

Original Article

Cite this article: Kwak J, Bang SH, Rajagopal S, Dronamraju N, Handzo G, Hughes BP (2024). Patients' spiritual concerns and needs and how to address them during advance care planning conversations: Healthcare chaplains' perspectives. *Palliative and Supportive Care* **22**, 49–56. <https://doi.org/10.1017/S1478951522001560>

Received: 30 July 2022

Revised: 13 October 2022


Accepted: 23 October 2022

Keywords:

Advance care planning; Serious illness conversations; Goals of care conversations; Spiritual care; Healthcare chaplain; Palliative care; Chaplain

Author for correspondence: Jung Kwak, School of Nursing, The University of Texas at Austin, 1710 Red River Street, Mail Code: D0100, Austin, TX 78701, USA.
Email: jkwak@nursing.utexas.edu

Patients' spiritual concerns and needs and how to address them during advance care planning conversations: Healthcare chaplains' perspectives

Jung Kwak, PH.D., M.S.W.¹ , So Hyeon Bang, M.S.N., R.N.¹, Shilpa Rajagopal, B.S.A., B.B.A.², Neha Dronamraju, B.S.³, George Handzo, M.DIV.⁴ and Brian P. Hughes, M.DIV.⁴

¹School of Nursing, The University of Texas at Austin, Austin, TX, USA; ²John Sealy School of Medicine, The University of Texas Medical Branch at Galveston, Galveston, TX, USA; ³The University of Texas at Austin, Austin, TX, USA and ⁴HealthCare Chaplaincy Network, New York, NY, USA

Abstract

Objectives. Advance care planning (ACP) conversations require the consideration of deeply held personal values and beliefs and the discussion of uncertainty, fears, and hopes related to current and future personal healthcare. However, empirical data are limited on how such spiritual concerns and needs are supported during ACP. This study explored board-certified healthcare chaplains' perspectives of patients' spiritual needs and support in ACP conversations.

Methods. An online survey of 563 board-certified chaplains was conducted from March to July 2020. The survey included 3 open-ended questions about patients' hopes and fears and about how the chaplains addressed them during ACP conversations. Written qualitative responses provided by 244 of the chaplains were examined with content analysis.

Results. The majority of the 244 chaplains were White (83.6%), female (59%), Protestant (63.1%), and designated to one or more special care units (89.8%). Major themes on patients' hopes and fears expressed during ACP were (1) spiritual, religious, and existential questions; (2) suffering, peace, and comfort; (3) focus on the present; (4) hopes and fears for family; and (5) doubt and distrust. Major themes on how chaplains addressed them were (1) active listening to explore and normalize fears, worries, and doubts; (2) conversations to integrate faith, values, and preferences into ACP; and (3) education, empowerment, and advocacy.

Significance of results. ACP conversations require deep listening and engagement to address patients' spiritual needs and concerns – an essential dimension of engaging in whole-person care – and should be delivered with an interdisciplinary approach to fulfill the intended purpose of ACP.

Introduction

Advance care planning (ACP), according to an international multidisciplinary Delphi panel, is defined as “a process that supports patients at any age or state of health in understanding and sharing personal values, life goals, and preferences regarding future medical care” (Sudore et al. 2017, p. 826). Over the years, the focus of ACP has shifted from the narrow goal of completion of advance directives to preparing patients and surrogates for communication and medical decision-making (Sudore et al. 2022), with the general consensus that ACP is a critical element of high-quality care that facilitates respecting and honoring patients' autonomy and supports patients' families (Jimenez et al. 2018; McMahan et al. 2021). For those with serious illnesses that come with a high risk of mortality and burden for function or quality of life, ACP can elicit serious conversations about illness that help to align patients' values, goals, priorities, and preferences with goals of care so that care can become goal concordant (Jacobsen et al. 2022).

There are, however, several notable psychosocial barriers to engaging in ACP because it is a process that addresses complex, weighty topics. International studies of patients' perceptions of ACP have highlighted a sense of optimism, fears of death and dying, and worries about family members as main issues that prevent individuals from readily engaging in conversations about goals of care (Bernard et al. 2020; Cheung et al. 2020; Jimenez et al. 2018). Some patients believe they are “too young” or “not sick enough” to partake in ACP, whereas others are daunted by the emotional difficulty of such discussions. They worry that the content of ACP conversations may place a burden on family members and loved ones, straining close relationships. Many of these barriers are linked to spiritual concerns, with spirituality here defined as “the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others,

to nature, and to the significant or sacred” (Puchalski et al. 2009, 887). ACP often requires contemplating what is unknown and uncertain, accompanied by naturally occurring fears surrounding the end of life. Yet it also involves considering what is personally meaningful to the patient in order to inform treatment decisions consistent with the patient’s values and beliefs. Accordingly, important facilitators of ACP amid barriers include a strong patient–provider relationship that is rooted in trust, involvement of loved ones, conversations about goals of care, and proper timing (Jimenez et al. 2018; Oyedeji et al. 2020).

