

UNIVERSITY OF CALGARY

The Desire for Hastened Death among Cancer Patients Near the End of Life:
Are Hopelessness, Depression, and Quality of Life Mediated by the Valuation of
Life Construct?

by

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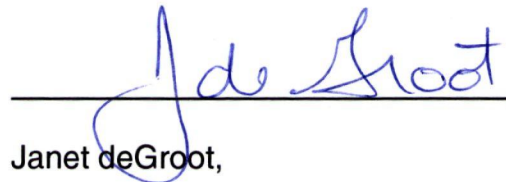
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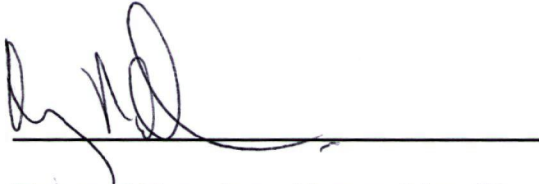
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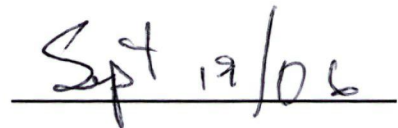
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Abstract

This study provides a test of a mediation hypothesis proposed by M.P. Lawton and colleagues (2001) which asserted that an existential construct, titled the Valuation of Life (VOL), mediates the relationship between quality of life variables and the desire for hastened death. The VOL construct is theorized to be a cognitive-affective schema through which the positive and negative aspects of life are evaluated by those who are facing serious illness to provide an overall evaluation of the total worth of life. VOL is comprised of five domains: purpose and meaning, persistence, futurity, hope, and self-efficacy. Forty-nine cancer patients receiving palliative care services completed a self-report questionnaire that assessed their levels of quality of life (FACTG), depression (BDI-SF), hopelessness (BHS), desire for hastened death, and valuation of life. Functional status (KPS) was also assessed. Results of a mediation analysis that followed the causal modeling approach outlined by Baron & Kenny (1986) and which used a bootstrap method to test the significance of the mediation effects indicated that VOL mediated the relationship between desire for death and all four predictor variables (FACTG, BDI-SF, BHS, KPS). This research highlights the pivotal role that existential constructs play in the desire for early death among those with advanced cancer. This research also stresses the need for clear definitions of existential and spiritual constructs and accentuates the value of theory-driven research in palliative care.

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Dedication

To my children, Xesca and Dominic. I love you.

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The Desire for Hastened Death among Cancer Patients Near the End of Life:
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Introduction

While it is societal values, not empirical data, that must determine the legality of physician-assisted suicide, the identification of factors that differentiate between people with terminal illness who desire prolonged life and those who wish for a hastened death has become a priority for those who work in palliative care (Batavia, 2000; Rosenfeld, 2000a & 2000b). The increased attention on end of life despair originates from a growing belief that quality palliative care involves a holistic approach that works to alleviate not only physical discomfort, but also the psychosocial, spiritual and existential distress that sometimes accompanies illness at the end of life (Chochinov, 2006). Concomitantly, there has been a dramatic increase in the interest in the role of existential factors on the well-being of those with advanced illness (Chochinov, 2006). Along with the growth of interest in existential and spiritual factors, the recent development of psychometrically sound measures that assess the desire for death among those with terminal illness (Chochinov, Wilson, Enns, Mowchun, Lander, Levitt, et al., 1995; Rosenfeld, Breitbart, Stein, Funesti-Esch, Kaim, Krivo, & Galietta, 1999) has resulted in a steady expansion of findings regarding the factors that predict a desire for shortened life. The current study attempts to add to this rapidly

growing body of knowledge by examining the premise that existential variables play a specific and pivotal role in differentiating between those who wish for longer life and those who wish for a faster death. Specifically, near the end of his career, the late American psychologist M. P. Lawton developed a concept and scale which he theorized would mediate the relationship between quality of life factors and the desire for more, or less, life among those with serious illness. This research project aims to test Lawton's valuation of life mediation model.

Valuation of Life: A Construct and Theory

In recent years, a team of Gerontologists working in the field of health-related quality of life proposed that a new construct plays a critical role in the decisions people make about whether they would prefer to live or die when faced with serious illness or disability (Lawton, 1999; Lawton, Moss, Hoffman, Grant, Ten Have, & Kleban, 1999; Lawton, Moss, Hoffman, Kleban, Ruckdeschel, & Winter, 2001). In reaction to the exclusive focus on negative life experiences (such as physical disability and pain) in the health utility literature, M.P. Lawton and colleagues (2001) argued that researchers were neglecting important aspects of the human condition. To address this issue, Lawton and colleagues (1999) proposed that positive dimensions of life contribute independently to the wish for longer life. As such, they maintained that research in health-related quality of life would have greater predictive power in assessing the desire for death versus the desire for longer life if researchers included measures of

positive mental health and positive life experiences in their studies, along with traditional measures of negative quality of life experiences.

Instead of simply identifying the need for the inclusion of measures of positive mental health and positive life experiences in health-related quality of life research, Lawton and his colleagues (1999; 2001) went further and developed a concept and scale to capture what they felt were the critical elements that play a role in the desire for more or less life. Based on the belief that judgments about desired length of life are more than a simple matter of adding up the positive aspects of life and subtracting the negative experiences of life, Lawton and colleagues (1999; 2001; Lawton, Moss, Winter, & Hoffman, 2002) proposed that a distinct psychological mechanism intervenes between health and judgments about whether or not a person wishes to live or die. They argued that this mechanism, which they called "valuation of life" (VOL), is a cognitive-affective schema that involves a complex weighting of both the positive and negative features of life. Significantly, they purported that the outcome of the weighting process of the VOL schema is expressed through a person's experience of futurity, hope, seeking of meaning and purpose, perseverance, and sense of self-efficacy. In consequence, VOL is a reflection of how someone thinks and feels about the current meaning of their life, their view of how positive and worthwhile the future is, and their sense of personal agency.

Lawton and colleagues (2001) further speculated that the mechanism underlying the VOL schema is an adaptation process on both emotional and cognitive levels whereby assimilation and accommodation occur to compensate

for distress. Assimilation is defined as a process that involves incorporating new ideas or experiences into our existing ideas and belief systems (Penguin Dictionary of Psychology, 2004). With assimilation, our belief systems do not change. Accommodation, on the other hand, involves altering our existing ideas and beliefs as a result of new information or new experiences (Penguin Dictionary of Psychology, 2004). Lawton and colleagues (2001) speculated that when VOL is positive assimilative adaptation is successful in integrating changes in personal circumstances into existing value systems and allows the individual to maintain his or her pre-existing values and belief systems. Extremely low levels of VOL, on the other hand, are argued to represent negative accommodation to the point where meaning and life itself become devalued. Although not explicitly stated by Lawton and colleagues (2001), it would appear that this devaluation of meaning and life is caused by the erosion of confidence in one's belief and value systems and of one's sense of self.

The underlying processes of valuation of life therefore reflect a dynamic balance between adapting to change and maintaining continuity of self. In essence, it assesses the degree to which people adjust their standards for what is acceptable in everyday life in accord with changes in both their personal characteristics and circumstances under which they live. The outcome measure of this process, the Valuation of Life scale, places these judgments in the context of existential domains of purpose and meaning, hope and futurity along with overall assessments of self-efficacy and persistence.

The VOL Scale

In order to operationalize the newly proposed construct, Lawton and colleagues (2001) worked to include positive aspects of mental health that reflected the active embrace of life. Five core constructs were defined as: (1) Futurity, an outlook that views the future as worth anticipating and planning for, (2) Hope, the expectation that the present and future will be positive, (3) Self-efficacy, the belief that one is competent, (4) Persistence, the view that one's efforts are worthwhile and likely to succeed, and (5) Purpose, the adoption of goals that guide one's life. Based on what Lawton and colleagues (2001) viewed as being critical features of the VOL construct the core domains were deliberately weighted unevenly: the purpose domain has the most influence on the scale followed by the persistence domain and then by futurity, hope, and self-efficacy, which are equally weighted. The VOL scale was developed in several stages, the first of which was the consideration of existing measures of positive mental health. The existing scales were rejected because they failed to represent the full range of what the VOL construct was meant to capture. Next, a pool of items, each rated on a 5-point scale ranging from 5 = *agree very strongly* to 1 = *disagree very strongly*, was generated from the existing measures and, for the most part, by the research team. In the final stages of the VOL scale development, four studies were conducted to assess the reliability and validity of the scale (Lawton et al., 2001).

In the first of four studies described in Lawton and colleagues (2001), 616 elderly volunteer participants completed the VOL questionnaire and exploratory

principal components analyses were performed to determine the number of factors represented by the scale. Based on the results from this initial study, several items were removed from the scale and a second study of 462 elderly volunteers completed the revised scale in order to conduct confirmatory factor analysis and to examine the internal consistency of the scale. Based on the findings from these studies, the final version of the VOL scale (identical to the one tested in the second study) consisted of 19-items, representing two correlated factors. The first factor represents positively worded items, while the second factor represents negatively worded items (see Appendix A).

Construct validity was built into the VOL scale by its inclusion of items representing each of the five core constructs. The pattern and strength of correlations of the VOL scale with five other measures of positive mental health provided evidence of concurrent validity: there were moderate relationships (median $r = .51$) with all the measures of positive mental health. Criterion validity was established through a prospective and hypothetical indicator that asked people whether they would or would not choose to prolong their lives under a range of health scenarios. Results supported the criterion validity of the positively worded items, but not the negatively worded items. Investigation of the cause of the discrepancy in responding between positively and negatively worded items suggested that errors in comprehension of the negatively worded scale items were the cause of the scale difficulties. These errors in comprehension were more frequent when participants had fewer years of education and poor health. Finally, the discriminant validity of the VOL scale was moderately

supported; the VOL scale was not independent of health and was significantly and moderately related to measures of depression. Importantly, however, the VOL remained significantly correlated with the criterion variable (years of desired life), when depression and health were controlled. In conclusion, evidence from research with elderly participants at varying levels of health suggest that the VOL scale has acceptable levels of validity and relates to the desire for shortened life.

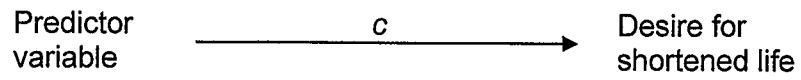
The Model

As per the rationale for the development of the VOL construct and scale outlined above, Lawton and colleagues (1999) argued that quality of life variables, background characteristics and mental health are related to years of desired life only indirectly through the VOL construct. As such, they argued that VOL mediates the relationship between internal and external quality of life factors and how long a person would prefer to live.

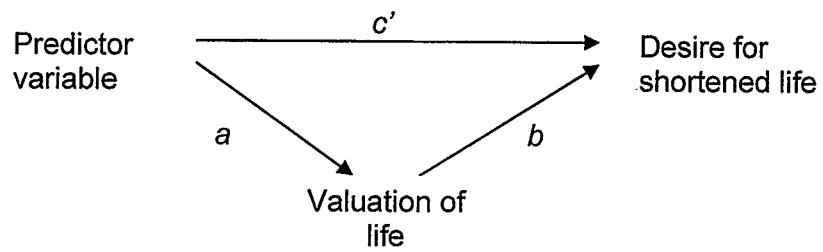
Figure 1 depicts VOL as a mediator between desire for shortened life and its predictor variables. The depicted model is a causal model, as indicated by the arrowheads. In causal models, the relationship between the variables is presumed to be one in which a change in one variable causes a change in the other variable (Baron & Kenny, 1986; Shrout & Bolger, 2002; Preacher & Hayes, 2004). As such, the mediation model first predicts that people will desire fewer years of life when there are decrements in quality of life (path c in Figure 1, Part A). This path provides evidence that there is a relationship between the predictor variable and outcome variable that can be mediated. Next, path a in the model

Figure 1. Lawton's VOL mediation hypothesis

Part A:



Part B:



When mediation occurs, the c' path in Part B is smaller than the c path in Part A.

indicates that there is a significant relationship between the predictor variable and the mediator variable (VOL). Path *b* indicates that there is a relationship between the mediator variable (VOL) and the desire for shortened life *after* taking into account the relationship of the predictor variable and the desire for shortened life. Finally, path *c'* is the relationship between the predictor variable and the outcome variable (desire for shortened life) after taking into account the role of VOL. The mediation effect is demonstrated by a reduction in the size of path *c* in Part A to path *c'* in Part B of Figure 1.

To summarize, the model described by Lawton and colleagues (1999) is a mediator model. Changes in quality of life are theorized to cause changes in VOL and VOL, in turn, is proposed to cause changes in the desire for shortened life. Moreover, the relationship between quality of life variables (predictor variables) and years of desired life (the outcome variable) is primarily indirect, through the VOL construct.

Evidence for VOL as a Mediator Variable

To date there are two research studies, both conducted by Lawton and his colleagues, that have attempted to ascertain the strength of the claim that VOL acts as a mediator variable between quality of life factors and the length of time one wishes to live. The first study (Lawton et al., 1999) examined interview data from 600 volunteer participants, aged 70 and older, across a broad range of physical health levels. The predictor variables assessed in the study included two measures of health (number of health problems and functional health), one

measure of cognitive functioning, objective quality of life (activities, friends, and family), subjective quality of life (activities, friends, family), and mental health (mastery, positive affect, and depression). The mediator variable was assessed through the 13-item positively worded VOL scale. The outcome variable was “years of desired life,” a measure that asked respondents to state how long they would like to live in each of ten hypothetical scenarios that varied in terms of functional health, location, cognitive function, and pain. Lawton and colleagues (1999) reported difficulty obtaining answers from participants on the Years of Desired Life scale with response rates on the outcome measure ranging from a low of 47% to a high of 69% across the ten scenarios.

In spite of the difficulties with the Years of Desired Life measure, results of the study supported the hypotheses predicted by the VOL model. As expected, increasing levels of disability in the hypothetical scenarios were associated with a decrease in the stated number of years of desired life. The variable most consistently associated with the outcome measure was the VOL scale; as predicted, people who had high scores on the VOL scale were more likely to desire more years of life than people with low scores on the VOL scale across all but two of the ten hypothetical scenarios. The two conditions in which VOL was not significantly related to years of desired life were the two most distasteful hypothetical scenarios (in bed in a nursing home; being permanently unconscious). Regression analyses were performed to assess whether VOL was associated independently with years of desired life and independently of the predictor variables. After controlling for the covariates and eliminating the

missing data from the analyses, VOL remained significantly and positively associated with years of desired life in eight out of the ten scenarios. Several different passes of the data were conducted in order to examine the effect of the missing data and the results of these analyses followed the same pattern as the original findings but with slightly reduced significance.

Findings from a second study conducted by Lawton and colleagues (2001) with a sample of 138 elderly volunteers mirrored the results of the first study. In the second study, in which the scale development and psychometrics were detailed, particular attention was paid to whether VOL was simply a proxy measure for positive mental health. In order to test the discriminant validity of VOL, the positive mental health scales that correlated most highly with VOL were used as control variables. Results indicated that the independent relationship of VOL to years of desired life persisted even after controlling for positive mental health.

Lawton and colleagues (1999) concluded that the VOL is a stronger predictor of how long people wish to live than are predictions that are based only on knowledge of the negative aspects of life, such as poor health and depression, or even from predictions that are based on positive aspects of mental health. Arguing that VOL gives people motivation to live longer than would be anticipated based on knowledge of quality of life factors alone, they further speculated that VOL would be expressed in the choices and decisions people make regarding life-extending treatments (Lawton, 1999; Lawton et al., 1999). Moreover, Lawton and colleagues (2001) asserted that the best criterion is one in which people at

the end of their lives are asked about their desire to prolong life or to hasten death.

The current study was designed to assess the VOL mediation hypothesis described by Lawton and his colleagues. The greatest weakness of the existing tests of the VOL mediation hypothesis has been the use of a measure of desired length of life that relied on hypothetical scenarios (i.e., If you were in situation X how long would you like to live?). The present investigation sought to address this weakness by using an outcome measure that directly assesses the desire for hastened death among those with terminal illness. In consequences, the following section details the research that has directly measured desire for death.

