

Original Article**Burden to Others and the Terminally Ill**

Harvey Max Chochinov, MD, PhD, Linda J. Kristjanson, PhD, Thomas F. Hack, PhD, CPsych, Thomas Hassard, PhD, Susan McClement, PhD, and Mike Harlos, MD

Departments of Psychiatry (H.M.C.), Family Medicine (H.M.C.), Community Health Sciences (H.M.C., T.H.), and Faculty of Nursing (T.F.H., S.M.), University of Manitoba, Winnipeg; Manitoba Palliative Care Research Unit (H.M.C., T.F.H., S.M.), and Patient and Family Support Services (H.M.C., T.F.H.), CancerCare Manitoba, Winnipeg; and St. Boniface General Hospital (M.H.), Winnipeg, Manitoba, Canada; and WA Centre for Cancer & Palliative Care (H.M.C., L.J.K.), Curtin University, Perth, Australia

Abstract

Studies of patients who are terminally ill consistently identify strong associations between “sense of burden to others” and marked end-of-life distress. However, little research has addressed the issue of burden to others among patients nearing death. The aim of this study was to carefully examine “burden to others” and clarify its relationship with various psychosocial, physical, and existential issues arising in patients who are terminally ill. A cohort of 211 patients with end-stage cancer was assessed, using an assortment of validated psychometrics to document psychosocial, physical, and existential aspects of their end-of-life experience. This included an assessment of their sense of “burden to others.” Forty percent of participants indicated a negligible sense of burden to others, scoring within the lowest quarter on an ordinal measure of “burden to others;” 25% scored within the second lowest quarter; 12% within the third quarter; and 23% within the highest or most severe range. The most highly correlated variables with “sense of burden to others” included depression ($r = 0.460$; $df = 201$, $P < 0.0001$), hopelessness ($r = 0.420$; $df = 199$, $P < 0.0001$), and outlook ($r = 0.362$; $df = 200$, $P < 0.0001$). Four variables emerged in a multiple regression analysis predicting burden to others, including hopelessness, current quality of life, depression, and level of fatigue [R^2 adj = 0.32, $F(6,174) = 13.76$, $P < 0.0001$]. There was no association between sense of burden to others and actual degree of physical dependency. Feeling a sense of burden to others is common among dying patients. Although 40% of the sample reported little in the way of sense of burden to others, the remainder endorsed higher degrees of burden-related distress, with 23% scoring within the most severe range. The lack of association between “sense of burden to others” and the degree of physical dependency suggests this perception is largely mediated through psychological and existential

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Address reprint requests to: Harvey M. Chochinov, MD, PhD, Department of Psychiatry, CancerCare Manitoba, 675 McDermot Avenue, Room 3021, Winnipeg, Manitoba R3E 0V9, Canada. E-mail: harvey.chochinov@cancercare.mb.ca

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Key Words

Burden to others, palliative care, psychosocial distress

Introduction

There is mounting evidence that sensing oneself to be a burden to others may be tantamount to existential extremis.^{1–7} When individual autonomy is conflated with personhood—so common in Western society—a significant assault on independence may lead to the feeling that life no longer has value. In some instances, the intensity of these feelings may be deemed incompatible with life itself. Not surprisingly, studies of terminally ill patients have consistently identified a strong association between sense of burden to others and an expressed wish for hastened death.^{3–7} For example, reports from family members of patients who had died indicated that, among patients who expressed a wish for a hastened death, 58–94% were distressed about being a burden to others.^{1,2} Other studies have indicated that according to physicians who had been asked to assist with death-hastening measures, patients' concerns about being a burden to others were a motivating factor in 41–75% of requests.^{3–5} Among dying patients who actually killed themselves, feeling a sense of burden to others was almost universal.^{6,7}

Although several studies have examined the issue of caregiver burden, few have looked at the issue of burden from the vantage point of dying patients. Although it seems clear that sensing oneself a burden to others and the devaluing of one's own life are intimately connected, little specific work has been done examining this particular relationship. Burden to others has been linked to quality of life in terminal illness, optimal end-of-life care, and maintaining a sense of dignity at the end of life.^{8–10} One of the few studies to specifically examine burden to others among dying patients noted its close relationship with existential, psychological, and to a lesser extent, physical symptoms, often seen toward the end of life.¹¹

The present study was undertaken as part of an ongoing program of research at the University of Manitoba and the Manitoba Palliative Care Research Unit at CancerCare Manitoba, examining various aspects of coping and adaptation to end-of-life challenges. This particular study sought to provide insight into the connection between a range of physical, psychological, and existential challenges facing patients approaching death and “burden to others.” Furthermore, this study sought to clarify the relationship between perceptions of burden to others and the reality of physical dependencies that patients come to accumulate during the course of their deteriorating, life-limiting illnesses.