Given the particularly important role of providers in initiating and facilitating ACP, various national organizations and consensus statements call for ACP facilitation with interdisciplinary care models (Institute of Medicine 2015; National Consensus Project for Quality Palliative Care 2018). Providers indicate that discussions would be most effective with an interprofessional approach (Institute of Medicine 2015; Kwak et al. 2022; National Consensus Project for Quality Palliative Care 2018). As key members of interdisciplinary care teams, board-certified healthcare chaplains are specialists who have a master’s degree in a spiritual care-related field and have been clinically trained in chaplaincy. Healthcare chaplains communicate with both patients and their families by assessing their spiritual and cultural contexts, needs, hopes, and resources, with careful consideration of their unique beliefs. These abilities help to make chaplains skilled in navigating matters that involve spiritual care, including engagement in ACP conversations (Lutz et al. 2018). Indeed, a study documented that chaplains were able to facilitate ACP conversations effectively in outpatient settings (Lee et al. 2018). Another study of hospital-based chaplains found that over half (55%) chaplains addressed goals of care 60% of the time or more in their practice (Jeuland et al. 2017). A more recent survey of 585 board-certified chaplains in the US has found that over 90% saw ACP as an important part of their role and over 70% felt confident or very confident in completing various ACP tasks (Kwak et al. 2021).

Nevertheless, despite the importance of exploring and addressing spiritual concerns and needs during conversations about ACP and serious illness, and despite the fact that chaplains routinely engage in these conversations with patients, there is limited empirical data on how patients’ spirituality is addressed during these conversations. To address this knowledge gap, the present study explored the spiritual concerns and needs that chaplains observe and address during ACP conversations with patients.

Methods

Design

An online survey of board-certified chaplains was conducted to examine the role of board-certified healthcare chaplains in conversations about goals of care, decision support, and spiritual care for patients across various healthcare settings (Kwak et al. 2021). A pragmatic perspective guided the survey design (Hanson et al. 2005). Pragmatists value both objective and subjective knowledge, and this perspective is considered as an appropriate philosophical basis of mixed methods research (Hanson et al. 2005). For the present study, there were 2 main questions: (1) What are the spiritual needs and concerns of patients expressed during ACP? (2) How do chaplains address patients’ spiritual needs and concerns during ACP? The study protocol was reviewed and approved by the BLINDED Institutional Review Board.

Population, sample, and recruitment

The target population was board-certified healthcare chaplains in the US. Using convenience sampling, healthcare chaplains were recruited from 3 US chaplaincy organizations: the Association of Professional Chaplains, the National Association of Catholic Chaplains, and the Spiritual Care Association. These are large North American certifying bodies for chaplains with a formal subspecialty certification in hospice and palliative care. The survey was available online from March 16 through July 31, 2020. The 3 organizations distributed information about the survey primarily through emails sent from their national offices in March 2020 to their members; reminder emails to complete the survey were sent to members at the end of June 2020. The emails about the study described its purpose and the online survey method, and they provided the principal investigator’s contact information and a link to the online survey site. The survey site stated that participation was voluntary and anonymous and that submission of the online survey signified consent to participate. Respondents were not compensated for their time. They were asked to self-report whether they were board-certified chaplains or not before they could start the survey. The final sample included 563 board-certified healthcare chaplains.

Data collection

The survey was cross-sectional, intended to take about 15–30 minutes to complete. It included closed- and open-ended questions, and it was conducted with Qualtrics software. The study team developed and piloted the survey’s questions for demographic and professional background characteristics (e.g., employment status, chaplaincy designation, and practice setting), the types of patients whom the chaplains served (e.g., the percentage of patients with serious life-threatening illnesses), and roles and experiences in facilitating ACP. The survey offered Sudore et al.’s (2017) definition of ACP as “a process that supports patients at any age or state of health in understanding and sharing personal values, life goals, and preferences regarding future medical care” (p. 826). Three open-ended questions about ACP were asked: “What are the most common fears, worries, or doubts you hear your patients express during ACP conversations?” “What are the most common hopes your patients express during ACP conversations?” and “How do you address these fears, worries, and doubts during ACP conversations?”

