · Religiousness

Introduction

Advanced cancer frequently causes physical symptoms and functional limitations and exerts a negative impact on the

social and emotional characteristics of patients. In addition, a diagnosis of advanced cancer brings the idea of the finitude of life to patients' minds, which may be a source of great conflict for patients and their relatives [1]. When relatives are the primary caregivers, they share all of the stages of the disease and its treatment with the affected individual as well as the moments devoted to considering and ascribing new meanings to life [2].

The personal experience of a chronic disease should not be isolated from family life history because the personal experience is inserted into the particular cultural and spiritual/religious context and is impregnated by the values related to the perception of the process of becoming ill [3]. The values expressed by individuals who assume the responsibility for the care of their loved ones include hope, dignity, union, strengthening of family ties, and strong interpersonal engagement [4].

The care of individuals with severe chronic diseases may impose a heavy physical and emotional load on family caregivers (FCs) because they must combine their usual activities with those related to caregiving, frequently resulting in withdrawal from their professional, family, and social life [5, 6].

Within the cancer palliative care setting, where both patients and FCs undergo a transition from the end of curative treatment to palliative therapy, spirituality and religiousness (S/R) may be a strategy to help the patients and FCs cope with the disease, in addition to exerting a possible impact on symptoms, particularly emotional symptoms [7–9], and quality of life [10]. Therefore, S/R represent one of the most widely used strategies to help patients and FCs cope as best as possible with current and future changes [11]. However, few studies have assessed caregivers' views concerning the role of S/R in palliative care, particularly in Latin American countries [12–14]. Understanding these cultural differences could provide further evidence for this field of research and foster discussion on how to address this issue in clinical practice worldwide. Thus, the present study aimed to understand how S/R influence FCs of cancer patients undergoing palliative care.

Materials and methods

Study design and setting

This study was an exploratory and descriptive qualitative study. Interviews were conducted from April to June 2012 at the Palliative Care Unit, Barretos Cancer Hospital (BCH; Barretos, São Paulo, Brazil).

The BCH has a separate facility consisting of a 50-bed inpatient unit dedicated exclusively to palliative care and a palliative care outpatient clinic that schedules approximately 750 medical appointments per month. In the outpatient clinic,

care is provided by an interdisciplinary team composed of palliative care physicians, registered nurses, a pharmacist, a nutritionist, social workers, psychologists, physical therapists, a speech therapist, an occupational therapist, and a music therapist. Presently, the palliative care team does not have a specific health professional dedicated to spiritual counseling. Notably, the hospital is a Catholic-driven institution and has an active chapel with routine masses in which every patient and their FCs can voluntarily participate.

The consolidated criteria for reporting qualitative research (COREQ-32) [15] was used to describe the study results (Supplementary Table 1).

Eligibility criteria

The sample included 30 FCs of individuals with advanced cancer undergoing palliative care. They were selected by convenience in the palliative care outpatient and inpatient clinics from the BCH. The FCs included both genders but had to be older than 18 years and able to communicate in Brazilian Portuguese. FCs were defined as individuals significantly involved in the ill individual's treatment and care (most of the week) and could be the individual's child, spouse, parent, sibling, boy/girlfriend, grandparent, uncle, aunt, or first cousin.

Data collection

The interviews were conducted by the principal investigator, a nurse, and a researcher with more than 10 years of experience in qualitative research. The researchers did not perform any care-related activities at the investigated palliative care unit and therefore did not have any connection with the study participants.

The questionnaire used for data collection included sociodemographic questions and a guiding question, "How does your relative's disease interfere with your spiritual/religious life?" Two other predefined questions were used when the interviewer perceived that FCs did not answer completely to the guiding question: "Have you been searching for help from God or a higher being?" and "Did you realize that your faith has increased?"

The interviews were performed in person, always in the hospital, on an individual basis, in rooms exclusively allocated for data collection without the interference or presence of other people. Then, it was taped and then fully transcribed. The sample size was calculated based on data saturation.

