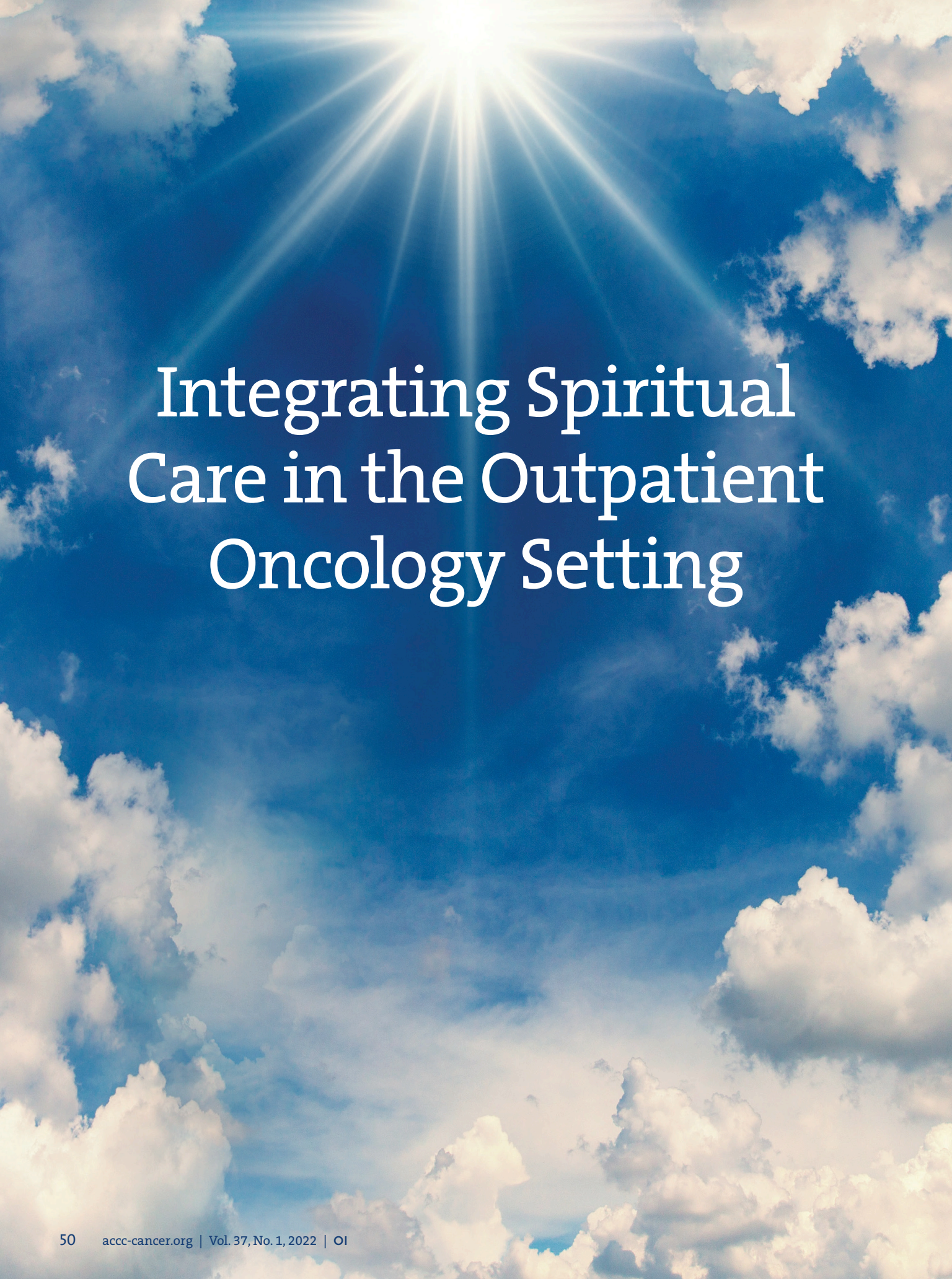

Integrating Spiritual Care in the Outpatient Oncology Setting

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In Brief

Spiritual care is recognized as an essential component of caring for patients with serious illnesses, like cancer. Chaplains are a unique part of the healthcare team, addressing patients' concerns around sacred and existential questions. This article highlights findings from a 38-item needs assessment survey of 82 patients in an outpatient New York City cancer center who shared their level of spirituality and/or religiosity, interest in spiritual care, and key demographic and clinical data. This survey also assessed patients' interest in meeting with a chaplain, and for those who elected to meet with a chaplain, feedback was obtained on the provided services. Study results suggest that most patients were open to receiving a visit from a chaplain in the outpatient setting. Based on this demonstrated interest, the cancer center implemented a referral protocol for this service.