Methods

Participants

Between January 2001 and January 2004, 411 patients were approached to participate in this study. Participants were recruited from the Winnipeg Regional Health Authority Palliative Care Program in Winnipeg, Manitoba. This program offers inpatient care (at St. Boniface General Hospital and the Riverview Health Centre) and coordinated, community-based, palliative end-of-life care services. Eligibility criteria included being 18 years of age or older; having a diagnosis of terminal cancer with a life expectancy of less than 6 months, as determined on the basis of clinical consensus of the palliative care team; an ability to read and speak English; demonstrating no evidence of dementia or delirium that might make completion of the study protocol difficult; and the ability to provide informed consent. Patients were not to be referred to the study if they were cognitively impaired, unable to give informed consent, or too gravely ill to take part in the protocol. Whether being treated in hospital or in the community, the medical status

of every patient was reviewed by the palliative care staff, which independently and collectively ascertained patient eligibility for the study.

The Health Research Ethics Board at the University of Manitoba approved the study and the Hospital Research Review Board of each hospital granted formal access to patients. Before data collection, all patients provided written informed consent.

Procedures

Patients were asked to complete a battery of self-report measures to provide a thorough assessment of their emotional state. This included a 10 cm visual analog scale (VAS) measuring burden to others, anchored by “no sense of burden to others” at one extreme [0], and “an overwhelming sense of burden to others” at the other extreme [10]. VAS measures have been used extensively in palliative care research, largely because they are easily and quickly administered to patients,^{12,13} and allow a way of rating a variety of subjective phenomena.¹⁴ Wilson et al. recently demonstrated excellent interrater correlations between the “burden to others” VAS and a single interview item designed to assess this construct within the palliative care setting ($r = 0.85$; $P < 0.001$).¹⁵ The reported test-retest reliability (within 1–3 days of initial administration) for this VAS was also excellent ($r = 0.73$; $P < 0.001$).

Other measures selected for this protocol were based on those with a putative influence on sense of burden to others or a desire for death, given the known association between these two variables.^{3–7} Anxiety, hopelessness, depression, and will to live¹⁶ were addressed with additional 10 cm VAS measures (with higher scores indicating a greater sense of anxiety, hopelessness, depression, and will to live). Measures of dignity, desire for death, and mood were structured on the Schedule of Affective Disorders and Schizophrenia,¹⁷ an approach we have reported on extensively in previous research, and one that has recently been incorporated into Wilson et al.’s Structured Interview Assessment of Symptoms and Concerns in Palliative Care.^{15,18–20} Each of these items is rated 0 (the complete absence of distress) to 5 (extreme distress). The interrater reliability, correlations with the equivalent VAS measure and test-retest for these

items have been reported as follows: dignity (0.98; 0.74; 0.57 [$P < 0.001$]), desire for death (0.99; 0.88; 0.90 [$P < 0.001$]), and mood (0.98; 0.78; 0.70 [$P < 0.001$]).¹⁵ A brief measure of quality of life was obtained, using the Quality-of-Life Scale.²¹ This two-item scale rates the patient’s self-assessed quality of life and his or her satisfaction with the current quality of life (ranging from 1 [poor] to 10 [excellent]).

