

Original Research Reports

Understanding the Will to Live in Patients Nearing Death

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This study examined concurrent influences on the will to live in 189 patients with end-stage cancer. The authors found significant correlations between the will to live and existential, psychological, social, and, to a lesser degree, physical sources of distress. Existential variables proved to have the most influence, with hopelessness, burden to others, and dignity entering into the final model. Health care providers must learn to appreciate the importance of existential issues and their ability to influence the will to live among patients nearing death.

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How can we understand the various things that help support or, in some instances, undermine a patient's wish to go on living in the face of a progressing terminal illness? Prior studies have shown that psychiatric issues influence the dynamics of how patients move to and from a wish to go on living toward the end of life.¹ As a case in point, the association between a desire for death and depression has been well established.² Other sources of physical symptom distress, such as uncontrollable pain or shortness of breath, have also been found in some studies to hold considerable sway.^{3,4}

More recently, some investigators have started to report on the more ephemeral and largely existential issues that bear consideration in these matters. For instance, feeling a burden to others or a sense of losing dignity, meaning, and purpose have each been shown to have an important influence on a dying patient's outlook and the wish to go on living.^{5,6} In the present study, we attempted to concurrently examine a broad range of these diverse variables, including psychiatric, physical, social, and existential influences on the will to live in a cohort of patients with end-stage cancer.

METHOD

Patients recruited to this study represent part of a broader research initiative examining a range of psychosocial end-

of-life care issues.⁶ They were recruited from two palliative care units in Winnipeg, Manitoba, Canada. These units provide inpatient care and coordinate community-based end-of-life care services. A consecutive sample of consenting cancer patients meeting the inclusion criteria was recruited over 36 months. Eligibility criteria included the following: age of at least 18 years, a terminal cancer diagnosis with a life expectancy of less than 6 months, ability to read and speak English, no evidence of dementia or delirium that might make it difficult to complete the protocol, and ability to provide written acknowledgement of informed consent. The Faculty of Medicine Ethics Committee of the University of Manitoba approved the study, and the hospital research review board granted formal access to the patients.

Patients were asked to provide information on various standard measures to rate their end-of-life experiences. Each patient's sense of symptom distress was measured

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with the Symptom Distress Scale, a 13-item scale designed for use with cancer patients.⁷ The scale measures the degree of distress associated with the following areas: nausea, appetite, insomnia, pain, fatigue, bowel pattern, concentration, appearance, breathing, coughing, and depression. Pain was further evaluated with the McGill Pain Questionnaire.⁸

The Index of Independence in Activities of Daily Living⁹ was used to measure functional dependency in areas including bathing, dressing, toileting, continence, transferring, and feeding. A brief global quality-of-life measure was obtained with the Quality of Life Scale rating the quality of the patient's life and a second question rating the patient's satisfaction with his or her current quality of life.¹⁰ Each patient also completed a brief battery of self-report measures to provide a further assessment of his or her emotional state. This included a single-item screening measure for desire for death² and visual analogue scales addressing anxiety, hopelessness, the will to live,¹ and the burden to others.

RESULTS

Of the 369 patients who were identified as candidates for participation in the study, five died before the interview could take place, 13 patients were transferred to a different care setting before their interview, and one patient denied having cancer. In addition, 55 patients experienced sufficient symptom distress and/or further deterioration in their general condition that they were unable to participate. Of the remaining 295 patients, 213 (72%) agreed to participate, with 189 providing complete data. Of these, 152 were outpatients, and 37 were inpatients; the median length of survival from the time of study entry to death was 69 days. The mean age of the participants was 69 years ($SD = 12$), and 81 (49%) were men. Primary tumor sites included the lung (29%), the gastrointestinal tract (26%), the genitourinary system (16%), the breast (15%), and the head and neck (2%); 5% had hematological malignancies. Two percent had primary brain tumors, and the remainder (5%) had miscellaneous various solid tumors.

Spearman's correlation coefficients were used to assess the relationships between the will to live and patient characteristics (see Table 1). Each of the existential issues, including desire for death ($r_s = 0.427$, $df = 187$, $p < 0.00001$), sense of dignity ($r_s = 0.207$, $df = 187$, $p = 0.003$), burden to others ($r_s = 0.259$, $df = 187$, $p = 0.0002$), and hopelessness ($r_s = 0.394$, $df = 187$, $p < 0.00001$), were found to correlate significantly with the

will to live. Psychiatric issues, such as depression ($r_s = 0.329$, $df = 187$, $p < 0.00001$), anxiety ($r_s = 0.226$, $df = 187$, $p = 0.001$), and concentration ($r_s = 0.194$, $df = 187$, $p = 0.005$), were also found to be strongly associated with the will to live. The physical issues did not show the same consistent degree of correlation, with dyspnea ($r_s = 0.239$, $df = 187$, $p = 0.001$), appetite ($r_s = 0.143$, $df = 187$, $p < 0.04$), and appearance ($r_s = 0.138$, $df = 187$, $p < 0.05$) showing the strongest associations. Finally, all of the social variables (support and satisfaction with support from family, friends, and health care providers) ($r_s = 0.289$ to 0.394 , $df = 187$, all $p < 0.0001$) and quality-of-life measures ($r_s = 0.210$, $df = 187$, $p = 0.002$) were shown to correlate significantly with the will to live.

