Spirituality, Religiosity, and Spiritual Pain in Advanced Cancer Patients

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Abstract

Context. Spirituality, religiosity, and spiritual pain may affect advanced cancer patients' symptom expression, coping strategies, and quality of life.

Objectives. To examine the prevalence and intensity of spirituality, religiosity, and spiritual pain, and how spiritual pain was associated with symptom expression, coping, and spiritual quality of life.

Methods. We interviewed 100 advanced cancer patients at the M.D. Anderson palliative care outpatient clinic in Houston, TX. Self-rated spirituality, religiosity, and spiritual pain were assessed using numeric rating scales (0 = lowest, 10 = highest). Patients also completed validated questionnaires assessing symptoms (Edmonton Symptom Assessment Scale [ESAS] and Hospital Anxiety and Depression Scale), coping (Brief COPE and Brief R-COPE), the value attributed by the patient to spirituality/religiosity in coping with cancer (Systems of Belief Inventory-15R), and spiritual quality of life (Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being-Expanded [FACIT-Sp-Ex]).

Results. The median age was 53 years (range 21–85) and 88% were Christians. Almost all patients considered themselves spiritual (98%) and religious (98%), with a median intensity of 9 (interquartile range 7–10) of 10 and 9 (range 5–10) of 10, respectively. Spiritual pain was reported in 40 (44%) of 91 patients, with a median score of 3 (1–6) among those with spiritual pain. The value attributed by the patient to spirituality/religiosity in coping with cancer (Systems of Belief Inventory-15R), and spiritual quality of life (Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being-Expanded [FACIT-Sp-Ex])

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Conclusion. A vast majority of advanced cancer patients receiving palliative care considered themselves spiritual and religious. Spiritual pain was common and was associated with lower self-perceived religiosity and spiritual quality of life. J Pain Symptom Manage 2011;41:986–994. © 2011 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
Spirituality, religiosity, spiritual pain, coping, quality of life, cancer, palliative care

Introduction

Spirituality can be defined as a “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.”1 Another similar yet distinct construct from spirituality is religiosity. Spirituality can be seen as a dimension of personhood, whereas religion is a construct of human making, which enables the conceptualization and expression of spirituality.2 Spirituality and religiosity become increasingly important as patients approach the end of life.3 Spirituality and religiosity are well recognized as factors that affect patients’ quality of life, quality of care, and satisfaction.2,4–8 There is evidence that support for patients’ spiritual needs is associated with better quality of care, higher hospice utilization, and less aggressive care at the end of life.9

One of the key goals of palliative care is to alleviate suffering for patients living with life-threatening diseases such as cancer. Suffering is a multidimensional construct that includes physical, emotional, and spiritual distress. However, the concept of spiritual pain has not been well studied, and no standard definition for spiritual pain exists. For instance, it remains controversial whether spiritual pain represents an identical entity as suffering and spiritual distress, and whether it is the polar opposite of spiritual well-being. Saunders10 and Heyse-Moore11 conceptualized spiritual pain as part of total pain. Mako et al.12 defined spiritual pain as a “pain deep in your being that is not physical,” and identified three domains of expression through qualitative analysis: 1) as an intrapsychic conflict, 2) as interpersonal loss or conflict, and 3) in relation to the divine. In a personal reflection, Millspaugh13 viewed spiritual pain as identical to suffering and defined it as the complex interplay among various factors, including awareness of death, loss of relationships, loss of self, loss of purpose, loss of control, life affirming, transcending purpose and internal sense of control. Murata14 defined spiritual pain as “pain caused by extinction of the being and the meaning of the self” and evaluated its structure based on three dimensions: a being founded on temporality, a being in relationship, and a being with autonomy.

It remains unclear how spiritual pain is associated with spirituality and religiosity, and how spiritual pain affects patients’ expression of physical and emotional symptoms, their ability to cope with their illness, and quality of life. A better understanding of spiritual pain would allow health care professionals to adequately address patients’ spiritual needs, and ultimately to improve their quality of life. In this prospective cross-sectional survey, we examined the prevalence and intensity of spirituality, religiosity, and spiritual pain in a palliative care population, and how spiritual pain was associated with symptom expression, coping, and spiritual quality of life.