The Symptom Distress Scale, a 13-item scale designed for use with cancer patients, measured the degree of distress associated with the following symptoms: nausea, appetite, insomnia, pain, fatigue, bowel pattern, concentration, appearance, breathing, coughing, and outlook (concern or worry about the future).²² Respondents reported their symptoms on a five-point scale, with high scores reflecting more distress. Pain was further evaluated using The McGill Pain Questionnaire.²³

Relatively little is known about the issue of personality and how it affects the individual coping with various end-of-life experiences. Of particular interest for this study was whether personality issues influence the perception of feeling a burden toward the end of life. To examine the association between sense of burden to others and the personality dimension of neuroticism (a trait tendency to experience psychological distress and coping difficulties), a brief measure of neuroticism—the 12 items from the NEO-Five Factor Inventory [NEO-FFI]—was included.^{24,25} Unlike most personality inventories, this instrument is brief enough to be feasible for inclusion in a palliative care protocol.

The Katz Activities of Daily Living (ADL) Scale was used to measure actual, rather than perceived, functional dependency.²⁶ The Katz ADL comprises a rating form that is completed by an observer, based on a patient’s responses to questions about his or her degree of independence within six areas of functioning, including bathing, dressing, toileting, continence, transferring, and feeding (scores can range from 0 [independent in all six functions] to 6 [dependent in all six functions]). Ten-centimeter VASs were used to measure two conceptual dimensions of social support: the structural aspects of support network (i.e., the availability of social support) and satisfaction with the degree of support provided.^{27,28} Using this approach, patients’

perceptions of support from their family members, friends, and health care providers were measured. Basic demographic information was also collected from all participants.

Experienced palliative care research nurses administered the study psychometrics, with regular monitoring by the principal investigator (H. M. C.) to ensure data integrity and standardized application of the protocol. The protocol was generally well tolerated by patients, taking between 30 and 45 minutes to administer.

Statistical Analysis

Spearman's correlation coefficients were calculated between "sense of burden" to others and other measures of symptoms and concerns. To determine whether inpatients experience sense of burden to others differently from patients being looked after in their homes or a community setting, the total sample, and these two component subsamples, were each examined separately. Unless otherwise specified, all tests were done on a two-tailed basis. Given the number of tests being carried out, only *P*-values of less than 0.01 were judged statistically significant to safeguard against Type I error. Forward stepwise multiple regression modeling was used to address the issue of inevitable variable intercorrelation. In this way, we were able to examine the predictive value of individual symptoms or concerns and burden to others, while offering a way of simplifying and unifying these key relationships.

Results

Of the 411 patients identified as potential participants for the study, 10 died and the health of 39 deteriorated before the interview could take place; 27 felt too sick or were too confused to allow for their participation; three had communication problems (either were unable to speak or did not speak English); two referred patients did not have cancer. Of these remaining 330 patients meeting eligibility criteria, 211 (64%) agreed to participate in the study (123 inpatients and 88 outpatients). Median length of survival from the time of study entry to death was 52 days (25th percentile = 19

days, 75th percentile = 114 days, interquartile range = 95 days).

The mean age of participants was 67 years (SD = 13.5). Eighty-nine (43%) were men. Forty percent of the study group had less than a high-school education, 20% had graduated from high school, and 40% had some college or postgraduate training. Fifty-seven percent of patients were married or cohabiting, with the remainder being divorced (7%), never married (8%), widowed (25%), or separated (2%). Religious affiliation was Protestant 46%, Catholic 26%, Jewish 2%, other 15%, and no religious affiliation 11%. Primary tumor sites included lung (26%), gastrointestinal tract (24%), genitourinary system (11%), and breast (13%). A further 7% of individuals had hematological cancers and the remaining 19% had various solid tumors.

The mean "sense of burden to others" rating for the total sample was 4.03 cm (SD 3.49). For inpatients, the mean "sense of burden to others" rating was 4.21 cm (SD 3.69), compared to 3.80 (SD 3.22) for outpatients ($t = 0.84$, NS); there was no significant relationship between sense of burden to others and length of survival ($r = -0.050$; $df = 172$, $P = 0.513$). Forty percent of total study participants scored within the lowest quarter of the "burden to others" VAS (0–2.5 cm) or least sense of burden to others; 25% scored within the second quarter (2.5–5.0 cm); 12% within the third quarter (5.0–7.5 cm); and 23% within the highest quarter (7.5–10 cm) or most severe range.

Although religious affiliation and marital status showed no significant relationship to sense of burden to others, other demographic variables, such as education ($t = 2.74$, $df = 200$, $P = 0.007$) and age ($t = -0.181$, $df = 201$, $P = 0.010$), did; that is, being younger and having a higher level of education were associated with feeling a sense of burden to others.

