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Factors associated with the wish to hasten death: a study of patients with terminal illness

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ABSTRACT

Background. There is considerable debate regarding the clinical issues surrounding the wish to hasten death (WTHD) in the terminally ill. The clinical factors contributing to the WTHD need further investigation among the terminally ill in order to enhance understanding of the clinical assessment and treatment needs that underlie this problem. A more detailed understanding may assist with the development of appropriate therapeutic interventions.

Method. A sample of terminally ill cancer patients ($N=256$) recruited from an in-patient hospice unit, home palliative care service and a general hospital palliative care consulting service from Brisbane Australia between 1998–2001 completed a questionnaire assessing psychological (depression and anxiety), social (family relationship, social support, level of burden on others) and the impact of physical symptoms. The association between these factors and the WTHD was investigated.

Results. A high WTHD was reported by 14% of patients. A discriminant function analysis revealed that the following variables were associated with a high WTHD ($P<0.001$): higher levels of depressive symptoms, being admitted to an in-patient hospice setting, a greater perception of being a burden on others, lower family cohesion, lower levels of social support, higher levels of anxiety and greater impact of physical symptoms.

Conclusions. Psychological and social factors are related to a WTHD among terminally ill cancer patients. Greater attention needs to be paid to the assessment of psychological and social issues in order to provide appropriate therapeutic interventions for terminally ill patients.

INTRODUCTION

While there have been extensive studies of the attitudes of the general community and health professionals towards various forms of assisted or hastened death, research investigating these issues among individuals with terminal illnesses is limited. There is a scarce empirical base for understanding the problems that might underlie requests for assisted suicide among the

terminally ill, specifically the impact of the range of physical, psychological and social changes that accompany severe illness and the relative contribution of each to the desire for hastened death and assisted suicide.

Studies based on retrospective accounts of doctors and family members describing the key reasons for a patient's request for assisted suicide (van der Maas *et al.* 1991; Sullivan *et al.* 2000) have highlighted themes such as the loss of autonomy, lack of 'dignity', fear of the future, and unrelieved pain or suffering experienced by terminally ill patients. Detailed case reports

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outlining the experience of a small number of cases in Australia (Kissane *et al.* 1998*b*) suggest a range of complex clinical issues underlying the wish to hasten death (WTHD), particularly the assessment and treatment of depression, and the factors affecting a patient's perception of their illness (Kelly & Varghese, 1998).

The prevalence of a high or persistent WTHD among terminally ill individuals range between 8.5% and 17% (Chochinov *et al.* 1995; Breitbart *et al.* 2000; Emanuel *et al.* 2000) and fluctuate over time (Chochinov *et al.* 1995; Emanuel *et al.* 2000; Wilson *et al.* 2000), often with a reduction in levels as clinical interventions are initiated (Ganzini *et al.* 2000). The 'will to live' and the varying influences of both psychological and physical symptoms over time have also been investigated (Chochinov *et al.* 1999).

Psychological symptoms, especially depression, have been significantly associated with a WTHD (Chochinov *et al.* 1995; Breitbart *et al.* 2000; Akechi *et al.* 2001). The unique contribution of hopelessness (independent of levels of depression) on the WTHD has also been identified (Chochinov *et al.* 1998; Ganzini *et al.* 1998; Breitbart *et al.* 2000).

Social factors linked to attitudes to assisted suicide, and the WTHD, have included a lower perceived level of family and social support (Owen *et al.* 1994; Chochinov *et al.* 1995; Kissane *et al.* 1998*b*; Street & Kissane, 1999–2000; Breitbart *et al.* 2000) and the patient's perception of burden on family, friends and health care providers (Sullivan *et al.* 1998; Street & Kissane, 1999–2000; Breitbart *et al.* 2000; Wilson *et al.* 2000).

It is often assumed that the severity of unrelieved physical symptoms and disability are key triggers to the wish to hasten death or assisted suicide (Wilson *et al.* 2000). Nevertheless, this has not been supported in research findings, where levels of hopelessness and depression are identified as the variables mediating a link between disease severity and the WTHD (Breitbart *et al.* 1996; Emanuel *et al.* 1996, 2000; Chochinov *et al.* 1998, 1999; Wilson *et al.* 2000).