Data analysis

The sample’s overall characteristics and relationships among key themes (e.g., frequency distributions and percentages for categorical variables; means and standard deviations for continuous variables) were examined using SPSS Statistics v25. The constant comparative method was used to analyze the chaplains’ free-text responses (Maxwell 2010). An audit trail was maintained by the first author – a gerontologist and academic researcher who designed and implemented the survey, tracked the research team’s developing ideas, and participated in coding and thematic analysis. Multiple coders were engaged to enhance analytical rigor. The first author worked with research team members including co-authors to conduct the initial coding of free-text responses and develop an initial code book. Each of the 3 open-ended questions was initially assigned to 2 coders, who individually coded responses to the same

question. The 2 coders met with each other to compare and discuss the codes until complete agreement was reached. Then the first author, who coded the first 20% of the data separately from the 2 coders, met with them and discussed codes until complete agreement was reached again. The 2 coders then met to review and finalize the coding. The same process was used in coding the other 2 open-ended questions. Following procedures outlined by Braun and Clarke (2006), the team members then collated codes into potential themes, using thematic mapping to visualize relationships between themes. This dialogue was ongoing, and the research team met several times throughout the thematic analysis to review and refine codes, themes, and subthemes and to reach a final agreement. Reflexivity was maintained by the research team throughout the analysis and writing, by recording, discussing, and challenging assumptions about responses.

Results

Participants' characteristics

Of the 563 board-certified chaplains participating in the survey, 244 responded to the 3 open-ended questions (see Table 1 for details). Community hospitals were their most common place of employment (46%), followed by academic medical centers (33%). Over half of the 244 chaplains (57%) were designated for intensive or critical care units. Over one-third (37%) reported that over 80% of their patients had a serious life-threatening illness; most of the chaplains worked with nurses (96%), social workers (93%), and medical doctors (91%).

Salient themes for patients' hopes and fears

Five major themes emerged from the chaplains' responses about patients' hopes and fears during ACP: (1) existential, religious, and spiritual questions; (2) suffering, peace, and comfort; (3) focus on the present; (4) hopes for family; and (5) doubt and distrust.

Existential, religious, and spiritual questions

Many patients' hopes and fears during ACP discussions were intertwined with existential matters. These included faith in God to heal and/or forgive them, desire for reunification with deceased loved ones in the afterlife, and discomfort regarding the uncertainty and great unknown of death. For some patients, the faith that "God decides whether and when I die" led to "limiting their options" because of the belief that they "could recover" or that "ACP is a slippery slope to doubting God." As an intensive care unit (ICU) chaplain at an academic medical center noted from personal experience, "even after making the patient DNR or no escalation of care, there is usually some sort of mention of a miracle to be had" (ID:30). Other patients found "hope in their medical team (chaplain included) as agents of God to render the care needed." Additionally, chaplains recounted patients' "hope of being reunited with deceased loved ones in the afterlife" (ID:24). These hopes, reported by chaplains, were often accompanied by patients' fear of the unknown at the end of life. This uncertainty in the ACP process was highlighted by one ICU and oncology chaplain at a community hospital who stated that

Most patients with chronic illnesses only hear about treatment options from physicians/specialists. Never what a chronic illness trajectory really looks like. When a chaplain sees someone inpatient, it is typically later in

Table 1. Respondents' background characteristics (N = 244)

Background characteristics	n	%
<i>Chaplain characteristics</i>		
Gender		
Male	98	40.2
Female	144	59.0
Other	2	0.8
Race		
White	204	83.6
Black or African American	23	9.4
Asian and Pacific Islander	11	4.5
American Indian or Alaska Native	2	0.8
Hispanic	4	1.6
Religion		
Protestant	154	63.1
Catholic	64	26.2
Jewish	4	1.6
Other	21	8.6
Employment status		
Full time	200	82.0
Part-time	26	10.7
Other ^a	17	7.0
Years of practice as a professional chaplain		
<1	1	0.4
1-5	50	20.5
6-10	66	27.0
11-15	44	18.0
15-20	38	15.6
>21	45	18.4
<i>Work setting characteristics</i>		
Settings		
Academic medical center	80	32.8
Community hospital	111	45.5
Specialty hospital (VA, oncology, rehab, and psychiatric)	37	15.1
Extended care facility/assisted living/nursing home	10	4.1
Inpatient or home hospice	48	19.7
Other	46	18.8
Service Line Designation ^b		
Yes ^c		
Palliative care chaplain	88	36.1
Intensive or critical care unit chaplain	138	56.6
Oncology chaplain	91	37.3
Patients that chaplains serve ^d		

(Continued)

Table 1. (Continued.)

Background characteristics	n	%
Patients with Alzheimer's or other dementia, Parkinson's disease, or a serious cognitive impairment		
0–20%	143	58.6
21–40%	72	29.5
41–60%	14	5.7
61–80%	10	4.0
81–100%	5	2.0
Patients with serious life-threatening illnesses		
0–20%	23	9.4
21–40%	40	16.4
41–60%	33	13.6
61–80%	58	23.7
81–100%	89	36.5
Patients with Hispanic background		
0–20%	162	66.3
21–40%	62	25.4
41–60%	13	5.3
61–80%	5	2.0
81–100%	2	0.8
Patients with Non-Hispanic racial/ethnic minority background (Black/African American, Asian and Pacific Islanders, American Indians, or Alaska Natives)		
0–20%	109	44.7
21–40%	92	37.7
41–60%	25	10.2
61–80%	14	5.8
81–100%	3	1.2
Health professionals chaplains work with ^e		
Medical doctor	233	91.4
Nurse	235	96.3
Social worker	226	92.6
Chaplain	181	74.2
Counselor	45	18.4
Medical doctor, nurse, social worker, and chaplain ^f	36	14.8

^aOther: ACP volunteers, adjunct professor, retired hospice chaplain, and self-employed.