A cancer diagnosis and its treatment frequently engender a personal and spiritual struggle as patients and those around them grapple with existential issues related to life and meaning.[1-5] For patients who receive a diagnosis of a life-threatening illness, such as cancer, spiritual beliefs can offer guidance and a sense of support and belonging.[6] A chaplain is a trained spiritual care expert who holds an essential position within the multidisciplinary cancer care team.[7] Spirituality is increasingly recognized as a critical component of a multidimensional understanding of one's psychological well-being and as a means of supporting the holistic needs of patients.[1-5] The National Cancer Institute (NCI) defines spirituality as "an individual's sense of peace, purpose, and connection to others, and beliefs about the meaning of life. Spirituality may be found and expressed through an organized religion or in other ways."[8,9] The National Cancer Institute defines religion as "a set of beliefs and practices that center on questions about the meaning of life and may involve the worship of a supreme being."[8,9] Spiritual care providers support the religious and spiritual needs of patients and their caregivers. National organizations, like the Association of Community Cancer Centers, have identified these services as a key component to comprehensive cancer care.[10] As such, spiritual care is incorporated into national care quality guidelines, including those of the National Consensus Project for Quality Palliative Care and The Joint Commission.[11]

Religion, Spirituality, and Cancer

Numerous studies have examined the relationship between religion and spirituality and their impact on coping with illness, specifically cancer. Alcorn and colleagues conducted a qualitative study of patients with advanced cancer in the United States and found that 78 percent of patients identified religion and/or spirituality as an important factor of their cancer experience.[12] These studies suggest that the majority of patients with cancer view religion and spirituality as personally significant.[13,14] Moreover, there is growing recognition of religious and spiritual importance in association with improved quality of life among oncology patients.[15-17]

There is a need for spiritual providers to extend their services beyond the walls of the inpatient setting and integrate their expertise into the outpatient, multidisciplinary care team to better meet the needs of patients across all care settings.

Though there is evidence that spiritual well-being can positively contribute to health-related quality of life,[18,19] Balboni and colleagues reported that 72 percent of patients in the United States with advanced cancer felt that their spiritual needs were met minimally or not at all by their care team and were not incorporated into their care planning.[14] Patients and caregivers whose spiritual needs are not addressed may experience higher levels of distress and feelings of hopelessness.[20] On the other hand, addressing the spiritual needs of patients and caregivers can help mitigate anxiety, as well as help them to create meaning in relation to their circumstances.[21] Furthermore, spiritual struggles are associated with poor physical outcomes and higher rates of morbidity.[22] A healthcare team's support of patients' religious and spiritual needs has also correlated with improved patient satisfaction with their care.[23] Patients who reported that their spiritual needs were not being met gave lower ratings of the quality of their care and reported lower levels of satisfaction with their care.[24]

Though the importance of addressing spiritual needs in the inpatient setting has been demonstrated, with the shift in oncology care to outpatient clinics, the literature supporting the provision of spiritual care in the outpatient setting is building.[25-30] There is a need for spiritual providers to extend their services beyond the walls of the inpatient setting and integrate their expertise into the outpatient, multidisciplinary care team to better meet the needs of patients across all care settings.

This study, consisting of a needs assessment and referral protocol, examines and addresses patients' level of interest in receiving spiritual care in the ambulatory cancer care setting and describes the implementation of a system to improve access to spiritual care.

Study Methods

In 2018 Mount Sinai Beth Israel Cancer Center, New York City, N.Y., developed a one-time survey to give to patients who received outpatient oncology services during a one-year period. Approved by the internal review board of Mount Sinai Beth Israel, the survey tool included questions on key demographics, clinical data, self-identified levels of personal spirituality and/or religiosity, and participants' desire to receive spiritual care support in the outpatient setting. Eligible participants were 18 years of age or older, able to read and write in English, and patients of Mount Sinai Beth Israel Cancer Center. Patients were approached for the survey by a trained volunteer in the waiting rooms of medical and radiation oncology and the chemotherapy suite.

