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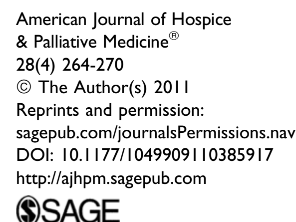

David Hui, MD[1], Maxine de la Cruz, MD[1], Steve Thorney, MDiv, MA[1], Henrique A. Parsons, MD[1], Marvin Delgado-Guay, MD[1], and Eduardo Bruera, MD[1]

Abstract

Limited research is available on the frequency of spiritual distress and its relationship with physical and emotional distress. We reviewed patients admitted to our acute palliative care unit (APCU) and determined the association between patient characteristics, symptom severity using the Edmonton Symptom Assessment scale (ESAS), and spiritual distress as reported by a chaplain on initial visit. In all, 50 (44%) of 113 patients had spiritual distress. In univariate analysis, patients with spiritual distress were more likely to be younger (odds ratio [OR] = 0.96, P = .004), to have pain (OR = 1.2, P = .010) and depression (OR = 1.24, P = .018) compared to those without spiritual distress. Spiritual distress was associated with age (OR = 0.96, P = .012) and depression (OR = 1.27, P = .020) in multivariate analysis. Our findings support regular spiritual assessment as part of the interdisciplinary approach to optimize symptom control.

Keywords

palliative care, spirituality, distress, advanced cancer, symptoms, depression

Introduction

A diagnosis of cancer or news of recurrent or progressive disease is a very traumatic event that can cause significant spiritual distress. Patients with advanced cancer have to face the fear of suffering, disability, helplessness, isolation, and impending death.[1,2] Spiritual distress has been found to be associated with psychosocial needs, communication issues, death anxiety, hopelessness, and despair.[3-6] Since quality of life is affected by all domains of personhood, spirituality in the context of overall care needs to be given importance.[7]

Spirituality is a subjective experience that occurs both within and outside the context of religious traditions. It is not defined by a set of beliefs about humanity, divinity, or the ultimate truth[8] but rather as a means by which people understand and live in view of their ultimate meaning and value.[9] Spirituality is characterized by the capacity to love and forgive, to worship, to see beyond the current circumstances, and to transcend suffering.[10] Spiritual concerns are typically awakened at the end of life, and the lack of meaning at that time may have important bearing on the will to live.[11] Lack of spiritual well-being is also associated with depression and lower tolerance to physical symptoms.[12,13] Spiritual pain may manifest itself as symptoms in any area of a person's experience[14,15] and can threaten the intactness of the person as a complex psychological and social entity.[14,16,17] Evidence suggests that spiritual well-being is an important protective factor against psychological distress in patients with terminal disease such as advanced cancer.[18]

In recent years, there has been a growing body of literature on psychosocial and spiritual well-being in patients with terminal illness, as it relates to their quality of life. There have been numerous studies describing the relationship of psychosocial distress such as depression, anxiety, and hopelessness with patients' physical symptoms and well-being.[19] However, there remains limited information on the frequency of spiritual distress and its relationship with physical and psychological symptoms, particularly in patients with advanced cancer. The purpose of this study was to determine the frequency and factors associated with spiritual distress in patients with advanced cancer admitted to the acute palliative care unit (APCU).

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Methods

We reviewed the electronic charts of 165 consecutive patients with advanced cancer that were admitted to the APCU at MD Anderson Cancer Center between July 1, 2007 and October 31, 2007. The study protocol was approved by the Institutional Review Board of the University of Texas MD Anderson Cancer Center, with waiver of informed consent. The APCU is a 12-bed unit that provides inpatient palliative care services with the goal of enhancing quality of life.

Demographic data including age, gender, and religion were collected for each patient as well as length of APCU stay and reason for admission. The Edmonton Symptom Assessment scale (ESAS)[20] was collected from the day corresponding to the date of the initial chaplain evaluation. ESAS is a validated tool that assesses 9 different symptoms (pain, fatigue, nausea, depression, anxiety, drowsiness, sleep, appetite, and shortness of breath) and feeling of well-being using numeric rating scales ranging from 0 to 10, where 0 = *no symptom* and 10 = *worst possible*, and is usually completed by the patient independently. However, a family member, physician, or nurse can help the patient complete in the assessment if he is unable to rate all the symptoms. Patients were excluded from the study if they were unresponsive, had delirium or if sedation limited their participation.