Data analysis

The qualitative approach to the data was based on Bardin's content analysis technique [13]. Interviews were audio-recorded and transcribed. The pre-analysis included

organization of the data, rapid reading of the full transcripts, and selection and preparation of documents for analysis.

The next stage consisted of the exploration of the material, which included data encoding and categorization, followed by inference-making and interpretation of the data [16].

Data encoding and categorization were independently performed by two investigators (BSRP and CEP). First, the entire interview was read to get a sense of the whole interview and to make first impressions. Second, while reading through the interview for the second time, categories and subcategories were identified and a conceptual framework was created. The two investigators compared the identified categories and the FC's quotes and revisited conceptual framework, and then, they reached a consensus. In the present study, the transcripts were not revised by the interviewees for eventual corrections or comments. Moreover, field notes were not used for data analysis.

Ethical issues

This study was approved by the ethics committee of the Barretos Cancer Hospital, no. 544/2011. In compliance with the Declaration of Helsinki and Resolution 196/96 of the Brazilian National Health Council, which addresses research on humans, the study aims were explained to the participants, who then signed provided informed consent.

Results

Of the 31 FCs recruited, 16 were recruited at the outpatient clinic waiting room and 15 were recruited in the hospital wards. Only one FC refused participation due to emotional distress.

Sample sociodemographic characteristics

The mean age of the participants was 40 years (range=19–68 years), 27 (90 %) were female, 19 (63.3 %) were married, 20 (66.7 %) were Catholic, 15 (50 %) exhibited a low educational level, and 25 (83.3 %) were unemployed and devoted 24 h of the day to caring for their ill relative (13 of 25 (43.3 %) had provided care for more than 1 year). Twenty-three (76 %) FCs were the ill individual's closest relatives, i.e., either his or her spouse or child. Regarding the patients, there were 17 (56.7 %) women with a mean age of 61 years (range=31–86 years). The degree of functional dependency of the ill individuals was considerably high, as 20 (66.7 %) exhibited Eastern Cooperative Oncology Group Performance Status (ECOG-PS) scores of ≥ 3 . All of them ($n=30$, 100 %) were receiving palliative care only. With regards to the primary tumor site, the diagnoses were as follows:

gastrointestinal ($n=6$, 20 %), head and neck ($n=6$, 20 %), breast or gynecological ($n=6$, 20 %), sarcoma ($n=3$, 10 %), and other types ($n=5$, 16.7 %). Table 1 describes the sociodemographic characteristics of the FC sample.

Table 1 Sociodemographic characteristics of family caregivers of individuals undergoing palliative care

Characteristics	N (%)
Age (years)	
Median (range)	40 (19–68)
Gender	
Female	27 (90.0)
Male	3 (10.0)
Marital status	
Married	19 (63.4)
Single	9 (30.0)
Divorced	1 (3.3)
Widowed	1 (3.3)
Religion	
Catholic	20 (66.7)
Evangelical	7 (23.4)
Spiritualist	2 (6.6)
Jehovah's witness	1 (3.3)
Education	
Incomplete elementary school	12 (40.0)
Complete elementary school	3 (10.0)
Incomplete secondary school	2 (6.6)
Complete secondary school	7 (23.5)
Incomplete higher education	1 (3.3)
Complete higher education	5 (16.6)
Kinship	
Child	13 (43.3)
Spouse	10 (33.3)
Grandchild	4 (13.3)
Sibling	2 (6.7)
Nephew/niece	1 (3.3)
Professionally active	
No	25 (83.3)
Yes	5 (16.7)
Stopped working to provide care to ill relative	
No	5 (16.7)
Yes	25 (83.3)
Number of hours spent on caregiving per day	
Up to 12 h	5 (16.7)
24 h	25 (83.3)
Length of caregiving	
1 to 6 months	9 (30.0)
7 to 12 months	8 (26.7)
More than 12 months	13 (43.3)

Qualitative analysis

According to their narratives, the participants considered religiousness, spirituality, and related issues as a source of strength to help cope with the suffering associated with caring for a relative with advanced cancer. Many participants emphasized that talking about God was somehow comforting and made them feel at peace with themselves

