Screening the soul: Communication regarding spiritual concerns among primary care physicians and seriously ill patients approaching the end of life

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Abstract

The purpose of this study was to explore the spiritual concerns of seriously ill patients and the spiritual-care practices of primary care physicians (PCPs). Questionnaires were administered to outpatients (n = 65, 90 percent response rate) with end-stage illness and to PCPs (n = 67, 87 percent response rate) in a diverse general medicine practice. Most patients (62 percent) and PCPs (68 percent) considered it important that physicians attend to patients' spiritual concerns. However, few patients reported receiving such care, and most (62 percent) did not think it was the PCP's job to talk about spiritual concerns. Although both seriously ill outpatients and PCPs assert the importance of spiritual concerns, PCPs often do not provide spiritual care. Appropriate provision of spiritual care within a diverse population of seriously ill outpatients is complex, necessitating appropriate and attentive screening.

Key words: doctor-patient relationship, end-of-life care, spirituality, communication

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> "You know how to screen the soul, too, which I say is a good thing, because many helping people do not know how to do this." —Study participant

Introduction

Spirituality is important to most patients[1-6] and influences both medical decisions[7,8] and health outcomes.[9] Several studies have shown that the majority of primary care physicians (PCPs) believe they should listen to and support patients through their spiritual and existential concerns.[5,10,11] Yet, the literature indicates that PCPs infrequently practice this conviction, citing multiple barriers to spiritual discussions.[5,11] Spiritual concerns appear to be particularly important for patients facing the end of life,[7] and physicians report being much more inclined to provide various kinds of spiritual care for patients identified as dying.[12,13] Most patients would like to be able to address spiritual concerns with their physicians if they become gravely ill,[1] and seriously ill patients report wanting to be treated as "whole persons" inclusive of spirituality.[14,15]

Based on available empiric evidence and clinical experience, numerous experts have made (sometimes contradictory) recommendations to physicians about the importance of and means toward addressing patient spiritual concerns.[16-24] Many authors indicate

clear needs for physician attention to the spiritual and existential concerns of their patients.[19-23] Others have voiced concerns about the boundaries in the patient-physician relationship and the use of medical power for religious proselytizing.[18,19,24,25]

The literature attempting to confront important questions related to spirituality and medicine is fraught with limitations. Much of the spirituality and medicine research has been conducted in areas of the country with high percentages of Christian physicians and patients,[2-4,11] thus limiting interpretations of spirituality to Judeo-Christian religiosity.[2-4,10,11] Most studies have also focused primarily on family physicians.[2,3,5,8,10-13] Some studies have been limited by low response rates, bringing up important questions of response bias.[10,12] No prior study has analyzed the attitudes about spirituality and practices of physicians in the same outpatient practice. Thus, despite the growing awareness of the importance of spirituality in health and medicine, the appropriate role of the PCP and their actual practices regarding spiritual care for seriously ill outpatients remain unclear.

While the importance of physician attention to patient spirituality has been most clearly and convincingly articulated in the hospice and palliative care setting,[16,19,23,26] most outpatients with serious illness do not receive formal palliative care services.[27] Although difficult to achieve in our current system of healthcare financing, many patients with advanced disease desire to continue curative treatments along with palliative care simultaneously.[28] The need for comprehensive care of dying patients is well studied,[6,13-14,29] although few have written about the needs and treatment of seriously ill outpatients with nonterminal diagnoses.[26,30] PCPs often do not recognize these patients as being at the end of life[26] and may be especially unsure of their role in spiritual care with such patients.[20,24] Given the complexity of the role of spirituality in this context, further understanding both patient and physician attitudes and practices as well as appropriate screening strategies may lead to improved care.

Methods

Participant selection and description

After receiving approval from the Institutional Review Board's Committee on Human Research, we explored physician-patient communication around spiritual concerns at the "beginning of the end of life" via questionnaires completed by both groups. Involved patients were recruited from an ongoing controlled trial of care for outpatients with end-stage illness being conducted in the general medicine practice (GMP) of an urban university medical center in a multicultural city on the West Coast.[26,30] Adult patients were eligible for the study if they received curative primary care in the GMP and matched one of the following criteria:

1. cancer with metastases, albumin less than 2.5 gm/dL, or a six-month weight loss greater than 10 percent;

2. congestive heart failure (CHF) with an ejection fraction less than 20 percent or New York Heart Association (NYHA) class IV symptoms;

3. chronic obstructive pulmonary disease (COPD) with a forced expiratory volume in 1 second (FEV1) of less than 30 percent predicted, oxygen saturation less than 90 percent, or NYHA class IV symptoms; or

4. their PCP considered them one of their "sickest patients" with cancer, CHF, or COPD and expected them to die in one to five years.

