

Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients With Cancer

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UNDERSTANDING WHY SOME PATIENTS with a terminal illness seek to hasten their death remains an important element in both the physician-assisted suicide debate as well as the practice of palliative care.¹⁻³ Conflicting findings regarding the importance of factors such as pain, depression, and physical functioning have fueled debates regarding how best to respond to patient expressions of a desire to die.^{4,5}

Unfortunately, the growing literature on interest in physician-assisted suicide has been plagued by methodological shortcomings that limit the conclusiveness of published findings.⁶ In response to methodological concerns, researchers have identified the concept of "desire for hastened death" as a unifying construct underlying requests for assisted suicide, euthanasia, and suicidal thoughts in general.⁷⁻⁹ Studying desire for death may be preferable to studying requests for assisted suicide because the latter are influenced by legal and social constraints as well as desire for hastened death. Studying factors

Context Understanding why some terminally ill patients desire a hastened death has become an important issue in palliative care and the debate regarding legalization of assisted suicide.

Objectives To assess the prevalence of desire for hastened death among terminally ill cancer patients and to identify factors corresponding to desire for hastened death.

Design Prospective survey conducted in a 200-bed palliative care hospital in New York, NY.

Patients Ninety-two terminally ill cancer patients (60% female; 70% white; mean age, 65.9 years) admitted between June 1998 and January 1999 for end-of-life care who passed a cognitive screening test and provided sufficient data to permit analysis.

Main Outcome Measure Scores on the Schedule of Attitudes Toward Hastened Death (SAHD), a self-report measure assessing desire for hastened death among individuals with life-threatening medical illness.

Results Sixteen patients (17%) were classified as having a high desire for hastened death based on the SAHD and 15 (16%) of 89 patients met criteria for a current major depressive episode. Desire for hastened death was significantly associated with a clinical diagnosis of depression ($P = .001$) as well as with measures of depressive symptom severity ($P < .001$) and hopelessness ($P < .001$). In multivariate analyses, depression ($P = .003$) and hopelessness ($P < .001$) provided independent and unique contributions to the prediction of desire for hastened death, while social support ($P = .05$) and physical functioning ($P = .02$) added significant but smaller contributions.

Conclusions Desire for hastened death among terminally ill cancer patients is not uncommon. Depression and hopelessness are the strongest predictors of desire for hastened death in this population and provide independent and unique contributions. Interventions addressing depression, hopelessness, and social support appear to be important aspects of adequate palliative care, particularly as it relates to desire for hastened death.

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associated with desire for hastened death enables researchers to explore issues central to end-of-life care in a broad spectrum of terminally ill individuals rather than the minority who request assisted suicide.

Recently, researchers have developed scales designed to assess the construct of desire for hastened death.⁸⁻¹⁰ Chochinov et al⁸ developed the first such scale, a clinician-rated single-item scale, the Desire for Death Rating

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Table 1. Subject Characteristics

| Characteristic | No. (%) |
|-----------------------------|---------|
| Sex | |
| Male | 37 (40) |
| Female | 55 (60) |
| Age, y | |
| ≤50 | 18 (20) |
| 51-65 | 21 (24) |
| 66-75 | 24 (27) |
| 76-85 | 18 (20) |
| >85 | 8 (9) |
| Education | |
| Less than high school | 22 (24) |
| High school/GED* | 31 (34) |
| More than high school | 39 (42) |
| Marital status | |
| Single | 26 (29) |
| Married/cohabiting | 26 (28) |
| Separated/divorced | 29 (32) |
| Widowed | 10 (11) |
| Race | |
| White | 64 (70) |
| African American | 19 (21) |
| Hispanic | 8 (9) |
| Religion | |
| Catholic | 46 (52) |
| Protestant | 16 (18) |
| Jewish | 14 (16) |
| Other | 12 (13) |
| Prior psychiatric treatment | |
| Yes | 28 (32) |
| No | 60 (68) |
| Prior suicide attempt | |
| Yes | 4 (5) |
| No | 82 (95) |

*GED indicates General Educational Development certificate.

