# Spiritual Experiences of Adults with Advanced Cancer in Outpatient Clinical Settings

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#### **Abstract**

#### **Context**

Adults who have advanced cancer experience distress, and many use religion and spirituality to cope. Research on the spiritual experiences of advanced cancer patients will help guide the provision of high-quality spiritual care.

#### **Objectives**

To qualitatively describe advanced cancer patients' spiritual experiences of illness.

#### **Methods**

We conducted semi-structured qualitative interviews at a single cancer center with 21 patients with stage IV solid malignancies who had a prognosis of less than 12 months, as estimated by each patient's medical oncologist. Five investigators conducted a thematic analysis of the transcribed interviews.

#### **Results**

We found 31 patients who were eligible for enrollment, and 21 (67.7%) participated in interviews to thematic saturation. Using a thematic-analysis approach, five major themes emerged. *Relationships with family and friends* was the most important theme among all 21 patients irrespective of their religious or spiritual identity. *Relationship with God and faith community* was frequently identified by those who considered themselves spiritually religious. Cancer often led to reflection about the *meaning of life* and the nature of *existential suffering* Patients addressed the extent to which *identity* was changed or maintained through the cancer experience, and some expressed *acceptance* as a way of coping with illness.

#### **Conclusions**

Spiritual care for dying cancer patients should always include the exploration of relationships with family and friends, as well as God and faith community for some patients. Relationships with family, friends, and God can be a source of strength for many. Making meaning, addressing identity concerns, supporting acceptance as a resource for coping with illness, and acknowledging existential suffering will often arise for these patients.

Keywords: Advanced cancer; coping; spirituality; religion; experiences; distress; spiritual care

#### **INTRODUCTION**

Religion and spirituality are important to a majority of cancer patients and affect the cancer experience in various ways. <sup>1,2</sup> Religion and spirituality may cause distress for up to 50% of cancer patients, <sup>3,4</sup> yet a significant number of people use religion and spirituality to cope with life crises. <sup>5–10</sup> Spiritual and religious well-being may improve quality of life for patients with cancer <sup>11,12</sup> and may be important to the quality of end-of-life experiences for both patients and caregivers. <sup>12–17</sup> Moreover, religious belief is important in medical decision-making for some patients. <sup>18,19</sup> Consequently, attention to the significance of religion and spirituality is important for end-of-life care. <sup>20,21</sup>

Spirituality has been defined in different ways<sup>22</sup> to include philosophical, secular, and religious beliefs.<sup>23</sup> For our study, we follow the International Consensus Conference's definition of spirituality as "a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices."<sup>24</sup> This definition is in line with how religion is defined as a search for significance often related to the sacred. <sup>25</sup> We broadly use "spiritually religious" to interpret the experiences of patients who consider themselves both religious and spiritual while we use "spiritual" to refer to those patients who clearly identify themselves to be only spiritual and not religious.

The National Consensus Project for Quality Palliative Care (NCPQPC), a consortium of palliative care organizations, identifies addressing religion and spirituality as one of eight guidelines for clinical practice. Since advanced cancer diagnosis triggers deep existential and spiritual questions that may impact meaning and purpose of life, <sup>27–29</sup> addressing those

questions through a fully integrated approach is part of quality patient care. <sup>30,31</sup> Unfortunately, most healthcare systems have not yet completely incorporated this approach to care. Spiritual care may therefore be infrequent among cancer patients. <sup>32,33</sup> One study found that 47% of cancer patients reported that their religious community supported their spiritual needs minimally or not at all, and 72% reported the medical system supported their spiritual needs minimally or not at all. <sup>34</sup> Understanding the spiritual and religious experiences of patients with advanced cancer can guide high-quality spiritual care for those going through end-of-life care.

A small number of prior qualitative studies have described spiritual and religious needs of cancer patients in the United States, Europe and Taiwan.<sup>35</sup> Studies have identified their need for meaning, purpose, love, relationships and comfortability with physician inquiry about spiritual needs.<sup>36-39</sup> Patients may also experience losses related to roles, identity and fear of death.<sup>40</sup> This focus on needs or challenges may be incomplete. Spiritual strengths have been identified as a potential resource during stressful life events<sup>41</sup> and cancer patients may use positive religious coping.<sup>42-44</sup> We conducted individual semi-structured qualitative interviews to better understand the spiritual and religious strengths and distress of adults with advanced cancer. This is an essential step toward developing interventions to better support these patients using both their own strengths and providing resources to meet their distress.

#### **METHODS**

#### **Participants**

We recruited adult outpatients from clinics in a large academic cancer center in the Midwestern United States from November 1, 2016 to March 15, 2017. The Indiana University

Simon Cancer Center Scientific Review Committee and the Institutional Review Board of Indiana University approved the study.

Eligibility criteria included a diagnosis of a stage IV solid malignancy with an estimated survival of <12 months in the opinion of the patient's primary oncologist and receiving cancer care at the outpatient clinic of the Indiana University Health Simon Cancer Center. Determination of survival estimation was made by the attending oncologist in response to our question, "Would you be surprised if this patient died in the next year?" Patients had to be age 18 years or older, >2 weeks from the time of advanced cancer diagnosis, have a working phone number, be able to provide informed consent, and be able to obtain a score of 3 or higher on a six-item cognitive screener. 46

Exclusion criteria included significant psychiatric or cognitive impairment (dementia/delirium, active psychosis) that in the judgment of the physician or nurse would impede providing informed consent, involvement in another psychosocial research study at the cancer center, and inability to complete interviews in English.