As a part of our interdisciplinary approach, all patients that are admitted to the APCU are seen by a chaplain early in the course of their admission, who provides spiritual assessment and support for patients and family members/caregivers. Although a number of questionnaires such as the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being, Expanded version (FACIT-SpEx)[8] are available for the assessment of spiritual well-being, there is a lack of validated assessment tools to specifically assess spiritual distress. Thus, our chaplains developed an empiric clinical tool based on the work of Roy Nash, a pastoral psychotherapist who has written about spirituality, ethics, and clinical pastoral care. In his work, *Life's Major Spiritual Issues*, Nash described 22 spiritual polarities or domains that people experience throughout the course of their life journey.[21] Examples of such spiritual domains include meaninglessness and fullness of life, brokenness and wholeness, despair and hope, and dread and courage. A person journeys freely at different time points along these domains. For example, difficult life experiences may bring about fear of loss or function or even life, but if life goals are reframed, then one may move toward the opposite end of the pole which is courage. In developing the spiritual assessment tool, Jenkins and Thorney reduced the list to include 7 spiritual distress domains that were felt most relevant to supportive cancer care: hope versus despair, wholeness versus brokenness, courage versus anxiety/dread, connected versus alienated, meaningful versus meaningless, grace/forgiveness versus guilt, and empowered versus helpless. This assessment tool is used by chaplains throughout our institution.

Operational definitions used in the MD Anderson spiritual assessment tool are listed here. Hope is a realistic and adaptive response to extreme stress or crisis that requires a patient to surrender to transcendent forces. In contrast, despair is a more objectless and profound depressed state of being than, for example, grief, which attaches to a specific loss. Wholeness connotes right relationships with the self, others, and a higher power, whereas brokenness is the spiritual unrest stemming from the knowledge that 1 or more of these relationships are conflicted. Anxiety and dread are thought to be an individual's response to the threat of nonbeing, a threat which includes nihilism and death. Courage, however, is the confrontation of this anxiety of nonbeing. Individuals are connected through a variety of relationships to a higher power, self, and others. When these relations are in harmony, there is a sense of connectedness as opposed to alienation when the person isolates or withdraws from 1 or more of those relationships as a response to crisis. The concept of meaningful or meaningless stems from the existentialist's position that a person's finite freedom is distorted by the anxiety it engenders. Guilt is a violation of the laws, norms, and values of the community in which a person is connected. Subjectively, it is a feeling that results when one violates his or her own conscience. Forgiveness is one aspect of remedy for guilt in both the secular and religious worlds. Grace is generally understood from a Christian vantage point as an expression of God's unconditional, forgiving, and empowering love for humanity. In the context of hospital-based spiritual care, empowerment and helplessness address the capacity of an individual to act (empowerment) as well as the attendant necessity to be acted on by others (helpless), ostensibly in the patient's best interest.

There is only one chaplain in our palliative care service, who works closely with other members of the interdisciplinary team and routinely attends the morning patient rounds, as well as weekly interdisciplinary rounds and family conferences. The board-certified APCU chaplain has more than 22 years of experience as pastor of a local congregation in Houston, clinical ethicist, and also as a clinical chaplain working with cancer patients. The chaplain outlines in his progress notes important spiritual distress domains covered during the visit. For this study, the APCU chaplain retrospectively reviewed his initial visit notes for each of the spiritual distress domains. Spiritual distress was considered present if patients had 2 or more of the following distress domains: despair, dread, brokenness, helplessness, alienation, meaningless, and guilt/shame.

We summarized baseline demographics using descriptive statistics, including medians, means, standard deviations, ranges, and frequencies. We conducted univariate logistic regression analysis to determine the association between spiritual distress and various clinical factors. Subsequent multivariate logistic regression analysis was performed using variables with $P < .20$ in univariate analysis. We also assessed factors association with severity of spiritual distress using multivariate nonparametric linear regression analysis. Two-sided P values less than .05 were considered statistically significant. The same statistical analyses were performed for each of the 7 spiritual distress domains. The Statistical Package for the Social Sciences (SPSS version 16.0, SPSS Inc, Chicago, Illinois) software was used for statistical analysis.