^bService line designation: assignment to one or more specific clinical service lines such as palliative care as opposed to providing general coverage in the facility.

^cYes: includes multiple responses, so percentages do not add to 100%.

^dChaplains were asked what percentage of patients they served had the following characteristics – Alzheimer's or other dementia, Parkinson's disease or a serious cognitive impairment, serious life-threatening illnesses, Hispanic background, and Non-Hispanic racial/ethnic minority background.

^eHealth professionals chaplains work with: includes multiple responses, so percentages do not add to 100%.

^fMedical doctor, nurse, social worker, and chaplain: includes responses that said yes to all 4 professional types.

their treatment cycle. People are unsure where they are and are uncomfortable (as well as family members) entering into EoL [end-of-life] discussions. (ID:12)

Chaplains also described patients' fears that ACP is somehow indicative of, or inviting, or hastening death. A chaplain from an inpatient/home hospice agency (ID:25) reported that some individuals believed that "making a plan 'makes' it [death and dying] happen. [The] concept of advanced planning may/does imply giving up hope under this mindset," which can elicit heightened unease about this unknown frontier.

Suffering, peace, and comfort

ACP conversations encourage patients to think tangibly about the elements that constitute a "good death" aligned with their own meaning-making or spirituality, with their own deeply held values. According to the chaplains, among the salient hopes expressed by patients about the process of death and dying was the wish to avoid and reduce suffering. Although each individual understands and views suffering in a different way, one ICU chaplain at a community hospital summarized this as patients' hope to be "pain free in the[ir] concluding days of life on earth" (ID:22). For some patients, mitigating pain and suffering specifically meant avoiding unnecessary use of life support. As one hospice chaplain described, for some this is about "not prolong[ing] life unnecessarily if the quality of life is not there" (ID:11).

In tandem with a desire to ease pain, chaplains reported patients' hopes for a peaceful, comfortable death. The responses from the chaplains suggest that definitions of a "good death" that brings peace and comfort are personal and unique to the patient, often reflecting that individual's personal values and idiosyncratic spiritual beliefs. One palliative chaplain at a community hospital described this as patients' "hoping to be comfortable at home surrounded by loved ones at the end of life" (ID:26). Another chaplain from an ICU in an academic medical center noted, however, that "peaceful" death is not universal: "most often they [patients] want a peaceful death, sometimes they want to fight to the last breath" (ID:33).

Focus on the present

Many chaplains shared patients' renewed hopes that ACP would in turn enable them to focus on the present, although the idea of ACP generally evokes the immediacy of death and dying in people's minds. Chaplains noted that patients felt that ACP provided them with a "new sense of empowerment and personal agency," allowing them to "find meaning and purpose in the time they have." As an ICU chaplain at a community hospital stated,

Often people express that they hope they never need to have these [ACP] decisions come up. But they feel better knowing that they've had at least one of these necessary conversations with someone who can communicate to other medical professionals and get the documents into their chart. (ID:4)

Thinking about patients' perspectives, a palliative chaplain provided the following thoughts expressed by an individual who began participating in ACP conversations: "I am grateful we did this [ACP], now I can relax and live the rest of my life knowing this is complete, and that we will revisit during every PC

[primary care] visit to redefine my wishes" (ID:27). In this way, ACP offered the opportunity to both clarify goals of care and continue engaging in moments that brought joy, meaning, and fulfillment.

Hopes for family

Family was an important reason why patients engaged in ACP. Patients expressed hope for their families during ACP discussions: "They have made their wishes known to their family and the family won't be stuck having to make that decision," wrote one chaplain who worked in a specialty hospital (ID:16). Another ICU chaplain at a community hospital referred to "a sense of relief that their family knows their desires" (ID:29).

Healthcare chaplains also reported that patients desired a sense of belonging and connectedness with family and/or loved ones at the end of life: Patients were "hoping to be comfortable at home [and] surrounded by loved ones at the end of life" (ID:26, palliative care chaplain at a community hospital) and "wanting to be able to interact with loved ones to the end, hoping to die at home" (ID:1, ICU chaplain at an academic medical center). At the same time, patients were also concerned for their families, expressing that they were "fearful of how EOL decisions may affect their family" (ID:5, inpatient chaplain at a hospital) and hoping to "protect their families from grief, hurt, or confusion during the ACP process" (ID:6, oncology and palliative chaplain at a community hospital).