# Recruitment

Potentially eligible participants were identified by review of daily schedules in the oncology clinic. The principal investigator (PI) and clinic nurse then conducted a medical-record review in advance of scheduled outpatient oncology clinic appointments, and the treating oncologist was asked to estimate prognoses and identify patients who were ineligible based on known cognitive impairment. Potentially eligible patients were approached in person and introduced to the study at a time that did not interfere with clinical care (either before or after a clinic visit). If potentially eligible patients could not be approached at the clinic, we mailed the

study information, including a signed letter by the PI that introduced the research team and the study. Additionally, we provided a phone number so that patients could contact the study team with any questions or to opt out of study participation. The study team followed up with potential participants by phone or in person at the outpatient clinic within approximately two weeks of mailing the introductory letter. The PI (a board certified chaplain) was introduced to patients as a "researcher" throughout the interview process to limit bias that may result from participants' expectations of what a chaplain may want to hear. Informed consent was obtained from each participant.

## **Interview Process**

The qualitative interview included open-ended questions focusing on the patients' perspectives about their spiritual or religious identity, what that meant to them, and how illness affected their spiritual and emotional well-being throughout their cancer experiences.

Interviews collected rich and detailed data on the patients' spiritual strengths and distress throughout their metastatic cancer trajectory. We collected data until we achieved thematic saturation which is according to the standard approach for determining sample sizes in qualitative research. To establish thematic saturation, the principal investigator (SM) determined when three consecutive transcripts did not identify any new themes. To characterize the sample, we also administered the six-item, validated Kessler Psychological Distress Scale (K6 Distress Scale). Low scores were 0-12 and high scores 13-24. Furthermore, we administered a one-item health literacy question, and one question (i.e., "Do you consider yourself religious, spiritual, both religious and spiritual, or neither religious nor spiritual?" [Appendix 1]) to describe our sample.

#### **Data Collection**

The participants selected the interview setting within the outpatient clinic. Each patient provided written informed consent. Interviews were digitally audio-recorded to facilitate verbatim transcription. The principal investigator (SM), an experienced qualitative researcher with particular expertise in chaplaincy research, conducted the interviews. The interview guide used 15 questions (Appendix 1 p# 21) with additional probes to explore the topics in greater detail. During and after each interview, the interviewer noted reflections and observations to inform analysis.

#### **Data Analysis**

We conducted a thematic analysis<sup>51</sup> for interview data. Five investigators (SM, AT, AC, SJ, PH) independently read and coded two interviews. We discussed preliminary codes and also provided feedback about topics to explore in greater depth. Then three investigators (SM, AT, AC) read and coded an additional three interviews and a preliminary codebook was developed. After this, all subsequent interviews were coded using this codebook by two investigators (SM and AC), who met regularly to refine codes, identify themes and subthemes, identify quotations, and develop a framework. Then the refined list of themes, codes, and quotations was reviewed by all investigators (SM, AT, AC, SJ, PH). Quantitative items were analyzed using SAS v9.4 (SAS Institute, Cary, NC).

#### Results (Table 1)

We identified 352 adults with advanced cancer. Of these, 296 (84.09%) had >12 months estimated survival while 56 (15.9%) had <12 months. Of the 56 patients, 25 (44.6%) were judged by the oncologist or nurse to be ineligible due to being too sick or cognitively impaired. Ten declined to participate due to pain, time limitation, no interest and conflict with other responsibilities. We enrolled 21/31 eligible patients (67.7% enrollment rate) and reached theme saturation after 21 interviews.

Participants were predominantly female (66.7%) and married (72.2%) with majority reporting a college degree or completing some college (66.7%) and a comfortable income (61.7%). Participants identified as Protestant (47.6%), Catholic (23.8%) or other (28.6%). We found that four patients defined themselves as only religious (19.0%), five as only spiritual (23.9%), eight patients as both religious and spiritual (38.1%), and four as neither religious nor spiritual (19.0%). Average time interview was 27:03 minutes (range 14:01 to 50:59 minutes). Across the 21 interviews, a total of 146 pages, 64,238 words, 1,782 paragraphs and 5,181 lines were analyzed. Five major themes emerged: supportive relationships, meaning, identity, acceptance coping and existential suffering.

#### Themes (Table 2)

#### 1. Supportive Relationships

*Family and Friends.* All 21 participants consistently shared that supportive relationships were central to their experience of cancer. When asked "What gives your life meaning?" the majority of participants identified family and friends. One participant described it this way:

Well, [cancer] weeded out the superficial friendships and enhanced the lifelong friendships that are the ones that are really meaningful. Most people, if they don't

experience things like this, it's kind of like a filter that weeds out, like I say, the superficial friends and the true friends, are the cream that come to the top (patient # 11). Participants described supportive spouses as their "champions" during illness, the need for family to "go through" the experience of illness, and the importance of communicating with family and deepening family relationships as a result of their illness.

Although the majority of participants reported having received positive support from family, others described difficult family relationships, including estrangement, abandonment, and conflict, that the stress and challenge of cancer exacerbated. Loved ones' physical or emotional distance became more evident and painful when experienced within the context of cancer. Lack of attentiveness, care, or nurturing during a time of great distress was experienced as a source of struggle. Some participants also expressed fear about leaving children behind after their death. The fear of leaving young children without a mother, for example, was described as more frightening than the anticipation of death itself.