Scale. More recently, Rosenfeld et al^{9,10} published a 20-item self-report measure of desire for hastened death for use with medically ill patients, the Schedule of Attitudes Toward Hastened Death (SAHD). Both of these measures assess the extent to which medically ill individuals desire a more rapid death than would occur naturally. In our study, we used the SAHD to assess the factors influencing desire for hastened death among hospitalized, terminally ill cancer patients. The purpose of this investigation was to explore the relationships between desire for hastened death and depression, hopelessness, social support, and physical symptoms to improve end-of-life care.

METHODS

Patients

Patients were recruited after admission to a 200-bed palliative care hospital in New York City between June 1, 1998, and January 31, 1999. Patients had a life expectancy of less than

6 months and the average time until death was 28 days. Patients were eligible for study participation if they spoke English, were sufficiently cognitively intact to provide informed consent and valid data, and were not considered likely (by their physician) to suffer psychological harm from participation. Patients approached for participation represented 22% of the total patients admitted during the study period (most patients admitted were too cognitively impaired or ill to participate in research). Prior to participation, all patients were informed of the nature, risks, and benefits of study participation and consented to participate. The study was approved by the Calvary Hospital institutional review board.

Of 154 patients offered participation, 122 consented (79%; most patients who refused cited physical discomfort and/or fatigue as the reason). An additional 22 patients were excluded because their Mini-Mental State Examination score¹¹ was below 20, resulting in a sample of 100 patients who met inclusion and exclusion criteria. Only 92 of these 100 patients provided sufficient data to permit data analysis (80 subjects completed the entire battery). Eight patients were unable to complete the study because of physical deterioration or death; 3 patients withdrew because of psychological distress, and 7 withdrew for other reasons (eg, increased confusion, family member request). The data presented herein are based on the 92 patients who provided sufficient data to permit most statistical analyses.

The sample included 55 women and 37 men (TABLE 1), with an average age of 65.9 years (SD=15.6) and an average of 12.7 years of education (SD=3.7). Most patients were white (70%); 21% were African American, and 9% were Hispanic. The demographic composition of the sample was roughly comparable to the overall composition of patients hospitalized during the study period (female, 54%; average age, 70.2 years; white, 60%; African American, 24%; Hispanic, 13%; and other, 2%). Fifty-two percent of the sample was

Catholic, with 18% Protestant, 16% Jewish, and 13% other (or no) religious affiliation. Seventy-eight percent of the sample (63 of 81, data were missing for 11 subjects) reported pain during the preceding 2 weeks; the average pain intensity (based on a 0-10 rating scale) for these patients was 4.3 (SD=2.1), reflecting mild to moderate pain. At the time of study participation, 37 (40%) of 92 were prescribed antidepressants, although these medications were occasionally prescribed for pain.

Procedures

Participants who consented to participate and scored 20 or higher on the Mini-Mental State Examination were administered several clinician-rated and self-report measures (because of potential fatigue or vision problems, all questionnaires were read to participants). Most evaluations were completed in a single interview, although testing was occasionally divided into 2 sessions conducted over the next few days (incomplete data were retained whenever possible, providing patients had completed the SAHD and most of the relevant measures; because the order of administration was varied, missing data are not likely to be systematically biased).

The measures administered included the following: the SAHD,^{9,10} the Structured Clinical Interview for DSM-IV [Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition] (SCID),¹² the Hamilton Depression Rating Scale (HDRS),¹³ the Beck Hopelessness Scale (BHS),¹⁴ the Duke-University of North Carolina Functional Social Support Questionnaire (FSSQ),¹⁵ the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale,¹⁶ the Brief Pain Inventory,¹⁷ the Memorial Symptom Assessment Scale,¹⁸ the Karnofsky Performance Rating Scale (KPRS),¹⁹ and an abbreviated version of the McGill Quality of Life Questionnaire.²⁰ Assessments were conducted jointly by 2 investigators to establish reliability. Demographic and medical data were elicited from subjects and hospital charts. Patients diagnosed with major depression (based on SCID interviews) were referred to the

institution's psychiatrist for further evaluation and treatment.

Statistical Analysis

Because the distribution of SAHD scores was skewed, nonparametric statistics were used for most analyses. Spearman correlation coefficients were used to quantify the association between SAHD scores and independent variables (eg, HDRS, BHS), and Kruskal-Wallis tests were used to assess whether SAHD scores differed across sex, race, and other categorical variables. Interrater reliability was assessed using intraclass correlation coefficients for the HDRS and KPRS and κ coefficients for SCID diagnosis. The reliability coefficients were as follows: HDRS, 0.80; KPRS, 0.76; and SCID, 0.55.

