

# Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients

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## Summary

**Background** The importance of spirituality in coping with a terminal illness is becoming increasingly recognised. We aimed to assess the relation between spiritual well-being, depression, and end-of-life despair in terminally-ill cancer patients.

**Methods** 160 patients in a palliative care hospital with a life expectancy of less than 3 months were interviewed with a series of standardised instruments, including the functional assessment of chronic illness therapy—spiritual well-being scale, the Hamilton depression rating scale, the Beck hopelessness scale, and the schedule of attitudes toward hastened death. Suicidal ideation was based on responses to the Hamilton depression rating scale.

**Findings** Significant correlations were seen between spiritual well-being and desire for hastened death ( $r=-0.51$ ), hopelessness ( $r=-0.68$ ), and suicidal ideation ( $r=-0.41$ ). Results of multiple regression analyses showed that spiritual well-being was the strongest predictor of each outcome variable and provided a unique significant contribution beyond that of depression and relevant covariates. Additionally, depression was highly correlated with desire for hastened death in participants low in spiritual well-being ( $r=0.40$ ,  $p<0.0001$ ) but not in those high in spiritual well-being ( $r=0.20$ ,  $p=0.06$ ).

**Interpretation** Spiritual well-being offers some protection against end-of-life despair in those for whom death is imminent. Our findings have important implications for palliative care practice. Controlled research assessing the effect of spirituality-based interventions is needed to establish what methods can help engender a sense of peace and meaning.

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## Introduction

The importance of spirituality as a central component of psychological well-being is increasingly recognised by doctors and mental-health professionals.<sup>1,2</sup> Among the medically and terminally ill in particular, patients struggle with questions about their mortality, the meaning and purpose of life, and whether a greater power exists, forcing them to grapple with issues they had previously ignored. Kearney and Mount stated that spiritual issues “lie at the very centre of the existential crisis that is terminal illness”.<sup>1</sup> Spirituality is perhaps best defined as “the way in which people understand their lives in view of their ultimate meaning and value”.<sup>3</sup> Many patients turn to religion for answers to these difficult questions, but others find support through their spiritual beliefs outside the context of organised religion.

Growing data have provided empirical support for the hypothesis that spiritual well-being might help to bolster psychological functioning and adjustment to illness. Results of several studies of medically-ill patients show a strong inverse relation between spiritual well-being—ie, a sense of meaning and purpose in life, faith, and comfort with existential concerns—and depression.<sup>4–6</sup> Coward<sup>7</sup> noted that her self-transcendence intervention provided important benefits for a group of women with breast cancer. In studies of physically healthy individuals, similar results have been reported, suggesting that spiritual well-being is a central component of psychological health.<sup>8</sup>

Because psychological distress happens frequently at the end of life, maintenance or development of a sense of spiritual well-being might be a crucial aspect of coping with terminal illness. Feelings of depression, hopelessness, and anxiety are common reactions of individuals as they approach the terminal phase of an illness.<sup>9</sup> Whereas many patients manage to avoid feeling distressed as they approach death, others have a great sense of despair during their final weeks or months of life. End-of-life despair could manifest itself as general feelings of hopelessness or demoralisation, or in the extreme might develop into a desire for hastened death or thoughts of suicide. Although results of studies of terminally-ill populations consistently show a higher risk of suicide, hopelessness, and desire for hastened death than for the general population,<sup>10,11</sup> the link between spiritual well-being and end-of-life despair has not been assessed in the context of other, potentially relevant, effects.

On the other hand, the link between depression and desire for hastened death, suicidal ideation, and hopelessness is consistently seen in studies of medically-ill and terminally-ill individuals. For example, results of studies in cancer patients show that depression is significantly associated with desire for hastened death,<sup>10,12</sup> hopelessness,<sup>13</sup> and suicidal ideation.<sup>14</sup> In studies of patients with AIDS and amyotrophic lateral sclerosis, researchers have noted closely similar findings,<sup>15</sup> lending support to the important role of depression in end-of-life despair.