The relationship between the will to live and patient characteristics was further examined with a forward stepwise multiple regression modeling approach, with the alpha for model entry set to the standard 0.05 level of significance. In order of entry, our model included hopelessness ($t = -3.37$, $df = 1, 185$, $p = 0.001$), burden to others ($t = -2.91$, $df = 1, 185$, $p = 0.004$), and dignity ($t = -2.32$, $df = 1, 185$, $p < 0.03$); the final model was highly significant ($F = 14.90$, $df = 3, 185$, $p < 0.00001$).

DISCUSSION

Prior studies on the issue of the will to live in the terminally ill have shown it to be a measurable, albeit fluctuant, construct.¹ Its sources of variance have been traced to key variables, such as depression, anxiety, and physical symptom distress, particularly dyspnea. Unlike this study, however, prior reports have not attempted to unravel the will to live by concurrently examining a diverse range of physical, psychiatric, social, and existential domains of influence.

The univariate analysis confirms that existential, psychiatric, social, and, to a lesser degree, physical variables are highly correlated with the will to live. The prominence of psychiatric issues within this discussion has been well established.¹⁻⁴ Depression, which can color existential despair, is much more likely to be found among terminally ill patients endorsing a strong desire for death.² Therefore, it remains imperative that clinicians identify and treat syndromal depression in order to decrease suffering and improve the quality of life for patients nearing death. While the secondary role of physical variables may seem surprising, it is consistent with prior reports.^{1,2,11,12} For example, studies on the desire for death and interest in physician-

assisted suicide have found depression and not pain to be most predictive of group identification.^{2,11}

Hopelessness, the first variable to enter the model, is highly predictive of suicidal ideation in this patient population.^{11,12} The construct of hope among the dying connotes having a sense of meaning and purpose.^{13,14} It would appear that losing one's sense of meaning and purpose—experiencing life as having become redundant or futile—is an important existential underpinning of the loss of will to live among the dying. The second variable to enter the model, burden to others, has been reported in several studies examining the issue of physician-assisted suicide.^{3,4} For example, patients availing themselves of the Death with Dignity Act in the state of Oregon often report a sense of burden to others and an inability to accept the various dependencies that accompany a life-limiting illness.¹⁵ Finally, dignity, the third model variable, has been shown to be a complex construct, with various dimensions and layers of

meaning.^{6,13,14} Like burden to others, dignity has frequently been invoked in death-hastening discussions. It has been shown to correlate with appearance or the perception of how one perceives oneself to be seen. No one wants to be viewed merely as the embodiment of a disease process, suggesting that health providers have an important dual role of acknowledging illness as well as whole persons. The inclusion of dignity in the model would suggest that losing one's sense of essence or personhood or sensing that these qualities are no longer valued or appreciated could undermine the will to live toward the end of life.

It is difficult to disentangle various sources of suffering, such as depression, hopelessness, despair, pain, or even the effects of social isolation, in the context of end-of-life care. The process of drawing to the end of life can engender angst or demoralization, marked by a sense of meaninglessness, hopelessness, and helplessness.¹⁶ The univariate correlational analysis, however, helps to define

TABLE 1. Spearman's Correlations Between Various End-of-Life Issues and the Will to Live

| Measure | Correlation Coefficient (r_s) | df | p |
|--|-----------------------------------|-----|-------------|
| Existential issues | | | |
| Desire for death ^a | -0.427 | 187 | 0.000000004 |
| Sense of dignity | -0.207 | 187 | 0.003 |
| Burden to others | -0.259 | 187 | 0.0002 |
| Hopelessness | -0.394 | 187 | 0.000000009 |
| Psychiatric issues | | | |
| Depression | -0.329 | 187 | 0.000002 |
| Anxiety | -0.226 | 187 | 0.001 |
| Concentration | -0.194 | 187 | 0.005 |
| Outlook | -0.166 | 187 | <0.02 |
| Physical issues | | | |
| Pain (frequency) | -0.032 | 187 | 0.64 |
| Pain (severity) | -0.064 | 187 | 0.36 |
| Nausea (frequency) | -0.135 | 187 | 0.051 |
| Nausea (severity) | -0.096 | 187 | 0.17 |
| Appetite | -0.143 | 187 | <0.04 |
| Insomnia | -0.047 | 187 | 0.50 |
| Fatigue | -0.036 | 187 | 0.61 |
| Bowel functioning | 0.011 | 187 | 0.87 |
| Dyspnea | -0.230 | 187 | 0.001 |
| Independent Activities of Daily Living score | -0.020 | 187 | 0.78 |
| Appearance | -0.138 | 187 | <0.05 |
| Social issues | | | |
| Family support | 0.289 | 187 | 0.00003 |
| Family satisfaction | 0.375 | 187 | 0.00000005 |
| Friend support | 0.345 | 187 | 0.0000005 |
| Friend satisfaction | 0.362 | 187 | 0.0000001 |
| Health care provider support | 0.394 | 187 | 0.000000009 |
| Health care provider satisfaction | 0.392 | 187 | 0.00000001 |
| Quality of life | | | |
| Satisfaction | 0.210 | 187 | 0.002 |
| Rating | 0.212 | 187 | 0.002 |