Doubt and distrust

With regard to ACP, patients expressed some doubt: "Will my healthcare representatives follow my directives?" (ID:22). "Will the medical team do what I want them to do?" (ID:23). An ICU chaplain from an academic hospital described concern about families following patients' wishes as "lack of confidence in their decisions being carried out, especially family members who are not named as decision-makers being able to strong-arm the decision-maker at end of life" (ID:15). Other patients' lack of trust in institutions partially accounted for the concern that "ACP documents will not be honored by institutions" (ID:3). As a chaplain from an academic hospital explained,

Patients doubt that the legal document's wording will lead providers to end life sooner than necessary (feels like giving up too much control – due to the poor legal wording and lack of clarity – even when explained, the terms and phrasing are too ambiguous to trust completely). (ID:7)

Another chaplain, who worked in a VA hospital, noted that "some believe we're looking for a reason to stop medical treatment, regardless of their preferences" (ID:4). Although an ICU chaplain at a community hospital described documented wishes as being honored by family, healthcare providers, or institutions as "the most common hope," patients had doubts about ACP's ability to honor their wishes and protect their interests.

Salient themes for how to address hopes and fears

Three key themes emerged from the chaplains' responses about how to address patients' hopes and fears during ACP conversations: (1) active listening to explore and normalize fears, worries, and doubts; (2) conversations to integrate faith, values, and preferences into ACP; and (3) education, empowerment, and advocacy.

Active listening to explore and normalize fears, worries, and doubts

Chaplains emphasized the importance of intentional, nuanced proactive listening, frequently described as "thoughtful active listening," "active and empathetic listening," or "always listening more than I speak, examining the idea of the heart" as they worked to identify and explore the fears, doubts, worries, uncertainties, and other emotions of patients during ACP conversations. Empathetic active listening was a necessary part of acknowledging, validating, and normalizing patients' various emotions. As one hospice chaplain stated, "In addressing these fears, I find that empathic listening, affirming the fears and allowing the patient to feel heard and respected in the conversation is a good starting point which can move the conversation forward" (ID:19). Another chaplain from a community hospital described the process as "listening and affirming the patients' hopes and desires. Accompanying them and letting them lead the way in terms of their personal comfort with the conversation" (ID:12). One chaplain from a specialty hospital wrote the following: "Validate their concerns and emotional reactions by affirming the resources/inner strengths they may already possess, such as their family, connection to a faith community, personal faith, resilience, humor etc." (ID:31). With active listening and validating, chaplains aimed to affirm and normalize patients' experiences and feelings and to reassure and support patients' resources.

Conversations to integrate faith, values, and preferences into ACP

During ACP conversations, chaplains from various settings – academic hospitals, long-term care facilities, and other facilities – focused on having conversations with patients about their faith, values, and preferences. They explored how to best integrate these into advance directives and goals of care, for example, by "focusing conversations about their values and work to try to direct treatment to match their values" (ID:18). Others offered descriptions in the form of recommendations: "Utilize patient's spiritual world view and assistance in relating that world view to Advance Care Planning" (ID:3). "Assure that the patient's preferences are included in the plan of care. Reinforce that agent only comes into play when the patient is unable to express his/her wishes directly" (ID:21).

Chaplains also addressed broader religious and spiritual needs of patients from various faith traditions during ACP conversations. As one chaplain from a long-term care facility noted,

For those who believe in a God/higher power we remind them they are never alone. Through the gift of the Holy Spirit God abides in us and healing is attainable. For Native Americans/First Nations to be part of nature (Hopi prayer) is comforting. If a person is Jewish or Muslim for example we will call clergy Rabbi or Imam. Recently we have Buddhist monks chanting. There is too much to list here on how we support our precious residents. Peace. (ID:34)

Another community hospital chaplain described integrating faith into ACP by asking questions as follows:

"We want to honor your faith and your beliefs. When the time comes, who can help us know what your wishes are?" "I appreciate your willingness to share your faith with me. I've known of situations where it would have really helped a medical team to hear directly from the patient about their wishes, but the patient couldn't talk in that moment. Would you be willing to put some of those beliefs and preferences on paper, so that if we can't ask you directly we can have that?" (ID:17)

Chaplains also often mentioned their role in explaining the connection between ACP and family. One chaplain who worked in both a community hospital and outpatient settings described saying the following to patients:

“When your healthcare wishes are discussed with family, loved ones, and your physician and documented, you can be assured that your wishes will be honored.” And, “Making your wishes and decisions known will take the burden off of your loved ones in the future.” (ID:10)

Chaplains worked to “process their [patients’] emotions, determine how their spirituality connects to their beliefs, and facilitate conversations with family around the patients end of life preferences” (ID:11) and “invite them to reflect on these fears and worries and, when possible, invite their families or loved ones into that conversation” (ID:8).