**Assessments used in study**

Assessment	Abbreviation	Measure of
Functional assessment of chronic illness therapy—spiritual well-being scale	FACIT-SWB	Spiritual well-being
Mini-mental state examination	MMSE	Cognition
Hamilton depression rating scale	HDRS	Depression/ suicidal ideation
Beck hopelessness scale	BHS	Pessimism and hopelessness
Schedule of attitudes toward hastened death	SAHD	Desire for a hastened death
Functional social support questionnaire	FSSQ	Perceived social support
Memorial symptom assessment scale	MSAS	Symptom prevalence, frequency, and distress
Karnofsky performance rating scale	KPRS	Physical functioning ability

Unlike these studies of depression, systematic research addressing the relation between spiritual well-being and end-of-life despair is virtually absent. Results of a few studies report an association between spiritual well-being and a sense of hope in the context of a medical illness;<sup>6,16,17</sup> however, the relation between spiritual well-being and either desire for hastened death or suicidal ideation has rarely been studied. In one of the few such studies, Breitbart and colleagues reported that spiritual well-being was significantly correlated with desire for hastened death in terminally-ill cancer patients.<sup>10</sup>

The hypothesis that religion could deter people from suicide dates back to the 19th century.<sup>18</sup> Results of several empirical studies have identified a relation between religious involvement and suicidal ideation;<sup>19,20</sup> however, these studies focused mainly on the amount of religious affiliation rather than spirituality per se. We aimed to assess the relations between spiritual well-being and end-of-life despair in a large sample of terminally-ill cancer patients. In particular, we sought to investigate the role of spiritual well-being relative to that of other potential effects, such as depression, physical symptoms, and social support, in prediction of hopelessness, desire for hastened death, and suicidal ideation.

**Participants and methods****Participants**

Study participants were recruited shortly after admission to a palliative care hospital in New York, NY, USA. Recruitment took place between December, 2000, and June, 2002. All participants were diagnosed with cancer and had a life expectancy of less than 3 months. To be eligible for study participation, we first asked individuals to complete a brief cognitive assessment with the mini-mental state examination (MMSE).<sup>21</sup> Those who obtained a score of 19 or less were excluded from the study because of concerns they might not be capable of provision of meaningful informed consent or accurate responses to the study tests. We also excluded from the study those who were unable to speak English fluently or who had a psychotic mental disorder. Eligible individuals were informed of the risks and benefits of study participation and, if willing, they provided written informed consent. Institutional review boards of Calvary Hospital, Memorial Sloan-Kettering Cancer Center, and Fordham University (NY, USA) approved the study.

**Procedures**

One or more study investigators interviewed participants at the bedside with several self-report and clinician-rated tests, typically in one or two sessions within the first week after admission. Self-report measures were read to the participants, in a predetermined order, to keep fatigue to a minimum and to ease completion of the tests.

We assessed spiritual well-being with the functional assessment of chronic illness therapy—spiritual well-being scale (FACIT-SWB), a measure of spiritual well-being that includes two subscales measuring meaning and peace (meaning) and faith (faith).<sup>2</sup> The meaning subscale measures the extent to which an individual feels inner harmony and feels at peace with themselves, whereas the faith subscale measures the extent to which they find comfort and strength in their religious beliefs. We measured depression with the Hamilton depression rating scale (HDRS), a clinician-rated measure of depressive symptoms that has been widely used in studies of medically-ill and physically healthy individuals.<sup>22</sup> End-of-life despair was thought of as a triad of hopelessness, desire for hastened death, and suicidal ideation. We assessed these constructs with the Beck hopelessness scale (BHS), a measure of pessimism and hopelessness;<sup>23</sup> the schedule of attitudes toward hastened death (SAHD), a measure of desire for hastened death in the context of medical illness;<sup>10</sup> and responses to the HDRS item pertaining to suicidal ideation—ie, patients who either had no thoughts of suicide or felt that life was not worth living were classified as having no suicidal ideation and contrasted with patients who expressed some suicidal ideation or intent. Additional measures included the Duke-UNC functional social support questionnaire (FSSQ), a measure of perceived social support;<sup>24</sup> the memorial symptom assessment scale (MSAS), a measure of symptom prevalence, frequency, and distress used with a wide range of medically-ill populations;<sup>25</sup> and the Karnofsky performance rating scale (KPRS), a clinician-rated index of physical-functioning ability frequently used in studies of patients with cancer.<sup>26</sup> A summary of the assessments we used is shown in the panel.