^aBecause of its conceptual overlap with the will to live, this variable was not included in the regression analysis.

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the strength of individual relationships between the will to live and each of the range of influences considered in this study. While these influences are clearly interconnected to one another in varying degrees, the multiple regression analysis permits the development of an integrated model that defines the dominant factors that affect the will to live while ensuring that confounding influences have been controlled for. The variables in the final regression model, therefore, each have a unique impact on the will to live. The regression model demonstrates that when a broad range of influences are considered concurrently, existential issues emerge most prominently.

This study has several limitations, such as its large cancer focus and the use of a psychometric battery that measured various constructs in a concise, albeit necessarily brief, fashion. As in all palliative care research, thoroughness and measurement rigor must be counterbalanced with

sensitivity to protocol burden in patients whose time and energy are limited. The prominent influence of existential issues on the will to live should in no way undermine the importance of remaining vigilant to pain management, identifying and treating depression, and bolstering the patient's support network whenever possible. However, health care professionals are prone to relegating existential issues as beyond their domain of concern or expertise.¹⁷ If we are to understand the will to live and the suffering of dying patients in all of their complexities, we simply can no longer afford to do so. This holistic approach to understanding what moves patients to and from embracing life will lead to better care for patients as they approach death.

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References

1. Chochinov HM, Tataryn D, Dudgeon D, Clinch J: Will to live in the terminally ill. *Lancet* 1999; 354:816–819
2. Chochinov HM, Wilson K, Enns M, Mowchun N, Lander S, Levitt M, Clinch J: Desire for death in the terminally ill. *Am J Psychiatry* 1995; 152:1185–1191
3. Wilson KG, Scott JF, Graham ID, Kozak JF, Chater S, Viola RA, de Faye BJ, Weaver LA, Curran D: Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide. *Arch Intern Med* 2000; 160:2454–2460
4. Meier DE, Emmons CA, Litke A, Wallenstein S, Morrison RS: Characteristics of patients requesting and receiving physician-assisted death. *Arch Intern Med* 2003; 163:1537–1542
5. McClain CS, Rosenfeld B, Breitbart W: Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet* 2003; 361:1603–1607
6. Chochinov HM, Hack T, Hassard T, Kristjanson L, McClement S, Harlos M: Dignity in the terminally ill; a cross sectional cohort study. *Lancet* 2002; 360:2026–2030
7. McCorkle R, Young K: Development of a symptom distress scale. *Cancer Nursing* 1978; 1:373–378
8. Melzack R: The McGill Pain Questionnaire: major properties and scoring methods. *Pain* 1975; 1:277–299
9. Brorsson B, Asberg KH: Katz Index of Independence in ADL: reliability and validity in short-term care. *Scand J Rehabil Med* 1984; 16:125–132
10. Graham KY, Longman AJ: Quality of life in persons with melanoma: preliminary model testing. *Cancer Nursing* 1987; 10:338–346
11. Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funesti-Esch J, Galietta M, Nelson CJ, Brescia R: Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA* 2000; 284:2907–2911
12. Chochinov HM, Wilson KG, Enns M, Lander S: Depression, hopelessness, and suicidal ideation in the terminally ill. *Psychosomatics* 1998; 39:366–370
13. Chochinov HM, Hack T, McClement S, Harlos M, Kristjanson L: Dignity in the terminally ill: an empirical model. *Soc Sci Med* 2002; 54:433–443
14. Chochinov HM: Dignity conserving care: a new model for palliative care. *JAMA* 2002; 287:2253–2260
15. Ganzini L, Dobscha SK, Heintz RT, Press N: Oregon physicians' perceptions of patients who request assisted suicide and their families. *J Palliat Med* 2003; 6:381–390
16. Kissane D: Demoralization: its impact on informed consent and medical care. *Med J Aust* 2001; 175:537–539
17. Cherny NI, Catane R: Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer: report on a survey by the European Society of Medical Oncology Taskforce on Palliative and Supportive Care. *Cancer* 2003; 98:2502–2510