Desire for Hastened Death

Instead of directly assessing the desire for hastened death with psychometrically tested measures, researchers have until recently relied on hypothetical scenarios, interest in life-sustaining treatments, and poorly defined and unvalidated questions such as “interest” in physician-assisted suicide (Rosenfeld, et al., 1999; Rosenfeld, 2000b). Two groups of researchers, however, have recently developed direct measures of dying patients' desire for death and these measures have facilitated an increase in the implementation of studies using quantitative methodology.

Measures Directly Assessing the Desire for Hastened Death

A research study by Chochinov and colleagues (1995) represented the first direct assessment of the desire for death using quantitative methods. Specifically, the “desire to die” was assessed during a diagnostic interview by asking participants if they ever wished that their illness would progress more rapidly so that their suffering could be over sooner. If the patient answered in the affirmative, then follow up questions were asked so that the interviewer could rate the severity of the desire to die on a 6-point rating scale. Hence, the “Desire for Death Rating Scale” provided a global rating of the desire for death based on clinician ratings. The authors reported no data regarding the reliability or validity of the scale.

Shortly thereafter, another group of researchers developed a self-report measure that directly assessed the desire for death in palliative care patients. Rosenfeld and colleagues (1999) developed the Schedule of Attitudes toward Hastened Death (SAHD), a brief, 20-item, self-report questionnaire [see Appendix B]. Questions are answered in a true/false format and scores can range from 0 (no desire for hastened death) to 20 (high desire for hastened death). The scale development relied on item generation from panels of experts in the field of palliative care and pilot testing with 55 patients with AIDS. Initial validation of the SAHD was established in 195 patients with HIV/AIDS. Results of the study indicated that the SAHD is highly skewed, with few patients endorsing large numbers of items ($M = 3.05$; $SD = 3.80$). Internal consistency of the SAHD was high ($\alpha = .89$) and the average inter-item correlation was .53

(range .25 to .74). Predictive validity of the scale was established by demonstrating that the SAHD correlated significantly in the expected directions with measures of depression and distress. Concurrent validity was established with the Desire for Death Rating Scale ($r = .69$) developed by Chochinov and colleagues (1995). Principal components analysis indicated a single factor structure for the SAHD.

Stemming from this review of the existing measures of desire for shortened life, it is clear that reliable, validated measures do exist with which to test the VOL model. A review of the variables that have been found to relate to the desire for hastened death among those receiving palliative care follows in the section below.

Frequency of the Desire for Hastened Death

The frequency of the desire for hastened death among cancer patients who are terminally ill appears to vary depending on the stage of illness under consideration and patient nationality, but the overall rates of desire for death are relatively low. Perhaps the evidence closest to a “gold standard” regarding the prevalence of a prolonged and serious desire for hastened death comes from data gathered from the Netherlands, where physician-assisted suicide and euthanasia have been legal practices since 1984. In reviewing research from the Netherlands, Rosenfeld, Krivo, Breitbart, and Chochinov (2000) reported that 4.7% of all deaths in the Netherlands were accounted for by euthanasia or physician-assisted. According to data cited by Chochinov and colleagues (1995),

the majority of the cases in the Netherlands were patients with advanced cancer diagnoses, with between 6% and 7% of advanced cancer patients choosing either euthanasia or physician-assisted suicide.

The strongest evidence regarding the prevalence of desire for hastened death in countries like Canada, where physician-assisted suicide is not legal, comes from studies that have used rigorous measures of desire for hastened death, such as the Desire for Death Rating Scale (DDRS) and the SAHD. With a sample drawn from a palliative care hospital in Winnipeg, Canada, Chochinov and colleagues (1995) used the DDRS and reported that 44.5% of advanced stage cancer patients receiving palliative care described occasional wishes to die. This number dropped to 8.5%, however, when the cutoff score of 4 or greater on the DDRS was used to identify serious or pervasive desire for death. Interestingly, the score of 4 was used to indicate both “occasional” and “pervasive” desire for death (Chochinov et al., 1995). The score of 4 reflects that the participant has “a genuine desire for death; has discussed this desire with others, but is not consumed with the prospect.” Based on the numbers reported in the article, it is possible to calculate that 36.2% of participants are categorized as having “occasional” wishes to die when scores of 4 are included only in the “pervasive” category.

Another Canadian study (Jones, Huggins, Rydall, & Rodin, 2003) used the SAHD and identified lower rates of desire for death among 151 cancer patients with varying stage of disease: 7% reported moderate levels of desire for hastened death, while only 2% reported high levels of desire for hastened death.

They also reported lower numbers of people endorsing a desire for death than did Chochinov and colleagues (1995) when they examined only those with participants with advanced cancer (13% indicated moderate levels, 6.5% endorsed high levels) a finding that is possibly due to the use of different measures to assess the desire for death. Overall, these two studies suggest that between 6.5% and 8.5% of Canadian patients with advanced cancer endorse a high level of desire for early death with the majority of patients reporting low levels (56% using DDRS and 80.5% using SAHD) or moderate levels (36.2% with DDRS and 13% using SAHD). These findings are consistent with Sullivan's (2005) review of the literature in which he states that there is a high desire for death in between 5 and 10% of patients in palliative care settings.

Although Sullivan (2005) reports rates of high desire for death as falling between 5 and 10%, the reported frequency rates of desire for death in the studies reviewed in the current investigation suggest that the rates across nationalities and settings has a higher ceiling than reported by Sullivan. For example, Rosenfeld and colleagues (Rosenfeld, Breitbart, Galietta, Kaim, & Funesti-Esch, 2000; Breitbart, Rosenfeld, Pessin, Kaim, Funesti-Esch, Galietta, et al., 2000) used the SAHD with an American sample of terminally ill cancer patients and found that with a conservative cutoff point ($\text{SAHD} \geq 11$), 16.3% reported a high desire for death, 37% reported moderate levels ($\text{SAHD} = 4 - 10$) and 55% reported low levels ($\text{SAHD} \leq 3$) of desire for hastened death. An Australian sample of terminally ill cancer patients drawn from home care services, hospice, and an outpatient counseling service indicated their desire for

early death using a modified version of the DDRS: 59% reported no desire for early death, 27% reported a moderate desire for hastened death, and 14% reported a high desire for early death (Kelly, Burnett, Pelusi, Badger, Varghese, & Robertson, 2003). A sample of 120 terminally ill Greek cancer patients indicated 78% of participants reported a low desire for hastened death ($SAHD \leq 3$) while 8.3% indicated a “high” level and 5% indicated a “strong” desire for hastened death (Mystakidou, Parpa, Katsouda, Galanos, & Vlahos, 2005). Cut points to distinguish the high and strong groups were not provided. A retrospective study of family-reported incidence of expressed desire for death and desire for hastened death among terminally ill cancer patients indicated that 21% had expressed a desire for death and 10% had expressed a desire for hastened death (Morita, Sakaguchi, Hirai, Tsuneto, & Shima, 2004).

In summary, it appears from the current review that Canadian who are terminally ill with cancer report levels of high desire for hastened death that are consistent with those reported in other countries, albeit on the lower end of the scale. These findings lend strong support to the argument that research findings from around the world have relevance to the Canadian context. In consequence, despite variation between nationalities in frequency rates of desire for hastened death, studies from multiple nations will be included in the following review.

Predictors of the Desire for Hastened Death

Concomitant with the growth in the reliable identification of the number of patients with terminal illnesses reporting a high desire for hastened death, a body

of evidence has been developing that identifies factors associated with desire for death (Sullivan, 2005). Overall, there has been a trend demonstrating that dimensions of psychological distress are more potent predictors of desire for hastened death than are symptoms of physical suffering (Sullivan, 2005). For simplicity, the literature review has been organized into the following categories: pain, depression, hopelessness, social support, existential and / or spiritual-well being, and other quality of life factors.

Pain.

Much of the debate surrounding the legalization of physician-assisted suicide and euthanasia has focused on whether pain relief reduces the desire for death (Sullivan, 2005) and unrelieved pain has been cited as an important reason why cancer patients may seek a hastened death (Sullivan, Rapp, Fitzgibbon, & Chapman, 1997). Reviews of the literature, however, suggest that the relationship between pain and a desire for hastened death is not straightforward. In general, studies that used indirect measures of desire for hastened death and imprecise measures of pain have reported few relationships between pain and desire for death (Mishara, 1999). Studies that used more precise measures of desire for death and pain have generally found that severe pain can result in an increased desire for hastened death but they also frequently find that the relationship fails to demonstrate a unique relationship to desire for death (Rosenfeld, Krivo et al., 2000, Sullivan, 2005).

When 48 patients with painful metastatic cancer were asked about their interest in hastened death if they developed severe pain that could not be relieved, 80% reported that they would request a “do not resuscitate” order, 40%-50% would request information on physician-assisted suicide, and 34% indicated that they would request a lethal injection from their physician (Sullivan et al., 1997). Findings from this same study, however, indicated that *current* pain was not associated with interest in hastening death. In their study of 200 terminally ill cancer patients, Chochinov and colleagues (1995) used the DDRS, and the Memorial Pain Assessment Card. Findings from the study indicated that 76.5% of participants who reported a high desire for hastened death also reported moderate to severe levels of pain. In contrast, only 46.2% of participants with a low desire for death reported moderate to severe levels of pain. Interestingly, 17.6% of participants reporting no pain at all also reported having a high desire for hastened death. In regression analyses pain did not uniquely contribute to the regression model once depression had been entered into the model.

Rosenfeld, Breitbart and colleagues (2000) administered the SAHD and the Brief Pain Inventory to 92 terminally ill cancer patients. Findings from the study indicated that a high desire for hastened death was not significantly associated with either dichotomous ratings of pain (pain or no pain) or pain intensity ratings. Pain-related functional impairment, however, was significantly correlated with the SAHD ($r = .31, p = .02$). A separate analysis of the same data using regression analyses by Breitbart and colleagues (2000), however, indicated that pain ratings did not contribute uniquely to the prediction of SAHD scores.

More recent studies support and strengthen these earlier findings that the role of pain is secondary to psychological variables in the desire for death. While Mystakidou, Parpa, and colleagues (2005) reported that pain demonstrated a statistically significant relationship with hastened death, Mystakidou, Rosenfeld, Parpa, Katsouda, Tsilika, Galanos, & Vlahos (2005) report that pain and functional status were not related to the desire for hastened death after psychological variables of depression and anxiety had been accounted for. These findings are consistent with those reported by Kelly and colleagues (2003) using the DDRS who found that physical symptoms, while related to a desire for death, were not as strongly related to the outcome variable as were psychosocial factors. These results are further supported by a longitudinal study that was undertaken to assess the impact of improvements in cancer pain control on the desire for death (O'Mahoney, Goulet, Kornblith, Abbatiello, Clarke, Kless-Siegel et al, 2005). The study used measures of DDRS and the Brief Pain Inventory at two points in time, separated by a 4 week interval. Results of the study demonstrated that while there was a correlation between desire for death and pain that interfered with functional status ($r = .27, p < .05$), improvements on this pain variable were not predictive of desire for death at time 2. Finally, in a Canadian sample of those with cancer, Jones and colleagues (2003) demonstrated that pain was mediated by both hopelessness and depression: while pain had a significant direct relationship with SAHD, this relationship was non-significant when the effects of depression or hopelessness were accounted for.

In summary, while pain and suffering are frequently identified as being factors influencing the desire for hastened death (Rosenfeld et al., 1999; Sullivan et al., 1997), the relationship appears to be secondary to the influence of psychological factors.

Depression.

Reviews of the literature support strong associations between depression and a desire for hastened death across studies; studies have demonstrated that depression plays a significant role in terminally ill patients' desire for a hastened death (Lawton, 2000b; Mishara, 1999; Rosenfeld, Krivo et al., 2000). Following from their review of early work in the area, Rosenfeld, Krivo and colleagues (2000, p.58) concluded that, "while strong evidence exists that depression contributes significantly to a desire for death among terminally ill patients, the precise magnitude of this relationship is not known." For example, 58.8% of terminally ill cancer patients who reported a significant desire for death (as measured by the DDRS) were diagnosed with a major depressive episode on the Schedule for Affective Disorders and Schizophrenia (Chochinov et al., 1995). Clearly, many, but not all, terminally ill cancer patients who have an interest in hastened death also have significant depressive symptoms. Similarly, when examining a related construct, the "will to live," in 168 Canadian participants with terminal cancer diagnoses, Chochinov, Tataryn, Clinch, and Dudgeon (1999) found that depression was a major predictor of will to live in relatively early stages of the dying process. The role of depression as a predictor of will to live,

however, appeared to decrease as death drew nearer. In the last few days of life, psychological determinants were replaced by physical variables (such as pain and dyspnea) as the major predictors of will to live.

More recent studies have helped to better isolate the relationship between depression and the desire for hastened death and have demonstrated that while depression is clearly related to a desire for hastened death it has also been shown in some studies to be surpassed as a predictor variable by hopelessness, spiritual well-being, and existential variables (Sullivan, 2005). Regardless, support for depression as an important predictor of desire for hastened death in its own right continues to mount (Kelly, et al., 2003; McClain, Rosenfeld, & Brietbart, 2003; Mystakidou, Rosenfeld et al., 2005). Jones and colleagues (2003) examined a mediation hypothesis and demonstrated that depression remained a significant predictor of desire for hastened death (measured by the SAHD) after controlling for the effects of stage of disease, physical symptoms, and pain intensity. The overall pattern of findings supported the conclusion that depression partially mediates the relationship between stage of disease, physical symptoms and pain intensity. Finally, longitudinal work by O'Mahoney and colleagues (2005) demonstrated that change in depression scores from baseline was associated with change in DDRS ratings.

Hopelessness.

In studies measuring the desire for hastened death, there has been consistent evidence that hopelessness is strongly linked with increased desire for

hastened death. Analyses have revealed that hopelessness, as measured by the Beck Hopelessness Scale (BHS), is more highly correlated with desire for death than is depression and independently contributes to an increased desire for hastened death (Chochinov, Wilson, Enns, Lander, 1998; Breitbart et al., 2000; Rosenfeld, Breitbart, et al., 2000; Jones et al, 2003; Breitbart & Heller, 2003). Jones and colleagues (2003) examined a mediation hypothesis for hopelessness and demonstrated that hopelessness remained a significant predictor of desire for hastened death (measured by the SAHD) after controlling for the effects of stage of disease, physical symptoms, and pain intensity. The overall pattern of findings in Jones and colleagues' (2003) study supported the conclusion that hopelessness, like depression, partially mediates the relationship between stage of disease, physical symptoms and pain intensity. Finally, in a study assessing the validity of the BHS in palliative care populations, Abbey, Rosenfeld, Pessin, and Breitbart (2006) reported a significant and unique association between the BHS and the SAHD even after depression had been entered into the model. These results combine to suggest that hopelessness is a vitally important predictor of the desire for hastened death.

Abbey and colleagues (2006) and Breitbart and Heller (2003) have recently questioned the use of the BHS in palliative care populations. Specifically, some scale items are frequently endorsed by those in palliative care even when they otherwise do not score high on the hopelessness scale. Abbey and colleagues (2006) developed three shortened versions of the BHS by eliminating items based on item-total correlations and concluded that the

abbreviated versions were as reliable and valid as the original BHS in palliative care settings. While their assertion that the shortened versions represent an improvement over the original BHS remains to be confirmed in future research, their critique of the BHS has thrown some doubt about whether the measure assesses the construct as originally envisioned by Beck and Steer (1988). Breitbart and Heller (2003), however, note that research findings using the BHS are “rather robust” in spite of the scale’s apparent limitations.

Social support and burden to others.