Patients and Methods

Consecutive patients who attended the palliative care clinic for a follow-up visit at M.D. Anderson Cancer Center were first screened, and subsequently approached if deemed eligible for this study. Inclusion criteria included a diagnosis of advanced cancer, age 18 years or older, and a Karnofsky performance status (KPS) of 40% or greater. Patients with impaired cognition or who did not speak English were excluded.

After providing informed consent, patients were interviewed by our study coordinator and provided information regarding demographics, self-rated spirituality, religiosity and spiritual...
pain, physical and psychological symptoms, coping strategies (COPE and R-COPE), and spirituality-related quality of life. The M.D. Anderson Cancer Center Institutional Review Board approved this study.

Spirituality, Religiosity, and Spiritual Pain

Self-rated spirituality was assessed by asking “Do you consider yourself a spiritual person?” Self-rated religiosity was assessed by the question “Do you consider yourself a religious person?” Patients reported their intensity of spirituality and religiosity using an 11-point numeric rating scale from 0 (‘not at all’) to 10 (‘very much’). For the purpose of this study, a patient was considered to be spiritual/religious if he or she provided a score of one or higher for the respective question.

To provide a point of reference for patients answering questions regarding spiritual pain, we first provided respondents with the following operational definition: “Spiritual pain is a pain deep in your soul (being) that is not physical.” Self-rated spiritual pain was then assessed by asking “Do you think you are experiencing spiritual pain now and how would you rate your overall spiritual pain?” The intensity of spiritual pain was assessed using an 11-point numeric rating scale from 0 (‘none’) to 10 (‘worst’). Spiritual pain was defined based on a score of one or higher for this question.

To assess patients’ perception of how spirituality and religiosity affect their health, we asked them the following three questions: “Is spirituality/religiosity a source of strength/comfort to you?”, “Does spirituality/religiosity help you cope with your illness?”, and “Does spirituality/religiosity help your family member/caregiver cope with your illness?” The responses were provided using an 11-point numeric rating scale from 0 (“not at all”) to 10 (“a great deal”). These questions have not been previously validated.

Physical and Psychological Symptoms

General physical and psychological symptoms were assessed using the Edmonton Symptom Assessment Scale (ESAS), a validated tool to assess patients’ grading of nine symptoms common in the cancer arena (pain, fatigue, nausea, depression, anxiety, drowsiness, shortness of breath, appetite, and overall sensation of well-being). A tenth item (“other problems”) also was asked but not analyzed. Patients were requested to grade their symptom severity in the last 24 hours on 0 (“no symptom”) to 10 (“worse possible symptom”) scales. The test-retest reliability has been high (>0.8), and this tool has been validated in many settings including advanced cancer.

In addition to the ESAS, psychological distress indicated by the presence of depression and anxiety were evaluated by the Hospital Anxiety and Depression Scale (HADS). Patients were asked to answer 14 items on 4-point numeric rating scales. Independent scores were derived for depression (HADS-D) and anxiety (HADS-A). HADS has been validated for depression and anxiety in different settings. The average Cronbach’s alpha for HADS-A was 0.83, whereas the HADS-D was 0.82; using a cutoff of 8 or greater for either subscale, the sensitivity and specificity were both approximately 80% for both HADS-A and HADS-D.

Coping and Religious Coping

General coping strategies were assessed by the Brief COPE, an abridged version of the longer COPE inventory. Patients were requested to answer how frequently they had engaged in 28 behaviors/activities, using a scale ranging from 1 (“I haven’t been doing this at all”) to 4 (“I’ve been doing this a lot”). Scores for three subscales were derived independently, including the emotions subscale, the problem-based subscale, and the dysfunctional coping subscale. This scale has been validated in the noncancer setting, and has been used in multiple studies with cancer patients.

