

Original Article

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 patients with advanced cancer will help guide the provision of high-quality spiritual care.

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

Methods. We conducted semistructured 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. *J Pain Symptom Manage* 2019;57:576–586. © 2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Advanced cancer, coping, spirituality, religion, experiences, distress, spiritual care

Introduction

Religion and spirituality are important to a majority of patients with cancer and affect the cancer

experience in various ways.^{1,2} Religion and spirituality may cause distress for up to 50% of patients with cancer,^{3,4} yet a significant number of people use religion

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and spirituality to cope with life crises.^{1,2,5-8} Spiritual and religious well-being may improve quality of life for patients with cancer^{9,10} and may be important to the quality of end-of-life experiences for both patients and caregivers.¹⁰⁻¹⁴ Moreover, religious belief is important in medical decision-making for some patients.^{15,16} Consequently, attention to the significance of religion and spirituality is important for end-of-life care.^{17,18}

Spirituality has been defined in different ways¹⁹ to include philosophical, secular, and religious beliefs.²⁰ 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."²¹ This definition is in line with how religion is defined as a search for significance often related to the sacred.²² We broadly use "spiritually religious" to interpret the experiences of patients who consider themselves both religious and spiritual, whereas 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, a consortium of palliative care organizations, identifies addressing religion and spirituality as one of eight guidelines for clinical practice.²³ Because advanced cancer diagnosis triggers deep existential and spiritual questions that may impact meaning and purpose of life,²⁴⁻²⁶ addressing those questions through a fully integrated approach is part of quality patient care.^{27,28} Unfortunately, most health care systems have not yet completely incorporated this approach to care. Spiritual care may therefore be infrequent among patients with cancer.^{29,30} One study found that 47% of patients with cancer reported that their religious community supported their spiritual needs minimally or not at all, and 72% reported that the medical system supported their spiritual needs minimally or not at all.³¹ 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 patients with cancer in the U.S., Europe, and Taiwan.³² Studies have identified their need for meaning, purpose, love, relationships, and comfortability with physician inquiry about spiritual needs.³³⁻³⁶ Patients may also experience losses related to roles, identity, and fear of death.³⁷ This focus on needs or challenges may be incomplete. Spiritual strengths have been identified as a potential resource during stressful life

events³⁸ and patients with cancer may use positive religious coping.³⁹⁻⁴¹ We conducted individual semistructured 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?"⁴² Patients had to be of age 18 years or older, more than two 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.⁴³

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 prognosis 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. In addition, 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.⁴⁴ To establish thematic saturation, the PI (S. M.) 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).⁴⁵ Low scores were 0-12, and high scores 13-24.⁴⁶ Furthermore, we administered a one-item health literacy question⁴⁷ 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 PI (S. M.), an experienced qualitative researcher with particular expertise in chaplaincy research, conducted the interviews. The interview guide used 15 questions (Appendix 1) 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 analysis⁴⁸ for interview data. Five investigators (S. M., A. M. T., A. H. C., S. A. J., and P. R. H.) independently read and coded two interviews. We discussed preliminary codes and also provided feedback about topics to explore in

greater depth. Then, three investigators (S. M., A. M. T., and A. H. C.) 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 (S. M. and A. H. C.), 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 (S. M., A. M. T., A. H. C., S. A. J., and P. R. H.). Quantitative items were analyzed using SAS v9.4 (SAS Institute, Cary, NC).

Results

We identified 352 adults with advanced cancer. Of these, 296 (84.09%) had >12 months of estimated survival, whereas 56 (15.9%) had <12 months. Of the 56 patients, 25 (44.6%) were judged by the oncologist or nurse to be ineligible because of 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 (Table 1).

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, 1782 paragraphs, and 5181 lines were analyzed. Five major themes emerged: supportive relationships, meaning, identity, acceptance coping, and existential suffering.

Themes

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?” most participants identified family and friends (Table 2). 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

Table 1
Participant Characteristics (n = 21)

Age (mean and standard deviation), yrs	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%)
Nondenominational	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; all categorical variables are represented with frequencies (percentages). Psychological distress is measured with the Kessler 6 Psychological Distress Scale.

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 most 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, coworkers, 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).

Although 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 do not want to offend anyone, but I kind of want to tell him, I do not need so much, I do not need a sappy e-mail every day. I do not need you to tell me you love me every other day. I do not 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 e-mails 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).