Patients were excluded if they did not speak English or Spanish; were demented, delirious, or psychotic; or were already enrolled in hospice.

Outpatients fitting the study criteria (n = 72) received a written, confidential, self-administered survey assessing their attitudes and experiences with spiritual concerns in primary care. The 29-item patient survey, which used a Likert scale format, open response, as well as yes/no questions (Appendix 1) was developed and refined by the authors with review for content validity by national multidisciplinary experts in the field of comprehensive care of seriously ill patients. The survey was pretested by several patients for readability and comprehensibility.

A complementary survey for PCPs (Appendix 2) was developed by the authors, reviewed for content validity by multidisciplinary experts in the field, pretested by several PCPs for readability and comprehensibility, and mailed to all 77 physicians in the GMP. The 21-item survey was developed to assess PCP attitudes and practices regarding the spiritual concerns of seriously ill outpatients. For each survey, two subsequent survey distributions were made to nonresponders at two-week intervals.

Definitions and statistics

In defining "spirituality" and "spiritual concerns," we sought to avoid the cultural and religious biases of previous research. Similarly to other recent authors in this field,[11,31] we defined these terms as relating not only to religious themes but also to existential issues, e.g., "What is my purpose in life?" "Why is this happening to me?" "What will happen to me after life ends?"

Table 1. Demographic characteristics of patients (n = 65)			
Characteristic		**Mean (SD)**	**Range**
Age		67.9 (14.1)	34 – 93
Education		13.3 (3.9)	5 – 22
		n (%)	
Sex	Female	45 (69)	
	Male	20 (31)	
Ethnicity	Caucasian	32 (49)	
	Black	13 (20)	
	Latino	8 (13)	
	Asian	4 (6)	
	Pacific Islander	4 (6)	
	Other	4 (6)	
Employed	Yes	7 (11)	
	Retired	38 (58)	
	Disability	16 (25)	
	Unemployed	4 (6)	
Born a US citizen	Yes	45 (69)	
	No	20 (31)	
Income	< 10,000	38 (59)	
	10,000 – 19,999	11 (17)	
	20,000 – 29,999	8 (12)	
	30,000 +	8 (12)	
Relationship status	Married/partnered	20 (31)	
	Other	45 (69)	
Lives alone	Yes	28 (43)	
	No	37 (57)	
Primary diagnosis	Cancer	18 (28)	
	Congestive heart failure	26 (40)	
	Chronic obstructive pulmonary disease	21 (32)	
Secondary diagnosis	Cancer	1 (9)	
	Congestive heart failure	8 (73)	
	Chronic obstructive pulmonary disease	2 (18)	

Data were assigned confidential study numbers and entered into a CRUNCH® database (Crunch Software Corp., Oakland, CA) for management. Analyses were performed using t-tests, chi-square tests, and logistical regressions, again using CRUNCH software.

Results

Of 72 patients contacted, 65 returned completed questionnaires (90 percent). The average age of the patients was 68; 43 percent lived alone; 69 percent were female; 49 percent were white; and 59 percent had annual incomes below $10,000 (Table 1). Most patients (71 percent) considered themselves to be "quite a bit" or "very" spiritual (4 or 5 on a 5-point Likert scale, respectively). While most patients (62 percent) considered it "moderately" to "incredibly" important (5 to 10 on an 11-point numeric rating scale) that their PCP address their spiritual concerns, most (60 percent) patients did not want their PCP to "have a spiritual discussion" with them (Table 2). Only 11 percent of patients had ever been asked by a PCP if they would like to discuss spiritual concerns. Only 12 percent had been asked about the importance of spirituality to them, 15 percent had been asked if they were part of a religious or spiritual community, and 14 percent had been offered a chaplaincy referral.

The majority of patients (75 percent) indicated that they pray about their health. Of note, 70 percent responded that they did not want their PCPs to pray with them, while 54 percent reported that they did want their PCPs to pray for them on their own. The majority of patients had engaged in spiritual conversations with friends (62 percent) and family members (52 percent), and a large minority had engaged in such conversations with religious leaders (42 percent).