Table 1 summarizes the significant correlations between sense of burden to others and common symptoms and concerns reported toward the end of life. Noteworthy associations included those of a psychological nature: rating of depression ($r = 0.460$; $df = 201$, $P < 0.0001$), hopelessness ($r = 0.420$; $df = 199$, $P < 0.0001$), outlook ($r = 0.362$; $df = 200$, $P < 0.0001$), perceived ability to concentrate

Table 1
Correlations Between Burden to Others and Common End-of-Life Symptoms and Concerns

Symptom (Scale Range)	Variable Ratings		Inpatients		Outpatients		Total Sample	
	Mean	SD	Correlation	PValue	Correlation	PValue	Correlation	PValue
Depression rating (0–10)	1.91	2.47	0.52	0.0001	0.35	0.001	0.46	0.0001
Description of mood (0–5)	1.96	0.83	0.24	0.009	0.18	NS	0.23	0.001
Hopelessness (0–10)	2.68	3.08	0.48	0.0001	0.32	0.002	0.42	0.0001
Anxiety (0–10)	2.75	2.66	0.25	0.007	0.17	NS	0.23	0.002
Outlook (1–5)	1.96	1.19	0.50	0.0001	0.16	NS	0.36	0.0001
Q/L rating (1–10)	5.77	2.53	–0.30	0.002	–0.29	0.006	–0.30	0.0001
Q/L satisfaction (1–10)	5.67	3.01	–0.34	0.0001	–0.32	0.003	–0.33	0.0001
Level of concentration (1–5)	1.91	1.04	0.21	0.027	0.38	0.0001	0.28	0.0001
Appearance (1–5)	3.00	1.48	0.31	0.001	0.27	(0.012)	0.28	0.0001
Fatigue (1–5)	3.10	1.22	0.26	0.005	0.31	0.003	0.28	0.0001
Loss of sense of dignity (0–5)	0.74	1.04	0.31	0.001	0.34	0.001	0.32	0.0001
Will to live (0–10)	8.34	2.71	–0.27	0.004	–0.34	0.001	–0.30	0.0001
Desire for death (0–5)	0.72	1.24	0.36	0.0001	0.16	NS	0.29	0.0001
Neuroticism (12–52)	30.1	8.45	0.38	0.0001	0.26	(0.017)	0.33	0.0001

($r = 0.277$; $df = 200$, $P < 0.0001$), personality characteristics tending toward neuroticism ($r = 0.333$; $df = 198$, $P < 0.0001$), and overall ratings and satisfaction with quality of life ($r = -0.295$ – 0.332 , respectively; $df = 198$, $P < 0.0001$). Some significant associations between sense of burden to others and concerns of an existential nature were obtained, such as sense of dignity ($r = 0.32$; $df = 201$, $P < 0.0001$), will to live ($r = -0.30$; $df = 200$, $P = 0.0001$), and desire for death ($r = 0.30$; $df = 199$, $P < 0.0001$).

Aside from fatigue ($r = 0.276$; $df = 200$, $P < 0.00011$) and appearance ($r = 0.29$; $df = 199$, $P < 0.0001$), other physical issues, such as nausea, appetite, pain, and dyspnea, were neither significantly associated with sense of burden to others, nor was the actual degree of physical dependency, as measured by the Index of Independence in ADL. In analyzing the sample as a whole, satisfaction with social support and availability—from friends, family, and care providers—did not correlate significantly with patient ratings of sense of burden to others.

The list of significant inpatient correlations with burden to others was identical to those reported for the total sample. Regarding outpatients, however, there were some minor variations (Table 1), with outlook ($t = 2.56$; $P = 0.011$) and desire for death ($t = 2.08$; $P = 0.039$) showing significant differences in their correlation with the inpatient sample. It is also important to note that, as was the case in the entire sample, no significant

correlations were found between actual degree of physical dependency—measured by the Katz ADL—and “sense of burden to others” within either inpatients or outpatients.