Table 2
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
<p>Positive: My husband is very, very supportive ... Whether it's sickness, whether it's a new job, whether it's buying a car, does not make any difference. My husband has always been my champion.</p>	<p>Being distant from him [son], he does not even know I have cancer, as far as I know. I talked to him after I had my surgery and I had the cancer removed from my esophagus ... The only thing he said was "What's wrong, dad?" ... The rest of it was about him.</p>	<p>I used to be scared of dying and everything, but now I'm not scared of dying. I'm scared of them having to live without a mother at a young age.</p>	<p>I was worried about life, worried about insurance, my health insurance, and my job. So I was worried about health insurance, but I find out I did not have to worry about that thanks to K—.</p>
Subtheme: God			
God as Source of Support	God as Source of Control	Abandoned by God	Abandoning God
<p>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.</p>	<p>And what do you do, and at one point, I remember thinking, "Well, I do not know what to do, but whatever happens, happens. It's not in my hands." So I thought, "Well, I'll just do whatever God wants and I'll just leave it up to that." When I did that, I did not worry anymore.</p>	<p>I've always tried, even though I do not go to church or anything, to live my life as straight-laced and how I think that I am supposed to in God's eyes ... Then, I think, "Why do I still get this awful disease when there's other people out there that have smoked and drank their entire lives and done bad things, and here I am trying to be the best persona that I can?"</p>	<p>Before I found out I was sick, probably I was pulling away [from God] a little bit.</p>
Subtheme Faith Community			
Support From Faith Community		Separation From Faith Community	
<p>All the people (from church) that brought me little gifts or flowers... made a huge difference in my day.</p>		<p>Yes. I do miss those activities in church. I used to attend a church, but sometimes my 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.</p>	
Theme 2: Meaning			
My Life Is an Example	Wake-Up Call	Why?	
<p>Maybe He's using me to show people what faith can do for a serious thing like this. And that if I let people know how much I truly believe... and then I have good results, maybe that would be my way to work for God, to show people that if they believe and have faith in Him... that He will get them through awful things like stage-four lung cancer ... I feel it's a miracle.</p>	<p>It's like a wake-up call. You go to church and you feel like you do the right thing and all of a sudden it's a kaboom. This is the real deal. What now?</p>	<p>It does make me wonder, like, why are you here if you're just going to be meant to suffer.</p>	

(Continued)

Table 2
Continued

Theme 3: Identity		
Maintaining Identity	Who I Am	Losing Identity
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.	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?	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.
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.		

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 participant 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).

Meaning

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

Identity

The concerns of illness and identity were expressed by some patients. One nonreligious patient 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).

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 do not 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 one 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).

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 were not present. This is consistent with past research that also found an emphasis on relationships and existential suffering in end-of-life care for patients with cancer.^{49–51} 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 patients with cancer.^{52,53} 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.⁵⁴

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,⁵⁵ peace,⁵² and calm⁵⁶ through cancer trajectory have been discussed in research. The importance of relationship with God has also been identified in other qualitative studies of patients with cancer.⁵⁰ 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.⁵⁷

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, whereas 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 by Bužgová et al.,⁵⁸ Pearce et al.,¹⁸ Moadel et al.,⁵⁰ and

Grant et al.⁵⁹ 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 used 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 and National

Consensus Project for Quality Palliative Care, we concur that health care systems should be prepared to incorporate the religious and spiritual values of patients with cancer in their treatment plans. Spiritual care experts (board-certified chaplains) and generalists (interprofessional team members) both play a role in this. Interprofessional 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.