Patients' friends were identified as former high-school buddies, co-workers, neighbors, and sometimes extended family members. Patients explained how their friendships deepened during the illness. One patient described it this way:

My friends have been great. The outpouring of love like I never experienced before. I didn't know so many people really cared that deeply about me (patient # 3).

While friendship was seen as a source of support to patients, it may become toxic if not well managed. For example, a participant told us:

I have a really good friend, he's probably my closest friend, and you don't want to offend anyone, but I kind of want to tell him, I don't need so much, I don't need a sappy email every day. I don't need you to tell me you love me every other day. I don't need you to

tell me you're praying for me every day, because honestly, sometimes it's like I'm just having a good time, and life feels normal, and I get a text, hey man, reality, at a time when I just want to relax. You don't want to offend him, but I find myself thinking maybe I just need to let him know, dude, I'm trying to keep things as normal as possible, and getting emails from your buddy saying I love you isn't . . .(patient # 12).

As illustrated by this quotation, participants' perception of true support from friends differed by individual.

*God.* For patients who identified as spiritually religious, their sense of a personal relationship with God was an important part of coping with their cancer. Several participants explained how God had become a greater source of support after the cancer diagnosis:

Through the years I have turned my back on my God. Tried to do things on my own. Since my illness I've called on him to help me through this (patient # 3).

To others, God and the doctor had unique roles to play. For example, one participant convincingly shared that "I really feel like God's going to take care of this. I think Dr. Q thinks I'm crazy but that's okay" (patient # 5). This conviction led the participant to see healing as stopping cancer-directed therapies:

Maybe the ultimate healing is when God says you don't have to do this anymore. Maybe it's done. You ran a good race and now it's over. Maybe that's the healing. I don't know. But healing is healing (patient # 5).

Some participants who identified as religious or spiritual expressed feeling abandoned by God.

One expressed anger toward God this way:

At first I was kind of angry. . . . I thought we made a covenant, God, and now you've just let me down (patient # 5).

Such anger came with feelings of guilt, as another participants shared that "you know that God is going to make everything all right, and He didn't, so I'm kind of a little disappointed right now" (patient # 8). The participant goes on to explain, "But I'm going to ask him for forgiveness for me having those feelings of disappointment" (patient # 8).

*Faith Community*. Several patients described how their faith community surrounded them with prayers, comfort, courage, and gifts.

The people that I go to church with, they're always asking me how I am and they're saying "I'm praying for you." You share how you feel and you just lift each other up. You give each other hugs, high fives, thankful for those little accomplishments. You just support each other (patient # 5).

A number of religious participants explained that they appreciated this kind of care from their faith community. One participant said that "all the people [from church] that brought me little gifts or flowers . . . made a huge difference in my day"(patient # 1). For others, group prayers were identified to help them through church involvement. As one participant said, "the biggest thing is that being involved with the church it helps. It helps me in a very, you know, a lot. I've got friends over there that pray for me every day"(patient # 6).

## 2. Meaning

Patients' cancer diagnosis led them to reflect on the question of why bad things happen.

As described above, some religious patients felt their faith and relationship with God were

shaken when they wondered how God could have allowed their illness to occur. This implies a sense that God was in control of bad events as well as good. But other participants still felt reassured by the belief that God was in control:

This illness has just made my faith stronger because it's forced me to pray more. Who do I want to be in charge? I love Dr. Q——, and I really let him believe that he is in charge, but he's not. God is the one that's in control of all of those things (patient # 5).

Although religious and spiritual (R/S) participants discussed how their cancer diagnosis may have played a role in their deeper commitment, others felt as though, for example, "the devil is trying to work on me. Get him away from me"(patient # 6). The participant explained the need to have God on her side to take control of the devil's power. Some participants indicated God was the most important thing in their life. One participant described how depending upon God through faith was helpful this way:

My God . . . My Jesus. It's my faith in God. I've depended upon that since I've been struck with this illness (patient # 5).

In these ways, deepened faith in God and tension between God's authority or power and the devil were described as strengthening or weakening some participants' experience of God.

#### 3. Identity

The concerns of illness and identity were expressed by some patients. One non-religious patients expressed the need to maintain a sense of identity but questioned whether religion might be of value. A specific example was shared:

I just decided I'm not going to let this [illness] fundamentally change who I am and it would be easy. . . . I respect religion, and I respect religious people. . . . [T]here is a huge

part of me that realized my life would be a little easier if I had that component (patient # 12).

However, a number of people expressed a new way of self-perception. For example:

I believe that no matter what, I'm a spiritual person. I'm a good person. I'm good to people. I try to do the right thing all the time, and I believe that no matter what if there is a good and bad place, I'm going to a good place. How could someone send me to a bad place? (patient # 4)

Another explained a loss of identity because of the illness:

I used to love politics. Politics and music. Now since what has just happened to us, no, I can't watch TV. I can't. I have just withdrawn from everything, and it's like nothing that I participate in anymore (patient #7).

#### 4. Acceptance as coping

We also found a few patients who explained acceptance of current illness as a normal part of life. As one patient described:

It [cancer] just causes you to accept reality of what it is. . . [A]t first you think, well, you can beat it, but the more treatments I get and the more things that go on, you kind of discover you really can't cure it. You can delay it. So at some point, you just accept that there is a stopping point somewhere. You just don't worry about it (patient # 5).