The aim of this study was to investigate clinical factors associated with the WTHD among a population of terminally ill cancer patients recruited across the range of in-patient hospice care, home-based palliative care and general hospital palliative care services. This builds on

previous research by evaluating a broad population of patients receiving palliative care across in-patient hospice, general hospital and home-based services, and by investigating a range of potential physical, psychological and social correlates of the WTHD, using multivariate analytical methods.

It was hypothesized that the WTHD among a sample of terminally ill cancer patients would be associated with a range of psychological and social variables, specifically levels of psychological distress (depression and anxiety), aspects of family functioning and social support and current physical symptoms. The chief aim was to examine, through multivariate analytical methods, the key clinical predictors of the WTHD in this population and the independent effect of each of the clinical variables.

METHOD

Participants

Terminally ill cancer patients ($N=256$) were consecutively recruited from three settings: (a) a 28-bed in-patient hospice unit; (b) Home Palliative Care Service; and (c) General Hospital Palliative Care Consulting Service, in Brisbane Australia between 1998–2001. Inclusion into the study was based on each patient: (i) demonstrating an adequate level of cognitive capacity (using a threshold score of 17 out of 30 on the Mini-Mental State Examination (Folstein *et al.* 1975); (ii) possessing an adequate command of English; and (iii) possessing adequate communication (e.g. speech and hearing). Consenting patients were assessed within 48 h after referral to the palliative care service. Questionnaires were completed with assistance from an interviewer if required. During the course of the study 1299 patients were referred to the clinical services. Five hundred and eighteen patients met inclusion criteria, and were physically well enough to participate. Of these, 256 agreed to participate in the study (response rate 49%).

The relevant institutional ethics committees from the University of Queensland, Princess Alexandra Hospital, and Mt Olivet Hospital approved the project.

Data collection

Instruments were used to assess a range of clinical and social factors that included physical

and psychological symptoms, social support, family relationship, perceived burden and the WTHD.

A modified version of a six-item WTHD Scale (Chochinov *et al.* 1995), previously used in terminally ill patients, was administered to assess the intensity and persistence of the WTHD. This modified scale retained similar wording used in the original scale items except that one item, 'Have you discussed with anyone that your desire is to hasten death?' was replaced with the following two items. 'Have you ever discussed a wish to die with family or friends?' and 'Have you ever discussed a wish to die with your doctor or nurse?' A sixth item, 'Have you ever asked your doctor or nurse to do something that might help end your life?' was also included. The inclusion of the three new items enabled increased variability of scores obtained from this scale and broadened the degree of the wish for death measured. The WTHD items are stem questions that were administered by a research assistant, who then clarified the time-frame and frequency of responses. While the original scale used a clinician's rating of the presence or absence of the item to assess the patient's level of WTHD, the modified scale used a five point Likert response format (no = 0, occasionally = 1, often = 2, almost always = 3 and constantly = 4). Scores across the six items were summed to give a composite score of the intensity of the WTHD for that patient. Scores could range between zero and 24. The items are indicated in Table 1.

Physical symptoms were assessed using 24 physical symptom items from the Memorial Symptom Assessment Scale (MSAS) (Portenoy *et al.* 1994), which measures the presence and severity of, and distress associated with physical symptoms in cancer patients. A total symptom score was calculated as a sum of the frequency and distress scores for each of the 24 symptoms endorsed by the patient. Summing the frequency and distress scores was reported to have greatest utility in providing what has been described as the total 'impact' of physical symptoms on quality of life (Portenoy *et al.* 1994).

Depression and anxiety were assessed through the 14-item Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The 12-item Social Support Scale (Sarason *et al.* 1983) provided scores on both the total number of, and satisfaction with social supports, and

Table 1. *Items from the Wish to Hasten Death Scale (modified after Chochinov et al. 1995) and frequency of endorsement*

1	Do you ever wish that your illness would progress more rapidly so that your suffering could be over? (35.5%)
2	Do you ever wish/pray for an early death? (22.7%)
3	Do you ever wish/pray that you were already dead? (16%)
4	Have you ever discussed a wish to die with family or friends? (18%)
5	Have you ever discussed a wish to die with a doctor or nurse? (13.7%)
6	Have you ever asked a doctor or nurse to do something that might help end your life? (3.1%)

the 12-item Family Relationships Index (FRI) (Kissane *et al.* 1998a) was used to evaluate the patient's perception of family interaction. Level of Perceived Burden was assessed by asking patients to rate the level of burden they believed their illness had become on family, friends, and medical staff. Patients selected from four options ranging from 'no burden' to 'extreme burden' with scores on each item ranging between one and four.