Social factors have been demonstrated to relate to a desire for hastened death (Rosenfeld, Krivo, et al., 2000). In general, studies have found that as social support increases, desire for hastened death decreases, while the desire for death increases as one’s sense of being a burden to others increases (Chochinov, 2006). For example, Chochinov and colleagues’ (1995) work using the DDRS reported that family support was among the three main correlates of the desire for death. The importance of this variable was brought into question once the predictive value of family support was examined; family support did not make a unique contribution to desire for death after depression had been entered into the model. In contrast, Kelly and colleagues (2003) also used the DDRS and found that higher desire for death was associated with greater perceptions of being a burden on others, lower family cohesion, and lower levels of social support. Similarly, in a retrospective study of family-reported description of their deceased relative’s experience at the end of life, being a burden on others and

dependency were among the major reasons cited for patients expressing a desire for hastened death (Morita et al., 2004). In contrast, findings from a series of studies using the SAHD suggest that social support may play a limited role in the desire for hastened death. In studies with terminally ill cancer patients (Breitbart et al., 2000; Rosenfeld, Brietbart et al., 2000) and participants with HIV/AIDS (Rosenfeld et al., 1999), no significant zero-order relationship between social support and desire for hastened death was found. Interestingly, when conducting more detailed analysis of the data obtained from terminally ill cancer patients, Breitbart and colleagues (2000) found that social support was a significant predictor of the desire for hastened death. In conclusion, there is evidence that social support and perceptions of being a burden on one's loved ones contributes to the desire for hastened death. The strength of these findings, however, do not appear to mark social support or burden as being as significant in predicting desire for hastened death as are depression and hopelessness.

Existential and / or spiritual well-being.

Since this study was originally proposed there has been an expansion in research assessing the role of spirituality and existential factors in the desire for hastened death and end of life distress (Chochinov, 2006, Breitbart & Heller, 2003). The literature on existential and spiritual variables at the end of life reveals that the two constructs are conceptually overlapped and often used interchangeably, although it would appear from recent reviews (Breitbart, Gibson, Poppito, & Berg., 2004; Chochinov & Cann, 2005) that "spirituality" is the

dominant term. For example, the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-sp), a commonly used measure of existential and spiritual well-being, is comprised of two subscales; one that measures faith and one that measures meaning and peace / contentment (Brady, Peterman, Fitchett, Mo, & Cella, 1999). In a recent review article Chochinov and Cann (2005) cite evidence of 92 definitions of spirituality and acknowledge the difficulty in defining the term. Bergman (2004, p. 157) posits that the term spirituality is an “incredibly popular term” that is vague and has expanded in recent years to encompass the constructs of both faith and the existential domain. Bergman’s (2004) assertion certainly has credence given that the most common definitions of spirituality suggest that there is a faith component, which is often associated with religion, and there is a meaning component, which is associated with finding meaning in life (Chochinov & Cann, 2005).

Despite the conceptual overlap between terms, studies investigating the role of spiritual and / or existential variables have demonstrated that spirituality and existential factors are not only significant correlates of the desire for hastened death; they are beginning to demonstrate that existential and spiritual factors may have greater influence on the desire for death than do other predictors, including hopelessness. For example, in Canadian study of 189 cancer patients with terminal illness, Chochinov, Hack, Hassard, Kristjanson, McClement, and Harlos (2005b) reported that existential variables had more influence on will to live than did hopelessness, burden to others, and dignity. In their longitudinal study, O’Mahoney and colleagues (2005) reported a significant

zero-order correlations between spiritual well-being and desire for death ($r = -.38$) while Rosenfeld, Breitbart and colleagues (2000) reported similar findings ($r = -.42$) using the same measure of spiritual well-being (the FACIT-sp) but different outcome measures: O'Mahoney and colleagues (2005) used the DDRS while Rosenfeld, Breitbart and colleagues (2000) used the SAHD.

McClain, Rosenfeld, & Breitbart (2003) demonstrated significant correlations between spiritual well-being (measured by the FACIT-sp) and desire for death and hopelessness and found that spiritual well-being was the strongest predictor of desire for hastened death and continued to provide a unique contribution after depression had been entered into the model. They also found that spiritual well-being moderated the relationship between depression and desire for death: depression and desire for death were correlated in participants low in spiritual well-being ($r = .40, p < .05$) but were not correlated ($r = .20, p > .05$) in those with high spiritual well-being. McClain-Jacobson, Rosenfeld, Kosinski, Pessin, Cimino, & Breitbart (2004) examined belief in afterlife and spiritual well-being (measured by FACIT-sp) and desire for death. They found a significant relationship between afterlife beliefs and desire for death but also found that this relationship did not hold if spirituality was entered first into the model. In consequence, they conclude that spirituality has more effect on end-of-life despair than do beliefs about an afterlife.

In conclusion, the current review of the literature linking spirituality and existential factors to desire for hastened death supports the conclusion drawn by Breitbart and Heller (2003, p. 981) who note that, "spiritual well being, in

particular loss of meaning, is more highly correlated to that whole constellation of constructs that make up despair at the end of life than depression alone or hopelessness alone.”

Other quality of life factors.

Reviews of the literature provide evidence that other factors may be involved in the desire for hastened death but the research evidence regarding these factors is more limited than the factors reviewed above due to either conflicting or weak evidence across studies or by research that has not been replicated by another research group. These additional factors include physical distress (O’Mahony et al., 2005), dependency (Morita et al., 2004), functional status (Rosenfeld, Breitbart et al., 2000; Rosenfeld, Krivo et al., 2000), communication with physicians (Mishara, 1999), dignity (Chochinov, Hack, Hassard, Kristjanson, McClement & Harlos, 2002), demoralization (Kissane, Wein, Love, Lee, Lee, & Clarke, 2004), and cognitive dysfunction (Pessin, Rosenfeld, Burton, & Breitbart, 2003).

Temporal Stability.

One question remaining about the desire for hastened death is how stable the construct is over time. One study attempted to address this issue by examining the “will to live” several times a day in terminally ill cancer patients. In attempting to ascertain the temporal stability of desire for death in advanced stage, palliative care cancer patients, Chochinov and colleagues (1999)

developed a "will-to-live" visual analogue scale modeled after the visual analogue scales of the Edmonton Symptom Assessment Scale (Chang, Hwang, & Feuerman, 2000). Participants were asked to make a vertical mark on a 100 mm visual scale (anchored by "complete will to live" and "no will to live" as the extremes) to indicate the intensity of their will to live. No information was provided in the report of any attempts to establish the reliability or validity of the measure. Findings from the study indicate that the will to live fluctuates a great deal in terminally ill cancer patients, with some patients exhibiting "extreme changes" in will to live in only a 12-hour period. Specifically, the average maximum change in individual scores on the 100 mm will to live scale over a 12-hour period was 33.1 mm (95% CI 28.4 to 37.8), with some participants reporting fluctuations of 100 mm in that period. A longitudinal study by O'Mahony and colleagues (2005) used the DDRS with 4 weeks between assessments and found that there was significant stability of the construct over time: less than 18% of the sample changed classification levels (low versus high desire for death) in the four week interval. In reviewing the findings, however, O'Mahony and colleagues (2005) suggested that these results may reflect poor sensitivity of the measure to relatively small changes in desire for death as opposed to providing strong support for the stability of the construct over time. Hence, there is conflicting evidence regarding how much the desire for death fluctuates over time.

VOL in Comparison to Other Existential Constructs

Given the existential domains encompassed by the VOL construct, a final area of literature to be reviewed is the conceptualization of existential and spiritual constructs in the field of palliative care. This section is intended not as an exhaustive review of models, therapies and measures of spiritual and existential well-being and is instead intended to provide exemplars of current thinking around existential and spiritual well-being in palliative care. This review is undertaken to enable comparison of the similarities and differences between existing constructs in palliative care and Lawton's VOL construct. As noted earlier in this paper, definitions of spiritual and existential constructs are frequently vague. Perhaps because of the difficulties in defining and parsing out the existential component from the current general definition of the spiritual construct, little has been written about the foundations of existential variables in palliative care despite strong roots in the tenets of existential psychotherapy (Breitbart et al., 2004). In the last few years, however, there have been three groups of researchers that have devoted considerable effort toward defining distinct existential constructs.

Meaning-Centered Therapy. Breitbart and colleagues (2004) describe the theoretical foundations and implementation of a meaning-centered psychotherapy that is based largely on Viktor Frankl's (1992) existential logotherapy. In consequence, meaning-centered therapy is aptly named given its primary focus on helping to facilitate meaning making at the end of life. An

assumption underlying this work is that facing the reality of impending death provides a natural impetus for people to search for a way to ascribe meaning to their lives and to their suffering. Meaning-centered therapy reflects Frankl's thesis that living a life with meaning involves viewing oneself as having a role and purpose in life and, concomitantly, reflects his belief that life can be lived with a sense of meaning and purpose up to the moment of death. In consequence, the intervention attempts to increase patients' sense of meaning and purpose in life. Feeling that one's life has meaning and that one has a purpose in life are also important features reflected in Lawton's VOL construct. Recognizing the obvious similarities between the construct they were trying to articulate and Frankl's work, Lawton and colleagues (2001) evaluated Frankl's work (in the form of the Purpose in Life scale [Crumbaugh, 1972]) to see if captured the construct that Lawton and colleagues (2001) had in mind; however, Lawton and colleagues felt that VOL represented a broader construct than the Purpose in Life scale as evidenced by the inclusion of the domains of persistence, hope, futurity, and self-efficacy in the VOL construct.

Dignity Model. Chochinov and colleagues (Chochinov, 2002; Chochinov et al., 2002; Chochinov, 2006) developed a model of dignity from a qualitative analysis of dignity concerns identified by 50 terminally ill participants. The model they developed, which has since lead to an intervention, describes three major categories: (1) illness-related issues, (2) dignity-conserving repertoire, and (3) social dignity inventory. The themes subsumed under the category of dignity-

conserving repertoire include 'dignity-conserving perspectives' which reflect ways of looking at or coping with one's situation and 'dignity-conserving practices' that are used to buffer one's sense of dignity. Further, the 'dignity-conserving perspectives' theme is comprised of the following subthemes: continuity of self, role preservation, maintenance of pride, hopefulness, autonomy/control, generativity/legacy, acceptance, and resilience/fighting spirit. Chochinov (2002, p.2256) describes the dignity-conserving repertoire as being based on "pre-existing personality characteristics and on internal resources that patients bring to their illness experience." The dignity model was developed to reflect a broad range of domains to better enable it to capture the unique topography of each person's experience with their sense of personal dignity at the end of life. The intervention that developed from this model, through use of tape recorded conversations of issues that matter most to them or that they would want most remembered, attempts to reduce depression and suffering while bolstering a sense of meaning, purpose, and will to live (Chochinov & Cann, 2005; Chochinov, Hack, Hassard, Kristjanson, McClement, & Harlos, 2005a).

It is striking how many portions of the Dignity Model correspond to Lawton's VOL construct. The 'dignity-conserving perspectives' domain, in particular, resonates with the construct underlying the VOL scale. The subthemes of continuity of self, role preservation, maintenance of pride, hopefulness, and resilience/fighting spirit mesh particularly well with the construct articulated by Lawton and colleagues (2001), while the subthemes of autonomy/control and generativity/legacy mesh less well. Further, the 'dignity-

conserving perspectives' theme includes a subtheme of acceptance that has been defined as the ability to accommodate to changing life circumstances. This subtheme appears to reflect to some extent what Lawton and colleagues (2001) considered the processes underlying VOL – the capacity to assimilate and accommodate as needed in response to change.

The VOL construct, however, can be distinguished from the Dignity Model in its entirety and, to a more limited extent, also from the 'dignity-conserving perspectives' domain; VOL is less inclusive than either of these two constructs. In developing the VOL scale, Lawton and colleagues (2001) reviewed a large number of existing measures of positive mental health and ruled each out due to either an over or under representation of the core domains of VOL. The Dignity Model, had it existed as a scale at the time of the VOL development, would likely have been considered by Lawton and colleagues but dismissed as over inclusive of the construct that they were trying to articulate. VOL is purposefully a more limited construct than is the Dignity Model in that VOL was created as a clear attempt to capture the core variables that are pivotal in the determination of whether one wishes to live or to die. The Dignity Model, on the other hand, is deliberately broader than the VOL because it was developed to help explain valuable patient experiences (with an eye to the development of an intervention) that collectively comprise key aspects of patient distress and was not developed explicitly as a construct that would predict desire for death, per se.

Demoralization. Kissane and colleagues (2004) have developed the Demoralization construct and scale which they suggest will eventually be recognized as an independent predictor of desire to die. Demoralization is a dimensional construct that represents existential distress in those with terminal illness such that a loss of meaning and hope can result in life being devalued to the point of being worthless. Its dimensional nature follows a path that begins with disheartenment, follows with despondency, and ends with profound despair. It has been operationalized to include the following content areas: non-specific dysphoria, disheartenment, loss of confidence and development of subjective incompetence, loss of meaning, hopelessness and helplessness, social disconnectedness, and desire to die. There is some overlap between Demoralization and the VOL in the joint focus on meaning, hopelessness and loss of confidence. The overlap between these two constructs, however, is limited by the fact that VOL assesses the positive aspect of these constructs (meaning/purpose, hope, self-efficacy) while Demoralization measures the negative aspects of these constructs (meaninglessness, hopelessness, loss of confidence) and it cannot be ascertained that they measure the same construct. VOL not only represents the positive aspects of Demoralization, but it is also a more inclusive construct in that it includes domains of futurity, persistence, and purpose.

Given the growth of research in existential issues in palliative care since this study was initially developed, a pertinent question is whether the VOL concept and scale will provide additive information to the literature base. As a

construct, it appears that there is considerable overlap between VOL and existential constructs in palliative care. VOL appears, however, to represent a construct that is distinct from other existing definitions of spirituality and existential factors. In essence, the boundaries that define VOL differ from those articulated by meaning-centered therapy (VOL incorporates the dimensions of hope, futurity, self-efficacy, and persistence), the dignity model (VOL represents a smaller construct than dignity but closely relates to 'dignity-conserving perspectives'), and demoralization (VOL focuses explicitly on positive mental health while demoralization focuses explicitly on pathology). It also differs significantly from existential thinking in palliative care in the way in which it is assumed to arise: VOL is hypothesized to be the end point of the weighing of the positive and negative aspects of one's current and future life – these judgments are dependent on how people adapt to changes in their inner and outer world through the processes of assimilation and accommodation. In summary, the construct of VOL appears to overlap considerably with the content of existential concepts already under investigation in the palliative care literature. It appears, however, to be a distinct construct as evidenced by the fact that it has been operationalized differently than other constructs and by virtue of being theory-driven in terms of how it is proposed to function.

Purpose and Rationale

The present study aims to test the valuation of life (VOL) mediation model proposed by Lawton and colleagues (1999, 2001) in a population cancer patients

receiving palliative care. This represents an advancement in the research on the desire for hastened death in two ways: (1) it introduces a new existential measure to the literature, and (2) it is driven by a theoretical model. In addition, this study extends the research on the VOL to a population that is comprised of individuals across the age spectrum and in so doing expands VOL research from the field of Gerontology. Further, by assessing the VOL model in a population of cancer patients who are receiving palliative care services, this study improves upon existing VOL research by eliminating the reliance on hypothetical measures of desire for death. In consequence, this study represents a stronger assessment of the VOL mediation model than previous research.

Within the field of palliative care, by testing the VOL mediation hypothesis, this study attempts to refine our understanding of the role that existential variables play in the desire for death: it moves existential variables from the role of either predictor or outcome measure to holding a central position in a mediating role. As such, this research represents a move away from descriptive research of the variables believed to be of significance to the desire for hastened death to a theory-driven explanatory model. The need for theory-based research is evidenced by recent literature reviews. After reviewing the literature on death and dying, Corr, Doka and Kastenbaum (1999) argued that, to date, few predictive theories exist to be tested in the field of death and palliative care. Similarly, as noted above, Mytko and Knight (1999) reviewed the literature pertaining to religion/spirituality and quality of life in cancer patients and

concluded future research should be hypothesis-driven. This study is an attempt to address these issues.