We conducted a forward stepwise multiple regression analysis across the total sample to examine the predictive value of individual symptoms or concerns on sense of burden to others. Given that education and age were found to have a significant relationship with sense of burden to others, both were controlled for within the regression analyses. The final model for the total sample comprised four variables, entered in the following order: hopelessness ($\beta = 0.23$, $t = 3.03$, $P \leq 0.003$), current quality of life ($\beta = -0.14$, $t = 2.07$, $P = 0.04$), depression ($\beta = 0.21$, $t = 2.61$, $P = 0.01$), and level of fatigue ($\beta = 0.16$, $t = 2.30$, $P = 0.023$) [R^2 adj = 0.32, $F(6,174) = 13.76$, $P < 0.0001$]. Similar modeling was done for the inpatient and outpatient subsamples. For inpatients, the final model consisted of three variables, which entered as follows: hopelessness ($\beta = 0.21$, $t = 4.81$, $P < 0.0001$), outlook ($\beta = 0.24$, $t = 2.57$, $P = 0.012$), and bowel pattern ($\beta = 0.17$, $t = 2.05$, $P = 0.044$) [R^2 adj = 0.36, $F(5,98) = 12.76$, $P < 0.0001$]. For outpatients, the final model consisted of four variables, entered as follows: concentration ($\beta = 0.33$, $t = 3.2$, $P = 0.002$), satisfaction with friend support ($\beta = -0.21$, $t = 2.13$, $P = 0.037$), current quality of life ($\beta = -0.27$, $t = 2.63$, $P = 0.011$), and desire for death ($\beta = -0.21$, $t = 2.11$, $P = 0.039$) [R^2 adj = 0.308, $F(6,70) = 6.64$, $P < 0.0001$].

Discussion

Sensing oneself a burden to others is common among patients nearing death.¹¹ Although 40% of the patients in our study reported little in the way of feeling themselves to be a burden to others, the majority (60%) indicated varying degrees of burden-related distress, with 23% scoring within the highest quartile of distress. The findings are compelling, both with respect to the significant and nonsignificant associations reported regarding dying patients' sense of burden to others. As previously indicated by Wilson et al., the bearing of physical symptoms on terminally ill patients' sense of burden to others was outweighed by psychological and existential considerations.¹¹ In fact, within our sample of palliative cancer patients, the most significant correlations were seen between sense of burden to others and hopelessness, depression, and outlook. The prominence of these associations was reinforced in the regression model, where the first two variables entered first and third, respectively.

Hopelessness, besides its correlation with depression, has been shown to be a good predictor of suicidal ideation among patients nearing death.²⁹ Our more recent qualitative analysis of "hopelessness" in this patient population suggests that it approximates one's sense of meaning or purpose, or the lack thereof.¹⁰ Like self-deprecation, patients who feel life no longer has intrinsic meaning or purpose will not intuit that others view them as still having value, in spite of advancing disease and increasing dependency. Sensing themselves no longer having—or being seen as having—value, meaning, or purpose, patients with advanced illness may perceive their neediness or dependency as unfolding in a context shaped by an inability to give anything in return. This perception of needing to take while having little to provide in return, further clarifies the psychological landscape of "sense of burden to others."

Cohen et al. found that several issues have an influence on a dying patient's quality of life, including physical and cognitive functioning, psychological state, and physical condition; quality of palliative care; physical environment; relationships; and outlook.⁸ Regarding quality end-of-life care, Singer et al.

identified five important domains, including receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, strengthening relationships with loved ones, and relieving burden.⁹ Patients were most concerned about the burden related to the provision of physical care, witnessing their death, and substitute decision making for life-sustaining treatment. These were allayed when dying patients shared their concerns with loved ones, thus decreasing their sense of isolation in the face of death, and relieving their loved ones of the burden of having to make treatment decisions alone.

Feelings of depression are often accompanied by self-deprecation and a lack of sense of self-worth.^{30,31} These feelings, in the face of cumulative losses that accompany the dying process, can invoke or maintain a "sense of burden to others." If patients experience their very lives as lacking value or worth, they are unlikely to perceive that others will ascribe these same attributes to their current or continued existence.^{32,33} Hence, the perceived inability to bring something of value or worth within the context of interpersonal relationships might easily transform itself into sensing oneself as a burden to others.