Data analysis

The factorial structure of the modified WTHD Scale, HADS and FRI was examined using maximum likelihood extraction with an oblimin rotation. A sample size of 256 participants in the study fulfilled the requirements for a minimum of 2.5–5 subjects per variable for such analyses (Tabachnick & Fidell, 1989). Internal reliability of measures was examined using the calculation of Cronbach's alpha coefficient.

The WTHD total scores exhibited a leptokurtic, positively skewed distribution. Total scores ranged from 0 to 18. The majority of patients ($N=152$) had a total score of 0. There was a linear taper of scores between one and four, with a cluster of 68 patients in this group, and then the scores exhibited a plateau from five to the highest total of 18. On the basis of the frequency distribution of scores for the WTHD, patients were categorized into those with an absent WTHD (score 0; $N=152$, 59%), those with a moderate WTHD (score from 1–4; $N=68$, 27%) and those with a high WTHD (a score of ≥ 5 ; $N=36$, 14%). This provided subgroups, based upon the distribution characteristics of the WTHD scores, of sufficient size for multivariate analysis. On the basis of these results a decision was taken to focus

on patients with no WTHD and to compare them to those patients who had the highest WTHD, in order to investigate the most clinically distinct groups.

A discriminant function analysis was used as a method of identifying a linear model that would best predict membership of the group with the highest WTHD scores, as compared with those patients without a WTHD. Statistical analysis was conducted using the windows version of the Statistical Package for Social Sciences (SPSS – Windows Version 10, 2000). Statistical significance was set at the level of $P < 0.05$.

RESULTS

WTHD

Factor analysis of the six WTHD items identified a unidimensional factor with an eigenvalue of 3.76. All items loaded on this factor at ≥ 0.34 . An alpha coefficient of 0.86 was computed indicating high internal consistency. The modified WTHD Scale has sound construct validity and high reliability. The percentage endorsing each item (i.e. 'occasionally' through to 'constantly') is described in Table 1. Eighteen per cent ($N=46$) had discussed a wish to die with a family member, almost 14% of all patients ($N=35$) reported having discussed a wish to die with a doctor or nurse and a smaller proportion (3.1%, $N=8$) had requested interventions to end their life.

Of those classified in the high WTHD group based on total WTHD scores, 31 of the 36 in this group endorsed at least one of the three items indicating a discussion of a wish to die with either family, doctor or nurse or having asked for euthanasia. Among the other WTHD items, the remaining five patients endorsed the item of wishing they were 'already dead' at as 'often', 'almost always', or 'constantly'.

The frequency of the high WTHD category varied significantly across the three recruitment sites, with 23% ($N=23$) of in-patient hospice unit patients being in this group, while 8% ($N=9$) of the home care and 5% ($N=7$) of the general hospital patients scored in this range ($\chi^2 = 18.82$, $df=4$, $P=0.001$).

HADS

Factor analysis was conducted on each of the 14 items from this scale, with the number of factors

to be extracted set to two on theoretical grounds. This analysis was conducted to confirm the construct validity of this measure in this sample. Two items, 'I can sit at ease and feel relaxed' (anxiety) and 'I feel as if I have slowed down' (depression) were omitted on the basis that both items did not demonstrate a sufficient independent loading on either factor at the 0.4 level as recommended by Stevens (1992). The first factor had an eigenvalue of 4.63 and accounted for 38.6% of the variance. The second factor had an eigenvalue of 1.89 and accounted for 15.8% of the variance. These scales, consisting of the six remaining items from the original depression scale and the six remaining items from the original anxiety scale were subsequently used in the discriminant function analysis.

FRI

This instrument has been reported to provide three subscale scores: family cohesion, family conflict and family expressiveness (Kissane *et al.* 1998a). Factor analysis of the 12 items was conducted with the number of factors to be extracted set to three on theoretical grounds. The resultant structure matrix indicated only one robust factor with items loading >0.4 (Stevens, 1992). The factor to emerge from this analytical process contained four items with loadings >0.4 . There were three items measuring cohesion from the original scale and one item measuring expressiveness. This variable, made up of these four items was labelled 'cohesion' and was subsequently used in the discriminate analysis to assess the level of family relationship.