Positive and negative religious coping were assessed by the validated Brief R-COPE questionnaire, which consists of two subscales: positive religious coping and negative religious coping. Patients graded their frequency of use of seven “positive” and seven “negative” religious coping strategies using a 4-item numeric scale from 0 (“not at all”) to 3 (“a great deal”). This tool has been validated in different populations, and has been widely used in cancer studies.

Religious Beliefs and Spiritual Quality of Life

The value attributed by the patient to spirituality/religiosity in coping with cancer was assessed by the Systems of Belief
Inventory-15R (SBI-15R), in which the patient answered 15 questions by rating his or her agreement and frequency of use of specific coping strategies using Likert-type scales.25 The SBI-15R has two subscales: one for “beliefs and practices” and a second related to “social support.” It has been found to have high internal consistency (Cronbach’s alphas of 0.98 and 0.96 for the two subscales, respectively) and high convergent validity.26

The spiritual/religious aspects of quality of life were assessed by the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being-Expanded (FACIT-Sp-Ex), a widely used and validated questionnaire.27 Patients rated their agreement with 23 statements on 5-point Likert scales. FACIT-Sp-Ex consists of two subscale scores: “faith” (related to traditional religiousness dimensions) and “meaning/peace” (related to spirituality dimensions). In addition to the two subscales, two total scores were available, FACIT-Sp-12 (ranging from 0 to 48) and the FACIT-Sp-Ex (ranging from 0 to 96), with higher scores meaning greater spiritual aspects of quality of life.

Statistical Analysis

We summarized baseline demographics, spirituality, religiosity, and spiritual pain using descriptive statistics, including medians, means, and ranges. Spirituality, religiosity, and spiritual pain were not normally distributed. Scores for validated questionnaires were prorated if 50% or more of the items within individual subscales or 80% of the items were completed by the patient.28 For FACIT total score, a cutoff of 80% was used. The majority of questionnaires were answered in full, with only a small proportion of missing values.

We used the Spearman’s correlation test to determine the association among spirituality, religiosity, and spiritual pain. By including 100 patients in the study, we calculated that we would be able to detect correlation coefficients of 0.25 or higher, assuming a one-sided significance level of 0.05 and 80% power.

The presence of spiritual pain was defined as $\geq 1/10$ in the question asking about spiritual pain. We compared the characteristics between patients with and without spiritual pain. Comparisons were made using the Mann-Whitney test for continuous, nonparametric variables, and the Pearson’s Chi-squared test and Fisher’s exact test (for small numbers) for categorical variables. We used the Bonferroni correction to correct for multiple testing, with a $P$ value of less than or equal to 0.002 considered statistically significant.

The Statistical Package for the Social Sciences (SPSS version 16.0, SPSS Inc., Chicago, IL) software was used for statistical analysis.

Results

A total of 100 patients were enrolled. Recruitment rate was not available for the first 28 patients. For the remaining 72 patients, a total of 112 individuals were approached, giving a recruitment rate of 63%.

The patient characteristics are shown in Table 1. The median age was 53 years, and 61% were female. A majority identified themselves as Christians, and few considered themselves atheists. Table 2 highlights the prevalence and intensity of self-rated spirituality, religiosity, and spiritual pain among our cohort. Almost all patients considered themselves spiritual (98%) and religious (98%), with a median score of 9 (interquartile range 7–10) and 9 (5–10), respectively. Almost all patients agreed that spirituality/religiosity was a source of strength, and helped them and their caregivers cope with their illness.

Spirituality was strongly associated with religiosity (Spearman’s correlation coefficient $\gamma = 0.74$, $P < 0.001$). Furthermore, spiritual pain was negatively associated with religiosity ($\gamma = -0.35$, $P = 0.001$) and a negative trend also was observed for spirituality ($\gamma = -0.26$, $P = 0.01$).

Spiritual pain was reported in approximately half of our cohort, with a median score of 3 (1–6) among those with spiritual pain (Table 2). Table 3 examines the association between spiritual pain and various clinical and psychological factors. Patients with spiritual pain did not differ from those without spiritual pain with regard to the baseline demographics (e.g., age, sex, religious affiliation, and performance status). The expression of spiritual pain was significantly associated with lower self-reported religiosity (median 10 vs. 7, $P < 0.001$) and lower spiritual quality of life (FACIT-Sp-Ex median score 68 vs. 81, $P < 0.001$).