When asked about barriers to talking about spiritual concerns with their

Table 2. Selected patient responses (n = 65)	
Question	**Response (% positive)**
How important do you think it is that your general medicine provider care for your spiritual concerns?	62 (moderately important to incredibly important)
Would you ever want your physician to pray for you on his or her own?	54
Would you ever want your physician to pray with you?	30
Would you ever want your physician to discuss spiritual concerns with you?	40
Which of the following keep you from talking about your spiritual concerns with your provider? (*please circle **all** that apply*):	
You do not have any spiritual concerns.	17
You do not think it is part of your provider's job.	62
There is not enough time.	31
You think your provider would not want to.	17

PCPs, 62 percent of patients reported that they do not think it is part of the physician's job, 31 percent reported they do not think their PCP has the time, and 17 percent indicated they think their PCP would not want to discuss it. Ninety-one percent of patients indicated that they had never brought up their spiritual concerns with their PCP.

Patients gave quite divergent responses when asked about the ideal amount of spiritual care they wanted from their PCP. Many (37 percent) wanted their PCP never to address their spiritual concerns, while many others (37 percent) wanted no change, and still others (22 percent) wanted this care more often. Patients who did not want their PCP to "have a spiritual discussion" with them were more likely to think talking about such issues was not part of the PCP's job ($p = 0.006$). Male patients were more likely than women to have been offered a chaplaincy referral ($p = 0.01$). In the free response area, several patients added concerns that being asked about spiritual issues by their PCP might bring up fear about their deaths.

Of the 77 surveys sent to PCPs, 67 were returned complete (87 percent). The average age of the PCPs was 33. Fifty-five percent were female, 61 percent were white, 62 percent were residents, and 38 percent were fellows or faculty (Table 3). Although a minority of PCPs (30 percent) considered themselves "quite a bit" or "very" spiritual, most (68 percent) reported that it was "moderately" to "incredibly" important to address patients' spiritual concerns. Nonetheless, 64 percent indicated that they "never" ask seriously ill patients if they would like a chaplaincy referral. When asked what percentage of such patients they think would like to discuss their spiritual concerns with them, the mean response was 42 percent (SD 26.3, min 5, max 90). When asked what hinders them from addressing their patients' spiritual concerns, 82 percent cited lack of time, 37 percent did not feel competent, and 21 percent did not feel it was part of their job. Compared with their male colleagues, female PCPs believed it more important to attend to patients' spiritual concerns ($p = 0.03$), more frequently asked whether patients were part of a spiritual community ($p = 0.05$), and prayed more often for patients ($p = 0.001$). Fellows and faculty were more likely than residents to ask if patients were part of a spiritual community ($p = 0.0001$), to ask about the importance of spirituality ($p = 0.001$), and to offer a chaplaincy referral ($p = 0.01$). These differences persisted when controlled for age and number of weekly clinical sessions practiced.

Discussion

The majority of both seriously ill outpatients and PCPs in this urban general medicine practice consider spiritual care in the outpatient encounter important. However, few patients have experienced, and few PCPs practice, such care. These findings are consistent with previous research in other settings,[5,11] indicating unfulfilled desires on the part of most patients to address spiritual and existential concerns with their physicians.

Table 3. Demographic characteristics of providers (n = 67)			
Characteristic		**Mean (SD)**	**Range**
Age		33.5 (7.0)	26 – 53
		n (%)	
Sex	Female	37 (55)	
	Male	30 (45)	
Ethnicity	Caucasian	41 (61)	
	Black	2 (3)	
	Latino	5 (8)	
	Asian	12 (18)	
	Other	7 (10)	
Training level	First-year resident	1 (2)	
	Second-year resident	20 (30)	
	Third-year resident	20 (30)	
	Fellow	5 (7)	
	Faculty	17 (25)	
	Nurse practitioner	4 (6)	

Yet, other findings require further consideration. The majority of seriously ill outpatients think it is important that their PCP "care" for their spiritual concerns, yet most do not want their PCP to discuss spiritual concerns with them, and many do not think "talking about [the patient's] spiritual concerns" is part of their PCP's job. For some patients, this seeming contradiction may reflect the prevailing Western dichotomy of body versus mind/spirit[32] or a triage ethic whereby patients fear that spiritual care would take time away from other medical care. However, one recent study suggested that many patients would be willing to forego some medical care to allow time for spiritual care by their physician.[33] In our study, the patients who did not want their PCP to discuss spiritual concerns with them were more likely to believe talking about these concerns was not part of the physician's job.