**Statistical analysis**

We analysed data with Spearman correlation coefficients to assess the relation between FACIT-SWB scores and scores on the criterion variables (BHS, SAHD, and suicidal ideation) and potential covariates (HDRS, FSSQ, MSAS, and KPRS).

The second level of analyses consisted of a series of regression models, chosen on the basis of past research,<sup>10</sup> which were used to quantify the relative contribution of spiritual well-being and depression in prediction of end-of-life despair (desire for death, hopelessness, and suicidal ideation). HDRS scores were calculated without the item pertaining to suicidal ideation for analyses that included this criterion. We used logistic regression analysis to analyse suicidal ideation whereas linear regression models were used to assess SAHD and BHS scores. Furthermore, a comparable set of analyses were done, substituting the two FACIT-SWB subscales (meaning and faith) for FACIT-SWB total score, to determine which elements of spiritual well-being are most strongly associated with psychological adjustment. Multiple regression analyses were used to establish whether spiritual well-being provided a unique contribution, beyond that of depression, in predicting end-of-life despair.

The final level of analysis entailed assessment of the presence of an interaction effect between depression and spiritual well-being in prediction of end-of-life despair. To

	FACIT spiritual well-being						HDRS	p
	Total	p	Meaning	p	Faith	p		
<b>Dependent variables</b>								
Hopelessness (BHS) (mean 5.94, SD 4.7)	-0.68	<0.0001	-0.67	<0.0001	-0.55	<0.0001	0.53	<0.0001
Desire for hastened death (SAHD) (mean 4.35, SD 4.4)	-0.51	<0.0001	-0.52	<0.0001	-0.36	<0.0001	0.41	<0.0001
Suicidal ideation (yes 19%, no 81%)	-0.41	<0.0001	-0.41	<0.0001	-0.33	<0.0001	0.37	<0.0001
<b>Covariates</b>								
Depression (HDRS) (mean 10.94, SD 6.6)	-0.51	<0.0001	-0.52	<0.0001	-0.39	<0.0001	1.00	..
Social support (FSSQ) (mean 3.57, SD 0.6)	0.35	<0.0001	0.37	<0.0001	0.26	0.004	-0.20	0.012
Physical functioning (KPRS) (mean 39.34, SD 8.7)	0.04	0.610	0.04	0.645	0.05	0.568	-0.17	0.022
Number of symptoms (MSAS) (mean 12.04, SD 6.0)	-0.30	<0.0001	-0.34	<0.0001	-0.19	0.014	0.52	<0.0001

Table 1: Correlations with spirituality and depression measures

do these analyses, we divided participants into two groups on the basis of their scores on the FACIT-SWB: a highly spiritual group had a mean score of 3.0 or greater, and a low to moderately spiritual group had a mean score less than 3.0. This cut-off was chosen on the basis of the distribution of FACIT-SWB scores and the labels that correspond to this score: a score of 3 indicates “quite a bit” whereas scores below this correspond to “somewhat” or lower. We judged  $p < 0.05$  significant with tests including the F test for ANOVA models and Wald’s  $\chi^2$  test for the logistic regression models.