In regard to physical and psychological symptoms, spiritual pain was associated with worse depression (2 vs. 1, $P = 0.01$), anxiety
(2 vs. 1, \(P = 0.03\)), anorexia (3 vs. 3, \(P = 0.04\)), and drowsiness (3 vs. 1, \(P = 0.004\), as measured by the ESAS, and higher anxiety, as measured by the HADS (\(n = 23\) vs. 15, \(P = 0.02\)); however, these results did not reach statistical significance after Bonferroni correction. We also observed a nonstatistically significant trend for decreased self-reported spirituality (8 vs. 10, \(P = 0.02\)) and decreased spiritual beliefs and practices by SBI-15R (24.5 vs. 28, \(P = 0.02\)). No associations were found between spiritual pain and coping by either Brief COPE or Brief R-COPE.

Patients also were asked a number of questions regarding their perception of how spirituality, religiousness, and spiritual pain affected their symptoms and coping. Patients who reported spiritual pain were significantly more likely to feel that spiritual pain made their physical (6 vs. 0, \(P < 0.001\)) and emotional (6 vs. 0, \(P < 0.001\)) symptoms worse. We also observed a trend toward a less favorable view of spirituality/reli giosity in their illness among those with spiritual pain (\(P < 0.05\)).
Discussion

In our study, we found that almost all patients at our palliative care clinic considered themselves spiritual (98%) and religious (98%), pointing to the clear significance of spirituality and religiosity in the advanced cancer setting. In a study with 68 advanced lung cancer patients from Caucasian and African-American ethnicities, 84% considered themselves “moderately to very spiritual” and 75% as “moderately to very religious.” These numbers are comparable to our results. The high proportion of self-reported spirituality/religiosity observed in our study might be related to the fact that our study was conducted in the American Southwest, where a high percentage of individuals consider themselves religious. A recent prospective longitudinal study revealed increased existential distress as patients approach the end of life, possibly suggesting an increasingly important role for spirituality/religiosity among advanced cancer patients.

A majority of our patients reported that spirituality and religiosity helped them cope with their cancer and served as a source of strength and comfort, suggesting that religious coping was mostly of a positive nature. Consistent

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<th>Clinical Factors Associated with Spiritual Pain*</th>
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IQR = interquartile range.

*Nine of 100 patients did not answer the question regarding spiritual pain, giving a total of 91 responses for analysis.

Unless otherwise stated.

Comparisons were made between patients with spiritual pain and those without spiritual pain using the Wilcoxon rank sum test for continuous variables, and the Fisher’s exact test for categorical variables.
with our findings, Alcorn et al.\textsuperscript{32} reported in a qualitative study that religiosity/spirituality was important for coping among advanced cancer patients. This was further supported by another study demonstrating that participation in religious services was associated with decreased feelings of anger and lower social isolation, allowing patients to better adjust to their illness.\textsuperscript{33}

Spiritual pain was reported to be present in 44\% of our patients at the time of the study, and was generally rated as mild (median score of 3, interquartile range 1–6). As suggested by Mako et al.,\textsuperscript{12} spiritual pain was explained to patients as “a pain deep in your soul (being) that is not physical.” Using this description, Mako et al. found that 96\% of patients had experienced spiritual pain sometime in their lives and 61\% reported experiencing it at the time of the interview, with a mean intensity of 4.7. Thus, despite having a research coordinator instead of a chaplain performing the assessments, and conducting the study in an outpatient rather than inpatient setting, we had comparable results, with approximately half of the palliative care patients expressing spiritual pain.

In our study, spiritual pain was significantly associated with a lower self-rated religiosity, and there was also a trend toward lower self-rated spirituality. On the one hand, patients without a strong religious support system may be more susceptible to experiencing spiritual pain; on the other hand, greater spiritual pain as a result of a life-threatening illness could lead the patient to question his or her faith, resulting in a decrease in religious belief. This hypothesis was partly supported by a trend toward lower scores on the SBI-15R beliefs and practices subscale among those with spiritual distress in our study. Further studies are required to determine the cause-effect relationship between these important concepts.