Sociodemographic factors and the WTHD

The sociodemographic and disease characteristics of this sample of 256 patients are presented in Table 2. The mean age of the sample was 66 years (s.d. = 13.15 years, range 20–94 years). Mean time since initial diagnosis was 24.46 months (s.d. = 37 months, median time = 9 months). The most common cancer diagnoses were gastro-intestinal ($N=86$, 34%), lung/respiratory ($N=49$, 19%) and genito-urinary cancers ($N=49$, 19%). No significant differences between patients across treatment settings were found. Marital status differed significantly between the two WTHD groups, with more widowed patients expressing a high WTHD (39%) than no WTHD (19%, $P < 0.05$).

Table 2. Sociodemographic characteristics and cancer diagnoses of the total sample (N = 256)

Variable	N (%)
Sex	
Female	122 (48)
Male	134 (52)
Marital status	
Married/ <i>de facto</i>	136 (53)
Widowed	69 (27)
Divorced/separated/single	51 (20)
Religion	
None	87 (34)
Protestant	110 (43)
Catholic	56 (22)
Other	3 (1)
Living (with)	
Alone	65 (26)
Spouse/partner	134 (52)
Children	36 (14)
Brother/sister	8 (3)
Aged-care facility	13 (5)
Diagnosis	
Gastro-intestinal	86 (34)
Lung/respiratory	49 (19)
Genito-urinary	49 (19)
Central nervous system	18 (7)
Skin	12 (5)
Breast	12 (5)
Haematological	8 (3)
Bone/musculoskeletal	8 (3)
Head and neck	4 (1)
Primary unknown	10 (4)
Treatment setting	
Hospice	100 (39)
Home care	85 (33)
Hospital	71 (28)

Multivariate analysis

A discriminant function analysis was conducted to investigate a linear model that predicted WTHD group membership. A statistically significant function was detected which correctly classified 77.5% of cases ($\chi^2 = 39.30$, Wilk's $\lambda = 0.786$, canonical correlation = 0.46, $P < 0.001$). The following variables exhibited significant correlation with this function: higher depression scores, treatment setting (hospice), greater perceived burden on others, lower family cohesion scores, lower number of social supports, less satisfaction with social supports, higher anxiety and higher physical symptom scores (Table 3).

DISCUSSION

This study was concerned with identifying the key clinical factors associated with a wish to hasten death among a large sample of terminally

Table 3. Discriminant function analysis: clinical factors associated with the wish to hasten death

Variable	Standardized correlation coefficient	Within-group correlation
Depression	0.51	0.71
Treatment setting (hospice)	-0.45	-0.51
Perceived burden	0.42	0.52
Family cohesion	-0.29	-0.32
Number of social supports	-0.13	-0.21
Satisfaction with social supports	-0.10	-0.40
Anxiety	0.08	0.48
Physical symptoms	0.01	0.33
Centroids (No desire = -0.24, high desire = 1.12)		
Canonical correlation = 0.46		
$\chi^2 = 39.30$; df = 8, $P < 0.001$		

ill cancer patients recruited from three separate palliative care settings. This study investigates the relative contribution of a range of common psychological, social and physical dimensions of terminal illness, on the patient's wish for hastened death, using a data analytical method that provides a linear model of these variables that predicts, to a significant level, those patients with the highest wish to hasten death among this sample.

A high WTHD was found among 14% of the sample studied, while 59% reported having no WTHD. The proportion of patients expressing a high WTHD was comparable with the rates found in other studies of patients with a terminal illness (Chochinov *et al.* 1995; Breitbart *et al.* 2000; Emanuel *et al.* 2000).

The discriminant function analysis revealed that having a higher level of depressive symptoms, being admitted to an in-patient hospice setting, perceiving oneself as a greater burden on others, reporting less family cohesion, having fewer social supports and less satisfaction with social supports, being more anxious and experiencing greater impact of physical symptoms significantly predicted those more likely to indicate a high WTHD than no WTHD. This finding supports our hypotheses that psychological and social factors represent chief determinants of a WTHD in this sample.

