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Does desire for hastened death change in terminally ill cancer patients?

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ABSTRACT

Understanding why some terminally ill patients may seek a hastened death (a construct referred to as "desire for hastened death" or DHD) is critical to understanding how to optimize quality of life during an individual's final weeks, months or even years of life. Although a number of predictor variables have emerged in past DHD research, there is a dearth of longitudinal research on how DHD changes over time and what factors might explain such changes. This study examined DHD over time in a sample of terminally ill cancer patients admitted to a palliative care hospital. A random sample of 128 patients completed the Schedule of Attitudes toward Hastened Death (SAHD) at two time points approximately 2–4 weeks apart participated. Patients were categorized into one of four trajectories based on their SAHD scores at both time points: low (low DHD at T1 and T2), rising (low DHD at T1 and high DHD at T2), falling (high DHD at T1 and low DHD at T2) and high (high DHD at T1 and T2). Among patients who were low at T1, several variables distinguished between those who developed DHD and those who did not: physical symptom distress, depression symptom severity, hopelessness, spiritual well-being, baseline DHD, and a history of mental health treatment. However, these same medical and clinical variables did not distinguish between the falling and high trajectories. Overall, there appears to be a relatively high frequency of change in DHD, even in the last weeks of life. Interventions designed to target patients who are exhibiting subthreshold DHD and feelings of hopelessness may reduce the occurrence of DHD emerging in this population.

1. Introduction

Desire for hastened death (DHD) refers to the desire for a quicker death than would occur naturally, typically in the context of a life-shortening medical illness. However, while the desire for a more rapid death may be evidence of despair or psychological distress, it could also represent a response to chronic suffering for patients diagnosed with diseases such as Amyotrophic Lateral Sclerosis (ALS), HIV/AIDS or advanced cancer (Halpin, 2012; Leeman, 2009; Rosenfeld, 2003). Over the past two decades, roughly 20 publications have examined DHD in patients with advanced or terminal illness, revealing a number of consistent findings. For example, elevated levels of depression and hopelessness, and low levels of spiritual well-being, have emerged as the strongest predictors, regardless of illness or disease status (Albert et al., 2005; Breitbart et al., 2000; Chochinov et al., 1999; O'Mahony et al., 2005; Rosenfeld et al., 2006). However, demographic variables such as age, gender, education and religiosity have not been consistently associated with DHD. Pain, social support, and sleep disturbance have also been found to predict the desire for hastened death in occasional studies, albeit with less consistency.

Very few studies, however, have examined the course of DHD over time. O'Mahony and colleagues studied 64 cancer patients at baseline and a 4-week follow up assessment (O'Mahony et al., 2005). They found a modest increase in DHD over time but DHD

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was quite low at both assessments. They found a significant association between changes in DHD and changes in depression, but a decline in pain intensity and pain-related functional interference over time were not associated with changes in desire for hastened death. Breitbart and colleagues examined the impact of treatment for depression on DHD in 42 depressed patients with advanced AIDS (Breitbart et al., 2010a). They administered the Schedule of Attitudes toward Hastened Death (SAHD; Rosenfeld et al., 1999) to patients admitted to specialized nursing facilities shortly after admission and at two follow-up assessments (one and two months later). They grouped patients into several trajectories of change, distinguishing those who showed decreases in DHD over time versus those for whom DHD increased or remained stable. Using hierarchical linear models, the strongest predictor of changes in DHD was change in level of depressive symptoms and this effect was stronger (i.e., DHD decreased more) for patients who were prescribed antidepressant medications.

Chochinov and colleagues examined a related construct, "will to live", in 168 terminally ill cancer patients using a single-item visual analogue scale to measure will to live twice daily for the duration of the patients' stay in a palliative care facility (Chochinov et al., 1999). The authors calculated maximum and median fluctuations at four time points: 12 h, 24 h, 7 days and 30 days, and used cross-sectional data to predict will to live at 6 time points (using stepwise regression models). They found that will to live was highly unstable, but identified four main predictors of will to live in the cross-sectional models: depression, anxiety, shortness of breath, and sense of well-being. However, they did not analyze predictors of changes in will to live. Albert and colleagues conducted monthly interviews with patients diagnosed with advanced ALS, finding that 10 of the 53 patients expressed the wish to die at some point and three actually took actions that reflected an attempt to hasten death (e.g., requested increased sedation and persisted in this request until it was fulfilled; Albert et al., 2005). Interestingly, those patients who acted on their DHD appeared less distressed over time and reported a greater sense of control over the disease when compared to those who expressed the wish to die but did not act on it.