These findings suggest the issue of spiritual care in the outpatient setting is quite complex. Our results show that a physician "caring" for spiritual concerns is seen as important to patients, whereas a physician "discussing" or "talking about" such concerns is seen as inappropriate. As mentioned above, other studies indicate that patients with advanced illness want to be treated as whole—including spiritual—people.[14,15] Perhaps the wording, "discuss" and "talk about" connotes too much input from the PCP, thus mirroring the concerns of many experts in palliative and hospice care that physicians might proselytize.[18,19,24,25]

It seems patients tend to desire a sophisticated and somewhat controlled relationship with PCPs around spirituality: They want their concerns cared about but not discussed or talked about, and they want to be prayed for but not with. These results indicate that, instead of discussing spiritual issues, PCPs may more appropriately "care" for the spiritual concerns of their patients by simply asking and listening.[18,19] The appropriate role of the physician in the context of serious illness appears to be to ask about and listen to spiritual concerns and leave the more active roles to others who have specific training in this area, such as chaplains and other spiritual leaders, or to those with closer relationships (e.g., friends and family).

Another important finding is the wide divergence in the desires of seriously ill outpatients regarding the ideal amount of spiritual care. These results, coupled with the previous findings, highlight the importance of screening questions in this area. With appropriate screening, PCPs can identify the patients desiring an empathetic listener for their spiritual concerns

as well as those who would prefer to speak to the PCP versus a chaplain or someone else. A number of authors have presented helpful recommendations for such screening.[18,19,22]

We found several gender-related differences in spiritual care. Male patients were more likely than female patients to be referred to a chaplain. Female PCPs were more likely than males to address spiritual concerns. These findings are notable in that most previous research in spirituality and medicine has either lacked power to analyze gender differences[17] or found no difference in provider care based on gender.[12] Although further research is necessary to understand the etiology of these observed differences, these findings may reflect an unequal validity ascribed to the suffering of men versus women[34] as well as gender differences in communication.[35]

The academic medical setting included a good proportion of younger physicians, which allowed for comparison of spiritual-care practices according to training status. The finding of improved attention to spiritual concerns by more experienced physicians suggests that physicians may gain, over time, the desire or competency to communicate with patients about issues of deep meaning. This is heartening in the face of a common belief that humanism is "trained out" of medical students.[36,37] Although composition of faculty versus resident patient panels may confound the results, the significance of our results persisted when controlling for age and number of weekly clinical sessions practiced.

Further research, including both quantitative and qualitative assessments,[14,27,37,38] must be pursued to further elucidate the nuances of spirituality and medical care. We hope that the findings from our study will be utilized in the continued development of standardized measures of spiritual concerns and care. Further research into the gender differences and training characteristics involved in spiritual care may help PCPs overcome the identified barriers to communication at the end of life.

Although the study reports on a relatively small number of patients, these patients represent an important subset—those at the "beginning of the end of life." Additionally, the physician survey represents a sizeable majority of all the PCPs in a large, urban, academic practice. Although limited by self-report, this study strongly suggests that current practices of PCPs fail to address the spiritual and existential concerns of seriously ill outpatients. This extends previous research by showing that this generality is true for this subset of relatively unstudied patients with serious illness and in the relatively unstudied context of a multicultural, urban, general internal medicine practice. Although some research suggests that physicians tend to address patient spirituality only when patients are dying,[12] our study reminds physicians that outpatients with serious illness have spiritual concerns as well, that these patients generally want their PCPs to care for their spiritual concerns, and that these concerns are commonly not recognized.

The suggestion that screening for spiritual concerns is important does not imply the appropriateness of discussing or proselytizing. Our results point out that listening, instead of talking, may be the most appropriate form of spiritual care by physicians. This conclusion expands the imperative of patient-centered care into the realm of spirituality in medicine. Patient-centered listening ideally begins with screening for spiritual-care needs among seriously ill outpatients. This screening communicates that the domain of spiritual and existential concerns is open to discussion, and that there is an interest on the part of the PCP to listen. It also helps the PCP to identify patients who need referrals or further empathetic listening.