Fatigue also has the potential to diminish physical and psychological resiliency, eroding the ability to stave off feeling overwhelmed or defeated.³⁴ Interestingly, although fatigue appears to have a connection with sense of burden to others, the actual degree of physical dependency does not. Perhaps the state of psychological and physical vulnerability seen in dying patients experiencing these sources of symptom distress further promotes a sense of having become a burden to others, in spite of any objective reality regarding the actual degree of physical dependency.

This seemingly counterintuitive finding regarding the lack of association between "sense of burden to others" and the actual degree of physical dependency experienced by people as they approached death was consistent across the inpatient, outpatient, and total sample analyses. If a robust cause and effect relationship between burden to others and dependency were accurate, one would expect "burden-related distress" to invariably occur among people with the highest degrees of

physical dependency or compromise their individual autonomy. In this regard, the disabilities literature is telling. Among patients with spinal cord injuries, for example, subjective quality of life or life satisfaction is related less to severity of injury or level of functional independence than to social and psychological functionings.^{35–37} Although this is a very different population than the end-stage cancer patients examined in our study, it does suggest the relationship between dependency and subjective distress is complex and largely mediated through various psychological, social, and existential considerations. As such, reducing perceptions of burden to others may have as much to do with strategies that target improved psychosocial well-being as it does with optimizing physical autonomy.

The association between personality characteristics and the way in which they influence the dying experience has not been extensively examined in the palliative care literature. Research of this nature is often hampered by the cumbersome nature of long personality inventories that are not well suited to a palliative care patient population. The inclusion of a measure of neuroticism within our protocol, to understand the influence of a trait tendency to experience psychological distress, offered a rare opportunity to examine the influence of personality characteristics and coping toward the end of life.^{24,25} The significant univariate association between neuroticism and “sense of burden to others” suggests that “who we are” may influence the experience of “how we die,” in ways that have not as yet been empirically explored. Although neuroticism did not enter into the various regression models predicting sense of burden to others, the influence personality has on end-of-life experience has yet to be fully explicated.³⁸

Although the ratings of sense of burden to others did not vary significantly between inpatients and outpatients, some differences in variable correlations and model entry across subsamples were noted. For example, compared to outpatients, an expected heightened vulnerability among inpatients was supported by the significant correlations between burden-related distress and measures of depression, desire for death, anxiety, and outlook. Like the total sample model, the regression equation for inpatients saw the variable

“hopelessness”—which has been shown to be closely aligned with depression and a loss of sense of meaning and purpose^{10,29}—enter first.

The regression model predicting “sense of burden to others” for outpatients saw “concentration” enter first, narrowly eliminating the mood description item from the model. Although concentration is phenomenologically related to depression, it may also be that for patients dying in the community, poor concentration reduces their ability to effectively engage with their support network, thus making them more vulnerable to burden-related distress. This is further supported by “lack of friend support” within this model, that is, those who felt lacking, or were unable to avail themselves of community support, were most likely to sense themselves becoming a burden to others. The connection between burden to others, quality of life, and desire for death, as previously discussed, demonstrates a logical consistency for the remaining variables entering this model.

This study has several limitations. Data were collected primarily from a group of patients with cancer, all of whom were receiving palliative care. Patients with nonmalignant illness, such as HIV-related disorders, neurodegenerative conditions, or end-stage renal or cardiac disease—particularly those being treated in nonpalliative care specialty units—may manifest different burden-related concerns. Rather than being disease specific, the trajectory of illness or more specifically, how long one has lived with cumulative losses resulting from an underlying condition, may have an important connection to adaptation and perceived sense of burden to others. Finally, this study did not address the degree to which health caregivers—formal and informal—may have felt burdened by the tasks of providing care. This information is critical, in that perceptions of burden to others may be influenced by the degree of burden-induced distress conveyed or implied by care providers. Future research of this kind, therefore, must address the issue of how a sense of burden to others might be shaped by the particularities of the relationship(s) between the patient and caregivers they perceived to be burdened.

Our prior research in end-of-life care has shown that there is strong association between

dignity, will to live, and a sense of burden to others. The current study offers a clearer understanding of the landscape of burden to others, with findings that suggest psychosocial strategies—targeting depression, anxiety, meaning, and purpose—could lessen this source of distress and thereby enhance comprehensive, quality, dignity-conserving care.

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