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References

1. Steinhauer 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, et al. 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. Steinhauer 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. Phelps AC, Maciejewski PK, Nilsson M, et al. Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *JAMA* 2009;301:1140–1147.
9. Ferrell BR, Dow KH, Grant M. Measurement of the quality of life in cancer survivors. *Qual Life Res* 1995;4:523–531.
10. 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.
11. Sulmasy DP. A biopsychosocial-spiritual model for the care of patients at the end of life. *Gerontologist* 2002;42:24–33.
12. Winkelman WD, Lauderdale K, Balboni MJ, 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.
13. Alcorn SR, Balboni MJ, Prigerson HG, 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.
14. Greisinger AJ, Lorimor RJ, Aday LA, Winn RJ, Baile WF. Terminally ill cancer patients: their most important concerns. *Cancer Pract* 1997;5:147–154.
15. Koenig HG. *Spirituality in patient care: Why, how, when, and what*. Philadelphia: Templeton Foundation Press, 2002: 165.
16. Silvestri GA, Knittig S, Zoller JS, Nietert PJ. Importance of faith on medical decisions regarding cancer care. *J Clin Oncol* 2003;21:1379–1382.
17. 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–E339.
18. 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.
19. Puchalski CM, Blatt B, Kogan M, Butler A. Spirituality and health: the development of a field. *Acad Med* 2014;89:10–16.
20. Zinnbauer BJ, Pargament KI, Scott AB. The emerging meanings of religiousness and spirituality: Problems and prospects. *J Personal* 1999;67:889–919.
21. 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.

22. Pargament KI, Magyar Russell GM, Murray Swank NA. The sacred and the search for significance: religion as a unique process. *J Soc Issues* 2005;61:665–687.
23. Ferrell B, Connor SR, Cordes A, 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.
24. Puchalski CM. Spirituality in the cancer trajectory. *Ann Oncol* 2012;23:49–55.
25. 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.
26. 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.
27. Balboni TA, Paulk ME, Balboni MJ, 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.
28. Peteet JR. The relationship between medicine, spirituality and religion: three models for integration. *J Reli Health* 2014;53:1586–1598.
29. 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.
30. Best M, Butow P, Olver I. Do patients want doctors to talk about spirituality? A systematic literature review. *Patient Education Couns* 2015;98:1320–1328.
31. Balboni TA, Vanderwerker LC, Block SD, et al. 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.
32. Mesquita AC, Chaves ÉDCL, de Barros GAM. Spiritual needs of patients with cancer in palliative care: an integrative review. *Curr Opin Support Palliat Care* 2017;11:334–340.
33. Hermann CP. Spiritual needs of dying patients: a qualitative study. *Oncol Nurs Forum* 2001;28.
34. 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. *Palliat Med* 2010;24:753–770.
35. Rohde G, Kersten C, Vistad I, Mesel T. Spiritual well-being in patients with metastatic colorectal cancer receiving noncurative chemotherapy: a qualitative study. *Cancer Nurs* 2017;40:209.
36. Hampton DM, Hollis DE, Lloyd DA, Taylor J, McMillan SC. Spiritual needs of persons with advanced cancer. *Am J Hosp Palliat Medicine* 2007;24:42–48.
37. 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. *J pain symptom Manag* 2018;55:56–64.
38. Spidell S. Resilience and professional chaplaincy: a paradigm shift in focus. *J Health Care Chaplain* 2014;20:16–24.
39. Pargament KI, Ensing DS, Falgout K, et al. God help me (I): religious coping efforts as predictors of the outcomes to significant negative lifeevents. *Am J Community Psychol* 1990;18:793–798.
40. Koenig HG, Larson DB, Larson SS. Religion and coping with serious medical illness. *Ann Pharmacother* 2001;35:352–359.
41. Pargament KI. The psychology of religion and coping: Theory, research, practice. Guilford Press, 2001.
42. Moss AH, Lunney JR, Culp S, et al. Prognostic significance of the “surprise” question in cancer patients. *J Palliat Med* 2010;13:837–840.
43. 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.
44. Glaser B, Strauss A. Grounded theory: the discovery of grounded theory. *Sociol* 1967;12:27–49.
45. Kessler RC, Andrews G, Colpe LJ, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psycholog Med* 2002;32:959–976.
46. Kessler RC, Barker PR, Colpe LJ, et al. Screening for a serious mental illness in the general population. *Arch Gen Psychiatry* 2003;60:184–189.
47. Chew LD, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med* 2008;23:561–566.
48. Boyatzis RE. Transforming qualitative information: Thematic analysis and code development. Sage, 1998.
49. 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.
50. Moadel A, Morgan C, Fatone A, 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.
51. 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. *J Clin Nurs* 2008;17:735–743.
52. Astrow AB, Wexler A, Teixeira 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.
53. 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.
54. 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.
55. 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.
56. 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. *Eur J Cancer Care* 2014;23:786–794.

57. 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.
58. 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. *Eur J Cancer Care* 2014;23:685–694.
59. 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. *Palliat Support Care* 2004;2:371–378.

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 question #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 help 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?