Analysis of the FC discourse allowed for the establishment of four different categories:

1. Increase in faith and closeness to God becomes stronger

Most participants emphasized that their faith in God had increased after their relative fell ill, and thus, they tended to seek His help more intensely, primarily through prayer. The participants further emphasized that the quest for a Supreme Being was a method that helped ease the pain caused by their loved one's suffering. Facing a state characterized by vulnerability and suffering caused by the full process of the disease and the unsatisfactory results of previous treatments, some FCs explained that they look to God for the strength to remain invested in their relative's care.

"My faith grew, right?... I'm becoming closer to God; I look to Him for the strength I need to go on." (FC 7)

"From the perspective of faith, it increased, for sure, especially his...you can see that faith is what keeps him going on now, faith, indeed..." (FC 15)

"Oh, yeah, it seems I got more connected with God; at a time like this, one clings to anything one can, and one indeed does." (FC 16)

"Yeah, see, it changes, it only changes because one seeks God in a more intense way..." (FC 17)

"...we ask to Jesus all day long to stay with us and give us strength, we ask God to stay with us.... Faith increased a lot.... Oh, yeah, one gets closer to God..." (FC 18)

"Faith increased, although I have a lot, but now I pray more." (FC 20)

"... Now he's much closer to God because our faith increased a lot, and I'm very happy with it, as there's a positive side to it, somehow.... I'm much closer to God; I look much more for Him. Gee, I'm clinging faithfully, and I'm trustful he'll overcome this, he'll recover..." (FC 24)

"See, dear, I say it interfered a lot because we started participating, to look for God everywhere; we got to look for Him in everything, to ask Him to help us, so we can save her. I asked him to give us strength to help her.... We're looking much more for Him. Perhaps,

when we were healthy, we didn't do what we're doing now, but now we realize how much we need Him; we need God's help a lot." (FC 26)

2. Rethink life issues

The FCs emphasized that their experience with the illness process of the relative undergoing palliative care was associated with significant changes in their lives and that S/R helped them reflect on several features related to their shared daily life and the meaning of life.

"...right, and the meaning of one's life changes too. One gets to stop complaining; I believe one gets a better relationship with everybody, a better understanding because there's some extra stuff you get from pain, right? And, yeah, this is how it interferes; faith increased because of the disease but also made everything change." (FC 17)

"Yeah, see, it interfered a lot because having more faith made me more like this, to stop complaining about everything in life, to stop thinking nonsense, and made me come closer to people I was removed from; this, the spiritual side, yeah, was very good.... Oh, yeah, I believe my heart grew; instead of one, I believe that now I have two; I became more sensitive to stuff, humbler..." (FC 21)

3. Negative interference in the extrinsic religiosity

Taking care of an individual with advanced cancer, which is often intense and exhausting, has the potential to adversely impact the caregiver's quality of life, particularly for those who use extrinsic religiosity as a strategy to strengthen themselves spiritually.

"... I was going over to church, to gospel, now I'm not going more because of her, I have to take care of her." (FC 5)

"Sometimes yes, because I want to go to the church but it isn't possible because I have to stay with her.... We haven't anyone to do this, only me." (FC 6)

"I used to go frequently to the church but now I rarely go I go only on Sundays.... I have to take care of him, so it is an exhausting life.... I am tired, very tired." (FC 8)

"Interfered by the fact that I attended the church very much, but now I can't go frequently anymore, I can't frequent the study group meetings because she doesn't want to go..." (FC 9)

4. Quest for religiousness to gain strength or support

Some FCs reported that religiousness afforded them strength, support and a base to better cope with the process of illness of the relative undergoing palliative care.