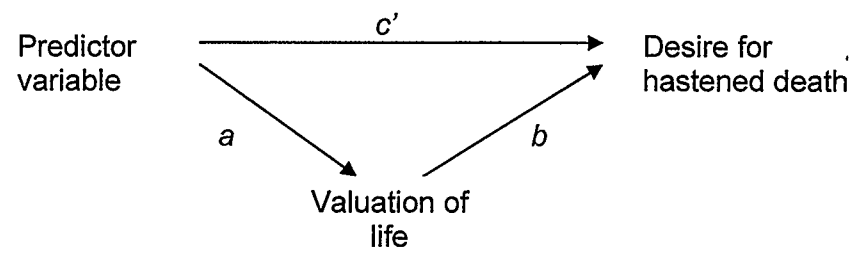
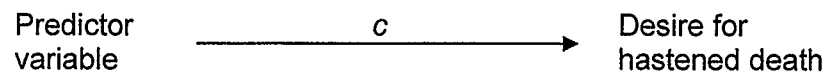
Hypotheses

The hypotheses of this study are designed to assess the predictions of the VOL model, namely, that quality of life variables are related to a desire for hastened death only indirectly through the VOL construct. Simply put, it is asserted that VOL mediates the relationship between quality of life factors and patients' preferences regarding a hastened death. These predictions are represented in graphic format in Figure 2. Based on the VOL mediation model the study hypotheses are as follows:

Hypothesis 1. VOL mediates the relationship between depression and desire for hastened death.

Depression will be significantly and positively related to a desire for hastened death (Path *c*). Depression will be significantly and negatively associated with VOL (Path *a*). VOL will be significantly and negatively related to a desire for hastened death after accounting for the contribution of depression (Path *b*). Depression will not be significantly related to desire for hastened death after accounting for the effects of VOL (path *c'*). The decrease in the strength of the relationship between depression and desire for hastened death after accounting for VOL (Path *c* to Path *c'*) will be significant.

Figure 2. VOL mediation hypothesis.



Hypothesis 2. VOL mediates the relationship between hopelessness and desire for hastened death.

Hopelessness will be significantly and positively related to a desire for hastened death (Path *c*). Hopelessness will be significantly and negatively associated with VOL (Path *a*). VOL will be significantly and negatively related to a desire for hastened death after accounting for the effects of hopelessness (Path *b*).

Hopelessness will not be significantly related to desire for hastened death after accounting for the effects of VOL (path *c'*). The decrease in the strength of the relationship between hopelessness and desire for hastened death after accounting for VOL (Path *c* to Path *c'*) will be significant.

Hypothesis 3. VOL mediates the relationship between subjective quality of life and desire for hastened death.

Subjective quality of life will be significantly and negatively associated with a desire for hastened death (Path *c*). Subjective quality of life will be significantly and positively associated with VOL (Path *a*). VOL will be significantly and negatively related to a desire for hastened death after accounting for the contribution of subjective quality of life (Path *b*). Subjective quality of life will not be significantly related to desire for hastened death after accounting for the effects of VOL (path *c'*). The decrease in the strength of the relationship between subjective quality of life and desire for hastened death after accounting for VOL (Path *c* to Path *c'*) will be significant.

Hypothesis 4. VOL mediates the relationship between functional status and desire for hastened death.

Functional status will be significantly and negatively related to a desire for hastened death (Path *c*). Functional status will be significantly and positively associated with VOL (Path *a*). VOL will be significantly and negatively related to a desire for hastened death after accounting for the contribution of functional status (Path *b*). Functional status will not be significantly related to desire for hastened death after accounting for the effects of VOL (path *c'*). The decrease in the strength of the relationship between functional status and desire for hastened death after accounting for VOL (Path *c* to Path *c'*) will be significant.

Method

Design

The research design is a cross-sectional approach that tests a priori hypotheses regarding the presence of a proposed mediating variable (valuation of life) in the relationship between known predictors of the desire for hastened death (dependent variable). Depression, hopelessness, subjective quality of life, and objective quality of life comprised the predictor variables.

Population & Sample

Participants were drawn from a population of individuals who had a cancer diagnosis and who were receiving palliative care services in the Calgary Health

Region. A sampling approach using referrals from health care providers was used in the design; participants were volunteers who were screened by their health care providers to ensure that they met inclusion / exclusion criteria (Table 1) before being approached about their interest in participating in the study. The recruitment handouts used by health care providers when approaching participants is provided in Appendix C. In addition to these formal inclusion / exclusion criteria, health care providers also used their judgment in deciding to approach potential participants about the study. Specifically, health care providers did not approach every individual who met the inclusion / exclusion criteria for the study but additionally considered the individual's demonstrated or suspected willingness to talk about end-of-life issues. It is notable that Breitbart et al. (2000, p. 2908) also used a prescreening approach in their study, with physicians providing judgment that the patient was "not likely to suffer psychological harm from participation" before being approached about the study. In reporting on the same sample, Rosenfeld and colleagues (2000) indicated that few patients were excluded due to concerns about their psychological distress but that larger numbers were excluded due to other reasons (such as cognitive impairment) that were not fully understood.

In the initial study protocol, all participants were to have been recruited through the Palliative Home Care program in the Calgary Health Region. Slow recruitment resulted in an expansion of the study into two palliative inpatient units in local hospitals and an outpatient psychosocial support service offered through the Tom Baker Cancer Centre. A total of 49 people participated in the study:

Table 1

Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
diagnosis of a terminal cancer illness (i.e., treatment is palliative, not curative); 18 years of age or older	life expectancy of only a few days terminal diagnosis other than cancer
proficient in English (either written or verbal) at about a grade 8 level	non-English speakers
Mini Mental Examination Status (MMSE) score of 21 or greater	MMSE less than 20
able to tolerate 30- 45 minutes of completing a questionnaire	a current diagnosis of delirium unable to tolerate 45 minutes of completing a questionnaire

35% ($N = 17$) were recruited from Palliative Home Care, 18% were from inpatient units ($N = 9$), and 47% were from psychosocial resources ($N = 23$). Table 2 provides background and demographic information about participants and indicates that the sample was comprised predominantly of individuals who were: (a) married, (b) of higher income status, (c) of Christian faith and, (d) of European decent.

Statistics documenting the refusal rate of those approached about the study were not available from the Palliative Home Care service. The refusal rate in the other three settings was 37.5% (3 of 8) on inpatient unit 1, 50% (7 of 14) on inpatient unit 2, and 25% (8 of 32) from psychosocial resources. Three participants recruited from the Palliative Home Care service died before being able to complete the questionnaire and one participant recruited from psychosocial resources did not meet the minimum MMSE inclusion criteria. In addition, three individuals recruited from inpatient unit 2 denied having been approached about the study (permission for contact) and a decision was made to defer approaching them further about the study until it could be ascertained that proper procedure had been followed by recruiting personnel. When it was confirmed that the three patients had indeed been approached according to study protocol none of the three were available to participate in the study due to death or transfer from the unit.

Unfortunately, it is not possible to estimate precisely the proportion of patients who were eligible for the study but who were not approached by their health care providers nor is the basis for these exclusions understood. To better

Table 2

Demographic information

	Group	N (%) ^a
Gender	Male	21 (43)
	Female	28 (57)
Age	30-39	2 (4)
	40-49	12 (25)
	50-59	14 (29)
	60-69	9 (18)
	70-79	9 (18)
	80-89	3 (6)
	M = 58.4 yrs (<i>SD</i> = 13.1)	
Cancer type	Brain and CNS tumours	1 (2)
	Breast	17 (35)
	Colorectal	12 (25)
	Endocrine	3 (6)
	Genitourinary	5 (10)
	Gynaecological	1 (2)
	Head and Neck	1 (2)
	Leukaemia	1 (2)
	Lung	6 (12)
	Urinary System	1 (2)
	Other	1 (2)
Time since diagnosis	Less than 1 year	2 (4)
	1 year	12 (25)
	2 - 3 years	8 (16)
	4 - 5 years	7 (14)
	6 - 10 years	13 (27)
	11 - 18 years	6 (12)

Group		N (%) ^a
No information		1 (2)
Stability of symptoms*	Stable	27 (55)
	Fluctuating	22 (45)
Religion	Christian	41 (84)
	<i>Roman Catholic</i>	13 (27)
	<i>Protestant</i>	19 (39)
	<i>Orthodox</i>	2 (4)
	<i>Christian</i>	7 (14)
	Buddhist	1 (2)
	Sikh	1 (2)
	No religion	6 (12)
Cultural Background	British	18 (37)
	French	4 (8)
	Western European	9 (18)
	Northern European	3 (6)
	Eastern European	4 (8)
	West Asian	1 (2)
	South Asian	2 (4)
	East/South Asian	1 (2)
	Caribbean	1 (2)
	Aboriginal	1 (2)
	Other	5 (10)
Marital Status	Married	42 (86)
	Widowed	3 (6)
	Divorced/separated	4 (8)
Monthly Income	Less than \$899	1 (2)
	\$900-\$1199	3 (6)
	\$1200-\$1499	7 (14)

	Group	N (%) ^a
	\$1500 or more	30 (61)
	No information	8 (16)
Years of Education	< Grade 12	6 (12)
	Grade 12	8 (17)
	Some post secondary	14 (29)
	Skilled trade	3 (6)
	Undergraduate degree	13 (27)
	Graduate degree	4 (8)
	Post-graduate degree	1 (2)

^a Totals may not equal 100% due to rounding error.

* Self-reported stability of symptoms over the previous 7 days.

assess the possible impact of the sampling approach, participant characteristics from this study were compared to those from two recent studies on desire for hastened death (see Appendix D). The sample for the current study appears to be comprised of individuals who were younger, more educated, more likely to identify as Christian, and more likely to be married than the samples in the two comparison studies.

Measurement

Power and Sample Size

Power analyses were not undertaken at the time of study development because there were no published records of the relationship between existential variables and the criterion variable. In consequence, it could not be determined a priori if the anticipated effect size was going to be small, medium, or large. The number of necessary participants was estimated based on a rule of thumb of 20 participants per predictor variable (Tabachnick & Fidell, 1996) resulting in a targeted sample size of 100.

Slow recruitment resulted in concerns about the feasibility of recruiting 100 participants to the study and after consultation with the supervisory committee and three outside statisticians it was agreed that data collection would cease at approximately 50 participants with a specific end date for accrual of December 31, 2005. The total number of participants in the study was 49. The decision to reduced the number of participants in the study reflected a combination of factors including: (a) recognition of the preliminary nature of the study, (b) the design

was based on clearly articulated theory which results in a small number of necessary analyses, (c) correlations from the first 35 participants provided preliminary evidence that the effect sizes in the study were large, and (d) data screening for statistical outliers on the first 35 participants suggested that the data was stable and therefore unlikely to reflect chance correlations.

Measures

Brevity of the instruments was a priority in their selection for this study in order to reduce the cognitive burden on the participants and to ensure that the study administration time was short. Primary consideration was given, however, to the psychometric properties of the instrument as evidenced by their prior performance in research with palliative care cancer patients while secondary consideration was given to the administration time of the measure. Features identified as desirable when choosing measures for palliative care patients are: self-administered, brief, simple, acceptable to patients, and psychometrically validated (Velikova, Stark, & Selby, 1999).

Demographic and background variables.

In order to reduce the burden on the participants, background variables were collected primarily through chart review and included the identification of primary type of cancer, date of diagnosis, and current medication regimen. Demographic variables included age, gender, education level, income, religion, ethnicity, living situation, and marital status.

Predictor variables.

Beck Depression Inventory – Short Form (BDI-SF; Beck & Beck, 1972). The 13-item BDI-SF (Appendix E) was developed as a rapid screening technique for use with medical patients and is highly correlated ($r = .96$) with the original 21-item Beck Depression Inventory (Beck & Beck, 1972; Berndt, 1979; Gould, 1982; Reynolds & Gould, 1981). The BDI-SF has been validated for use with cancer patients (Wilson, Chochinov, de Faye, & Breitbart, 2000) and has been demonstrated to have sensitivity of .79 and specificity of .71 in identifying terminally ill cancer patients who have a diagnosed depression when the cutoff is set at greater than or equal to 8 (Chochinov, Wilson, Enns, & Lander, 1997). Scores can range from 0 to 39, with high scores indicating higher levels of depression. In the current study, scores ranged from 0 to 30 and the internal consistency of the scale was “good” using Cicchetti’s (1994) evaluative criteria (*Chronbach’s* $\alpha = .85$).

Beck Hopelessness Scale (BHS; Beck & Steer, 1988). The 20-item BHS (Appendix F) has well-established psychometrics, with evidence of good internal consistency ($KR-20 = .82$ to $.93$) and validity (content, concurrent, discriminant, construct, predictive and factorial) across diverse samples of psychiatric and normal populations (Beck & Steer, 1988). The BHS measures the extent of negative attitudes about the immediate and long-range future and was originally developed to assess pessimism in psychiatric patients believed to be at risk for

suicide (Beck & Steer, 1988). According to Beck and Steer (1988), the scale has particular utility as an indicator of suicidal risk in depressed respondents. Each of the 20 items is scored 1 or 0, and scores can range from 0 to 20, with higher scores indicating greater hopelessness. A score of 9 or greater on the BHS is indicative of a high level of hopelessness (Beck & Steer, 1988). In the current study, the BHS scores ranged from 1 to 17 and the scale demonstrated “good” internal consistency ($KR-20 = .88$) using Cicchetti's (1994) guidelines. Recently, Abbey and colleagues (2006) developed three abbreviated versions of the BHS which they argue may be more valid measures of the hopelessness construct in palliative care populations. They developed the abbreviated scales by including items above specified item-total correlations. When exploring the reliability and validity of the BHS in the current study, however, it became clear that the BHS item-total correlations in the current study did not match with those found by Abbey and colleagues (2006): using the same criteria as delineated by Abbey and colleagues, this study would have produced three unique abbreviated versions of the BHS. In consequence, in the absence of further research supporting the abbreviated scales suggested by Abbey and colleagues, the current investigation used the full scale BHS.

Karnofsky Performance Scale (KPS; Karnofsky, Abelmann, Craver, & Burchenal, 1948). The KPS is a brief measure of objective of functional status that requires combined judgment of three areas of functional status: activity, work, and self-care. The KPS is expressed in percentage form, with criteria

being listed for each ten-point difference on the scale (see Appendix G). Higher percentages represent higher levels of functional performance. Developed in the 1940s, the KPS is widely used in palliative care settings despite its lack of validation and questionable test-retest reliability (Michael & Tannock, 1998). Despite these limitations, the KPS is included in the present study because of its common use in cancer clinical trials and because newer measures of the same construct, such as the Eastern Cooperative Oncology Group (ECOG) Performance Scale, have not been demonstrated to have greater validity or reliability than the KPS (Michael & Tannock, 1998). Scores in the current study ranged from 20 to 90 ($M = 58.1$, $SD = 19.5$).