When patients were asked if spiritual pain made their physical and emotional symptoms worse, those who reported spiritual pain were significantly more likely to agree. Indeed, ESAS symptom scores were worse for patients with spiritual pain (e.g., depression, anxiety, drowsiness, and appetite), although these findings were not statistically significant after Bonferroni correction (Fig. 1). The lack of a strong association between psychological symptoms and spiritual pain may partly be explained by the small sample and the overlapping yet distinct characteristics between these two entities. For instance, both Mako et al.’s study\textsuperscript{12} and ours did not find an association between physical pain and spiritual pain. Future studies should be conducted in larger patient populations to better characterize the association between reported spiritual pain and physical and emotional symptoms. In the meantime, our findings suggest that patients who report refractory symptoms might have spiritual pain as a contributor, highlighting the need for spiritual assessment. Indeed, unmet spiritual concerns and needs may be a contributing factor to spiritual pain.\textsuperscript{7,32,34} Further studies are necessary to determine how spiritual care can potentially alleviate spiritual pain.

The presence of spiritual pain did not appear to affect patients’ ability to cope with their illness by Brief COPE and Brief R-COPE. This was somewhat surprising given that patients reported spirituality and religiosity as important for coping, and those with spiritual pain had lower levels of self-reported religiosity. However, coping is a complex process involving many factors other than spirituality/religiosity, including a person’s physical function, mental and emotional state, locus of control, and support system.\textsuperscript{35} Further studies are required to clarify the role of spirituality/religiosity in coping, particularly for advanced cancer patients in the palliative care setting.

Patients with spiritual pain expressed lower scores in spiritual aspects of quality of life as assessed by FACIT-Sp-Ex. Case reports have previously demonstrated that spiritual...
interventions aimed at alleviating spiritual distress can successfully relieve physical and emotional symptoms. More research is needed to determine the effectiveness of different spiritual interventions in reducing spiritual pain and improving quality of life among advanced cancer patients.

This study had several limitations. First, its cross-sectional design makes it impossible to establish causality among spirituality, religiosity, spiritual pain, and various physical and psychosocial symptoms. Secondly, the sample size was relatively small. Thus, further studies are required to verify our findings. Thirdly, our study was conducted at an outpatient palliative care clinic at a tertiary care cancer center in a specific geographic region; thus, our findings may not be generalizable. Fourthly, despite a relatively high study enrollment rate, we did not collect information on patients who declined to participate, and thus could not account for potential “volunteer” bias. Fifthly, our primary measures for spirituality, religiosity, and spiritual pain were unidimensional and quantitative, which could not capture the complexity and qualitative nature of these concepts. Sixthly, although a definition for spiritual pain was provided in our questionnaire, respondents may have had their own interpretation of what spiritual pain means to them, given that no universal definition exists for this relatively undefined concept. This could have affected how our patients interpreted spiritual pain and completed the study assessments. However, the similarities between our study and Mako et al.’s study suggest that this definition is reproducible. Finally, in-depth discussions held in our clinic might have increased patients’ awareness and/or interest in spirituality, which could in turn have led to increased reporting of spirituality/religiosity in our sample.

Our study highlighted the high prevalence of spirituality, religiosity, and spiritual pain in advanced cancer patients seen in the palliative care setting. Importantly, patients considered these constructs to be of great importance, and could either positively or negatively affect their physical and psychological symptoms. Consistent with this observation, we also found that spiritual pain was associated with decreased spiritual quality of life. On the basis of our findings, it is important to consider routine spiritual assessments to identify patients’ needs, particularly in those with refractory symptoms. Prospective studies to examine the effect of various spiritual interventions on spiritual pain and associated distress would allow health care professionals to better address patients’ concerns and spiritual needs, and ultimately to improve their quality of life.

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The authors report no conflicts of interest.

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