



Religious/spiritual concerns of patients with brain cancer and their caregivers

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Abstract: Research conducted over the last 20 years supports that many patients with cancer engage religion and spirituality (R/S) when coping with their illness. Research on patients with brain cancer is more minimal but mirrors the same findings. This article provides a brief overview of the research about R/S and coping among cancer patients, then summarizes the research about R/S among patients with brain cancer and their caregivers. The following topics are discussed: (I) the importance of R/S to patients with brain cancer and their caregivers, (II) specific R/S needs experienced by patients with brain cancer and their caregivers over the cancer continuum, (III) R/S coping mechanisms engaged by brain cancer patients and their caregivers, and (IV) the healthcare systems' engagement of R/S needs within the healthcare setting. This is followed by professional chaplains' descriptions of their own experience with R/S concerns of patients with brain cancer and their caregivers, and the spiritual care they have offered them. Hear My Voice, a new spiritual life review intervention, is described. Research to deepen understanding of the R/S concerns of patients with brain cancer and their loved ones, and spiritual care interventions offered to them is recommended.

Keywords: Brain cancer; brain neoplasms; caregivers; chaplains; spiritual care

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Religion/spirituality of cancer patients

Over the past 20 years a substantial body of research about religion and spirituality (R/S) and coping with cancer has emerged (1-4). Large majorities of cancer patients cite R/S as one of the most important factors that helps them cope with their illness (5). Religious activities are important for many cancer patients. Among 700 newly diagnosed patients, over three-fourths reported the use of prayer (6). Further, a large meta-analysis has shown positive associations between R/S and measures of physical, emotional and social health

(7-9). Other studies have shown that as many as 50% of cancer patients experience some R/S struggle, pain or distress and that R/S distress is consistently associated with poorer emotional well-being and quality of life (10-12). Research also shows that most cancer patients welcome inquiry about R/S concerns from their health professionals (13) and they welcome spiritual care providers (chaplains) as part of their healthcare team (14). There is also evidence of lower ratings of the quality of care and satisfaction with care when R/S needs are not addressed (15).

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Religion/spirituality of patients with brain cancer

Importance of religion/spirituality

Compared to some other types of cancer (e.g., breast, prostate), there has been less research about R/S and coping among patients with brain cancer. While this research is more modest, its themes mirror those in the cancer literature in general. Patients with brain cancer may be particularly vulnerable to R/S needs due to the high risk of mortality and risk for loss of personality/self that accompany changes in cognitive and functional status associated with disease progression (16). One caregiver of a patient with brain cancer said, “*It’s not just a diagnosis, it’s almost like it’s a life sentence on all the other aspects of his life*” [(16), p. 4]. Up to 70% of neuro-oncology patients describe R/S as helpful during their disease experience (16,17). Compared to those with higher levels of education, patients and caregivers with lower education ranked R/S needs more highly (18). For some neuro-oncology patients R/S can intensify over the course of their disease (19-21) while for others it remains stable (22). R/S needs may be particularly salient for brain cancer patients and their caregivers prior to confirmation of malignancy (20).

Religious/spiritual needs

Different types of R/S needs have been described in the literature. Several studies describe patients exploring meaning in life as they deal with brain cancers (16,21,23,24), especially among patients with a strong desire for coherence (23). This can involve learning life lessons from the challenges one is facing (16), reflecting on life to assess the difference one made (21), and planning to live life with more meaning (21,23,24). Other research describes patients reappraising their values (23), including an increased focus on quality-of-life over quantity-of-life (16). Research has described a shifting experience of what patients hope for as cure became less of a possibility (23).

In a U.S. study, neuro-oncology patients explored their beliefs about God’s plans, grace, providence and forgiveness (21). In contrast, among patients in more secular Sweden, explicitly religious struggle was minimal, existential or spiritual struggle were present, and questions about “*Why is this happening to me?*” were prevalent (25). Studies also report fear of death and thoughts about the afterlife as a central R/S need for brain cancer patients (21,23). One study reported that fear of being separated from family/loved ones was the most distressing aspect of death (23).

Isolation is another commonly cited R/S need (20,21,24,26) including physical separation from daily activities, growing existential distance from others, and shifting relationships (21). Importantly, patients distinguish between isolation and solitude. Isolation may be distressing, but times of solitude, peace, and quiet spiritual practices are important (24).