Clinical applications

PCPs should screen seriously ill outpatients for spiritual and existential concerns while listening empathetically and directing patients and families who so desire toward further appropriate care. Simplistic calls for spiritual screening must be tempered by an awareness that many patients do not want their PCPs to initiate spiritual discussions or to "pray with them." After opening the door to spiritual concerns via screening, PCPs must take the cues from their patients in terms of the appropriate means for addressing such concerns within the physician-patient relationship as well as desires for more active care from other sources.

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Appendix 1: Patient Survey

Instructions and definitions: The following questions are about spiritual concerns in your medical care. Spiritual concerns are not limited to religious issues but also include issues of meaning such as, "What is my purpose in life?" "Why is this happening to me?" "What will happen to me after life ends?" Sometimes these questions are asked directly of physicians and sometimes only indirectly, if at all. Please keep this broad definition of spiritual concerns in mind as you fill out this survey.

1. How spiritual do you consider yourself? (Please circle one.)

Not at all A little Somewhat Quite a bit Very

2. How important do you think it is that your general medicine provider care for your spiritual concerns? (Please circle a number below.)

Not at all important Moderately important Incredibly important

0 1 2 3 4 5 6 7 8 9 10

3. Has your physician…? (Please circle YES or NO for questions 3-7.)

a) Asked if you are part of a religious or spiritual community. YES NO

b) Asked about the importance of spirituality to you. YES NO

c) Asked if you would like to discuss spiritual concerns with him or her. YES NO

d) Asked if you would like to speak with the chaplain. YES NO

4. Would you ever want your physician…?

a) To pray with you. YES NO

b) To pray for you on his or her own. YES NO

c) To discuss spiritual concerns with you. YES NO

5. Have you ever brought up your spiritual concerns with your provider? YES NO

6. Do you ever pray about your health? YES NO

7. Have you ever had a spiritual discussion with anyone? YES NO

8. If so, with whom did you have a spiritual discussion? (Please circle ALL that apply.)

Nurse practitioner Physician Pastor/priest Rabbi

Hospital chaplain Family member Friend Other

9. Would you want your provider to address your spiritual concerns? (Please circle one.)

Never Less often No change More often Every visit

10. Which of the following keep you from talking about your spiritual concerns with your provider? (Please check ALL that apply.)

____You do not have any spiritual concerns.

____You do not think it is part of your provider's job.

____There is not enough time.

____You think your provider would not want to.

Appendix 2: Primary Care Provider Survey

Instructions and definitions: The following questions pertain to spiritual concerns in patient care. Spiritual concerns are not limited to religious issues but also include issues of meaning such as, "What is my purpose in life?" "Why is this happening to me?" "What will happen to me after life ends?" Sometimes these questions are asked directly of physicians and sometimes only indirectly, if at all. Keeping in mind this broad definition of spiritual concerns, please fill out the following questions regarding the care of seriously ill patients with CHF, COPD, or cancer.

1. With what percentage of such patients does the following occur? (Please estimate.)
   a. You ask if they are part of a spiritual/religious community.____%
   b. You ask how important spirituality is to them. _____%
   c. You offer to discuss spiritual concerns with them. ____%
   d. You ask if they would like a referral for spiritual counseling. ____%
   e. Your patient initiates a spiritual discussion with you.____%
   f. You pray with them.____%
   g. You offer to pray for them on your own.____%
   h. Without offering, you pray for them on your own.____%

2. What percentage of such patients do you think would ever want the following? (Please fill in the blanks.)
   a. To discuss their spiritual concerns with you. ____%
   b. For you to pray with them. ____%
   c. For you to pray for them on your own. ____%

3. Which of the following hinder you from addressing the spiritual concerns of such patients? (Please check all that apply.)
   ____You do not feel competent.
   ____You do not have time.
   ____You do not feel it is part of your job.
   ____The patients do not want it.
   ____Other (please explain)_____.

4. How important is it that primary care physicians attend to the spiritual concerns of such patients? (Please circle a number below.)

Not at all important				Moderately important				Incredibly important		
0	1	2	3	4	5	6	7	8	9	10

5. How spiritual do you consider yourself (please circle one response)?

Not at all	A little	Somewhat	Quite a bit	Very much