Functional Assessment Cancer Therapy – General (FACTG [version 4]; Cella, Tulsky, Gray, Sarafina, Linn, Bonomi, et al., 1993; Functional Assessment of Chronic Illness Therapy website, 2006). The FACTG is a 27-item, multidimensional, subjective quality of life measure developed specifically for use with cancer patients. The FACTG consists of four subscales: physical well-being, social well-being, emotional well-being, and functional well-being (Appendix H). Each item is rated on a 5-point scale that applies to the previous seven days. A total score, representing overall subjective quality of life, is calculated from the 27-items. The psychometric properties of the FACTG are well-documented and support the reliability (total scale *Chronbach's* $\alpha = .89$; subscale *Chronbach's* α range from .69 to .82) and validity of the measure in assessing quality of life (Cella et al., 1993; Winstead-Fry & Schultz, 1997). In the current study, total

scale scores ranged from 36 to 107 (out of a possible range of 0 to 108) and the internal consistency (*Chronbach's* $\alpha = .90$) of the total scale was "excellent" using Cicchetti's (1994) guidelines. The internal consistency of the subscales is as follows: Physical well-being was "fair" (*Chronbach's* $\alpha = .74$), Emotional well-being was "good" (*Chronbach's* $\alpha = .81$), Functional well-being was "good" (*Chronbach's* $\alpha = .88$), and Social well-being was "fair" (*Chronbach's* $\alpha = .72$)

Valuation of Life Scale (VOL; Lawton et al., 2001). The VOL represents the mediator variable in the present study (Appendix A). VOL is comprised of five core constructs that are defined as: (1) Futurity, an outlook that views the future as worth anticipating and planning for, (2) Hope, the expectation that the present and future will be positive, (3) Self-efficacy, the belief that one is competent, (4) Persistence, the view that one's efforts are worthwhile and likely to succeed, and (5) Purpose, the adoption of goals that guide one's life (Lawton et al., 2001). In the VOL scale, purpose is the most heavily weighted construct, followed by persistence and then by futurity, hope, and self-efficacy (which are equally weighted). Although the five core constructs were used to aid in the development of the scale, the VOL is intended to represent a single overarching factor (VOL). Exploratory factor analysis indicated a two factor structure that divided the scale by positively worded items and negatively worded items (Lawton et al, 2001). Internal consistency was excellent for the positively worded questions (*Chronbach's* $\alpha = .94$) and good for the negatively worded questions

(*Chronbach's* $\alpha = .83$). All questions are asked on a 5-point scale ranging from 5 = agree very strongly to 1 = disagree very strongly (Appendix A).

In the current study, using the evaluative guidelines established by Cicchetti (1994), the total scale internal consistency was “excellent” (*Chronbach's* $\alpha = .93$). The internal consistency of the positively worded VOL questions was “excellent” (*Chronbach's* $\alpha = .93$) and “fair” for the negatively worded questions (*Chronbach's* $\alpha = .76$). Scores on the 19-item VOL scale ranged from 25 to 93 (out of a possible range of 19 to 95), with higher scores on the VOL indicating a strong sense of futurity, hope, self-efficacy, persistence, and purpose in life. Because this is the first use of the scale with participants with life-threatening illness, convergent validity for the scale was examined through its relationship with another measure of existential beliefs, the McGill Quality of Life Questionnaire Existential Well-being subscale (MCGILL). The MCGILL has been used extensively with samples comprised of individual's receiving palliative care treatment and has demonstrated reliability and validity in the population. The relationship between the VOL and MCGILL was large (*Spearman's rho* = .70, $p < .05$) and in the expected direction.

Given large number of participants needed for exploratory factor analysis (Tabachnick & Fidell, 1996), the factor structure of the VOL was not evaluated in this sample. Lawton and colleagues (2001) suggest using the VOL as a complete scale (instead of dividing it into “Positive VOL” and “Negative VOL”) when participant samples are reasonably well-educated and homogeneous. Participants in the current study reflect a relatively high level of education and

there are indications of homogeneity on a number of demographic variables (e.g., marital status, religion). In addition, the correlation between Positive VOL and Negative VOL was high ($r = .73, p < .05$). In consequence, a decision was made to use the entire VOL scale instead of splitting the scale by positively and negatively worded items. Means and standard deviations of the VOL items are presented in Appendix J.

Outcome variable.

Schedule of Attitudes toward Hastened Death (SAHD; Rosenfeld, Breitbart et al., 2000). The outcome variable in this study is a 20-item self-report measure that was developed specifically to assess the desire for hastened death in patients with terminal illnesses and to facilitate research into physician-assisted suicide and euthanasia. It has been validated in a North American sample of terminally ill cancer patients (Rosenfeld, Breitbart et al., 2000). Answered in true or false format, high scores on the scale represent a high desire for hastened death (see Appendix B).

Research by Rosenfeld, Breitbart and colleagues (2000) examining the reliability and validity of the SAHD has indicated that the SAHD has good internal consistency (coefficient $\alpha = .88$) and has demonstrated convergent validity (*Spearman's* $r = .67$) with the Desire for Death Rating Scale developed by Chochinov and colleagues (1995). Principal components analysis indicated a single factor structure for the SAHD. Cutoff scores were established for palliative care cancer patients; those scoring 11 and greater have a high desire for

hastened death while those scoring below 11 do not have a high desire for hastened death (Rosenfeld, Breitbart, et al., 2000). In the current study, scores on the SAHD ranged from 0 to 19 (out of a possible range of 0 to 20). Using Cicchetti's (1994) guidelines, internal consistency of the scale was "good" ($KR-20 = .88$).

Other measures.

McGill Quality of Life Questionnaire Existential Well-being subscale

(MCGILL; Cohen, Mount, Bruera, Provost, Rowe, & Tong, 1997). This 6 item subscale was included in the questionnaire package to provide a measure of the convergent validity of the VOL scale. Items are scored on a 10 point scale where high scores indicated higher levels of existential well-being (Appendix I). Internal consistency of the subscale was "fair" (*Chronbach's* $\alpha = .79$) in the original scale development and "good" (*Chronbach's* $\alpha = .87$) in the current sample.

Comfort ratings. Two measures were developed for the current study to provide a benchmark indication of how comfortable participants felt about answering questions that directly raised the issue of death. A 10 point Likert-type scale assessed the question, "Please indicate how comfortable you felt about answering questions about hastened death." The scale was anchored such that "0" indicated "extremely uncomfortable" and "10" indicated "completely comfortable". Scores on the scale ranged from 1 to 10 with a mean score of 8.6

($N = 49$, $SD = 2.0$). The second measure was an open-ended question asking, "Would you describe your reaction to this questionnaire?"

Procedure

This study was reviewed and approved by the Conjoint Health Research Ethics Board as meeting the ethical standards of the University of Calgary and the Calgary Health Region. Participants were recruited to the study through palliative home care, inpatient units at two local hospitals, and the psychosocial resources department in the Tom Baker Cancer Centre (TBCC). Staff at each site identified patients who met the study inclusion and exclusion criteria, described the study to eligible participants, and obtained their permission for the researcher to contact them if they were interested in participating in the study.

Patients agreeing to be contacted by a researcher from the study were contacted by phone by either the primary investigator (ALE) or by one of three research assistants (JW, PL, AB) and the study was described to them in detail to ascertain that they were interested in participating in the study. The research assistants were Master's level students in either Clinical or Applied Psychology and were trained on the administration of the questionnaire package by ALE. Training involved reviewing the scoring and administration manuals of each measure and accompanying ALE on three interviews with participants (with participant consent) to observe the data collection process. The KPS was completed independently by ALE and each of the trainees after the completion of each interview. The KPS scores were compared to ensure that they were within

a 10-point range of the other raters, with the rating by ALE providing the standard for comparison.

Following phone contact and overview of the study, the researcher then made arrangements to conduct the study at the home, unit, or current residence of the volunteer participant. Participants read and signed the study informed consent form and were administered the Folstein mini-mental status examination (MMSE; Folstein, Folstein & McHugh, 1975) which was used to screen for capacity to complete the study. A cut-off point of 21 or greater was used in the study and is a standard cutoff used to screen terminally ill cancer patients (Chochinov et al., 1999). Participants were provided with the option of completing the questionnaire on their own or of having the researcher read the questionnaire items to the participant. Participants then completed a pen-and-paper administered self-report questionnaire that took between 30 and 55 minutes to complete. The questionnaire package was typically completed in less than 45 minutes. The research assistant conducted a chart review to obtain demographic and background data and completed the objective quality of life measure following the interview.

Results

Data Screening and Treatment

Prior to analysis, SAHD, VOL, BDI-SF, FACTG, KPS, and MCGILL were examined through various SPSS 14.0.1 programs for accuracy of data entry, missing values, and fit between their distributions and the assumptions of

multivariate analysis. All values were within possible range for the respective scales. The data set contained over 5,000 data points and 0.7% ($N = 33$ items) were missing values (Table 3). Two cases with 5 or more missing items from the BHS scale were excluded from analyses that involved the BHS measure. All other missing values were replaced with the mean for all cases on the scale (or subscale) except for three items on which the respondents (cases 9 and 21) chose to circle both True and False on the scales. For these three items, the middle value for the scale (.5) was used to replace the missing value instead of replacing the missing value with the scale mean.

The data was screened for univariate outliers using box plots and descriptive statistics (frequencies). One case was a statistical univariate outlier on the SAHD, BDI-SF, and MCGILL. In examining the participant's scores on these scales it appeared that the respondent tended to select the extremes when endorsing items (i.e., an "all-or-nothing" approach) which created scores that were much higher than those of the other respondents. This pattern, in combination with evidence that the population from which the sample was drawn has more extreme values than a normal distribution (e.g., Rosenfeld, Breitbart et al., 2000), resulted in a decision to retain the participant in the data set. Values for this participant were changed, however, to be one point higher than the next most extreme score in the distribution so that the case would not have as much impact on the analyses (Tabachnick & Fidell, 1996, p.69). The SAHD score was changed from 19 to 13, the BDI from 30 to 20, and MCGILL from 7 to 27.

Table 3

Variable item numbers missing by case

Case Number	Variable			
	FACTG ^a	SAHD	BHS	VOL
1	7			
6	7			
8	6,7			
9		18 ^b		
10	7			
13			8,9,10,12,13,14, 16,17,18,19,20*	1
19			9,15,19	
20			6,12	
21			4 ^b ,6 ^b	
36		10		
40			4,7,10,14,15*	
46	7			
49	7			

Key: FACTG = Functional Assessment Cancer Therapy – General; SAHD = Schedule of Attitudes Toward Hastened Death; BHS = Beck Hopelessness Scale; VOL = Valuation of Life Scale

^a The FACTG had a relatively high number of non-respondents to item 7 on the scale; respondents had an option to check a box that allowed them skip the item that asked about their satisfaction with their sexual relationship(s).

^b In these cases, respondents circled both True and False on the scales, and the values were replaced with .5 instead of the scale mean.

* These two cases were removed from all analyses involving the BHS.

The variables were assessed graphically and statistically and revealed significant non-normality with high skew and/or kurtosis for SAHD, BDI-SF, BHS, VOL, and MCGILL. The following data transformations were conducted to reduce violations of the assumptions of key parametric tests: (1) square root transformations for SAHD, BDI-SF, BHS, and VOL (reflected) and (2) logarithmic transformation of MCGILL (reflected). Following data transformation, regression analyses were conducted to evaluate residuals using Mahalanobis distance. These analyses indicated that there were no significant multivariate outliers.

Descriptive Statistics

Unless otherwise noted, descriptive statistics are reported without data transformation to ease interpretability of the scale scores. Eighty-two percent of participants ($N = 40$) completed the questionnaire without help while the remaining 18% ($N = 9$) had the research assistant read the questionnaire to them. The average MMSE score was 28.5 ($SD = 1.6$, range 24 to 30). Participants indicated that they were generally comfortable completing the questionnaire, with 87.7% ($N = 43$) giving comfort ratings above 5 (the midpoint of the comfort scale). Out of a possible score of 10, the mean comfort score for the sample was 8.6 ($N = 49$, $SD = 2.0$).

Sixty-nine percent ($N = 34$) of participants chose to provide a comment to the open-ended question about their reaction to the questionnaire. Their verbatim responses, organized in chronological order by ID number, are reported in Appendix K. Several themes emerged in the content of their feedback. Many

people talked about the importance of giving something back to either society or to the medical system. For example, ID 11 wrote, "Give something back to the health system that has given me excellent care" while ID 36 stated, "If I can help someone in my answers that is worth my time!". A number of participants expressed frustration with the questionnaire format or with the measures. For example, ID 28 wrote, "I find the situation I'm in is in no way just black or white and I find many questions don't allow for that" and ID 13 wrote, "I think there is no way that this questionnaire will capture the complexity of this issue. The questions seem too simplistic and/or narrow in focus". Other participants chose to comment on the emotional comfort or discomfort they experienced while completing the questionnaire. For example, ID 23 wrote, "Very in your face questions" while ID 7 wrote, "I like surveys; it seems 'sincere and honest' and was comfortable to complete". Several participants wrote about their hope that the study would help in the advancement of knowledge about the experiences of those at the end of life. For example, ID 8 stated, "We need more questionnaires to find out how people really feel about euthanasia" and ID 9 wrote, "It will help doctors understand some emotional feeling the patients feel regarding a deathly illness...". In addition, several participants provided comments that indicated that completing the questionnaire had caused them to reflect on their changing life circumstances. For example, ID 29 wrote, "I found it interesting and realized that 'my' definitions of 'future' and 'goals' have changed considerably and would be quite different than a 'normal, healthy' persons" while ID 32 wrote, "Very satisfied as some of the questions opens my views of my sickness". Overall, comments

about the questionnaire were generally positive (56%, $N = 19$) while fewer people reported mixed or neutral feedback (11.8%, $N = 4$). Twenty-four percent (23.5%, $N = 8$) of respondents provided comments that were negative in tone. Many of those who provided neutral or negative comments expressed either dissatisfaction with the True/False format of the questionnaire and/or with the content of the BHS or they expressed discomfort with the questionnaire's focus on death and the pessimistic tone of some of the measures.

Using the SAHD cut scores established by Rosenfeld, Brietbart and colleagues (2000) a majority ($N = 40$, 81.6%) of the sample indicated a low desire for hastened death ($\text{SAHD} \leq 3$) while 18.4% ($N = 9$) indicated a moderate to high desire for hastened death: 10.2% ($N = 5$, $\text{SAHD} 4 - 10$) indicated "moderate" and 8.2% ($N = 4$, $\text{SAHD} \geq 11$) indicated "high" desire for death. Using a cut score of 8 or greater on the BDI-SF (Chochinov et al., 1997), 36.7% ($N = 18$) of participants indicated significant depressive symptoms while 22.4% ($N = 11$) of participants indicated high levels of hopelessness ($\text{BHS} \geq 9$, Beck & Steer, 1988). Means and standard deviations from the study are reported in Table 4 and are compared with results reported in published research. The current sample appears to score lower on the SAHD than in other studies; however, the two comparison studies did not attempt to minimize the impact of extreme outliers. A Canadian study by Jones and colleagues (2003) did not report the mean and standard deviation of the SAHD but the number of participants with advanced illness reporting moderate levels of desire for death (13%) and high levels of desire for hastened death (6.5%) correspond to the rates found in the current research. Values from

Table 4

Means and Standard Deviations

	Current study	Comparison Studies		
		Rosenfeld, Breitbart et al (2000)*	McClain et al (2003)	Chochinov et al (1995)
SAHD	2.9 (3.3)	4.8 (4.3)	4.4 (4.4)	
VOL	69.6 (16.1)			
BDI-SF	6.9 (4.9)			
Low desire for death	6.1 (4.3)			6.4 (4.0)
High desire for death	10.3 (6.3)			14.1 (8.2)
BHS	5.9 (4.2)	8.5 (6.4)	6.0 (4.7)	
FACTG	69.7 (17.0)			
KPS	58.2 (19.4)	40.1 (8.3)	39.3 (8.7)	

Key: SAHD = Schedule of Attitudes Toward Hastened Death; VOL = Valuation of Life Scale; BDI-SF = Beck Depression Scale-Short Form; BHS = Beck Hopelessness Scale; FACTG = Functional Assessment Cancer Therapy – General; KPS = Karnofsky Performance Scale.

* Combines the data in Rosenfeld, Breitbart et al (2000) and Breitbart et al (2000) who reported on a sample of 92 cancer patients from a palliative care hospital in New York city.

McClain et al (2003) sample of 160 cancer patients in a palliative care hospital in New York city.

Chochinov et al (1995) sample of 199 Canadian cancer patients in palliative care unit using the Desire for Death Rating Scale.

Table 4 suggest that the sample in this study appears to be comparable with other research in levels of hopelessness and depression but comprised of individuals with higher health status than previous research.