Contradictory R/S beliefs or thoughts have been reported (i.e., not being afraid of death and being afraid of death, not trusting God and only trusting God) (21,23). Piderman and colleagues view this as a vacillation between consolation (“*experience of comfort, reassurance, peace, gratitude hope or expectancy regarding a spiritual presence and/or the afterlife*”), and desolation (“*spiritual struggle that may include pleading, bargaining, and feelings of abandonment or fear*”) [(21), p. 20 and 22]. They view these discrepancies as part of people’s dynamic faith stories (21).

Religious/spiritual coping

Neuro-oncology patients and caregivers have described important R/S coping mechanisms including prayer (17,21), talking to a religious authorities for moral and religious support (27), positive reframing (21,28), having a quiet place to pray before surgery (27), reflecting on one’s R/S with another person (21,27), talking about death anxiety (23), re-evaluating life values (20), and other religious practices (27,28). According to patients and caregivers, receiving information about how to access spiritual support services is also important. Information from a pamphlet was preferred and described as very important by a third of Canadian patients with brain metastases and their caregivers (18).

Addressing religious/spiritual concerns

Most studies report brain cancer patients and caregivers desire R/S care from healthcare providers, but often felt like these needs were overlooked or unaddressed (16,23,25,28). One study reported that participants would desire R/S care, but not want their physicians to pray with them; they thought this placed “power” outside of the physician’s hands (27). Healthcare providers appear to have varying understanding of neuro-oncology patients’ and caregivers’ R/S needs (28). Nurses claim that lack of time and knowledge are limiting factors for providing R/S care (28,29); their R/S interventions are often limited to listening (29). The use of simple screening questions can help healthcare providers identify patients who may

Do you struggle with the loss of meaning and joy in your life?	Not at all	Somewhat	Quite a bit	A great deal
Do you currently have what you would describe as religious or spiritual struggles?	Not at all	Somewhat	Quite a bit	A great deal

Figure 1 Spiritual screening questions. A response of ‘Somewhat’ or greater for either item indicates potential R/S struggle. Consider referral to a chaplain for spiritual assessment and spiritual care if indicated (31).

be experiencing R/S distress and benefit from referral to a chaplain for spiritual assessment and spiritual care as indicated [(30); see *Figure 1*].

Spiritual care for neuro-oncology patients and their caregivers: oncology chaplains’ clinical experience

Chaplains with experience caring for patients with brain cancer and their caregivers note the life-limiting nature of this illness; symptoms are challenging, and the side effects of treatment are often toxic (32). Patients frequently face rapid cognitive decline and neurologic impairment. The R/S needs of patients are driven by these difficulties which threaten the core of patients’ identity.

As their disease progresses, some patients who are religious or spiritual express feelings of disconnection and abandonment in their relationship with their higher power/God. Some question why they have brain cancer and not the treatable kind of cancer which their neighbor has. “*Why me?*” “*Why now?*” are common questions. Some have expressed guilt that they have done something to warrant God’s punishment. Limited physical abilities affect participation in important religious activities such as attendance at church, temple, mosque, or other religious meetings. These can compromise patients’ sense of purpose as they question why they are still on earth. As patients’ memory diminishes and vision changes, they can no longer read comforting R/S texts and some patients report feeling their faith slipping through their fingers.

The spiritual concerns of patients with brain cancer are frequently driven by loss and grief, including loss of independence, control, identity, or purpose and meaning in life, as well as struggles with relationships and social support. Patients report no longer being able to engage in the basic elements of their work and family life as their disease progresses. Many have expressed frustration and embarrassment at not being able to perform activities of daily living. “*I cannot brush my own teeth or dress myself ... I feel exposed as I no longer have any privacy.*” Patients struggle

as they contemplate whether or not to have surgery as well as the outcomes of the surgery and other treatments. The question of quality-of-life comes up often. The thought of losing mobility/functionality is frightening for many brain cancer patients. “*How much cognition will I lose before I die?*” They have described seizures as a frightening experience associated with loss of independence, including not being able to drive or cook because having a seizure in the middle of these activities would be devastating.