“As concerns religious life, no, it doesn’t interfere, pretty much the opposite; I believe you get a religious basis to give strength to the person with the problem, with the disease, right? That kind of stuff, pretty much the opposite; it makes you stronger, got it?” (FC 3)

“... I believe that God comes and gives us support, holds us, and we go on because there’s no other option.” (FC 18)

“Right, we’ve got much faith and trust in God, and I even believe this gives me a lot of support. I used to read the Bible with him every day; it not for this faith and trust, I believe that religion, right now, was my basis, for sure.” (FC 23)

Figure 1 depicts the conceptual framework of the study results. Facing illness and the end of life of a beloved relative, FCs often feel emotional pain and seek some relief by using coping strategies, such as S/R. However, the task of caring for a patient in palliative care can negatively influence the religious practice of some FCs (extrinsic religiosity). The participants’ perceptions were subsumed under four different categories related to spirituality and religiousness.

Discussion

Using qualitative analysis of the FCs of individuals undergoing palliative care, the present study established that S/R are one of the coping strategies that FCs use to ease the pain caused by a loved one’s illness and end of life. In addition, the present study identified four categories relative to the participants’ perception that represent their quest for spirituality and religiousness.

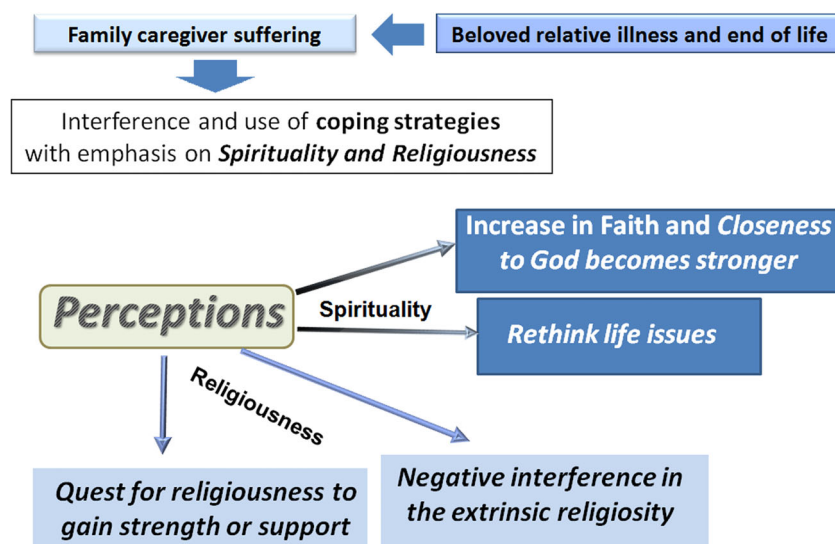
Religiousness may be characterized as a measure of an individual’s belief in, adherence to and practice of a given religion (an organized system of beliefs, practices, rituals, and religious symbols to gain access to holiness—God, a Supreme Being, a Higher Power). In turn, spirituality corresponds to the personal quest for meaning and purpose in life, which may or may not be associated with religions or institutions [17].

Thus, the FCs interviewed in the present study noticed that their faith increased, as the following transcript illustrates: “Faith increased, although I have a lot, but now I pray more.” Due to the difficult task of providing care to cancer patients, FCs often exhibit depression, anxiety, uncertainties, fear, and anticipatory grief. In addition, FCs face emotional wearying, albeit not necessarily pathological situations, such as an incurable diagnosis and the suffering of their beloved relative [18–20].

Therefore, in addition to the need for relief of their emotional pain, FCs also have deep spiritual needs, leading to a quest for faith, trust, and belief in God or a Supreme Being. Such a strong connection with faith is one of the paths that FCs find to strengthen themselves, and this strong connection with faith also helps FCs keep their hopes up and maintain their ability to cope with the various problems associated with the advanced stages of the disease and the little time that remains for the ill individual [21].

The quest for faith becomes more intense at the most difficult moments, as people search for deeper contact with their spiritual dimension to become closer to God/a Supreme Being’s power: “We’re looking much more for Him. Perhaps, when we were healthy, we didn’t do what we’re doing now, but now we realize how much we need Him; we need God’s help a lot.” Some studies have demonstrated that individuals with stronger R/S exhibit a better overall state of well-being and lower incidence of anxiety and depression, and they feel

Fig. 1 Conceptual framework of the study



more confident and protected, even under difficult circumstances [22–25].