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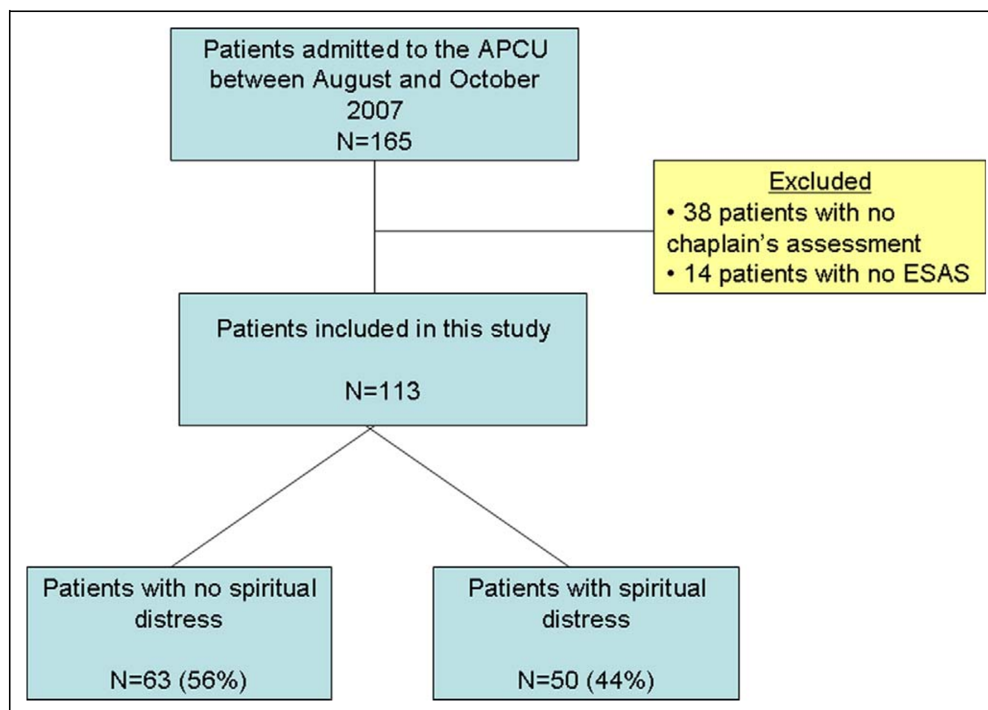

Figure 1. Study flowchart. APCU indicates acute palliative care unit; ESAS, Edmonton Symptom Assessment Scale.

Results

Among the 165 consecutive patients reviewed, 52 were excluded because of the absence of either a chaplain assessment or a recorded ESAS (Figure 1). Reasons for lack of chaplain assessment included delirium (N = 38, 73%), actively dying (N = 9, 17%), patient refusal (N = 3, 6%), and chaplain on holiday (N = 3, 6%). Table 1 shows the characteristics of the 113 patients included in the study. A majority were Christians. Spiritual distress was noted to be present in 50 (44%) of 113 patients. The distribution of the number of spiritual distress domains is shown in Figure 2.

In univariate analysis, younger age, pain, and depression were significantly associated with spiritual distress (Table 2). Other demographic and clinical variables tested did not show any significant association with spiritual distress. Multivariate logistic regression analysis showed younger age and depression to be independently associated with spiritual distress (Table 2). Younger age ($P = .009$), pain ($P = .027$), and depression ($P = .021$) were also found to be associated with a greater number of spiritual distress domains in multivariate nonparametric linear regression analysis.

The frequency of each of the 7 spiritual distress domains is shown in Table 3. On the initial chaplain visit, despair was the most common spiritual distress domain expressed by patients in the APCU, followed by dread and brokenness. Multivariate analysis for each of the spiritual distress domains is summarized in Table 4. Younger patients were more likely to report despair, brokenness, helplessness, and meaninglessness. Male patients were more likely to report despair. Patients with pain were more likely to feel alienation.