Measurement

The 38-item self-report questionnaire was developed based on clinical judgment and a literature review by oncology social workers and the chaplains assigned to this clinical setting. Following the approach of Schultz et al., patients were asked to provide demographic and clinical information (20 questions).[31] Demographic information explored patient gender, race, ethnicity, marital status, religion, educational level, and age. Patients were also asked about their attendance at religious services and their perception of the level of support they were currently receiving from friends, family, and their community. Clinical questions addressed patients' cancer diagnosis, treatment type, time since primary diagnosis, cancer recurrence, whether the cancer had metastasized, and how worried the patient was about their illness. One clinical question addressed overall satisfaction with care provided by the cancer program. Additionally, patients were asked about their spiritual identity and to describe their level of spirituality and/or religiosity on a four-item scale (*not spiritual/religious* to *very spiritual/religious*). Patients were asked the following questions about their attitudes toward spiritual care:

1. How important is it for the cancer program to incorporate spiritual care into its services?
2. How open do you think you would be to a visit from a spiritual care provider?
3. Do you think you have a good understanding of what a spiritual care provider does?

Participants were also given the Religious (n = 5) and Spiritual (n = 13) subscales of the Spiritual Needs Assessment for Patients (SNAP).[32] The Religious subscale consists of five items, with the sum of the scores ranging from 5 to 20, with higher overall scores indicating greater religious needs.[32] The Spiritual subscale consists of 13 items, with the sum scores ranging from 13 to 51, and higher scores indicate greater spiritual needs.

Lastly, patients who had already received a visit(s) from a chaplain were asked six additional questions. The first two questions explored whether the patient met with a chaplain (yes/no) and, if so, how many times they met. Four questions from the Patient Satisfaction Instrument for Pastoral Care-Chaplaincy Supportive Ministry of Chaplains subscale were used.[33] This is a six-item Likert scale in which patients are asked to identify within a range from *strongly disagree* to *strongly agree* regarding statements about their experience with a chaplaincy visit. The decision was made to not include two items from this subscale because they were not relevant to the current chaplaincy services being offered in the outpatient setting.

Patient Characteristics

A total of 83 participants completed the survey. Table 1, right, presents a descriptive analysis of the categorical study variables. Data reflect that the participant sample was half female and half

Table 1. Descriptive Analysis of Demographic Study Variables (*n* = 82)

Gender	
Male	41 (50)
Female	41 (50)
Education level	
Some high school	6 (7)
High school	15 (18)
Some college	19 (23)
College	21 (26)
Master's	11 (13)
Post-baccalaureate	2 (2)
Other/unknown	8 (10)
Ethnicity	
Hispanic	20 (24)
Non-Hispanic	62 (77)
Race	
White	48 (59)
African American	24 (29)
Asian	8 (10)
Other	2 (2)
Marital Status	
Single	28 (34)
Married	38 (46)
Divorced	12 (14)
Widowed	4 (5)
Recurrence	
Yes	22 (27)
No	52 (63)
Don't know	8 (10)
Metastases	
Yes	23 (28)
No	39 (48)
Don't know	20 (24)
Type of treatment	
Receiving chemotherapy	37 (45)
Receiving radiation therapy	17 (21)
Receiving chemo and radiation	17 (21)
Completed chemo and/or radiation in past six months	3 (4)
Other	8 (10)
Visits with chaplain	
Yes	28 (34)
No	54 (67)

male (*n* = 41; 50 percent). Participants had an average age of 58, and most participants had at least some college (*n* = 53; 64.6 percent) or a college degree or higher (*n* = 34; 41.4 percent). Most patients were of non-Hispanic ethnicity (*n* = 62; 76.6 percent). More than half of participants identified as White (*n* = 48; 58.5 percent), over a quarter identified as African American (*n* = 24; 29.3 percent), nearly 10 percent identified as Asian (*n* = 8; 9.8 percent), and two participants identified as "other." Close to half of participants were married (*n* = 38; 46.3 percent), about one-third were single (*n* = 28; 34.1 percent), 12 were divorced (14.6 percent), and 4 were widowed (4.9 percent). Roughly one-third of patients reported cancer recurrence (*n* = 22; 26.8 percent). Nearly half of patients did not have metastatic cancer (*n* = 39; 47.6 percent) and were receiving chemotherapy (*n* = 37; 45.1 percent). About one-third of the study sample reported receiving a visit from a chaplain (*n* = 28; 34.1 percent).