Another important finding is that many FCs have resources for religiousness. These values afford feelings of safety, comfort, sociability, and self-absolution, as one of the interviewees stated, "... I used to read the Bible with him every day.... I believe that religion, right now, was my basis, for sure." This assumption is corroborated by the fact that all of the FCs reported to have some religious affiliation, which accords with the results of the study by Moreira-Almeida et al. [26], who assessed 3007 individuals older than 13 years of age from 143 Brazilian cities. These researchers observed that 95 % of the participants had some religious affiliation, 83 % judged religion to be highly relevant, and 37 % reported that they participated in religious services at least once per week. Notably, the Brazilian population is considered one of the most religious-minded populations worldwide, with Catholicism being the most prevalent religion [27].

Some FCs indicated that having to care for a patient with advanced cancer excluded them from participating in their habitual religious life, especially going to the religious temple. Allport [28] emphasized that religiosity can be intrinsic; individuals can have religion intrinsically and seek to reconcile their needs and interests within their beliefs, thus striving to internalize their beliefs and follow them completely. Additionally, religion can be extrinsic, e.g., when it is a means used for other purposes or interests or to provide security and solace, sociability and distraction, status and self-absolution [23], as well as the extrinsic use of their religion and the intrinsic religion experience [29]. In our analyses, four FCs perceived a negative interference in their extrinsic religiosity, and among which, three were Evangelical and one was Catholic. Considering that the BCH is a Catholic institution with a very active chapel in the palliative care unit, our findings suggest that caregivers likely appreciate the opportunity to pray according to their religion when staying in the hospital. Moreover, the lack of a chaplain (or another health professional dedicated to spiritual counseling) in our palliative care team to function as an ecumenical counselor may partially explain this observation.

The perception of the frailty of the loved one's life during the course of the disease process and death induces FCs to rethink their own lives and search for the meaning of life in the smallest details, rather than in the larger picture. Frequently, FCs begin attributing greater value to simple things; they seek to talk and have more physical contact with people and to live their lives in a more intense manner. S/R represent a positive coping strategy, which gives FCs strength and hope to keep on going. The feeling of having a purposeful and meaningful life combined with the perception of having close ties with God is associated with a positive perception of religious well-being [17].

Our findings highlight one of the goals of palliative care, which is to provide holistic care to patients, demanding a

multi-professional staff [30]. Although they are usually neglected in everyday practice, FCs must be included in cancer care, as the definition of palliative care formulated by the World Health Organization (WHO) explicitly states: "palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness..." [31]. In addition to physical and psychosocial factors, spirituality should also be acknowledged as an essential component of the state of well-being of individuals who experience the end of a beloved person's life [32].

Our study has some limitations. First, the findings should not be generalized to all contexts, and the convenient sampling process was a key limitation. Second, two groups of FCs were interviewed: those recruited at the outpatient clinic waiting room and those recruited at hospital wards, which are places with different emotional loads. Third, our sample was composed by low-education patients, which could have influenced the retrieval of information.

However, the present study has also some potential strengths. This is a study carried out in Latin America, which has different cultural and religious backgrounds compared to Europe and North America. Likewise, we used consolidated criteria for retrieval of information and for reporting qualitative research, which could help in the comparison with future studies.

Conclusions

S/R are a coping strategy frequently used by FCs of individuals with advanced cancer. The perceptions of the FCs interviewed in the present study relative to S/R corresponded to the four distinct categories that were related to spirituality and religiousness. The results of the present study indicate that S/R are significant for FCs and that this construct should be more thoroughly assessed in future studies to establish the best strategy for S/R and enhance its use in everyday practice.

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Conflict of interest The authors declare no conflict of interest.

Author contributions BSRP, CEP, and ALC conceived and designed the experiments. BSRP and CEP performed the experiments. BSRP and CEP analyzed the data. BSRP, CEP, GL, EMB, and ALC wrote the paper.

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