Education, empowerment, and advocacy

Chaplains identified providing education and information about ACP as an integral component of their work. One community hospital chaplain described the attempt to assist patients “with facts ... palliative and hospice care often actually prolongs someone’s life because of the knowledgeable care being provided, directing care gives clear guidance to those who will make decisions should the patient be unable to do so” (ID:2). Chaplains also described the role of connecting and mediating between patients and clinical team members. Activities included “help[ing] them identify those important wishes, write them on the document, and communicate via electronic medical record the wishes to clinicians” (ID:13) and “assur[ing] them of their personal agency and support of health care team to honor their choices” (ID:32). Through these efforts, chaplains wanted to empower and facilitate informed decision-making, honor patient autonomy, and advocate for patients’ values and preferences. A chaplain working in an academic hospital described

focusing on their goal and what they want and how they want to LIVE instead of dying. Facilitate their agency and power to incorporate their beliefs, values, sense of meaning and purpose into actions they can take now to ensure their choices are realized. (ID:14)

Chaplains worked to advocate for patients, particularly to “encourage patient conversation with HCR and assure patient that medical staff has the same desire to keep the patient pain free” (ID:22).

Discussion

Conversations about ACP and serious illness require the contemplation of deeply personal values and beliefs, as well as concerns about the unknown and uncertainty in death and dying, which are spiritual in nature. With 244 chaplains’ free-text online survey responses, this study explored spiritual concerns and needs observed by chaplains in these conversations with patients and how chaplains address them.

During ACP conversations with patients, the chaplains met with existential, religious, or spiritual questions and issues, such as fear of the unknown, hope for miracles, concerns about the afterlife, and the individual’s relationship to God or a higher power. Patients turned to their faith and deeply held values to seek healing and recovery as well as guidance during decision-making, often concurrent with the overall ACP process and ongoing discussions. Chaplains also reported that patients experienced feelings of uncertainty, being unprepared, or being fearful of impending death while

hoping to avoid suffering and to achieve peace and comfort at the end of life.

Although some patients apparently continued to fight their illness, an important priority among patients was their relief from suffering, often through the limiting of unnecessary aggressive care, which made ACP conversations all the more important. Moreover, chaplains reported that ACP helped patients renew their resolve to focus on and make the most of the present moment of living. Families and loved ones were also important. Hope for closeness with family members and loved ones throughout the ACP process was followed by fears of having difficult conversations with family members and placing emotional and other burdens on them. Finally, patients hoped that their wishes would be shared with and honored by their families and their health-care teams. Letting families know of their wishes was a major motivation for patients to engage in ACP. At the same time, chaplains noted that patients feared that families, designated agents, health-care providers, medical teams, or institutions might not honor their documented wishes. Distrust, especially of health-care providers and institutions, was a major reason for this fear.

Many of these findings are not surprising, given the nature of ACP conversations and the circumstances in which these conversations take place in health-care settings. Patients’ concerns reported by the chaplains in this study were often existential and spiritual, even if without explicit, verbal expression or use of the words *spirituality* or *faith*. Chaplains reported that as patients contemplated their health, illness, and mortality, the patients’ hopes and fears involved how to live fully in the present, how to live and die peacefully and avoid suffering as much as possible. Patients desired to be connected with their families and loved ones, to consider and seek the sacred and meaning-making, and to contemplate the great unknown. It may be that patients were encouraged to express these hopes and fears because they were talking with chaplains rather than clinicians. Still, the chaplains’ observations of patients’ hopes and fears corroborate findings from past studies on psychosocial barriers to ACP such as patients’ sense of optimism, fears of death and dying, and worries about family members (Bernard et al. 2020; Cheung et al. 2020), as well as findings regarding the spiritual needs of patients with life-threatening illnesses (Balboni et al. 2010).

The findings of this study strongly suggest that patients want to have their religious and spiritual needs taken into account in planning for the end of life. Medical teams including chaplains should explore and address a broad range of existential, spiritual, and religious concerns, so that fears and doubts can be aired and assurance can be given. Helping patients explore, share, and translate these weighty topics into decisions about how certain medical treatment decisions should be made in the future requires special knowledge, deep listening, strong communication skills, time, and resources on the part of healthcare providers. Moreover, topics discussed during ACP conversations such as the afterlife or the patient’s relationship to a higher power require the engagement of a professionally trained health-care chaplain. The healthcare chaplain is the “spiritual care specialist” on the interdisciplinary team, the team member most equipped to lead such discussions with patients. Organizations such as Vital Talk (<https://www.vitaltalk.org>) offer training programs in communication for clinicians, but the knowledge and skills to address the deeply personal, spiritual concerns of patients have always been part of the training and board certification of professional healthcare chaplains. Thus, the chaplains in our study described their approach to addressing patients’ hopes, fears, and distrust as consisting of active listening to explore and normalize fears, worries, and doubts; the integration of faith, values,

and preferences within ACP; and education, empowerment, and advocacy.