Such acceptance may calm frightening experiences, as one patient described: "At first it was kind of scary, and then you just accept it. It is what it is and you can't get yourself down because that's probably the worst thing you can do. So just do what you've got to do and move on" (patient # 5). More specifically, for the R/S participants, complete trust in God facilitated

acceptance: "I just keep thinking that God has a plan, and if this is it, I'm accepting" (patient # 9). One participant told us:

One day, yeah, they're going to come knocking and saying that it's your turn now. . . . I mean when you're born one day, one day you've got to check out. I mean that's the whole life circle (patient # 5).

Illness was described by some as an expected part of their life journey. For others, a terminal cancer diagnosis was not easily accepted. The expected linearity of life for others meant embracing this new reality. A good description comes from one patient:

[J]ust pretty much reminding myself that it's how it's going to be. Who knows what's going to happen tomorrow? You could get stepped on by an elephant. So you don't have to have cancer to be dying. I guess that's just the biggest, you know. It's just the fatalist of what's going to happen is going to happen (patient # 2).

Accepting the reality of one's terminal illness is challenging yet not insurmountable for some. As on patient explained, "getting up and staying as healthy as possible to live a life as normal as possible" (patient # 4) may be a resource for dealing with cancer distress. Positive thinking together with a willingness to fight or access sources of strength was described by another participant: "[Y]ou don't know what tomorrow is going to bring. But stay positive and happy"(patient # 4).

#### 5. Existential Suffering

Patients described existential suffering leading to fatigue, pain, sadness, anger, confusion, and regrets as they went through medical decision-making, prioritizing responsibilities, receiving treatment, and dealing with associated side effects of those treatments. As one patient told us:

I'm so fatigued so much, and I don't have the energy I used to, and you know, right now, the kids being three months and two years, are not of an age where they're in sports and things, so I am hoping my health holds up so that I am able to be involved with them, and let them be involved in the things that, you know, they want to do (patient # 11).

Another reported "doing a lot of napping and sitting, and napping and sitting, just no motivation, no energy. All you want to do is sleep" (patient # 10), leading one "to kind of force yourself to even do housework" (patient # 10). As one participant told us, "I don't know whether it's a combination of the chemicals from the chemo or the cancer or both, but stress really causes me to have adverse reactions, that if something is very stressful, my whole body will break out in sweat. Sometimes I'll have to change a t-shirt three or four times a day. It just instantly gets wet"(patient # 11). Suffering was also existential, as participants described feeling worthless and causing suffering to others (Table 1).

Other patients described feeling reasonably well at times. One told us: "I feel great today, but there have been a lot of times where there's a lot of fatigue from the drugs" (patient # 12).

#### **DISCUSSION**

In this qualitative study of 21 patients with advanced, incurable cancer, relationships with family and friends repeatedly emerged as the most important theme for participants, irrespective of whether they were religious, spiritual, or neither. These patients strongly expressed the importance of relationships with others in improving meaning of life especially when those relationships weren't present. This is consistent with past research that also found an emphasis on relationships and existential suffering in end-of-life care for cancer patients. <sup>52,53,54</sup> However, prior studies have not found it to be as important as we did in

understanding relationship as both a strength and a distress to cancer patients. <sup>55,56</sup> As previous research has shown and our study confirms, for many R/S patients, a sense of a relationship with God and connection to a faith community were also important. Some patients reported feelings of abandonment by God, family, and faith community as a source of distress. Future spiritual interventions must assess the quality of relationships and the extent to which they are a source of support or distress. Patients may benefit from spiritual care interventions that include strategies to improve the individual's sense of connection to others when it is lacking. <sup>57</sup>

Among those patients who defined themselves as religious or spiritual, we found that many experienced a deepened faith in God or higher power. The experiences of hope, <sup>58</sup> peace <sup>59</sup> and calm<sup>60</sup> through cancer trajectory have been discussed in research. The importance of relationship with God has also been identified in other qualitative studies of cancer patients. <sup>61</sup> Our findings of patients' engaging in deeper prayers, reading scripture, commitment to faith in God, and supportive relationships are consistent with prior research that identified religious and spiritual sources of strength in patients with cancer. <sup>62</sup>

One important source of religious struggle was coming to terms with how God could allow the cancer to occur. Some individuals felt at peace or accepted the diagnosis, while others felt abandoned by God. Other participants struggled with their existential suffering and loss of function, which led in some cases to separation from others. Other prior studies Bužgová, <sup>63</sup> Pearce, <sup>64</sup> Moadel <sup>65</sup> and Grant <sup>66</sup> have identified spiritual struggle or unmet needs as well. Our study identifies a focus on unmet needs and strengths of adults with cancer. Experiences such as longing for connection with family, God, spiritual activities while making

meaning, getting in terms with identity and accepting the reality of cancer may be ways to clinically align quality spiritual care for such patients.

This study has several limitations. First, this study utilized a cross-sectional design and included patients from one large academic cancer center. Our population was highly Christian and religious, as well as mostly white and economically stable, which may limit generalizability of findings to other populations. Second, only one investigator (a research chaplain) conducted all the qualitative interviews, which may have created potential systematic response bias that may limit validity of the findings. Notably, data analysis was independently conducted by several investigators, including two physicians, a clinical psychologist, a health-services researcher, and a chaplain researcher to ensure validity of the coding. Finally, although qualitative interviews are designed to be open-ended, all have a structure that may introduce bias. Our initial question addressed what gives meaning to each participant's life and what is most important. We may have received different responses if we had initially asked about other aspects of religion or spirituality.