### Role of the funding source

The sponsors of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

### Results

During the 18-month study period, 3212 patients were admitted for end-of-life care. Of these, 2352 (73%) were ineligible to participate because severity of their medical disorder precluded provision of meaningful informed consent or study data—eg, they were comatose, severely cognitively impaired, or otherwise too ill to participate—or they died almost immediately after admission. Of the remaining 868 patients who underwent the cognitive screening test (MMSE), 266 scored less than 20 and were therefore not eligible for study participation. A further 402 patients declined to participate in the study, most of whom cited their illness and frail health as the reason, although a few patients indicated no interest in participating in research or had other reasons for declining to participate. The remaining 200 participants consented to participate in the study, although 40 were omitted from these analyses because of missing or incomplete data on one or more of the study measures, yielding a final sample of 160.

Of the 160 study participants, 91 (57%) were women and 69 (43%) were men (mean age 65.7 years [SD 13.4]). 114 (71%) were white, 34 (21%) African American, and

ten (6%) Hispanic; one individual was Asian and another did not specify an ethnic origin. 80 (50%) participants reported their religious affiliation as Catholicism, 33 (21%) as Protestantism, and 18 (11%) as Judaism; 29 (18%) reported other or no religious affiliation. Marital status was evenly distributed in the sample: 40 (25%) people had never been married, 42 (26%) were married at the time of the study, 34 (21%) were widowed, and 43 (27%) were divorced or separated at the time of study participation; one individual was cohabitating. 107 (67%) participants had children. Mean number of years of education completed was 13.0 (SD 3.1). Mean KPRS score was 39.3 (8.7), indicating a high degree of physical disability for all participants. All study participants were diagnosed with cancer, with the most typical diagnoses being lung ( $n=33$ ; 21%), colon (22; 14%), breast (22; 14%), and pancreatic (13; 8%) cancer.

Inter-rater reliability for the clinician-rated tests (HDRS and KPRS)—established by asking two clinicians to rate a subset of patients—showed a high degree of reliability for depression ratings (intraclass correlation 0.80) and Karnofsky ratings (0.76).

Table 1 lists the bivariate Spearman correlation coefficients between the spirituality and depression measures and the criterion variables and potential covariates. FACIT-SWB total score was significantly correlated with every outcome variable, as was each subscale (meaning and faith). Depression was also significantly correlated with every outcome variable, although somewhat less than FACIT-SWB total scores.

In the regression models, we included several potential covariates (FSSQ, MSAS, KPRS). The results of these models are summarised in table 2. For every model, FACIT-SWB provided a significant and substantial contribution even while controlling for the effect of other relevant covariates (depression, social support, etc). The effect of depression, although also significant in every model, was somewhat weaker than that of spiritual well-being. Social support and physical functioning, on the other hand, did not contribute significantly to any of these

Predictor variable	Individual regression model					
	Hopelessness (BHS)	p	Desire for hastened death (SAHD)	p	Suicidal ideation	p
FACIT-SWB total score	-0.56	0.0001	-0.45	0.0001	-1.01	0.0005
Depression (HDRS)	0.27	0.0003	0.26	0.004	0.11	0.014
Social support (FSSQ)	-0.04	0.533	0.08	0.257	0.43	0.327
Number of symptoms (MSAS)	-0.05	0.469	0.02	0.805	0.11	0.022
Physical functioning (KPRS)	-0.01	0.847	-0.02	0.781	0.01	0.755
<b>Model F</b>	36.08	0.0001	17.33	0.0001	46.49*	0.0001
<b>Model R<sup>2</sup></b>	0.54	..	0.36	..	0.25	..

Data are beta weights for BHS (hopelessness), SAHD (desire for hastened death), and suicidal ideation. \* $\chi^2$  value for logistic regression model.