Some patients report they do not recognize who they are anymore. Their sense of meaning and joy in life are diminished. As their diseases progress they worry about their new lifestyle, their functioning and ability to return to their job, sports, or hobbies. A future without important activities such as gardening, camping, fishing, or golfing seems meaningless. Patients fear losing the ability to make decisions for themselves as the disease causes problems with memory and judgment. Patients have also expressed regret about not having done enough in this life or completed their life’s journey.

As patients recognize their loss of cognition and identity, they often express fears of what is to happen to them and what will become of the loved ones they will leave behind. Some have reported the hardest thing for them is not being able to take care of their family. “*How will they cope without me?*” “*Who will take care of my spouse and children? I want to be sure they will be okay if something happens to me.*”

The loss of independence leads some patients to feel they have become a burden to their family. Being unable to provide leadership and stability to their family is a painful role reversal. In some cases, the patient has been the one who established and guided the family’s R/S beliefs and practices. As brain cancer diminishes their cognitive abilities, their role as spiritual leader is diminished or ends completely. Patients fear that their families might lose faith in the face of the patient’s disease and likely death. Patients have often asked what they can do to preserve their families’ R/S heritage. Patients grieve disconnection from future faith activities such as baptisms, marriages, and birth of grandkids, as well as their school and family activities.

Table 1 Hear My Voice: selected themes and interview questions (35)

Theme	Selected interview questions
Community	Have you ever been part of a religious or spiritual community? Has your connection changed in any way over your life time?
Contributions	Are there things you're proud of? How do you think your family, your community, your profession, your church are better because of you?
Challenges	Have you had periods in your life when you have faced questions about your faith or spiritual approach to life?
Communication	Is there anything that you still need to say to your loved ones? Do you have spiritual guidance or wisdom that you'd like to share or reinforce one more time?

Some family members of patients with brain cancer must decrease their participation in R/S activities in order to care for their loved one. As the patients' condition deteriorates, family members sometimes ask, "*Why is this happening to us?*" or "*Why is God doing this to my loved one?*" Family members express fear of losing an elder who provided reassurance and guidance in times of family and spiritual crisis. Family members are willing to be with and support their loved ones, but they worry about when they will be able to go back to work. "*We might lose the house if the bills are not paid.*" Family members also worry about future cognitive decline. "*When they are no longer able to understand us, that will be hardest because we would be guessing what they are going through and how they are feeling.*"

Family members accompany patients as they wrestle with decisions about treatment but are afraid to make decisions that might lead to negative outcomes. "*What if they are paralyzed? Life would have no meaning. I would not want my loved one to be a vegetable.*" Family members become very disillusioned when they do not have the information they need to understand the disease, the options available to help their loved ones, or access to these resources.

Spiritual care for neuro-oncology patient and their caregivers builds on core spiritual care activities. These include acknowledging and affirming the patient's and caregiver's emotions, identifying and addressing spiritual distress, and providing time for life review and meaning making. Chaplains also facilitate end-of-life discussions and advance care planning (33), advocate for patients and caregivers to have adequate information, and provide prayer and other R/S resources that will address patients' and caregiver's needs. Spiritual care may also include locating resources to fulfill specific R/S needs, as well as modalities such as guided imagery.

Hear My Voice: a spiritual care intervention

A spiritual life review intervention has been developed for patients with brain cancer and other advanced illnesses and their caregivers (34,35). The intervention, "Hear My Voice", was designed to give patients voice before they lost their ability to communicate. Specifically, it allows patients to tell their story and leave a spiritual legacy for their loved ones. In the intervention patients describe core spiritual beliefs, practices, values, struggles, and life-learned wisdom (see *Table 1*). The interviews are transcribed, edited and returned to the patient as a spiritual legacy document that can be shared with loved ones. Piderman and colleagues have assessed the feasibility, acceptability and impact of this chaplain-led intervention (35-38). Findings from studies show increased positive religious coping, quality-of-life, and emotional and spiritual wellbeing (36-38). Patients and caregivers provide positive evaluations for the intervention.

Conclusions

Coping with illness presents significant R/S challenges for brain cancer patients and their caregivers. Current research about the role of R/S in coping for these patients is promising but limited. Spiritual care and a new spiritual care intervention, Hear My Voice, can play an important role in improving R/S coping and quality-of-life. Additional research will advance our understanding of the role of R/S in coping with brain cancer and ensure that patients and their caregivers receive the best spiritual care possible.

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