Nevertheless, spiritual or religious support is not consistently offered during ACP conversations with patients and families. For example, a study of family meetings in ICUs (Ernecoff et al. 2015) found that 77% of the 249 participating families wanted religious issues included in their discussions, but that this happened only 16% of the time; indeed a chaplain was present in only 2 of the meetings. A recent meta-analysis of spirituality in serious illness (Balboni et al. 2022) has concluded that (1) spirituality is important for most patients; (2) spirituality can play a role in medical decision-making; (3) spiritual needs are common; (4) spiritual care is frequently desired by patients, yet spiritual needs are infrequently addressed in medical care; and (5) unaddressed spiritual needs are associated with poorer patient quality of life, whereas provision of spiritual care is associated with better patient end-of-life outcomes. Balboni et al. (2022) concluded that spiritual care should be incorporated within medical care for serious illness, that education about spiritual care in serious illness should be provided to interdisciplinary teams, and that spiritual care specialists – board-certified chaplains – should be included in serious illness medical care.

One reason for the limited spiritual or religious support for patients with serious illnesses may be that many settings where these discussions take place do not have the regular services of a professional chaplain as the team's spiritual care specialist. Although almost half of the survey responses in this study came from chaplains working in community hospitals, assisted living facilities, or nursing homes, these facilities are also least likely to have adequate professional chaplain resources. The disconnect between what patients clearly desire or need and what is offered by clinical teams could be bridged by integrating board-certified chaplains as members of teams who participate in processes, as well as by providing potential training and education for nonchaplain clinicians on interdisciplinary teams.

Moreover, often the chaplaincy resources in various types of facilities do not have advanced, specialized training or specialty certification in having conversations about serious illness or ACP or in working as members of interdisciplinary teams. Chaplains have specialized training in addressing existential, spiritual, and religious needs, but their training in certain communication skills is limited – training in how to elicit goals and values and how to productively participate in or even lead family meetings. Instruction on how to address issues raised in ACP discussions and in the dynamics of family meetings as parts of health-care chaplain training and certification may help. In the past, the isolation of facilities in small communities, often in rural areas, made the delivery of training to their chaplains difficult. Today, many online educational resources for ACP discussions are available to facilitate the effective engagement of healthcare chaplains in critical conversations with patients (e.g., Respecting Choices, <https://respectingchoices.org/advance-care-planning-courses>).

These findings and implications, however, should be interpreted with caution due to limitations in our study's design. The study's findings are based on written responses to open-ended questions by a convenience sample of board-certified health-care chaplains recruited from 3 of 14 North American certifying bodies for chaplains. The majority of chaplains in our sample were White (84%) and Protestant (63%). Thus, we may not have fully captured the perspectives and experiences of chaplains from racially and/or ethnically minoritized backgrounds or with different religious affiliations with regards to facilitating ACP

conversations. Past studies have consistently documented different attitudes and practices toward ACP among diverse racial/ethnic groups (Peterson et al. 2019). As such, racially/ethnically minoritized or non-Protestant chaplains may have different perspectives on the patient's need for ACP, spiritual, or religious concerns expressed during ACP, or how to facilitate ACP among various patient populations that are different from those of White and Protestant peers. Also, only 40% of survey participants responded to the survey's 3 open-ended questions. The views of chaplains who did not respond to these questions or who were members of other organizations (and therefore were not included in our sample) may not be reflected in our findings. In addition, our findings may lack the depth that might be found in face-to-face interviews, the main method of data collection in qualitative research.

Nevertheless, this study contributes to the small but growing body of literature on the role of chaplains in facilitating goals of care conversations. Our study findings document the personal, existential, and spiritual nature of conversations about ACP and goals of care, and that patients want to have their religious and spiritual needs taken into account in planning for the end of life. ACP conversations involve medical, psychosocial, familial, and spiritual concerns, and there is a need for deeper listening and engagement by providers to provide holistic support during these important conversations. The healthcare chaplain as the "spiritual care specialist" on the interdisciplinary team may be most equipped to lead such discussions with patients. Yet, many primary care and long-term care institutions do not have the regular services of a professional chaplain. Therefore, more concrete, systematic efforts should be made to have specialty-trained chaplains integrated within care teams at various settings, especially outside acute, inpatient settings where chaplain services are most likely to be found, and promote interprofessional communication and collaboration between team members to best address and meet the spiritual and existential needs of the patients and families whom they serve.

Acknowledgments. The authors would like to acknowledge the Association of Professional Chaplains (APC), National Association of Catholic Chaplains (NACC), and Spiritual Care Association (SCA) for their recruitment efforts. They thank the participants for their time. Editorial support with manuscript development was provided by the Cain Center for Nursing Research and the Center for Transdisciplinary Collaborative Research in Self-Management Science (P30, NR015335) at the University of Texas at Austin School of Nursing.

Conflicts of interest. Nothing to disclose.