#### CLINICAL IMPLICATIONS AND CONCLUSIONS

Our study identified relationships as an almost universally important dimension of life with advanced cancer. The central importance that patients placed on relationships may have been due to the use of the broad International Consensus Conference definition of spirituality. Participants almost always brought up relationships first when asked the first interview questions about what gave them meaning or was most important. This work emphasizes that supporting relationships should be a central focus of spiritual care for patients with advanced cancer. Future research could confirm the central importance of relationships using

quantitative methods and could identify how relationships could be bolstered by spiritual care interventions. Furthermore, these interventions must address questions about meaning, acceptance, patient suffering, and changes in identity. These findings are also useful for interprofessional team members, who should be trained to provide basic spiritual care, by developing awareness of the most common spiritual concerns of advanced cancer patients in outpatient settings.

#### **Future Directions**

Following the recommendations of The National Comprehensive Cancer Network (NCCN) and NCPQPC, we concur that healthcare systems should be prepared to incorporate the religious and spiritual values of cancer patients in their treatment plans. Spiritual care experts (board-certified chaplains) and generalists (inter-professional team members) both play a role in this. Inter-professional spiritual care training together with research on the impact of spiritual-care intervention on spiritual distress of outpatient advanced-cancer patients is a necessary next step.

#### Appendix 1: Interview Guide

- 1. Tell me about yourself.
- 2. Do you consider yourself spiritual, religious, both [religious and spiritual], or neither [religious nor spiritual]? Probe: What does that mean to you?
- 3. What gives your life meaning? If clarification needed, ask: What is most important to you in your life now? Probe: Tell me more about that.
- 4. How has this illness affected your faith/spirituality/sense of meaning? [If patient response to question #1 is "neither," ask, how has this illness affected you?
- 5. How has this illness affected your friendships? What does that mean to you?
- 6. How has this illness affected your family? Please explain.
- 7. How has this illness influenced your relationships with family members?
- 8. Are you part of a spiritual/religious/faith community? (If no, go to # 13)
- 9. If yes: How has this illness influenced your relationship with your faith community?
- 10. Has your illness affected your faith/spirituality/beliefs in any way? If yes, how?
- 11. Is there any way your faith/spirituality/beliefs helps you to cope with this illness? Please give examples.
- 12. Since the discovery of this illness, is there anything about your faith/spiritual experience that you are worried about? Probe: Tell me more.
- 13. Since the discovery of this illness, have you had any concerns about meaning or purpose in your life? Probe: What does that mean to you?
- 14. Have your faith, beliefs or values changed in any way during this illness? Probe: How?
- 15. Do you have any other concerns that you would like to share that I did not ask you about?

#### **DISCLOSURES**

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#### References

- 1. Steinhauser KE, Voils CI, Clipp EC, Bosworth HB, Christakis NA, Tulsky JA. "Are you at peace?": One item to probe spiritual concerns at the end of life. Arch Intern Med 2006;166:101–105.
- 2. Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, Pugliese K. Improving the quality of spiritual care as a dimension of palliative care: The report of the Consensus Conference. J Palliat Med 2009;12:885–904.
- 3. Fitchett G, Murphy PE, Kim J, Gibbons JL, Cameron JR, Davis JA. Religious struggle: Prevalence, correlates and mental health risks in diabetic, congestive heart failure, and oncology patients. Int J Psychiatry Med 2004;34:179–196.
- 4. Thuné□Boyle IC, Stygall J, Keshtgar MR, Davidson TI, Newman SP. Religious/spiritual coping resources and their relationship with adjustment in patients newly diagnosed with breast cancer in the UK. Psycho□Oncol 2013;22:646–658.
- 5. Pargament KI, Smith BW, Koenig HG, Perez L. Patterns of positive and negative religious coping with major life stressors. J Scientific Study Relig 1998;37:710–724.
- 6. Pargament KI, Koenig HG, Perez LM. The many methods of religious coping:

  Development and initial validation of the RCOPE. J Clin Psy 2000;56:519–543.
- 7. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000;284:2476–2482.
- 8. Steinhauser KE, Voils CI, Clipp EC, Bosworth HB, Christakis NA, Tulsky JA. "Are you at peace?": One item to probe spiritual concerns at the end of life. Arch Intern Med 2006;166:101–105.

- 9. Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, Chochinov H, Handzo G, Nelson-Becker H, Prince-Paul M, Pugliese K. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. Journal of palliative medicine. 2009;12;10:885-904.
- 10. Phelps AC, Maciejewski PK, Nilsson M, Balboni TA, Wright AA, Paulk ME, Trice E, Schrag D, Peteet JR, Block SD, Prigerson HG. Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. Jama. 2009;18;301;11:1140-7.
- 11. Ferrell BR, Dow KH, Grant M. Measurement of the quality of life in cancer survivors. Qual Life Res 1995;4: 523–531.
- 12. Tarakeshwar N, Vanderwerker LC, Paulk E, Pearce MJ, Kasl SV, Prigerson HG. Religious coping is associated with the quality of life of patients with advanced cancer. J Palliat Med 2006;9:646–657.
- 13. Sulmasy DP. (2002). A biopsychosocial-spiritual model for the care of patients at the end of life. Gerontologist 2002;42:24–33.
- 14. Winkelman WD, Lauderdale K, Balboni MJ, Phelps AC, Peteet JR, Block SD, et al. The relationship of spiritual concerns to the quality of life of advanced cancer patients:
  Preliminary findings. J Palliat Med 2011;14:1022–1028.
- 15. Alcorn SR, Balboni MJ, Prigerson HG, Reynolds A, Phelps AC, Wright AA, et al. "If God wanted me yesterday, I wouldn't be here today": Religious and spiritual themes in patients' experiences of advanced cancer. J Palliat Med, 2010;13:581–588.
- 16. Greisinger AJ, Lorimor RJ, Aday LA, Winn RJ, Baile WF. Terminally ill cancer patients: Their most important concerns. Cancer Pract 1997;5:147–154.