Table 2: Regression models by FACIT-SWB total score

	Individual regression model					
	Hopelessness (BHS)	p	Desire for hastened death (SAHD)	p	Suicidal ideation	p
<b>Predictor variable</b>						
FACIT-SWB meaning subscale	-0.44	0.0001	-0.44	0.0001	-0.84	0.019
FACIT-SWB faith subscale	-0.18	0.015	-0.06	0.493	-0.21	0.380
Depression (HDRS)	0.26	0.0004	0.23	0.006	0.11	0.015
Social support (FSSQ)	-0.04	0.589	0.09	0.217	0.46	0.301
Number of symptoms (MSAS)	-0.06	0.389	0.06	0.940	0.10	0.026
Physical functioning (KPRS)	-0.02	0.756	-0.03	0.652	0.01	0.820
<b>Model F</b>	30.35	0.0001	15.05	0.0001	46.78*	0.0001
<b>Model R<sup>2</sup></b>	0.54	..	0.37	..	0.25	..

Data are beta weights for BHS (hopelessness), SAHD (desire for hastened death), and suicidal ideation. \* $\chi^2$  value for logistic regression model.

Table 3: Regression models with FACIT-SWB meaning and faith subscales

models after controlling for the effect of depression and spiritual well-being. The number of physical symptoms on MSAS was significantly associated with suicidal ideation, but not with hopelessness or desire for hastened death.

A second set of analyses was calculated in which overall spiritual well-being (FACIT-SWB total score) was replaced with the two subscales (meaning and faith) to ascertain the effect of these aspects of spiritual well-being (table 3). In each of these analyses, the meaning subscale was significantly associated with the outcome variables for end-of-life despair (hopelessness, desire for hastened death, suicidal ideation). The faith subscale, on the other hand, was only associated with hopelessness and did not provide an independent contribution to prediction of desire for hastened death or suicidal ideation. The effect of depression on end-of-life despair was not affected by the change from overall spiritual well-being to the meaning and faith subscales, and remained significantly associated with all three criterion variables. The relation between the remaining covariates (FSSQ, KPRS, MSAS) and these outcome variables was almost identical to the previous analysis.

The final set of analyses addressed the possible interaction between level of depression and level of spiritual well-being in prediction of hopelessness, desire for hastened death, and suicidal ideation. A significant interaction was noted between depression and spiritual well-being in prediction of desire for hastened death ( $\beta = -0.26$ ,  $p = 0.05$ ). Specifically, the correlation between these measures was considerably stronger for the less spiritual group ( $r = 0.40$ ,  $p < 0.0001$ ) than for the more highly spiritual group ( $r = 0.20$ ,  $p = 0.06$ ). The interaction of depression with spiritual well-being was not significant for either hopelessness ( $\beta = -0.08$ ,  $p = 0.51$ ) or suicidal ideation ( $\beta = -0.10$ ,  $p = 0.33$ ).

## Discussion

Results of our study show spiritual well-being was a strong correlate of end-of-life despair, providing a unique contribution to the prediction of hopelessness, desire for hastened death, and suicidal ideation even after controlling for the effect of depressive symptoms and other relevant variables. Although much research addressing psychological adjustment in terminal illness has focused on depression, spiritual well-being might be a more powerful effect. In fact, in virtually every analysis, spiritual well-being provided a stronger contribution than did depressive symptoms, although both were significant in each model.

Understanding the mechanism by which spiritual well-being affects psychological functioning is difficult. One clue is the importance of meaning versus faith. We saw significantly stronger associations with the meaning

subscale of FACIT-SWB than with the faith subscale with respect to hopelessness, desire for hastened death, and suicidal ideation. Thus, the ability to find or sustain meaning in one's life during terminal illness might help to deter end-of-life despair to a greater extent than spiritual well-being rooted in one's religious faith. Of course, any conclusions about the importance of spirituality linked to or independent of religion are premature in view of the absence of any specific measure of religious beliefs in this study.