Discussion

Using the MD Anderson chaplains' clinical assessment tool, we found that nearly half of the patients admitted to the APCU had spiritual distress on initial chaplain visit. Spiritual distress was associated with younger age, pain, and depression. Further studies are required to elucidate the nature of spiritual distress and to identify strategies to better manage this multidimensional construct.

A significant number of patients living with cancer consider spirituality as an important part of their personhood that gains more relevance at the end of life.[22-25] Patients' spirituality may provide them with a sense of well-being by giving structure and meaning to their difficult experience and serve as a buffer against depression, hopelessness, desire for death, and existential suffering.[4,26,27] However, at the end of life, when patients are confronted with complex physical, psychosocial, and existential concerns, spiritual distress can occur. Frequent struggles with fear, anger, physical discomfort, loss of independence, changing self-image, roles and relationships,[28-31] and failure to find meaning[32] can also contribute to spiritual distress.

Almost half of our patients were found to have spiritual distress, defined here as the presence of at least 2 spiritual distress domains. In a survey of 57 patients with advanced cancer, Mako et al[33] reported that about 61% of patients had spiritual distress at the time of chaplain visit. The difference in observed frequencies may be related to how spiritual distress was defined and measured.[34] Spiritual distress that is present in the form of depression and hopelessness occur in a substantial minority of patients with advanced cancer.[18,27,35] The high prevalence of spiritual distress in the palliative care population highlights the

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Table 1. Patient Demographics

	No Spiritual Distress (%)[a], N = 63	Spiritual Distress Present (%)[a], N = 50
Mean age, in years (standard deviation)	64 (14.3)	55 (14.6)[b]
Gender		
Female	28 (44)	17 (34)
Male	35 (56)	33 (66)
Ethnicity		
African American	11 (18)	10 (20)
Hispanic	7 (11)	9 (16)
Caucasian	40 (64)	29 (58)
Asian	5 (8)	2 (4)
Median length of APCU stay in days (interquartile range)	8 (5-11)	7 (6-13)
Religion		
Christian	48 (76)	44 (81)
Jewish	3 (5)	0 (0)
Buddhist	2 (3)	2 (4)
Hindu	2 (3)	0 (0)
Muslim	1 (2)	1 (2)
Others	7 (11)	3 (6)
Median Edmonton Symptom Assessment scale (interquartile range)		
Pain	2 (1-4)	4 (1-7)[b]
Fatigue	4 (1-7)	4 (1-7)
Nausea	1 (0-1)	1 (1-1)
Depression	1 (0-2)	2 (1-4)[b]
Anxiety	1 (1-4)	3 (1-5)
Drowsiness	4 (1-6)	4 (1-6)
Dyspnea	2 (1-4)	2 (1-5)
Appetite	6 (3-8)	5 (2-8)
Sleep	3 (1-5)	4 (1-5)
Well-being	3 (1-5)	5 (1-5)

Abbreviation: APCU, acute palliative care unit.
[a] Unless otherwise specified.
[b] $P < .05$ in univariate analysis.

need to develop validated assessment tools and targeted interventions for this construct.

In our study, younger patients were found to have more spiritual distress as compared with older patients. When the domains were considered separately, younger age was likewise a risk factor for despair, brokenness, helplessness, and meaningless. For patients in the prime of their lives, the possibility of a life curtailed, of decline in function, and unfulfilled aspirations can be sources of great spiritual and psychosocial distress. A previous study showed that patients older than 50 years were more likely to describe themselves as being at peace than younger patients.[36] Ellis et al[37] reported that younger patients were referred more to a specialized psychology oncology service for management of both psychosocial and spiritual distress. Younger patients may be less likely to let go, as evident by the higher likelihood of receiving cancer treatments close to the end of life.[38] This, coupled with the lack of resources[39] and self-esteem issues,[40] could potentially exacerbate the sense of spiritual distress.