- 17. Sulmasy DP. A biopsychosocial-spiritual model for the care of patients at the end of life. Gerontologist 2002;42:24–33.
- 18. Koenig HG. Spirituality in patient care: Why, how, when, and what. Philadelphia: Templeton Foundation Press, 2002:165.
- 19. Silvestri GA, Knittig S, Zoller JS, Nietert PJ. Importance of faith on medical decisions regarding cancer care. J Clin Oncol 2003;21:1379–1382.
- 20. Buck HG, McMillan SC. A psychometric analysis of the spiritual needs inventory in informal caregivers of patients with cancer in hospice home care. Oncol Nurs Forum 2012;39:E332–339.
- 21. Pearce MJ, Coan AD, Herndon JE, Koenig HG, Abernethy AP. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. Support Care Cancer 2012;20:2269–2276.
- 22. Puchalski CM, Blatt B, Kogan M, Butler A. Spirituality and health: The development of a field. Acad Med 2014;89:10–6.
- 23. Zinnbauer BJ, Pargament KI, Scott AB. The emerging meanings of religiousness and spirituality: Problems and prospects. Journal of personality. 1999 Dec; 67(6):889-919.
- 24. Puchalski CM, Vitillo R, Hull SK, Reller N. Improving the spiritual dimension of whole person care: Reaching national and international consensus. J Palliat Med 2014;17: 642–656.
- 25. Pargament KI, Magyar-Russell GM, Murray-Swank NA. The sacred and the search for significance: Religion as a unique process. Journal of social issues. 2005 Dec;61;4:665-87.

- 26. Ferrell B, Connor SR, Cordes A, Dahlin CM, Fine PG, Hutton N, et al. The national agenda for quality palliative care: The National Consensus Project and the National Quality Forum.

  J Pain Symptom Manag 2007;33:737–744.
- 27. Puchalski CM. (2012). Spirituality in the cancer trajectory. Ann Oncol 2012;23:49-55.
- 28. Breitbart W. Spirituality and meaning in supportive care: Spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. Support Care Cancer 2002;10:272–280.
- 29. McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. Lancet 2003;361:1603–1607.
- 30. Balboni TA, Paulk ME, Balboni MJ, Phelps AC, Loggers ET, Wright AA, et al. Provision of spiritual care to patients with advanced cancer: Associations with medical care and quality of life near death. J Clin Oncol 2009;28:445–452.
- 31. Peteet JR. The relationship between medicine, spirituality and religion: Three models for integration. J Reli Health 2014;53:1586-1598.
- 32. Epstein-Peterson Z, Sullivan A, Phelps AC, Balboni MJ, Vanderweele TJ, Balboni TA.

  Spiritual care provided by oncology physicians and nurses to advanced cancer patients. J

  Clin Oncol 2012; 30:9116.
- 33. Best M, Butow P, Olver I. Do patients want doctors to talk about spirituality? A systematic literature review. Patient Education and Counseling. 2015 Nov 1;98(11):1320-8.
- 34. Balboni TA, Vanderwerker LC, Block SD, Paulk ME, Lathan CS, Peteet JR, Prigerson HG. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. J Clin Oncol 2007;25:555–560.

- 35. Mesquita AC, Chaves ÉDCL, de Barros GAM. (2017). Spiritual needs of patients with cancer in palliative care: An integrative review. Curr Opin Support Palliat Care 2017;11:334–340.
- 36. Hermann, CP. Spiritual needs of dying patients: a qualitative study. In Oncology nursing forum 2001 Jan 1 (Vol. 28, No. 1).
- 37. Edwards A, Pang N, Shiu V, Chan C. The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research. Palliative Medicine. 2010 Dec; 24;8:753-70.
- 38. Rohde G, Kersten C, Vistad I, Mesel T. Spiritual well-being in patients with metastatic colorectal cancer receiving noncurative chemotherapy: a qualitative study. Cancer nursing. 2017 May; 40;3:209.
- 39. Hampton DM, Hollis DE, Lloyd DA, Taylor J, McMillan SC, Spiritual needs of persons with advanced cancer. American Journal of Hospice and Palliative Medicine®. 2007 Feb; 24;1:42-8.
- 40. Astrow, AB, Kwok G, Sharma RK, Fromer N, Sulmasy DP. Spiritual Needs and Perception of Quality of Care and Satisfaction with Care in Hematology/Medical Oncology Patients: A Multicultural Assessment. Journal of pain and symptom management. 2018 Jan 1;55;1:56-64.
- 41. Spidell S. Resilience and professional chaplaincy: A paradigm shift in focus. J Health Care Chaplain 2014;20:16–24.
- 42. Pargament KI, Ensing DS, Falgout K, Olsen H, Reilly B, Van Haitsma K, Warren R. God help me (I): Religious coping efforts as predictors of the outcomes to significant negative lifeevents. American journal of community psychology. 1990 Dec; 18 (6): 793-8.