Data indicate that participants were split regarding their level of worry about their illness (Table 2, page 54). Eighteen participants (21 percent) reported that their illness was "not that worrisome," and nearly a quarter of respondents answered "quite worrisome" (*n* = 20; 23 percent). Most patients responded that their illness was "somewhat worrisome, but maybe manageable" (*n* = 28; 32 percent), and 21 patients (24 percent) answered "somewhat worrisome." Most participants reported that they attend religious services at least once per year (31 percent), and others responded that they attended religious services daily (5 percent), weekly (32 percent), once per month (11 percent), or never (21 percent).

In terms of the two questions on religiousness and spirituality, 38 percent (*n* = 33) identified as "very spiritual," while 28 percent (*n* = 24) identified as "not religious." Though 24 participants identified as not religious, only 8 (9 percent) identified as "not spiritual." Both "somewhat religious" and "somewhat spiritual" responses made up 20 percent and 25 percent of respondents, respectively. For both questions, nearly 25 percent of participants responded that they were "spiritual" and "religious."

For the SNAP Spiritual subscale, the mean score for the 13-item Spiritual Needs scale was 34, and scores ranged from 13 to 51. The mean SNAP Religious subscale score was 12, and scores ranged from 5 to 20.

Of the 82 participants, 65 percent (*n* = 53) responded that they would be "maybe interested" or "definitely interested" in having a visit from a chaplain. Nine participants (11 percent) said they felt indifferent about a visit from a chaplain, and 20 participants (24 percent) responded either "not at all" or "not really open" to a visit from a chaplain. These findings are summarized in Table 2, page 54.

Additionally, of those who received a visit from a chaplain prior to the survey (*n* = 28), 26 participants (93 percent) reported that they were satisfied with their care. In contrast, of the participants who did not previously receive a visit from a chaplain (*n* = 54), only 45 (83 percent) reported being satisfied with their care. A chi-square analysis of the questions regarding a visit from a chaplain and patients' satisfaction with their care is shown in Table 3, page 55; this relationship did not show significance.

Table 2. Spiritual Identification Responses

Spiritual Identification Responses	*n* (%)
How would you describe your level of spirituality?	
Not spiritual	8 (9)
Somewhat spiritual	22 (25)
Spiritual	19 (22)
Very spiritual	33 (38)
Declined to answer	6 (7)
How would you describe your level of religiousness?	
Not religious	24 (28)
Somewhat religious	18 (21)
Religious	22 (25)
Very religious	14 (16)
Declined to answer	11 (13)
How often do you attend religious services when healthy?	
Daily	4 (5)
Weekly	28 (32)
Once a month	10 (11)
Once a year	27 (31)
Never	18 (21)
Declined to answer	2(2)
How worrisome do you think your illness is?	
Not that worrisome	18 (21)
Somewhat worrisome	21 (24)
Somewhat worrisome but maybe manageable	28 (32)
Quite worrisome	20 (23)
Declined to answer	1 (1)
How open are you to have a visit from the chaplain?	
Not at all	5 (6)
Not really open	12 (14)
Indifferent	8 (9)
Maybe interested	26 (29)
Definitely interested	25 (29)
Declined to answer	13 (15)
Do you think you have a good understanding of what a spiritual care provider is or does?	
Not at all	10 (11)
Not really	13 (15)
Unsure	14 (16)
I think so	31 (36)
Definitely	21 (24)

Finally, most patients (*n* = 51, 58 percent) responded that they were "maybe interested" in having a visit from the chaplain. Most respondents also believed that they understood a spiritual care provider's role, as 36 percent (*n* = 31) answered "I think so" and 24 percent (*n* = 21) answered "definitely" to this question.