Pain, which may be a symbol of worsening disease for some patients, was associated with poor spiritual well-being. The term total pain recognizes the interaction of the 3 domains of personhood and how they influence each other. Cicely Saunders defined it as the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles.[41,42] Such other forms of pain may often be manifested and interpreted as physical pain without consideration of the psychosocial and spiritual components to it. Our study showed the association of pain and spiritual distress and is consistent with previous reports.[33,43-45] The presence of pain can often limit a person's ability to have meaningful interaction with others, possibly resulting in alienation. The search for meaning at the end of life also becomes difficult for patients struggling with uncontrolled symptoms and subsequently results in spiritual distress.

Most studies have demonstrated that spiritual well-being is positively correlated with better physical and psychological well-being.[4,46] A strong faith and belief system and the ability to find meaning and purpose positively affects spiritual well-being resulting in less psychological distress.[46] Several authors have recommended pastoral care interventions aimed at strengthening spiritual well-being in patients with psychosocial issues like depression and anxiety.[47] The inverse to this relationship which is the effect of psychological distress, such as depression, on spiritual well-being has not been fully investigated. Our study showed that depression was associated with spiritual distress. A similar study of 31 palliative care patients admitted to the hospital showed that spiritual distress was positively correlated with anxiety, depression, and fatigue.[29] Although spiritual distress may manifest as symptoms of depression, depression may also augment spiritual distress, preventing patients from adopting a more fulfilling approach to the end of life.[48]

Our study affirms the interconnectedness among the physical, psychosocial, and spiritual dimensions of personhood, with the important implication that an interdisciplinary team approach is necessary to address the complex needs of palliative care patients and their families. Specifically, the presence of a chaplain, who has acquired expertise in conducting spiritual assessments and providing spiritual interventions, is crucial. Good rapport between the patient and clinician is also essential for effective diagnosis and management of spiritual distress.[10]

This study has a number of limitations, including the small sample size, the retrospective data collection, and the use of an assessment tool for spiritual pain that has not been fully validated. Although this clinical assessment tool has content and face validity, further studies are required to examine its reliability, validity, and responsiveness to change. Importantly, spiritual pain as a construct also needs to be better defined through both qualitative and quantitative studies. Finally, we only examined spiritual pain when patients were first admitted to the APCU, which may not be representative of patients' experience. Multiple visits may be required before patients could fully engage at a very personal level and discuss their spiritual and existential concerns. Further research is required.

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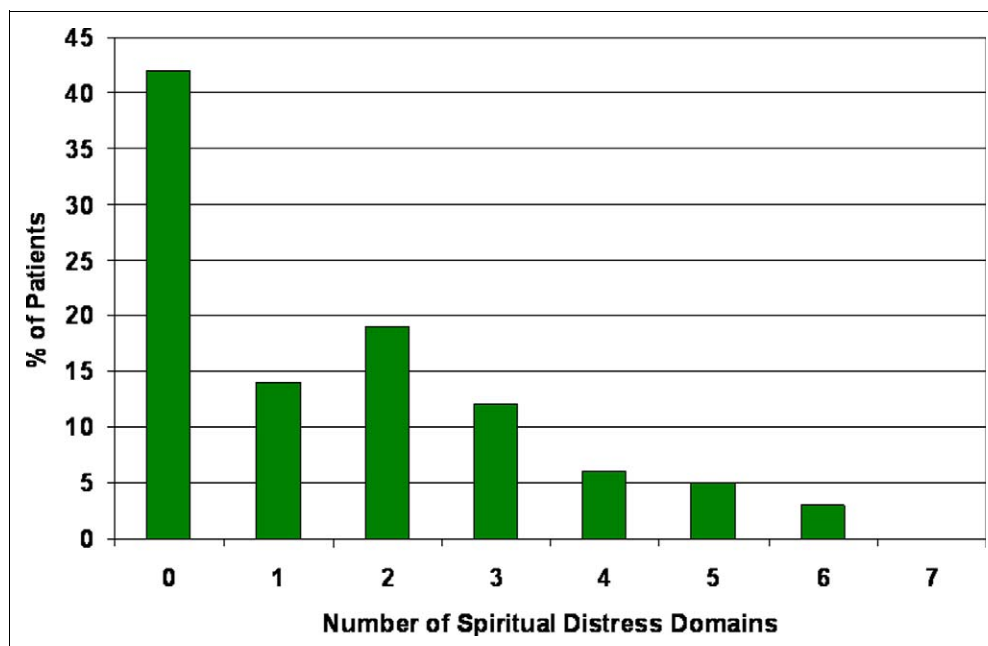

Figure 2. Number of spiritual distress domains. In this study, spiritual distress was defined as the presence of 2 or more spiritual distress domains.