- 43. Koenig HG, Larson DB, Larson SS. Religion and coping with serious medical illness.

  Annals of pharmacotherapy. 2001 Mar; 35 (3): 352-9.
- 44. Pargament KI. The psychology of religion and coping: Theory, research, practice. Guilford Press; 2001 Feb 15.
- 45. Moss AH, Lunney JR, Culp S, Auber M, Kurian S, Rogers J, et al. Prognostic significance of the "surprise" question in cancer patients. J Palliat Med, 2010;13:837–840
- 46. Callahan CM, Unverzagt FW, Hui SL, Perkins AJ, Hendrie HC. Six-item screener to identify cognitive impairment among potential subjects for clinical research. Med Care 2002;40:771–781.
- 47. Glaser B, Strauss A. Grounded theory: The discovery of grounded theory. Sociol 1967;12:27–49..
- 48. Kessler RC, Andrews G, Colpe LJ, Hiripi E, Mroczek DK, Normand SL, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. Psycholog Med 2002;32:959–976.
- 49. Kessler RC, Barker PR, Colpe LJ, Gfroerer JC, Hiripi E, Howes MJ, Normand SL, Manderscheid RW, Walters EE, Zaslavsky AM. Screening for a serious mental illness in the general population. Archives of general psychiatry. 2003 Feb 1;60 (2);184-9.
- 50. Chew LD, Griffin JM, Partin MR, Noorbaloochi S, Grill JP, Snyder A, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. J Gen Intern Med 2008;23:561–566.
- 51. Boyatzis RE. Transforming qualitative information: Thematic analysis and code development. sage; 1998 Apr 16.
- 52. Astrow AB, Kwok G, Sharma RK, Fromer N, Sulmasy D. Just what are spiritual needs of cancer patients? An empirical study in a diverse population. J Clin Oncol 2016;34:10005.

- 53. Moadel A, Morgan C, Fatone A, Grennan J, Carter J, Laruffa G, et al. Seeking meaning and hope: Self-reported spiritual and existential needs among an ethnically-diverse cancer patient population. Psycho-Oncol 1999;8:378–385.
- 54. Chio CC, Shih FJ, Chiou JF, Lin HW, Hsiao FH, Chen YT. The lived experiences of spiritual suffering and the healing process among Taiwanese patients with terminal cancer. Journal of Clinical Nursing. 2008; 17; 6:735-43.
- 55. Astrow AB, Wexler A, Texeira K, He MK, Sulmasy DP. Is failure to meet spiritual needs associated with cancer patients' perceptions of quality of care and their satisfaction with care? J Clin Oncol 2007;25:5753–5757.
- 56. Pearce MJ, Coan AD, Herndon JE, Koenig HG, Abernethy AP. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. Support Care Cancer 2015;20:2269–2276.
- 57. Shields M, Kestenbaum A, Dunn LB. Spiritual AIM and the work of the chaplain: A model for assessing spiritual needs and outcomes in relationship. Palliat Support Care 2015;13:75–89.
- 58. Vilalta A, Valls J, Porta J, Viñas J. Evaluation of spiritual needs of patients with advanced cancer in a palliative care unit. J Palliat Med, 2014;17:592–600.
- 59. Astrow AB, Wexler A, Texeira K, He MK, Sulmasy DP. Is failure to meet spiritual needs associated with cancer patients' perceptions of quality of care and their satisfaction with care? J Clin Oncol 2007;25:5753–5757.
- 60. Höcker A, Krüll A, Koch U, Mehnert A. Exploring spiritual needs and their associated factors in an urban sample of early and advanced cancer patients. European J Cancer Care 2014;23:786–794.

- 61. Moadel A, Morgan C, Fatone A, Grennan J, Carter J, Laruffa G, et al. Seeking meaning and hope: Self□reported spiritual and existential needs among an ethnically□diverse cancer patient population. Psycho□Oncol 1999;8:378–385.
- 62. Fawwaz A, Schreiber JA, Al Nusairat TS, Andrykowski MA. Spirituality in Arab Muslim hematopoietic stem cell transplantation survivors: A qualitative approach. Cancer Nurs 2016;39:E39–E47.
- 63. Bužgová R, Hajnová E, Sikorova L, Jarošová D. Association between unmet needs and quality of life in hospitalised cancer patients no longer receiving anti□cancer treatment. European J Cancer Care 2014;23:685–694.
- 64. Pearce MJ, Coan AD, Herndon JE, Koenig HG, Abernethy AP. Unmet spiritual care needs impact emotional and spiritual well-being in advanced cancer patients. Support Care Cancer 2012;20:2269–2276.
- 65. Moadel A, Morgan C, Fatone A, Grennan J, Carter J, Laruffa G, et al. Seeking meaning and hope: Self□reported spiritual and existential needs among an ethnically□diverse cancer patient population. Psycho□Oncol 1999;8:378–385.
- 66. Grant E, Murray SA, Kenda M, Boyd K, Tilley S, & Ryan, D. Spiritual issues and needs: perspectives from patients with advanced cancer and nonmalignant disease. A qualitative study. Palliative & Supportive Care, 2004; 2; 4: 371-378.