References

- Balboni TA, Paulk ME, Balboni MJ, et al. (2010) Provision of spiritual care to patients with advanced cancer: Associations with medical care and quality of life near death. *Journal of Clinical Oncology* 28(3), 445–452. doi:10.1200/JCO.2009.24.8005
- Balboni TA, VanderWeele TJ, Doan-Soares SD, et al. (2022) Spirituality in serious illness and health. *JAMA* 328(2), 184–197. doi:10.1001/jama.2022.11086
- Bernard C, Tan A, Slaven M, et al. (2020) Exploring patient-reported barriers to advance care planning in family practice. *BMC Family Practice* 21, 94. doi:10.1186/s12875-020-01167-0
- Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3(2), 77–101. doi:10.1191/1478088706qp063oa
- Cheung JTK, Au D, Ip AHF, et al. (2020) Barriers to advance care planning: A qualitative study of seriously ill Chinese patients and their families. *BMC Palliative Care* 19, 80. doi:10.1186/s12904-020-00587-0

- Ernecoff NC, Curlin FA, Buddhadharuk P, et al.** (2015) Health care professionals' responses to religious or spiritual statements by surrogate decision makers during goals-of-care discussions. *JAMA Internal Medicine* **175**(10), 1662–1669. doi:10.1001/jamainternmed.2015.4124
- Hanson WE, Creswell JW, Plano Clark VLP, et al.** (2005) Mixed methods research designs in counseling psychology. *Journal of Counseling Psychology* **52**(2), 224–235. doi:10.1037/0022-0167.52.2.224
- Institute of Medicine** (2015) *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington, DC: The National Academies Press.
- Jacobsen J, Bernacki R and Paladino J** (2022) Shifting to serious illness communication. *JAMA* **327**(4), 321–322. doi:10.1001/jama.2021.23695
- Jeuland J, Fitchett G, Schulman-Green D, et al.** (2017) Chaplains working in palliative care: Who they are and what they do. *Journal of Palliative Medicine* **20**(5), 502–508. doi:10.1089/jpm.2016.0308
- Jimenez G, Tan WS, Virk AK, et al.** (2018) Overview of systematic reviews of advance care planning: Summary of evidence and global lessons. *Journal of Pain and Symptom Management* **56**(3), 436–459.e25. doi:10.1016/j.jpainsymman.2018.05.016
- Kwak J, Cho S, Hughes BP, et al.** (2021) The role and activities of board-certified chaplains in advance care planning. *American Journal of Hospice and Palliative Medicine* **38**(12), 1495–1502. doi:10.1177/1049909121989996
- Kwak J, Jamal A, Jones B, et al.** (2022) Interprofessional approach to Advance Care Planning. *American Journal of Hospice and Palliative Medicine* **39**(3), 321–331. doi:10.1177/104990912111019316
- Lee AC, McGinness CE, Levine S, et al.** (2018) Using chaplains to facilitate advance care planning in medical practice. *JAMA Internal Medicine* **178**(5), 708–710. doi:10.1001/jamainternmed.2017.7961
- Lutz K, Rowniak SR and Sandhu P** (2018) A contemporary paradigm: Integrating spirituality in advance care planning. *Journal of Religion and Health* **57**(2), 662–671. doi:10.1007/s10943-017-0541-7
- Maxwell JA** (2010) Using numbers in qualitative research. *Qualitative Inquiry* **16**(6), 475–482. doi:10.1177/1077800410364740
- McMahan RD, Tellez I and Sudore RL** (2021) Deconstructing the complexities of advance care planning outcomes: What do we know and where do we go? A scoping review. *Journal of the American Geriatrics Society* **69**(1), 234–244. doi:10.1111/jgs.16801
- National Consensus Project for Quality Palliative Care** (2018) *Clinical Practice Guidelines for Quality Palliative Care*, 4th edn. Richmond, VA: National Coalition for Hospice and Palliative Care.
- Oyedemi CI, Oyesanya T, Gray N, et al.** (2020) Barriers and facilitators of advance care planning for older adults with sickle cell disease. *Blood* **136**(Supplement 1), 58–59. doi:10.1182/blood-2020-136231
- Peterson LJ, Hyer K, Meng H, et al.** (2019) Discussing end-of-life care preferences with family: Role of race and ethnicity. *Research on Aging* **41**(9), 823–844. doi:10.1177/0164027519858716
- Puchalski C, Ferrell B, Virani R, et al.** (2009) Improving the quality of spiritual care as a dimension of palliative care: The report of the Consensus Conference. *Journal of Palliative Medicine* **12**(10), 885–904. doi:10.1089/jpm.2009.0142
- Sudore RL, Hickman SE and Walling AM** (2022) Controversies about advance care planning. *JAMA* **327**(7), 685. doi:10.1001/jama.2021.24727
- Sudore RL, Lum HD, You JJ, et al.** (2017) Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *Journal of Pain and Symptom Management* **53**(5), 821–832.e1. doi:10.1016/j.jpainsymman.2016.12.331