RESULTS

Prevalence of Depression and Desire for Death

Based on SCID interviews, 15 (17%) of 89 patients met DSM-IV criteria for a major depressive episode (SCID interviews could not be completed for 3 subjects). The average HDRS score for this sample was 10.8 (SD=6.4; range, 0-27), indicating moderate depressive symptoms. The average number of items endorsed on the BHS was 8.5 (SD=6.4; range, 0-20), indicating a moderately high level of pessimism. Interestingly, patients who met the criteria for a diagnosis of major depression (based on SCID interviews) did not differ from nondepressed patients on the BHS (10.3 vs 8.2, $t=1.6$, $P=.12$). Further, depression and hopelessness scores (HDRS and BHS, respectively) were only moderately, although significantly, correlated ($r=0.29$, $P<.008$).

The average total score on the SAHD for this sample of terminally ill cancer patients was 4.76 (SD=4.3; range, 0-16; maximum possible range, 0-20). As expected, the distribution of SAHD total scores was positively skewed, with more than 55% (51 of 92) endorsing 3 or fewer items. Based on prior SAHD validation studies, we used a cutoff score of 10 to identify patients with a "high" desire for hastened death. Using this

cutoff, 16 (17%) of 92 patients studied indicated a high desire for hastened death.

Desire for Hastened Death, Depression, and Hopelessness

A SCID diagnosis of depression was significantly associated with desire for hastened death ($\chi^2_1=11.44$, $P=.001$). Of 15 patients who met criteria for a major depressive episode, 7 (47%) were classified as having a high desire for hastened death and 8 (53%) were not. Conversely, among the 74 patients who were not depressed, 9 (12%) had a high desire for hastened death while 65 (88%) did not. Thus, patients with a major depression were 4 times more likely to have high desire for hastened death (47% vs 12%). Likewise, mean SAHD scores for patients with a major depression were 8.9 (SD=5.4) compared with 3.9 (SD=3.6) for nondepressed patients (Kruskal-Wallis $\chi^2_1=11.17$, $P<.001$). Patients classified as having a high desire for hastened death also obtained significantly higher scores on the HDRS than patients with low desire for hastened death (16.7 vs 9.6, $t_{85}=4.20$, $P<.001$) and endorsed significantly more items on the BHS (13.6 vs 7.5, $t_{84}=5.58$, $P<.001$). There was a significant correlation between SAHD total scores and scores on both the HDRS and BHS ($r=0.49$, $P<.001$ and $r=0.54$, $P<.001$, respectively), with more depressed and hopeless patients endorsing more SAHD items.

Finally, using a 2-way analysis of variance we examined the role of hopelessness, in addition to depression, in predicting a desire for hastened death. Patients who endorsed more than 8 items on the BHS were classified as "hopeless" and compared with patients who endorsed 8 or fewer items. This analysis, which accounted for 37% of the variance in SAHD scores, revealed significant main effects for both depression and hopelessness ($F=9.33$, $P=.003$ and $F=15.16$, $P<.001$, respectively), but no interaction effect ($F=0.07$, $P=.96$). This analysis indicates that both depression and hopelessness provide independent contributions to predicting desire for hastened death. TABLE 2 displays the rela-

Table 2. Relationships Among Depression, Hopelessness, and Desire for Hastened Death*

| | Hopeless† | |
|---|-------------|------------|
| | Yes | No |
| Patients with high desire for hastened death, No./total (%) | | |
| Major depressive episode | 5/8 (62.5) | 2/7 (28.6) |
| No major depressive episode | 9/33 (27.3) | 0/41 (0) |
| Mean SAHD scores‡ | | |
| Major depressive episode | 10.88 | 6.71 |
| No major depressive episode | 5.93 | 2.32 |

*Major depressive episode based on data from Structured Clinical Interview of DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition).¹²
 †Patients who endorsed more than 8 items on the Beck Hopelessness Scale.¹⁴
 ‡SAHD indicates Schedule of Attitudes Toward Hastened Death (scale range, 0-20).^{8,9}

tionships among depression, hopelessness, and desire for hastened death, demonstrating that patients with neither depression (based on the SCID) nor hopelessness had low levels of desire for hastened death. The presence of either of these factors increased desire for hastened death somewhat, while the presence of both depression and hopelessness increased desire for hastened death considerably.