Discussion of Survey Findings

Although there was no statistically significant relationship between chaplain visits and patient satisfaction with their overall care, survey data suggest this effect because the proportion of study participants satisfied with their overall care is approximately three times higher among those who reported having a visit from a chaplain (Table 3, right). This finding is supported by a large study sample by Clark et al., which found that patient satisfaction was significantly associated with meeting their spiritual needs.[34] As public and private payers are increasingly linking patient satisfaction with their care to reimbursement, many cancer programs and practices are looking to improve patient reported satisfaction scores.

Most respondents (58 percent) were open to a visit from a chaplain and believed that they understood the role of the chaplain (60 percent). This is an important indicator that chaplains are being accepted into outpatient cancer care delivery.

The sample size for the needs assessment was small and limited to one treatment center location. Additionally, patients who declined to fill out the survey were not asked for their reasons why, nor did we track the number of total refusals. The respondents were disproportionately Christian; future research should explore whether chaplain interventions are welcomed by non-Christian patients.

Based on patient interest (as demonstrated through the survey) and an increased availability of chaplains in the outpatient setting, three ambulatory cancer centers (Mount Sinai Beth Israel Union Square and Chelsea Cancer Centers and Mount Sinai West Cancer Center in New York City) implemented practice changes, including a mechanism for chaplains to identify patients who have spiritual concerns.

Developing an e-Referral Protocol

Building on the established referral system already in place for social workers, the three Mount Sinai outpatient cancer programs above added questions to the electronic distress screening survey that is used to address patients' spiritual care needs. This e-distress screening tool CancerSupportSource® is given to patients at their medical oncology visits (at a patient's second visit and then once every three months). The screening tool has 18 questions that address cancer-related distress in addition to two customized self-referral questions. Patients answer the questions using a Likert scale (1 = *not at all concerned* to 5 = *very seriously concerned*). Distress screening is conducted via an iPad while medical assistants prepare patients for their visit with their oncologists. Patients have the option to decline the screening. Upon completing the distress screening, results are transferred automatically to the

Table 3. Chi-Square Analysis of Having a Visit from the Chaplain (Yes/No) and Care Satisfaction (Yes/No)

	Had a Visit from the Chaplain			
	Yes *n* (%)	No *n* (%)	X^2 (df)	*p*
Care satisfaction			1.86 (1)	0.17
Yes (scores = 4-5)	26 (36.6)	45 (63.4)		
No (scores = 1-3)	1 (12.5)	7 (87.5)		

patient's electronic health record and emailed to the cancer center's social workers.

Because there was no formal referral protocol in place for chaplains, one was developed using the survey item "finding meaning and purpose in life." Using a Likert scale, patients who respond "seriously" or "very seriously" to this question are now automatically referred to a chaplain. Additionally, there is also an option for patients to self-refer to chaplains. The self-referral is worded as: "You have the option to speak with a chaplain, and someone may reach out to you based on the concerns you shared. Would you like to speak to a chaplain?" The addition of the self-referral question allows patients to actively seek support, which empowers patients throughout the course of their treatment. Chaplains assigned to a specific outpatient clinic call patients who trigger an automatic referral or who self-refer. This distress screening measure also supports cross-discipline interaction and collaboration in support of patients.

Chaplains are tasked with providing support services to patients on an as-needed and ongoing basis. The e-referral protocol allows chaplains to streamline their workflow and identify and triage patients most at risk for spiritual distress. The automatic referrals, triggered by a positive answer to the meaning and purpose question, are consistently higher than patient self-referrals. From January 2019 to December 2020, three chaplains at the three ambulatory cancer centers received 413 automatic referrals and 174 self-referrals. Through distress screening, chaplains better identify patients who have spiritual concerns and who may be more likely to accept spiritual interventions.[29] Similarly, Sprik et al. found that using distress screening for "struggle to find meaning" among several other religious and spiritual concerns helped chaplains identify patients who had spiritual concerns and who would be receptive to chaplain interventions.[30]

Given the importance of spiritual well-being as a component of one's overall quality of life, particularly among patients with cancer, services that enhance spiritual well-being are essential. In addition, research shows that effective chaplain services improve patient-reported outcomes and programmatic effectiveness overall. An automatic referral process to chaplaincy for spiritual and religious needs should be considered an integral part of the assessment process. Future research should consider spiritual and religious care interventions and their impact on patients' experiences and satisfaction. Adding chaplains to the outpatient cancer care team provides patients an additional resource for support to maximize well-being and quality of life. OI

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