Table 2. Association Between Spiritual Distress and Clinical Features

	Univariate Analysis		Multivariate Analysis	
Characteristics and Symptoms	OR (95% CI)	*P*-Value	OR (95% CI)	*P* Value
Age (per year)	0.96 (0.93-0.99)	.004	0.96 (0.93-0.99)	.012
Male gender	1.55 (0.72-3.35)	.26	–	–
Religion	1.01 (0.67-1.11)	.96	–	–
Ethnicity	1.05 (0.71-1.56)	.80	–	–
Reason for APCU admission	0.85 (0.61-1.19)	.35	–	–
Length of APCU stay (days)	1.04 (0.98-0.11)	.21	–	–
Edmonton Symptom Assessment scale				
Pain	1.20 (1.04-1.37)	.010	–	–
Fatigue	0.96 (0.84-1.09)	.50	–	–
Nausea	1.10 (0.91-1.35)	.33	–	–
Depression	1.24 (1.04-1.48)	.018	1.27 (1.04-1.56)	.02
Anxiety	1.18 (0.997-1.40)	.05	–	–
Drowsiness	0.97 (0.85-1.11)	.67	–	–
Dyspnea	1.09 (0.95-1.26)	.23	–	–
Appetite	0.97 (0.86-1.09)	.59	–	–
Sleep	1.07 (0.93-1.24)	.34	–	–
Well-being	1.10 (0.95-1.26)	.20	–	–

Abbreviations: APCU, acute palliative care unit; CI, confidence interval; OR, odds ratio.

As patients approach death, the inward journey aimed to answer the questions of life's meaning occurs frequently. Clinicians must acknowledge the spiritual dimension of patients as an integral component of their personhood. Assessment for spiritual wellness and distress is, therefore, crucial in addressing end-of-life needs. Our findings support the interconnectedness among physical, psychological, and spiritual distress. An interprofessional approach to patient's suffering is essential in improving care at the end of life.

Authors' Note

The authors, David Hui and Maxine de la Cruz contrubited equally in this study. Findings from this study were partly presented at the 2009 Multinational Association for Supportive Care in Cancer in Rome as an oral abstract.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Table 3. Frequency of Spiritual Distress Domains

Domains	Number of Patients (%)
Despair	36 (32)
Dread	33 (29)
Broken	31 (27)
Helplessness	28 (25)
Alienation	18 (16)
Meaningless	17 (15)
Guilt/shame	10 (8)

Table 4. Multivariate Logistic Regression Analysis for Individual Spiritual Domains[a]

Spiritual Distress Domain	OR (95% CI)	*P* Value
Despair		
Age	0.96 (0.92-0.99)	.006
Male gender	3.54 (1.24-10.10)	.018
Appetite	0.83 (0.69-0.99)	.047
Well-being	1.28 (1.03-1.57)	.023
Dread		
Length of APCU stay	1.09 (1.01-1.17)	.032
Anxiety	1.35 (1.09-1.68)	.007
Brokenness		
Age	0.97 (0.94-1.0)	.048
Length of APCU stay	1.07 (0.99-1.14)	.075
Helplessness		
Age	0.96 (0.93-0.99)	.016
Sleep	1.21 (1.01-1.44)	.037
Alienation		
Pain	1.31 (1.08-1.56)	.006
Fatigue	0.82 (0.66-1.01)	.057
Meaningless		
Age	0.96 (0.92-0.99)	.015
Guilt/Shame		
Anxiety	0.61 (0.38-0.97)	.038

Abbreviations: APCU, acute palliative care unit; CI, confidence interval; OR, odds ratio.
[a] Only the significant factors were shown.

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