Although these studies have generated a handful of important findings, the paucity of longitudinal research on DHD in terminally ill populations is striking. Hence, there is a clear need for systematic research examining how DHD changes over time. More importantly, identifying factors that might explain such changes may have important implications for the care of terminally ill patients. The present study sought to fill this void by examining DHD over time in a sample of terminally ill cancer patients admitted to a palliative care hospital.

2. Method

2.1. Participants

Participants were recruited from a palliative care hospital in New York City serving adult patients with advanced cancer and a life expectancy of 6 months or less. All participants were 21 years of age or older, English speaking, and cognitively intact enough to provide informed consent and meaningful responses to study questionnaires (based on a Mini-Mental State Exam [MMSE] score of 20 or greater; Folstein et al., 1975). During the 42 month study period, a total of 1585 individuals were admitted to this facility, 990 of whom obtained an MMSE score of 20 or greater, suggesting cognitive functioning adequate for study participation; 595 individuals could not be assessed, either because they were too ill or too sedated to participate ($n = 332$) or they refused to complete the MMSE or were unable to understand English ($n = 263$). Of the 990 individuals who met inclusion criteria, 439 (44.3%) provided written informed consent and 128 of these (29.2%) provided sufficient follow-up data to be included in the present study; the 311 remaining individuals had either died or deteriorated to the point where study participation was no longer possible (no patients voluntarily withdrew from the study). The study sample was 52.3% female ($n = 67$), had an average age of 66.0 years old (SD = 13.87, range: 30–90) and 13.3 years of education (SD = 3.1, range: 6–23 years). The most common cancer diagnoses were lung cancer ($n = 25$; 19.5%), followed by gastro-intestinal ($n = 13$; 10.2%), prostate ($n = 12$; 9.4%), and breast cancers ($n = 9$; 7.0%). The majority ($n = 87$, 68.0%) of participants were white and identified themselves as Catholic ($n = 64$, 50.4%).

2.2. Procedures

All patients admitted to the study hospital, who were alert and met inclusion criteria, were invited to participate in this study within a few days after admission. Those individuals who consented to participate were administered an extensive structured interview and completed multiple self-report measures (detailed below). Medical and demographic data were elicited from the patient's medical record and through interview. All assessments were conducted by clinical psychologists or psychology doctoral students. Because many participants had visual impairments and/or fatigue, self-report measures were typically read aloud and when necessary, assessments were divided into two or more sessions.

The original study design involved three assessment points: baseline, 2-week follow-up and 4-week follow-up, with patients exhibiting clinically significant depressive symptoms at baseline being referred to the staff psychiatrist for antidepressant treatment. However, most patients were either too ill, or deteriorated too rapidly to complete the third assessment and some required multiple, shorter sessions to complete even the second assessment (extending the time between assessments). Thus, there were insufficient data to analyze participants across three time points and, for a handful of participants, the second and third assessment were merged into a single follow-up assessment roughly three to four weeks after the first assessment. In total, 133 participants completed a second assessment within 2–4 weeks after the baseline assessment, but 5 of these participants did not complete the SAHD and therefore were not included in these analyses.

The primary dependent variable was the Schedule of Attitudes toward Hastened Death (SAHD), a 20-item self-report measure of current DHD developed for use with patients diagnosed with life threatening illnesses (Rosenfeld et al., 1999, 2000). The SAHD has been widely used in studies of DHD and has demonstrated high levels of reliability and concurrent validity in samples of patients with HIV/AIDS, cancer and ALS. Although some differences have emerged across study populations, cut-off scores of 7 and 10 have been used to distinguish "low" versus "high" desire for hastened death (Rosenfeld et al., 1999, 2000). In the present study, we utilized a cut-off of 7 or greater to designate high desire for hastened death since the higher threshold ($\geq$10) resulted in too small a sample for the planned analyses.

In addition to the SAHD, patients were also administered the depression module from the Structured Clinical Interview for DSM-IV (SCID-D; First et al., 2002) and the Hamilton Depression Rating Scale (HDRS; Hamilton, 1960), two clinician-rated measures of depressive symptoms. Additional self-report measures included the Beck Hopelessness Scale (BHS; Beck et al., 1974), the Memorial Symptom Assessment Scale (MSAS; Portenoy et al., 1994), the Anxiety subscale from the Hospital Anxiety Scale (HADS-A; Zigmond and Snaith, 1983), the Brief Pain Inventory (BPI; Cleeland and Ryan, 1994), the FACIT Spiritual Well-being Scale (SWB;