Correlations among transformed variables are reported in Table 5 and indicate that while there are strong relationships between variables there is no multicollinearity ($r < .9$, Tabachnic & Fidell, 1996) between variables. All correlations are in the expected directions; variables scored so that higher values indicate a higher quality of life (VOL, FACTG, KPS) correlate negatively with variables scored so that high values indicate higher levels of distress (SAHD, BHS, BDI-SF). Appendix L provides nonparametric correlations of the subscales of the FACTG using non-transformed data. These results indicate that three of the four subscales of the FACTG relate significantly to a desire for hastened death: Physical Well-being, Emotional Well-being, and Functional Well-being relate significantly to desire for death while Social Well-being is not significantly related to desire for hastened death. The subscales correlate significantly in the expected direction with the predictor variables with the exception of a non-significant relationship between Social Well-being and the KPS.

Prior to conducting tests of the hypotheses, the data were examined for significant covariates. A series of Oneway Analysis of Variances (ANOVA) were conducted for each of the variables of interest (SAHD, BDI-SF, VOL, BHS, FACTG, KPS) by religion, site, culture, stability of symptoms, type of cancer, gender, education, income, living arrangements, time since diagnosis, and age. These analyses were conducted using transformed variables to better

Table 5

Pearson correlation matrix[†]

	SAHD	BDI-SF	VOL	BHS [‡]	FACTG	KPS
SAHD	1					
BDI-SF	.56**	1				
VOL	-.69**	-.62**	1			
BHS [‡]	.62**	.62**	-.67**	1		
FACTG	-.56**	-.77**	.63**	-.62*	1	
KPS	-.39**	-.37*	.42**	-.24	.48**	1

Key: SAHD = Schedule of Attitudes Toward Hastened Death; BDI-SF = Beck Depression Scale-Short Form; VOL = Valuation of Life Scale; BHS = Beck Hopelessness Scale; FACTG = Functional Assessment Cancer Therapy – General; KPS = Karnofsky Performance Scale.

[‡] Transformed variables: SAHD, BDI-SF, VOL, BHS

[†] All correlations are calculated with 49 participants except analyses with the BHS (which has 47 participants due to missing data).

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

correspond with the assumptions underlying ANOVA. Marital status was not included in the ANOVAs due to the low number of participants ($N = 7$, 14.3%) who were not married. A Bonferonni correction was applied to control the family-wise error rate resulting in a corrected critical p value of .008. There were no significant differences on any of the variables for age, gender, time since diagnosis, living arrangements, income, education, type of cancer, stability of symptoms, or religion. The sample differed by recruitment site on the KPS [$F(2,46) = 19.8$, $p < .05$], with participants recruited from psychosocial resources scoring significantly higher than those from either inpatient [$F(1,30) = 70.3$, $p < .05$] or home care settings [$F(1,38) = 4.4$, $p < .05$] and those recruited from home care scoring higher than those from inpatient units [$F(1,24) = 12.7$, $p < .05$]. The mean and standard deviations of the KPS by recruitment site are as follows: home care ($M = 58.2$, $SD = 19.7$), psychosocial resources ($M = 68.3$, $SD = 10.2$), and inpatient ($M = 32.2$, $SD = 12.8$). Without a strong theoretical basis for using recruitment site as a covariate and in the absence of a consistent pattern of site being a predictor on the other key variables, however, a decision was made to not use recruitment site as a covariate in the analyses.

Hypothesis Testing

In Psychology, the standard analytic approach to testing a mediation hypothesis is to demonstrate the presence of a mediator through a series of regressions outlined by Baron and Kenny (1986) and further articulated by Kenny, Kashy, & Bolger (1998). Referring to Figure 2, Kenny et al (1998)

describe four steps: (1) Show that the predictor variable is related to the dependent variable [Path c in part A of Figure 2], (2) Show that the predictor variable is related to the mediator variable [Path a in Part B of Figure 2], (3) Show that the mediator variable is related to the dependent variable while the predictor variable is held constant [Path b in part B of Figure 2], and (4) Test whether the relationship between the predictor variable and dependent variable is zero while the mediator variable is held constant (this would be “complete mediation”) [Path c' in Part B of Figure 2]. Step 4 of Kenny and colleagues (1998) approach attempts to determine if the difference between c' and c is meaningful but they do not mandate significance testing of the indirect effect. In cases of partial mediation effects, which are more common in Psychology research than are complete mediation effects, it is difficult using Baron and Kenny’s causal modeling approach to assess the whether the change from c to c' is meaningful. It is possible, however, to test the significance of the indirect (i.e., mediated) effect using Sobel’s (1982) large-sample test. The Sobel test is sensitive to small sample size (it becomes less conservative with small samples) and to non normal sampling distributions (Preacher & Hayes, 2004). The data in the current sample are therefore problematic in terms of the Sobel test on two counts: (1) small sample and (2) non-normally distributed variables. While data transformations rectify the difficulty with assumptions of normality and enables regression analyses, the small sample size hinders the use of the Sobel test.

Recent developments in statistical theory, however, provide alternatives to the Sobel test (Bollen & Stine, 1990). In particular, the bootstrap approach can

be applied to test simple mediation effects when sample sizes are moderate or small (i.e., when there are between 20 to 80 cases) and when the mediator and outcome variables are not normally distributed (Bollen & Stine, 1990; Shrout & Bolger, 2002; Preacher & Hayes, 2004). Specifically, bootstrapping is a nonparametric approach to effect-size estimation and hypothesis testing that makes no assumptions about the shape of the distributions of the variables or the sampling distribution of the statistic (Preacher & Hayes, 2004). Simulation studies have demonstrated that with small samples and/or with distributions that violate assumptions of normality, the bootstrap results of mediation effects yield more accurate probability estimates than does the Sobel test (Shrout & Bolger, 2002). With the recent publication of an SPSS macro, the bootstrap approach has now become widely accessible (Preacher & Hayes, 2004).

Bootstrapping involves having a computer program generate a series of data sets that are designed to resemble the ones that would be observed if the study were repeated many times. Each bootstrap data set is obtained by sampling (with replacement) from the original data. If 1000 bootstrap samples are requested, a percentile estimate of the 95% confidence intervals is computed by ordering the 1000 bootstrap sample means from the lowest to the highest. The 95% confidence interval for 1000 bootstrap sample means is then defined by the 25th score marking the lower limit and the 976th score marking the upper limit (Shrout & Bolger, 2002; Preacher & Hayes, 2004). If zero is not in the 95% confidence interval, we can conclude that the indirect effect is significantly different from zero at $p < .05$ (two-tailed) (Preacher & Hayes, 2004).

Given the sample size and the nature of the variable distributions in the current sample, statistical analyses of the mediation hypotheses were conducted in the following manner:

- (1) Regression analyses followed Kenny et al (1998)'s causal model approach and were conducted on transformed variables. The decision to use transformed variables was due to the fact that regression analyses assume multivariate normality.
- (2) Bootstrapping was used to assess the significance of the indirect effect (mediator) in place of the Sobel test to eliminate the bias introduced by the small/medium sample size.

All analyses were calculated with 49 participants except those computations involving the BHS where 47 participants were included in the analyses.

Hypothesis 1. VOL mediates the relationship between depression and desire for hastened death.

Step 1. BDI-SF and SAHD are positively and significantly related (unstandardized $\beta = .55$, $p < .05$). Step 2. BDI-SF and VOL are negatively and significantly related (unstandardized $\beta = -1.00$, $p < .05$). Step 3. VOL is negatively and significantly associated with SAHD after controlling for BDI-SF (unstandardized $\beta = -.33$, $p < .05$). Step 4. BDI-SF is not significantly related to SAHD after controlling for VOL (unstandardized $\beta = .21$, $p = .10$). Using bootstrap analyses, the mediation effect was shown to be different than zero (95% CI: {0.16, 0.55} with 3,000 resamples).

Hypothesis 2. VOL mediates the relationship between hopelessness and desire for hastened death.

Step 1. BHS and SAHD are positively and significantly related (unstandardized $\beta = .84, p < .05$). Step 2. BHS and VOL are negatively and significantly related (unstandardized $\beta = -1.44, p < .05$). Step 3. VOL is negatively and significantly associated with SAHD after controlling for BHS (unstandardized $\beta = -.30, p < .05$). Step 4. BHS is significantly and positively related to SAHD after controlling for VOL (unstandardized $\beta = .42, p < .05$). Using bootstrap analyses, the mediation effect was shown to be different than zero (95% CI: {0.20, 0.65} with 3,000 resamples).

Hypothesis 3. VOL mediates the relationship between subjective quality of life and desire for hastened death.

Step 1. FACTG and SAHD are negatively and significantly related (unstandardized $\beta = -.03, p < .05$). Step 2. FACTG and VOL are positively and significantly related (unstandardized $\beta = .06, p < .05$). Step 3. VOL is negatively and significantly associated with SAHD after controlling for FACTG (unstandardized $\beta = -.34, p < .05$). Step 4. FACTG is not significantly related to SAHD after controlling for VOL (unstandardized $\beta = -.01, p = .13$). Using

bootstrap analyses, the mediation effect was shown to be different than zero (95% CI: {-0.03, -0.01} with 3,000 resamples).

Hypothesis 4. VOL mediates the relationship between functional status and desire for hastened death.

Step 1. KPS and SAHD are negatively and significantly related (unstandardized $\beta = -.02$, $p < .05$). Step 2. KPS and VOL are positively and significantly related (unstandardized $\beta = .04$, $p < .05$). Step 3. VOL is negatively and significantly associated with SAHD after controlling for KPS (unstandardized $\beta = -.38$, $p < .05$). Step 4. KPS is not significantly related to SAHD after controlling for VOL (unstandardized $\beta = -.01$, $p = .30$). Using bootstrap analyses, the mediation effect was different than zero (95% CI: {-0.0274, -.0039} with 3,000 resamples).

Effect Size

The regression analyses were examined for change in R-squared values to provide an index of the effect size of VOL (Table 6). After the variance of the predictors had been accounted for (i.e., the predictor variables were entered first into the regression model), VOL explained between 14-34% of the variance in SAHD. In contrast, the strongest of the predictor variables (BHS) contributed only 6% of unique variance in SAHD after taking into account the role of VOL.

Table 6

Unique contribution of VOL and Predictor variables to the variance in SAHD

	R^2 value			Unique contribution of VOL*	Unique contribution of Predictor*
	Predictor alone	VOL alone	Predictor + VOL		
BHS	.42	.50 ^a	.56	14%	6%
BDI-SF	.32	.48	.51	19%	3%
FACTG	.32	.48	.51	19%	3%
KPS	.15	.48	.49	34%	1%

Key: SAHD = Schedule of Attitudes Toward Hastened Death; VOL = Valuation of Life Scale; BHS = Beck Hopelessness Scale; BDI-SF = Beck Depression Scale-Short Form; FACTG = Functional Assessment Cancer Therapy – General; KPS = Karnofsky Performance Scale.

* Expressed as percentage in the table, the amount reflects the change in the R^2 value.

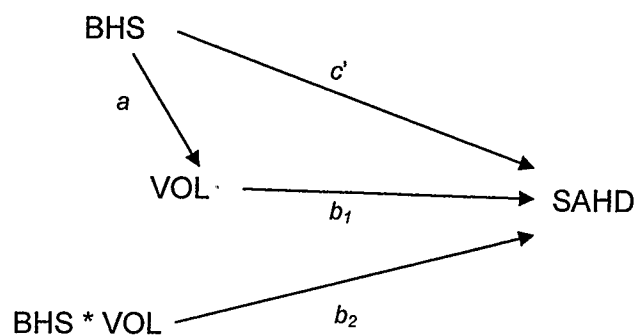
^a This value of R^2 differs from the other models due to smaller N used in analysis of BHS ($N = 47$).

Exploratory Analyses

Results of the mediation test of VOL on the hopelessness variable indicated that although there was a significant mediation effect, hopelessness remained a significant predictor in the model after taking into account the contribution of VOL. In consequence, the data were analyzed to explore whether there was a conditional indirect effect. A conditional indirect effect is one in which the mediation effect does not hold at all levels of the predictor variable. Instead, the mediation effect is active at some levels of the predictor variable but not at other levels of the predictor (Preacher, Rucker, & Hayes, 2006). In this model, which is depicted in Figure 3, the mediation effect of VOL is proposed to be moderated by hopelessness; VOL is proposed to mediate the relationship between BHS and SAHD at some levels of BHS but not at other levels of BHS. Because of the exploratory nature of this analysis, there was no *a priori* decision regarding whether the mediation effect worked only at high levels or only at low levels of BHS.

Regression procedures outlined by Preacher, Rucker, & Hayes (2006) were used to test this model. These analyses were conducted using non-transformed variables to facilitate the identification of the critical level at which the BHS moderated the indirect effect (using the Johnson-Neyman [J-N] technique, described below). Use of transformed variables would have produced a J-N value of the BHS that did not correspond with commonly understood parameters of the scale (e.g., a score of 9 or greater is indicative of high levels of hopelessness) because transformed variables have different means, standard

Figure 3. Moderated mediation.



Key: SAHD = Schedule of Attitudes Toward Hastened Death; VOL = Valuation of Life Scale; BHS = Beck Hopelessness Scale.

deviations, and ranges than do the raw scores.

There was a statistically significant interaction between BHS and VOL (unstandardized $\beta = -.01$, $p < .05$), indicating that the indirect effect of BHS on SAHD through VOL is moderated by the level of BHS. The sign of the interaction is consistent with the interpretation that the indirect effect of VOL is increased for participants with higher levels of hopelessness. To assess the critical point at which hopelessness becomes low enough such that the mediating effects of VOL become redundant, the Johnson-Neyman (J-N) technique was used to identify the value of BHS at which the conditional indirect effect is just statistically significant. These analyses indicated that the indirect effect was found to be significant at $\alpha = .05$ for any BHS value at or above the score of 4.2. This BHS value is below the mean BHS score for the sample ($M = 6.0$, $SD = 4.3$) which indicates that the VOL did not mediate the relationship between BHS and SAHD for participants who scored lower than average on the BHS. VOL did mediate the relationship between BHS and SAHD, however, for participants who scored at average or above average levels of hopelessness.

Discussion

The present investigation reaffirmed that depression, hopelessness, subjective quality of life and functional status are related to a desire for hastened death among cancer patients near the end of life. Using correlation coefficients as a measure of effect size, this study also confirmed that of these variables, hopelessness has the strongest relationship with the desire for early death

followed by depression, subjective quality of life, and objective functional status. The current study departs from the dominant body of research that examines the desire for death, however, by attempting to explain not *if* but *how* these predictor variables relate to the desire for hastened death.

While there is evidence from previous research that existential and spiritual factors are powerfully related to the desire for hastened death (McClain-Jacobson, et al., 2004) and, indeed, have been shown to provide a unique contribution to the desire for hastened death after controlling for the effects of depression (McClain, Rosenfeld, & Breitbart, 2003), the literature suffers from both a lack of clear definition and a lack of theory behind the analyses. In consequence, the existing literature has been descriptive in nature and lacks a clear conceptual focus of what to examine among the plethora of constructs and variables that fall under the rubric of “spiritual” and “existential” well-being. In examining the role of a cognitive-affective schema as a mediator between predictor variables and the desire for death, the current study adds clarity to the literature by providing preliminary evidence of an explanatory model of the desire for hastened death.

Findings from this study support M.P. Lawton’s contention that the Valuation of Life construct mediates the relationship between the desire for death and its predictor variables. The results of the causal modeling analyses corroborate the mediating role of valuation of life with all of the assessed predictors. The mediational hypothesis was further supported using a rigorous assessment of the significance of the indirect effect (MacKinnon, Lockwood,

Hoffman, West, & Sheets, 2002) of valuation of life with each of the four predictors (depression, hopelessness, subjective quality of life, and functional status). Measures of effect size of the valuation of life indicated that the variable accounts for approximately 50% of the variance in the desire for hastened death; meaningfully, the variable also demonstrated a unique contribution to the desire for death after controlling for the effects of the predictor variables (from a low of 14% after accounting for hopelessness to a high of 34% after accounting for functional status). In short, these analyses provide initial support for the hypothesis that depression, hopelessness, subjective quality of life, and functional status affect the desire for hastened death *because* they cause changes in the Valuation of Life construct and that the Valuation of Life construct in turn influences the desire for death.