Table 1: Participant Characteristics (n=21)

Age (mean & standard deviation)	60.95 (11.56)
Male	7 (33.3%)
White	20 (95.2%)
Income	
Comfortable	13 (61.9%)
Just Enough	5 (23.8%)
Not Enough	2 (9.5%)
Refused	1 (4.8%)
Marital Status	
Married	16 (76.2%)
Single	3 (14.3%)
Divorced	2 (9.5%)
Education	
High School or Less	7 (33.3%)
Some College or College Degree	14 (66.7%)
Religion/Faith	
None	4 (19.1%)
Protestant	10 (47.6%)
Catholic	5 (23.8%)
Other	2 (9.5%)
Protestantism	
Methodist	3 (30.0%)
Lutheran	2 (20.0%)
Southern Baptist	1 (10.0%)
Pentecostal	1 (10.0%)
Non-denominational	1 (10.0%)
Other	2 (20.0%)
Protestant Orthodoxy	
Liberal	0 (0%)
Moderate	5 (50.0%)
Conservative	2 (20.0%)
Other	3 (30.0%)
Health Literacy (trouble with medical forms)	
Extremely/Quite a Bit	16 (76.2%)
Somewhat/Little Bit/Not at all	5 (23.8%)
Psychological Distress	
Low	18 (85.7%)
High	3 (14.3%)
Values are mean (standard deviation) for age:	

Values are mean (standard deviation) for age; all categorical variables are represented with frequencies (percentages). Psychological distress is measured with the Kessler 6 Psychological Distress Scale.

Table I1: Examples of Patient Responses Exemplifying Five Major Themes of Spiritual Experiences for Adults with Advanced Cancer in Outpatient Clinical Settings

# Theme 1: Supportive Relationships

**Subtheme: Family and Friends** 

Support	Lack of Support	Abandonment	Worries
Positive:	Being distant from him [son], he doesn't	I used to be scared of dying and	I was worried about life, worried about
My husband is very, very supportive	even know I have cancer, as far as I know.	everything, but now I'm not scared	insurance, my health insurance and my job.
Whether it's sickness, whether it's a	I talked to him after I had my surgery and I	of dying. I'm scared of them having	So I was worried about health insurance, but
new job, whether it's buying a car,	had the cancer removed from my	to live without a mother at a young	I find out I didn't have to worry about that
doesn't make any difference. My	esophagus The only thing he said was	age.	thanks to K
husband has always been my	"What's wrong, dad?" The rest of it		
champion.	was about him.		

**Subtheme: God** 

God as Source of Support	God as Source of Control	Abandoned by God	Abandoning God
Through the years, I have	And what do you do, and at one point I remember	I've always tried, even though I don't go to church or	Before I found out I
turned my back on my God.	thinking, "Well, I don't know what to do, but	anything, to live my life as straight-laced and how I think	was sick, probably I
Tried to do things on my own.	whatever happens, happens. It's not in my hands."	that I am supposed to in God's eyes Then I think,	was pulling away
Since my illness, I've called on	So I thought, "Well, I'll just do whatever God	"Why do I still get this awful disease when there's other	[from God] a little bit.
him to help me through this.	wants and I'll just leave it up to that." When I did	people out there that have smoked and drank their entire	
	that, I didn't worry any more.	lives and done bad things, and here I am trying to be the	
		best persona that I can?"	

Subtheme Faith Community		
Support from Faith Community	Separation from Faith Community	
All the people (from church) that brought me little gifts or flowersmade a huge	Yes. I do miss those activities in church. I used to attend a church, but sometimes my	
difference in my day.	hands and my feet are hurting or aching and I'm not able to go. The energy level	
	hasn't got back up to par.	

## Theme 2: Meaning

My Life Is an Example	Wake-Up Call	Why?
Maybe He's using me to show people what faith can do for a serious thing like this. And that if I	It's like a wake-up call. You go to	It does make me wonder, like,
let people know how much I truly believe and then I have good results, maybe that would be	church and you feel like you do the	why are you here if you're just
my way to work for God, to show people that if they believe and have faith in Him that He	right thing and all of a sudden it's a	going to be meant to suffer.
will get them through awful things like stage,-four lung cancer I feel it's a miracle.	kaboom. This is the real deal. What	
	now?	

# Theme 3: Identity

Maintaining Identity	Who I Am	Losing Identity
I just decided I'm not going to let this [illness]	I believe that no matter what, I'm a spiritual person. I'm a	I used to love politics. Politics and music. Now
fundamentally change who I am, and it would be easy I	good person. I'm good to people. I try to do the right thing	since what has just happened to us, no, I can't
respect religion, and I respect religious people [T]here	all the time, and I believe that no matter what, if there is a	watch TV. I can't. I have just withdrawn from
is a huge part of me that realized my life would be a little	good and bad place, I'm going to a good place. How could	everything, and it's like nothing that I participate
easier if I had that component.	someone send me to a bad place?	in anymore.

# Theme 4: Acceptance (Coping)

At first, it was kind of scary, and then you just accept it. It is what it is, and you can't get yourself down, because that's probably the worst thing you can do. So just do what you've got to do and move on.

# Theme 5:Existential Suffering

I feel sick, tired, worthless, dragging everybody, family crashed, letting family down by being sick.