Additional Factors Influencing Desire for Hastened Death

A stepwise multiple regression analysis was conducted to identify the strongest predictors of desire for hastened death. This analysis resulted in a significant model that accounted for more than 51% of the variance in SAHD scores ($F=18.79$, $P<.001$). The variables remaining in this model were hopelessness (partial $F=29.77$, $P<.001$) and depression (partial $F=13.94$, $P<.001$), as well as overall physical functioning (KPRS: partial $F=5.77$, $P=.02$) and social support (FSSQ: partial $F=4.35$, $P=.05$). With these 4 variables included in the model, no other clinical or demographic variables contributed significantly to the prediction of SAHD scores. Of note, these findings were comparable when data

Table 3. Correlates of Desire for Death (Schedule of Attitudes Toward Hastened Death Total Scores)*

| Variable | All Subjects (N = 92) | | Nondepressed Subjects (n = 74) | |
|---|--------------------------|---------|--------------------------------------|---------|
| | | P Value | | P Value |
| Age | .20 | .06 | .14 | .23 |
| Sex | -.10 | .34 | -.06 | .59 |
| Race (white/nonwhite) | -.30 | .004 | .30 | .009 |
| Years of education | -.02 | .83 | -.09 | .44 |
| Hamilton Depression Rating Scale | .49 | <.001 | .40 | <.001 |
| Beck Hopelessness Scale | .54 | <.001 | .46 | <.001 |
| Spiritual Well-being Scale (FACIT) | -.42 | <.001 | -.35 | .004 |
| McGill Quality of Life Questionnaire | -.36 | .001 | -.25 | .04 |
| Social support (Duke-UNC FSSQ) | -.06 | .64 | -.06 | .65 |
| Number of physical symptoms (MSAS) | .38 | <.001 | .32 | .006 |
| MSAS Global Distress Index | .38 | <.001 | .27 | .03 |
| Pain (present/absent) | .04 | .75 | .06 | .65 |
| BPI pain intensity "on average" | .16 | .20 | .16 | .28 |
| BPI Pain-related Functional Impairment subscale | .31 | .02 | .26 | .07 |
| Karnofsky Performance Rating Scale | -.23 | .04 | -.16 | .18 |
| Mini-Mental State Examination | .12 | .25 | .13 | .29 |
| Concerned regarding becoming a burden in the future | -.16 | .20 | -.15 | .25 |
| Concerned about being a burden now | -.25 | .04 | -.08 | .57 |

*FACIT indicates Functional Assessment of Chronic Illness Therapy; Duke-UNC FSSQ, Duke-University of North Carolina Functional Social Support Questionnaire; MSAS, Memorial Symptom Assessment Scale; and BPI, Brief Pain Inventory. Data are Spearman *r*.

were analyzed only for the subset of patients who reported pain.

The univariate correlations between SAHD scores and the independent variables studied are reported in TABLE 3. Of the demographic variables measured, only race was significantly associated with desire for death (whites endorsed significantly more SAHD items than nonwhites, 5.5 vs 3.1, Kruskal-Wallis $\chi^2=8.03$, $P=.004$). The strongest correlates of desire for hastened death were measures of spiritual well-being and quality of life (both negatively correlated with SAHD scores) and the perception of being a burden to others, physical symptoms, and symptom distress (all of which were positively correlated with SAHD scores). There was no significant association between desire for hastened death and pain (Kruskal-Wallis $\chi^2=0.11$, $P=.75$) or pain intensity "on average" for patients who reported pain ($r=0.16$, $P=.20$), nor with perceived quality of social support ($r=-0.06$, $P=.64$). Of note, there were few differences when these correlations were recalculated for only those patients

who did not meet the criteria for a major depressive episode (Table 3).