The confounding relation between religion and spiritual well-being might explain the seemingly inconsistent set of results obtained in our analysis of the interaction between spiritual well-being and depression. We recorded a significant interaction effect in the model, predicting desire for hastened death but not for suicidal ideation or hopelessness. Thus, spiritual well-being might buffer the effect of depression on desire for hastened death, but does not affect the relation between depression and hopelessness or suicidal ideation. Because many religions specifically prohibit suicide, even individuals who are very depressed and are low in spiritual well-being (but still religious) might still not consider suicide as an option because of their religious beliefs. These findings are especially important in view of the role that depression has had in past studies of desire for hastened death and suicidal ideation.<sup>15,19,23</sup> On the other hand, the absence of an interaction effect in prediction of hopelessness is hardly surprising since terminally-ill individuals can maintain a sense of peace and spiritual well-being without necessarily feeling optimistic about the future. Further research distinguishing the effect of religious affiliation and religious beliefs on end-of-life despair could help to clarify these relations.

Our results have important implications for care of terminally-ill individuals because they show the importance of spiritual well-being in keeping psychological distress of patients who are facing death to a minimum. What is less clear, however, is whether interventions exist that can help raise a terminally-ill individual's sense of spiritual well-being. Mental-health and pastoral-care interventions can target spiritual well-being, although the effect of these has rarely been systematically studied. For example, several mental-health treatment approaches have been developed that specifically target spiritual well-being, although evidence of their efficacy is still limited. One such intervention was developed by Greenstein and Breitbart, who based their approach on the writings of Victor Frankl.<sup>27</sup> Their meaning-centered group psychotherapy is aimed at instilling a sense of meaning in patients with advanced cancer, focusing largely on existential concerns. Although promising, such interventions need further study to



establish whether different approaches are better suited than others to specific populations.

This study has several important limitations. Foremost of these pertains to measurement of (and the idea of) spiritual well-being. We used the FACIT-SWB scale, which measures the extent to which one finds support through spirituality rather than measuring spirituality itself. Thus, a highly spiritual individual who has been unable to successfully find strength or support through their beliefs might seem—on this scale—to be low in spiritual well-being. Because this scale essentially confounds spirituality and psychological well-being, one would expect a considerable overlap between depression and spiritual well-being (and indeed, these scales were highly correlated). However, the possible confounding of depression and spiritual well-being would probably handicap our analyses because both variables were judged as independent predictors. Thus, the observation that spiritual well-being provides a unique contribution beyond the effect of depression suggests that this scale taps a unique aspect of psychological functioning and is not simply a proxy for depression. Nevertheless, further research with a measure of spirituality rather than spiritual well-being could help to clarify some of these important issues.

Another possible limitation pertains to the cross-sectional nature of these data. Without assessment of end-of-life despair over time, we cannot establish whether spiritual well-being actually affects end-of-life despair or is merely associated—ie, one might deem absence of spiritual well-being simply another aspect of end-of-life despair. Likewise, the measures of end-of-life despair are not without limitation. For example, the BHS, although widely used in end-of-life research, is probably more accurately described as measuring a pessimistic cognitive style rather than hopelessness per se. Nevertheless, growing data lend support to the validity of this scale as a measure of end-of-life despair, because it has been a frequent correlate of desire for hastened death, suicidal ideation, and interest in doctor-assisted suicide.<sup>10,15,27</sup>

Was our sample representative enough to allow our findings to be relevant to other populations? Patients were drawn from a Catholic hospital (50% endorsed Catholicism as their religious affiliation) and a high proportion of participants were white, all of whom had terminal cancer. The relation between spirituality and psychological well-being could differ between patients of different ethnic or religious backgrounds, or become stronger as the illness progresses. Further research expanding these findings in other settings, with different populations, will help to clarify these important issues.

Our findings have important implications for palliative-care practice. Addressing spiritual needs and existential questions among the dying is generally neglected in palliative-care practice, but could be a crucial aspect of psychological functioning.<sup>1</sup> Mental-health care for the terminally ill would probably benefit from a more thorough incorporation of pastoral-care principals and practices. Our findings show the importance of an interdisciplinary approach to palliative care.

#### Contributors

All authors designed the study and wrote the report. C McClain gathered data and, with B Rosenfeld, did the statistical analysis.

#### Conflict of interest statement

None declared.

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