In interpreting the results of this study it critical to bear in mind that Baron and Kenny's (1986) causal modeling approach to assessing mediator effects does not test whether the relationship between variables are, in fact, causal. The cross-sectional design of the current investigation does not provide evidence of the temporal order of these events (i.e., first depression changes and causes a change in valuation of life which then impacts the desire for death). Studies that are longitudinal in design are required to provide evidence of order effects. The findings from the current study instead provide initial evidence that M.P. Lawton's model of the valuation of life as a mediator between predictors of desire for shortened life and the desire for death has merit.

The findings from the current study have implications for researchers investigating the attitudes, wishes and behaviours of those near death. M.P. Lawton and his team at the Philadelphia Geriatric Centre developed the Valuation of Life construct and scale because Lawton considered existing measures of health related quality of life to be too focused on reporting negative ways of interpreting one's situation (Jaracz, Gustafsson, & Hamrin, 2004). He argued that in becoming focused on negative dimensions of responding to illness and disability, researchers were missing key aspects of how people assess the value of their lives at any given time. It seems possible that researchers in palliative care may also be missing an important element in research on desire for death. While existing quality of life scales in palliative care certainly reflect both positive and negative aspects of physical, social, functional, spiritual, and emotional well-being, they do not provide an overarching measure of how these positive and negative aspects of life are condensed and sorted into decisions and feelings about desire for life and desire for death. Lawton's Valuation of Life construct and scale attempt to quantify this evaluative process.

In developing his scale, Lawton enlisted existential variables not as a dimension of quality of life *per se*, but as an outcome measure of how changes in quality of life are evaluated and adapted to. In contrast, existing research in palliative care has used existential measures as a dimension of quality of life, albeit a critical one (Cohen et al., 1997; Rosenfeld, Breitbart et al, 2000; McClain et al., 2003; McClain-Jacobson et al, 2004; O'Mahony et al, 2005). Even among research that more closely resembles the concept that Lawton and colleagues

were trying to articulate, such as Chochniow's (2006) theme of 'dignity conserving perspectives' in his Dignity model, the dimension is included as part of a larger whole and has not been proposed to hold a mediating role between quality of life and desire for death. The findings from the current study do not contradict theorizing and research within the field of palliative care research; they do, however, demonstrate the value of a clearly articulated explanatory model in advancing our understanding of the role and importance of existential factors. In short, findings from this study appear to support the argument that existential factors, at least as measured by the Valuation of Life scale, are the outcome of how quality of life factors are weighed and adjusted to by people with illness. These existential elements are then key in the determination whether one wishes to live for as long as possible or whether one wishes life to end quickly.

As discussed earlier in this paper, the overlap between the VOL and current thinking around existential issues in palliative care is striking. The convergence of theory across different fields of research and arising from different epistemologies suggests that VOL and related existential constructs are indeed central to experiences at the end of life. With its grounding in the philosophy of positive psychology, the Valuation of Life construct implicitly suggests that not all individuals facing death require a redefinition of the meaning and purpose of their life. Depending on how premorbid values are defined by the individual, adaptation may be strictly in the domain of functioning and spur little need for reviewing meaning and purpose. Valuation of life does not imply that meaning and purpose, persistence, futurity, hope, and self-efficacy are under

threat by the approach of death but instead acknowledges that these domains may undergo shifting and redefinition as personal circumstances change. Given the low number of terminally ill people who report high levels of distress at the end of life, there is strong evidence that most people adapt to life changes and approaching death without succumbing to crisis. The valuation of life schema, however, comes into consciousness with changes in circumstances and impending death (Lawton et al, 2001) regardless of whether these circumstances cause a shift in valuation of life. In consequence, interventions that focus on allowing room for discussion of meaning, purpose, and continuity of self are consistent with valuation of life theory. It seems possible, however, that Lawton and colleagues would place these treatments under the rubric of helping people adapt successfully to their changing lives.

In addition to highlighting the value of theory-based research and the convergence of thought across fields of research, the findings from this study also suggest that Lawton and colleague's Valuation of Life concept and scale are worth further investigation in their own right. In-depth evaluation of the Valuation of Life scale is needed to ascertain if the mediational effect is due to one particular aspect of the scale (such as purpose or, alternatively, persistence) or if the scale functions as an integrated whole, as was intended by Lawton. In addition, further validation of the scale using a factor analytic approach is needed to ensure that the scale is a valid representation of the construct when used with participants with palliative illnesses. Studies with longitudinal design would

assess whether the predicted temporal relationships between the predictors, valuation of life, and desire for early death support a 'causal model'.

The Valuation of Life scale appears to approach what researchers and practitioners in palliative care are attempting to hone in on as they strive to better understand and care for those at the end of life. In consequence, comparison of the predictive power of the Valuation of Life scale with the predictive power of existing measures of spiritual and existential well-being (in relation to the desire for death construct) are needed to provide evidence that the concept and scale represent a novel contribution to research in palliative care. Following from this line of thinking, future research that undertakes to determine whether the role of the Dignity Model's 'dignity conserving perspectives' subtheme plays a particularly critical role in the overall experience of dignity at the end of life seems warranted by the current research. Given the findings from this study, it can be hypothesized that if a measure of 'dignity conserving perspectives' were designed, the construct would be shown to play a mediating role between other dimensions of end of life experience and the desire for hastened death.

The current findings also suggest that the relationship between hopelessness and the desire for death are complex in nature. Although this study provides evidence that the influence of hopelessness on desire for death is primarily indirect, through the Valuation of Life construct, it also provides evidence that hopelessness remained a significant predictor after taking into account the role of valuation of life. Exploratory analyses provided tentative evidence that hopelessness is a variable that moderates the relationship between

valuation of life and desire for hastened death. Specifically, valuation of life was shown to mediate the effects of hopelessness at moderate to high levels of hopelessness but not at low levels of hopelessness. Instead, there was a direct relationship between desire for hastened death and hopelessness when scores on the BHS were low.

There are several possible explanations for this finding. First, it is possible that low scores on the BHS and SAHD may reflect a common factor of social desirability [i.e., wanting to promote oneself as being very healthy]. It is known from research on the BHS, for example, that in non-treatment seeking populations there is no relationship between hopelessness and suicidal ideation after controlling for social desirability (Beck & Steer, 1988). The current sample is comprised of a combination of treatment seeking (a portion of those recruited through psychosocial resources) and non-treatment seeking individuals (those recruited through home care or inpatient services) and, since social desirability was not measured in the current study, the confounding role of social desirability cannot be ruled out. An alternative hypothesis is that the Valuation of Life construct is not activated at low levels of hopelessness. Lawton and colleagues (2001) have contended that valuation of life remains largely out of awareness until the individual is threatened by illness or death. It is possible that participants in this sample, while confronted with their own mortality, did not face threats to their purpose and meaning in life if they were not also feeling somewhat hopeless about their future. On logical grounds, however, this explanation does not seem likely since decrements in functional capacity associated with advanced illness

require necessary adjustments in daily life (which would activate the valuation of life schema) regardless of whether one is feeling hopeless or not. A more plausible alternative explanation is that that denial was a common factor among those scoring low on both desire for death and hopelessness. Some people cope with advanced cancer by taking a stance in which they are highly motivated to maintain an optimistic attitude that negates the possibility of acknowledging that sometimes they may feel hopeless or that they may occasionally wish that death would come quickly. This “denial” approach would likely result in very low scores on measures of hopelessness and desire for death but would not have such a profound influence on responses to questions that were existential in nature.

Finally, it is also possible that the moderated mediator effect of hopelessness found in exploratory analyses in the present investigation is a spurious finding that is due to poor measurement of the construct. The use of the BHS as a measure of hopelessness in palliative care populations has come under fire recently (Abbey et al., 2006) and findings from the current investigation support the argument that the scale may not be functioning as it was originally constructed – participants skipped more items on this scale than on all other measures combined. These findings raise concerns about what the BHS is measuring in palliative care settings. Abbey and colleagues (2006) critique the measure based on item endorsement and applicability of items. They found that some items were frequently endorsed by participants who did not otherwise have high hopelessness scores. In consequence, Abbey and colleagues (2006) suggested limiting the scale to those items that had item-total correlation

coefficients of .50 or greater on the assumption that the remaining items provide a stronger, more pure, measure of hopelessness. Their modified BHS scales (three versions of varying lengths) were not, however, evaluated to ascertain if they did, indeed, provide a stronger measure of hopelessness. Regardless, the potentially poor measurement of hopelessness remains a possible explanation for the moderated mediation effect in the current study.

As a final note, in the last few years there appears to be a trend whereby researchers are moving away from one-dimensional outcome measures, such as the SAHD and DDRS, in favour of using a collective of variables that are subsumed under the title of “existential suffering” or “end-of-life despair”. This movement away from one-dimensional endpoints as measures of distress at the end of life reflects, at least in part, a reaction against what is viewed as the artificial parsing out of constructs that are fundamentally intertwined in the lived experience of suffering (Chochinov & Cann, 2005). In using measures of multiple domains of existential and spiritual well-being researchers are attempting to reflect a more holistic approach to the understanding and measurement of suffering. For example, Breitbart and Heller (2003, p.981) state:

In our research, we had focused on desire for death as a specific outcome for which to identify predictors. But we have now begun to think about a larger construct, which we call “despair at the end of life.” We think this construct includes several components, such as desire for hastened death,

demoralization, loss of dignity, loss of meaning, and suicidal ideation.

In light of this dominant zeitgeist, the current study might be viewed as a return to an older, less sophisticated model of understanding end of life concerns. The parsing out of variables from related constructs, however, was purposefully executed in this study in order to assess the VOL mediation hypothesis. The findings from this study do not threaten the movement toward broader definitions of end of life despair. The results of this study do, however, provide support for the value of *a priori* (i.e., theory-driven) research that examines the relative contribution of the factors that fall under the term “despair at the end of life”. It seems likely that not all of the constructs under the general term have equal import in the experience of those at the end of life.

There are several factors that may limit the conclusions that can be drawn from this study. A critical question when evaluating research is whether features of the participant selection process restrict the conclusions in some unique way or in some way represent a poor test of the hypotheses (Kazdin, 2003). Given a recruitment procedure that relied on a pre-screening approach, the results of the study are not expected or intended to be representative of the entire population of individuals with advanced cancer. It seems plausible, for example, that the pre-screening approach and the use of volunteer participants created a sample that was weighted toward individuals who were more interested in being helpful and contributing to the well-being of those who come after them than were individuals who were not approached about the study or who did not volunteer to participate

in the study. In being comprised of volunteers it seems possible that the study attracted individuals who were likely to have high scores on the Valuation of Life scale given that it assesses purpose in life.

It is my contention that the study is not, however, a poor test of the mediation hypothesis as evidenced by: (1) the sample was drawn from the population of interest instead of a proxy sample and, (2) the measures in the study appear to be functioning as expected. That fact that participants in this study scored in expected ranges (and averages) on key measures (BDI-SF, SAHD, and BHS) lends strength to the argument that the findings of the mediating effect of VOL are not likely to be limited to the current sample. Instead, the consistency of the findings between this study and those of other researchers suggests that there is a broader concern that research in palliative care, in general, may suffer from under representation of those who are not interested in either being helpful to those who come after them or contributing to science and knowledge.

Another factor that may limit confidence in the study findings was the decision to use a subset of the sample to estimate effect sizes in order to assist in decision making with regard to the number of people required for the study. While using one's own sample to estimate effect sizes is not unheard of in this research area (e.g., Kissane et al, 2004), there are concerns about the impact this approach has on p-values and confidence intervals. In consequence, an attempt was made to ensure the stability of the dataset before examining effect sizes to limit the potential hazards of over or under estimating effect sizes.

Finally, this study represents the first use of the Valuation of Life scale with a sample of individual that have terminal illness. Full evaluation of the scale's performance in this population requires a large sample size; the factor structure of the Valuation of Life scale could not be evaluated to ensure that it was consistent with the Valuation of Life construct.

In conclusion, this study provides initial evidence that M.P. Lawton's Valuation of Life construct functions as a mediator between depression, hopelessness, and quality of life and the desire for hastened death. In developing a scale that blends beliefs and feelings about life's purpose and meaning and about hope, futurity, persistence, and self-efficacy Lawton sought to provide an alternative to existing predictors of years of desired life that were, in his view, overly focused on negative factors and that neglected critical aspects of the human experience. Although he acknowledged (Lawton, 1999, p. 183) that it is, "... unreasonable to think that the primitive methods used to estimate concepts like the Valuation of Life or Years of Desired Life are able to provide closure on the important questions being asked," the current study suggests that his ideas provide a new and potentially rich area of enquiry for researchers in palliative care. Since this study was initially proposed, there has been an explosion in research, models, and interventions that have highlighted the importance of existential well-being at the end of life (Chochinov, 2006). As researchers in palliative care continue to further articulate their respective models of existential factors at the end of life it is hoped that they will move rapidly from descriptive research to research that examines specific and clearly articulated hypotheses

about the pivotal role that these factors appear to play in patient well-being generally, and desire for hastened death, specifically.

It is also hoped that future research will continue to explore the role of the Valuation of Life construct and scale in palliative care populations. While it is acknowledged that the Valuation of Life scale suffers from a lack of large scale testing of its performance in palliative care settings it also offers researchers the benefit of being able to assess questions that fall squarely in the existential domain without being compromised by the constructs of faith and religion. This separation of the existential construct from the larger spiritual construct seems warranted given the findings from this study and given a growing pattern of findings in the literature indicating that the existential elements of the spirituality construct are more salient in predicting end of life distress than are the faith components of spirituality. Lawton and colleagues (2001) explicitly designed the Valuation of Life scale to provide a measure of the existential elements that collectively make up a total reason for living. It is hoped that researchers in palliative care will chose to depart from a tradition that relies on the construct of spirituality and instead turn their attention to exploring the existential domain as assessed by the Valuation of Life scale.

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Appendix A

Valuation of Life Scale

Positively worded items (high scores denote high valuation of life):

1. I feel hopeful right now.
2. Each new day I have much to look forward to.
3. My life these days is a useful one.
4. My life is guided by strong religious or ethical beliefs.
5. I have a strong will to live right now.
6. Life has meaning for me.
7. I feel able to accomplish my life goals.
8. My personal beliefs allow me to maintain a hopeful attitude.
9. I intend to make the most out of my life.
10. I can think of many ways to get out of a jam.
11. I can think of many ways to get the things in life that are important to me.
12. Even when others get discouraged, I know I can find a way to solve the problem.
13. I meet the goals that I set for myself.

Negatively worded items (high scores denote low valuation of life):

14. It is very hard to find much meaning in my everyday life.
15. I have very few goals in my life, today.
16. I'm just putting in time for the rest of my life.
17. I spend very little time planning for the future.
18. The real enjoyments of my life are in the past.
19. There are very few ways around any problem.

Appendix B

Schedule of Attitudes toward Hastened Death

Answered as True (T) or False (F), the responses in **bold** indicate high desire for death.

1. I feel confident that I will be able to cope with the emotional stress of my illness. **F**
2. I expect to suffer a great deal from emotional problems in the future because of my illness. **T**
3. My illness has drained me so much that I do not want to go on living. **T**
4. I am seriously considering asking my doctor for help in ending my life. **T**
5. Unless my illness improves, I will consider taking steps to end my life. **T**
6. Dying seems like the best way to relieve the pain and discomfort my illness causes. **T**
7. Despite my illness, my life still has purpose and meaning. **F**
8. I am careless about my treatment because I want to let the disease run its course. **T**
9. I want to continue living no matter how much pain or suffering my disease causes. **F**
10. I hope my disease will progress rapidly because I would prefer to die rather than continue living with this illness. **T**
11. I have stopped treatment for my illness because I would prefer to let the disease run its course. **T**
12. I enjoy my present life, even with my illness, and would not consider ending it. **F**
13. Because my illness cannot be cured, I would prefer to die sooner, rather than later. **T**
14. Dying seems like the best way to relieve the emotional suffering my illness causes. **T**
15. Doctors will be able to relieve most of the discomfort my illness causes. **F**
16. Because of my illness, the idea of dying seems comforting. **T**
17. I expect to suffer a great deal from physical problems in the future because of my illness. **T**
18. I plan to end my own life when my illness becomes too much to bear. **T**
19. I am aggressively pursuing all possible treatments because I'll do anything possible to continue living. **F**
20. I am able to cope with the symptoms of my illness, and have no thoughts of ending my life. **F**

Appendix C

Recruitment Handout

How does quality of life relate to the desire to prolong life or to hasten death?