COMMENT

In a sample of terminally ill cancer patients receiving aggressive, inpatient palliative care, we found substantial rates of clinical depression (17%) and desire for hastened death (17%). Depressed patients were 4 times more likely to have high desire for hastened death compared with nondepressed patients (47% vs 12%). Hopelessness (characterized as a pessimistic cognitive style rather than an assessment of one's poor prognosis) also appears to be an integral determinant of desire for hastened death. We found that both depression and hopelessness provided independent contributions to predicting desire for hastened death. Among patients who were neither depressed nor hopeless, none had high desire for hastened death, whereas approximately one fourth of the patients with either one of these factors had high desire for hastened death, and nearly two thirds of patients with

both depression and hopelessness had high desire for hastened death.

We also found a number of social, physical, and psychological variables associated with desire for hastened death, including spiritual well-being, quality of life, physical symptoms, symptom distress, physical functioning, and perception of oneself as a burden to others. However, we found no significant association between desire for hastened death and either the presence of pain or pain intensity. This finding may reflect the quality of pain management practiced by the study institution (average pain intensity was <5, corresponding to relatively good physical functioning and quality of life).²¹ Alternatively, these results may simply confirm previous research that found little or no relationship between pain and desire for hastened death or interest in assisted suicide.^{8,22,23}

Our finding, that both depression and hopelessness provide independent contributions to desire for hastened death, is perhaps the most novel and clinically relevant contribution of these data. Chochinov et al⁸ found a strong association between desire for hastened death and clinical depression in terminally ill patients with cancer (58% of their patients with high desire for hastened death were diagnosed with a major depression compared with 44% in our sample), but that study did not include a measure of hopelessness. In a subsequent analysis, Chochinov and colleagues²⁴ found significant associations between depression, hopelessness, and suicidal ideation (rather than desire for death), concluding that "the correlation of depression with suicidal ideation is based largely on variance that it shares with hopelessness." Ganzini et al²⁵ found that hopelessness was significantly associated with "interest in physician assisted suicide" among patients with amyotrophic lateral sclerosis while depression was not, but this study used responses to hypothetical questions regarding interest in assisted suicide rather than a measure of desire for hastened death and used a measure of depression that did not generate a clinical diagnosis.

Disentangling the constructs of depression and hopelessness is particularly difficult in the context of terminal illnesses. Because terminal illness is by definition incurable, many individuals might confuse a "hopeless" prognosis with a "hopeless" cognitive style. Our experience and these data suggest that patients often maintain hope during the final weeks of life, although what they hope for may evolve as death nears. Indeed, less than half of our sample endorsed a large number of items on the BHS, a measure of pessimism. Further, because hopelessness can be a symptom of depression, these 2 constructs are often assumed to be more overlapping than may be justified. We found only a modest correlation between these 2 measures ($r=0.29$), indicating that depression and hopelessness are distinct constructs.

The data and conclusions described here are tempered by methodological limitations. First, although we measured desire for hastened death, we cannot determine which, if any, of these patients would have requested assisted suicide if this option were legal. A related

concern is whether the SAHD can differentiate individuals who have "accepted" death from those who desire a hastened death. While some SAHD items might be endorsed by those who accept their death yet do not want to hasten death, most items assess interest in hastening death. By analyzing these data using a cutoff score to reflect a high desire for hastened death, the likelihood of confusing "acceptance" of death with desire for hastened death is thereby minimized. Another methodological issue concerns the generalizability of our findings, as our sample was recruited from a state-of-the-art palliative care facility. This sample represents an ethnically and economically diverse group that is likely representative of terminally ill cancer patients receiving high-quality palliative care. It is possible that the prevalence of desire for hastened death and depression would be even greater in patients receiving less adequate palliative care.

Because depression and hopelessness are not identical, clinical interventions may need to target these issues selectively. There is a general consensus

that individuals with a major depression can be effectively treated, even in the context of terminal illness, but no research has addressed whether such treatment influences desire for hastened death.²⁶⁻²⁸ A more challenging question is how to address hopelessness, in the absence of depressive illness, among terminally ill patients. Interventions to address hopelessness have not been systematically studied and represent an important new frontier in palliative care. Psychotherapeutic interventions such as cognitive behavioral therapy targeting pessimistic cognitions or spirituality-based interventions to address existential issues such as a loss of meaning may help decrease hopelessness.²⁷⁻²⁹ Further research regarding the impact of treatments for depression and/or hopelessness on desire for hastened death is needed to formulate appropriate clinical responses to patients who express a desire for hastened death.

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