In this study: We want to better understand the circumstances and personal attitudes that are related to why some people with advanced cancer want to live for as long as possible while others wish for a shortened life (the desire for a "hastened death").

If I decide to take part in the study what would I be asked to do?

- The study is a questionnaire (a paper and pencil question and answer package) that asks about quality of life, your desire to prolong life or to hasten death, and your personal attitudes.
- The questionnaire takes about 30 minutes to complete.
- A researcher from the University of Calgary would come to your room at the Hospital to give you the questionnaire and answer any questions you have about the study. The researcher can also read the questionnaire to you if you would prefer it over completing the questions on your own.

Please check if you are interested in taking part in the study:

- ☐ **Yes; please contact me**
☐ **No; please do not contact me**

Formal study title: Does the Valuation of Life construct predict a desire for hastened death among cancer patients who are terminally ill? **Researchers:** Ann-Louise Ellwood*, MSc & Barry Bultz**, PhD

* Department of Psychology, University of Calgary
Resources

** Tom Baker Cancer Centre, Psychosocial

This study has been approved by the Conjoint Health Research Ethics Board
at the University of Calgary, Grant ID# 16863.

Appendix D

Comparison of Participant Demographics

Demographic information

		Current Study	Jones et al (2003)	Breitbart et al (2000)
Group		% ^a	%	%
Gender	Male	43	49	40
	Female	57	51	60
Age	Less than 50 years	31		20
	51-65	41		24
	66-75	18		27
	76-85	8		20
	Greater than 85	2		8
	Mean \pm S.D	58.4 \pm 13.1	56.0 \pm 15.3	65.9 \pm 15.6
	Range	39 - 87	18 - 97	--
Cancer type	Brain & CNS tumours	2	2	
	Breast	35	4	
	Colorectal	25	6	
	Endocrine	6	7	
	Genitourinary	10	4	
	Gynaecological	2	12	
	Head and Neck	2	10	
	Leukaemia	2	27	
	Lung	12	7	
	Urinary System	2	1	
	Other	2	19	

		Current Study	Jones et al (2003)	Breitbart et al (2000)
Group		% ^a	%	%
Years of Education	< Grade 12	12		24
	Grade 12	16		34
	More than Grade 12	71		42
Time since diagnosis	Less than 1 year	4	Mean \pm S.D. 23.8 \pm 42.4 (months)	
	1 year	25		
	2 - 3 years	16		
	4 - 5 years	14		
	6 - 10 years	27		
	11 - 18 years	12		
Religion	Christian	84		
	<i>Roman Catholic</i>	27		52
	<i>Protestant</i>	39		18
	Jewish	0		16
	No religion or other	16		13
Marital Status	Single	0	17	29
	Married	86	62	28
	Widowed	6	6	11
	Divorced/separated	8	9	32

Appendix E

Items from the Beck Depression Inventory – Short Form

A. Sadness

- 3 I am so sad or unhappy that I can't stand it.
- 2 I am blue or sad all the time and I can't snap out of it.
- 1 I feel sad or blue
- 0 I do not feel sad

B. Pessimism

- 3 I feel that the future is hopeless and that things cannot improve.
- 2 I feel I have nothing to look forward to.
- 1 I feel discouraged about the future.
- 0 I am not particularly pessimistic or discouraged about the future.

C. Sense of failure

- 3 I feel I am a complete failure as a person (parent, husband, wife)
- 2 As I look back on my life, all I can see is a lot of failures.
- 1 I feel I have failed more than the average person.
- 0 I do not feel like a failure.

D. Dissatisfaction

- 3 I am dissatisfied with everything
- 2 I don't get any satisfaction out of anything anymore.
- 1 I don't enjoy things the way I use to.
- 0 I am not particularly dissatisfied.

E. Guilt

- 3 I feel as though I am very bad or worthless.
- 2 I feel quite guilty.
- 1 I feel bad or unworthy a good part of the time.
- 0 I don't feel particularly guilty.

F. Self dislike

- 3 I hate myself.
- 2 I am disgusted with myself.
- 1 I am disappointed in myself.
- 0 I don't feel disappointed in myself.

G. Self-harm

- 3 I would kill myself if I had the chance.
- 2 I have definite plans about committing suicide.
- 1 I feel I would be better off dead.
- 0 I don't have any thoughts of harming myself.

H. Social withdrawal

- 3 I have lost all of my interest in other people and don't care about them at all.
- 2 I have lost most of my interest in other people and have little feeling for them.
- 1 I am less interested in other people than I used to be.
- 0 I have not lost interest in other people.

I. Indecisiveness

- 3 I can't make decisions at all anymore.
- 2 I have great difficulty in making decisions
- 1 I try to put off making decisions
- 0 I make decisions about as well as ever

J. Self-image change

- 3 I feel that I am ugly or repulsive looking
- 2 I feel that there are permanent changes in my appearance and they make me look unattractive.
- 1 I am worried that I am looking old or unattractive.
- 0 I don't feel that I look any worse than I used to.

K. Work difficulty

- 3 I can't do any work at all.
- 2 I have to push myself very hard to do anything
- 1 It takes extra effort to get started at doing something.
- 0 I can work about as well as I used to.

L. Fatigability

- 3 I get too tired to do anything.
- 2 I get tired from doing anything.
- 1 I get tired more easily than I used to.
- 0 I don't get any more tired than usual.

M. Anorexia

- 3 I have no appetite at all anymore.
- 2 My appetite is much worse now.
- 1 My appetite is not as good as it used to be.
- 0 My appetite is no worse than usual

Appendix F

Items from the Beck Hopelessness Scale with response key for hopelessness.

1. I look forward to the future with hope and enthusiasm.	F
2. I might as well give up because there is nothing I can do about making things better off for myself.	T
3. When things are going badly, I am helped by knowing that they cannot stay that way forever.	F
4. I can't imagine what my life would be like in ten years.	T
5. I have enough time to accomplish the things I want to do.	F
6. In the future, I expect to succeed in what concerns me most.	F
7. My future seems dark to me.	T
8. I happen to be particularly lucky, and I expect to get more of the good things in life than the average person.	F
9. I just can't get the breaks, and there's no reason I will in the future.	T
10. My past experiences have prepared me well for the future.	F
11. All I can see ahead of me is unpleasantness rather than pleasantness.	T
12. I don't expect to get what I really want.	T
13. When I look ahead to the future, I expect that I will be happier than I am now.	F
14. Things just don't work out the way I want them to.	T
15. I have great faith in the future.	F
16. I never get what I want, so it's foolish to want anything.	T
17. It's very unlikely that I will get any real satisfaction in the future.	T
18. The future seems vague and uncertain to me.	T
19. I can look forward to more good times than bad times.	F
20. There's no use in really trying to get anything I want because I probably won't get it.	T

Appendix G

Karnofsky Performance Scale

Definition	%	Criteria
Able to carry on normal activity and to work. No special care is needed.	100	Normal; no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs of symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work. Able to live at home, care for most personal needs. A varying amount of assistance is needed.	70	Cares for self. Unable to carry on normal activity or do active work.
	60	Requires occasional assistance, but is able to care for most of his needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self. Requires equivalent of institutional or hospital care. Disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospitalization is indicated although death is not imminent.
	20	Very sick; hospitalization necessary; active supportive treatment necessary.
	10	Moribund, fatal processes progressing rapidly.
	0	Dead

Appendix H

FACTG items and instructions

"Below is a list of statements that other people with your illness have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days."

All questions are answered on the following scale:

Not at all	A little bit	Some-what	Quite a bit	Very much
0	1	2	3	4

Physical Well-being items:

1. I have a lack of energy
2. I have nausea I have nausea
3. Because of my physical condition, I have trouble meeting the needs of my family
4. I have pain
5. I am bothered by side effects of treatment
6. I feel ill
7. I am forced to spend time in bed

Social/Family Well-being items:

1. I feel close to my friends
2. I get emotional support from my family
3. I get support from my friends
4. My family has accepted my illness
5. I am satisfied with family communication about my illness
6. I feel close to my partner (or the person who is my main support)

Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box _____ and go to the next section.

7. I am satisfied with my sex life.

Emotional Well-being items:

1. I feel sad
2. I am satisfied with how I am coping with my illness
3. I am losing hope in the fight against my illness
4. I feel nervous
5. I worry about dying
6. I worry that my condition will get worse

Functional Well-being items:

1. I am able to work (include work at home)
2. My work (include work at home) is fulfilling
3. I am able to enjoy life
4. I have accepted my illness
5. I am sleeping well
6. I am enjoying the things I usually do for fun
7. I am content with the quality of my life right now

Appendix I

VOL Item statistics

VOL Item	Mean	Standard Deviation
I'm just putting in time for the rest of my life.*	3.82	1.3
I have very few goals in my life, today.*	3.29	1.3
There are very few ways around any problem.*	3.67	1.3
The real enjoyments in my life are in the past.*	3.31	1.5
It is very hard to find much meaning in my everyday life.*	3.57	1.4
I spend very little time planning for the future.*	3.16	1.2
My life these days is a useful one.	3.29	1.4
I feel able to accomplish my life goals.	2.96	1.3
I have a strong will to live right now.	4.18	1.2
I can think of many ways to get out of a jam.	3.73	1.2
My personal beliefs allow me to maintain a hopeful attitude.	4.10	1.2
Each new day I have much to look forward to.	3.63	1.3
I intend to make the most out of my life.	4.39	1.0
My life is guided by strong religious or ethical beliefs.	3.43	1.5
I can think of many ways to get the things in life that are important to me.	3.76	1.2
Even when others are discouraged, I know I can find a way to self the problem.	3.69	1.1
I meet the goals that I set for myself.	3.65	1.1
I feel hopeful right now.	3.82	1.1
Life has meaning for me.	4.18	1.2

* These items were reverse coded so that higher scores indicate higher valuation of life.

Appendix J

McGill Quality of Life Questionnaire Existential Well-being subscale

1. My life has been ...

0	1	2	3	4	5	6	7	8	9	10
Utterly meaningless and without purpose						Very purposeful and meaningful				

2. When I thought about my whole life, I felt that in achieving life goals I have ...

0	1	2	3	4	5	6	7	8	9	10
Made no progress whatsoever						Progressed to complete fulfillment				

3. When I thought about my life, I felt that my life to this point has been ...

0	1	2	3	4	5	6	7	8	9	10
Completely worthless						Very worthwhile				

4. I have felt that I have ...

0	1	2	3	4	5	6	7	8	9	10
No control over my life						Complete control over my life				

5. I felt good about myself as a person ...

0	1	2	3	4	5	6	7	8	9	10
Completely disagree						Completely agree				

6. To me, the past two days were ...

0	1	2	3	4	5	6	7	8	9	10
A burden						A gift				

Appendix K

Verbatim reaction to questionnaire.

ID	Comments
4	I feel that I have contributed to the health program whether the survey helps change anything in the system or not.
5	Dying is part of living. I have no problems to talk about it.
6	Don't give up – there's another day tomorrow.
7	Some of the questions presume I will be stressed/suffering/in pain as a result of my illness when this is not the case. I like surveys; it seems "sincere and honest" and was comfortable to complete.
8	We need more questionnaires to find out how people really feel about euthanasia.
9	I think this questionnaire is excellent. It will help doctors understand some emotional feeling the patients feel regarding a deathly illness which is most important.
11	Give something back to the health system that has given me excellent care.
12	I think it makes a good deal of sense. Thought provoking for people who haven't thought about the future. I felt that if I could help you or someone like you and contribute to knowledge, I should. I anticipated what the questions would be like.
13	I think there is no way that this questionnaire will capture the complexity of this issue. The questions seem too simplistic and/or narrow in focus.
19	To put these questions* to a 67-year-old with cancer is not right or relevant. * physically indicating the BHS.
20	The questions can be vague and require a lot of thought so they take time. It's too long.
21	I hadn't thought of half the stuff in there – I don't think like that. My perspective hasn't changed despite knowing that others think about it (the study didn't depress me). [The BHS]* is absolutely not appropriate for palliative patients. You can go either way for someone who's palliative on all of these. * physically indicating the BHS.

ID	Comments
23	Very in your face questions.
25	I had no problem answering any of these personal questions. I think they are questions that need to be asked of a person at my stage of cancer.
26	The Paxil works fine*. Hopefully it helps. * In further conversation with the research assistant this comment was clarified to mean that the participant was not bothered by the research.
27	Typical to others that I have completed. No surprises.
28	I find the situation I'm in is in no way just black or white and I find many questions don't allow for that. Thanks.
29	I found it interesting and realized that "my" definitions of "future" and "goals" have changed considerably and would be quite different than a "normal, healthy" persons.
30	This questionnaire was very easy for me to go through. I just completed a much more rigorous open-ended study that allowed me to explore questions around my own experience of facing into my own death. It asked such specific questions as, "Do you have any unfinished business?" That made me really evaluate the quality of my life and make some changes in who I relate to those in my life.
31	It was good. I want to help anyone and everyone I can to make their life easier. This is important for the future which we all have.
32	Very satisfied as some of the questions opens my views of my sickness.
34	Very interesting.
35	Anything I can do to improve someone's quality of life or chances for happiness would be my objective or goal. Helping others has always been my priority.
36	I am used to interviews, questions. If I can help someone in my answers that is worth my time!
37	It's a little bit disturbing and also some questions I felt like I was border line. Sometimes or very rarely you might feel one way but mostly it's positive.

ID	Comments
38	I felt that all the questions were reasonable and well thought out because this gives evidentiary information to how a person with advanced stage cancer feels. I think that in my responding to these questions we will find a wall (sic) to help and encourage others. I think that a person's faith will help them survive.
39	Good research. I am terrified of dying and am going to fight hard to stay alive for a long time. I found some of the questions I really had to think about, as I don't usually think about some of the issues concerning my illness. I try to get through each day as it comes and have not really thought about the future too far down the road.
40	Wording of some questions makes answering difficult or inappropriate. Some questions re: future not uncomfortable to answer, just complicated, making giving of answers perhaps inconclusive or misleading??
41	Very positive. Good work to do research on. Informed and pleasant and realistic interview research assistant. A pleasant experience!
43	Surprise. Some of the questions seemed inappropriate but the further I went the more I understood. Also makes me think which is very good. [Name of research assistant] was very good and complete in his explanation of the study.
44	I am very comfortable with the questionnaire and worker.
46	On the true/false questions I find choosing difficult because of what the question means to me. I.e., future is: two weeks, two years, ten years, beyond life.
47	The word hastened death to me meant a lot of different meanings at first. I did not understand the meaning of hastened death.
48	The questions seemed quite appropriate, not very difficult or stressful to answer.

Appendix L

Nonparametric correlations of the subscales of the FACTG

	VOL	SAHD	BDI-SF	BHS ^a	KPS	FACTG
Physical well-being	.33*	-.32*	-.57**	-.39**	.39**	.78**
Social well-being	.31*	-.09	-.50**	-.40**	-.04	.52**
Emotional well-being	.53**	-.49**	-.57**	-.64**	.36*	.80**
Functional well-being	.68**	-.40**	-.62**	-.41**	.47**	.83**

Key: VOL = Valuation of Life Scale; SAHD = Schedule of Attitudes Toward Hastened Death; BDI-SF = Beck Depression Scale-Short Form; BHS = Beck Hopelessness Scale; KPS = Karnofsky Performance Scale; FACTG = Functional Assessment Cancer Therapy – General.

^a All reported Spearman correlations are calculated with 49 participants except those with the BHS which has 47 participants.

** $p < .001$

* $p < .05$