Depressive symptoms accounted for the largest shared variance of this cluster of variables in predicting those with a high WTHD. This finding supports those of previous studies that have indicated the significant association between depressive symptoms and a WTHD

in similar populations (Emanuel *et al.* 1996; Breitbart *et al.* 2000; Akechi *et al.* 2001).

Being admitted to an in-patient hospice unit, rather than receiving treatment in either a home care or general hospital setting was found to be the second most significant factor associated with a high WTHD. This requires further investigation. Patients were assessed generally within 48 h of admission to the hospice in-patient unit. Therefore, the findings regarding the setting are likely to reflect aspects of the patient's condition, acute response to the hospice admission or reflect the underlying problems resulting in admission to the hospice occurring, rather than a reflection of the quality of the care received in this unit. As the levels of physical symptoms did not have a significant overall effect, issues other than severity of illness alone may be pertinent, including the patient's reaction to referral to an in-patient hospice unit compared to those interviewed at home or in a general hospital ward.

This study did not follow the course of the WTHD in this sample but other research has indicated that the WTHD and the request for assisted suicide varies over time, and may have diminished in this group as the initial impact of in-patient hospice admission abated. The patient's escalating psychological distress may be a factor leading to hospice inpatient admission (Hinton, 1994), and the higher WTHD indicative of this distress, or of a depressive disorder complicating the patient's advanced physical illness.

Perceiving oneself to be a burden on others contributed to a WTHD, supporting earlier studies (Sullivan *et al.* 1998; Street & Kissane, 1999–2000; Breitbart *et al.* 2000; Wilson *et al.* 2000). Our finding that a lower level of family cohesion and social support was associated with a high WTHD confirms other findings on the role of social support in the WTHD (Chochinov *et al.* 1995).

The MSAS scores comprised a total of the subscales measuring the distress and frequency of a list of common physical complaints found among individuals with cancer (Portenoy *et al.* 1994). The level of distress noted from each physical symptom has been found to be most strongly linked with function and quality of life measures used in the validation of the MSAS, and a multidimensional approach incorporating both distress and frequency is suggested as a robust measure of the total impact on the patient

of the physical symptoms (Portenoy *et al.* 1994). It is interesting to note that these MSAS scores were much less significant in the predictive model than psychological and social variables. This confirms the more important independent effect of psychological symptoms, particularly depression, and the social factors outlined, in the development of the WTHD. This also suggests that the distress that patients associate with physical symptoms may represent a separate dimension to the psychological symptoms such as depression, and has a less significant link with the WTHD in this analysis when other variables such as depression are included. This is of key importance in challenging the view that unrelieved and distressing physical symptoms, particularly pain among patients with advanced cancer, make assisted suicide both a justifiable and appropriate response to incurable 'physical suffering'.

A limitation of this study was that it was not possible to determine causality based on the cross-sectional and correlational nature of the study. The study did not determine that the factors identified cause the WTHD in this population, but rather that the scores on these variables were able to differentiate those with a high WTHD from those without. The items used to measure the WTHD were a modification of those used by Chochinov *et al.* (1995) to expand the format in order to capture a greater variability in responses. The items have face validity in assessing a spectrum of wishes, through to requests for hastened death. Although the findings indicate robust construct validity and internal reliability, the measure has not been assessed alongside other well-validated scales such as the Schedule of Attitudes towards Hastened Death that have been published (Rosenfeld *et al.* 1999).

These findings, along with the growing base of empirical data in this field highlight the importance of clinical interventions aimed to assess and alleviate the emotional suffering that patients and their carers experience with particular emphasis on depression and the social impact of illness, factors that demonstrated the most powerful effects in multivariate analysis.

Impediments to adequate psychiatric care at the end-of-life have been described (Shuster *et al.* 1999). These findings are significant in further emphasizing the role of psychological and social factors in the WTHD that can be an achievable

focus for clinical care. The similarities to findings from research regarding suicide in other populations is noteworthy. A similar need exists to develop measures to prevent suicide among the terminally ill, particularly by improving the capacity of the care they receive to more satisfactorily address their psychosocial needs.

We wish to thank all the patients and their families who gave so much of their generous time and effort in taking part in this study. Many thanks also to the dedicated staff from the Mount Olivet Inpatient Hospice, Mount Olivet Home Care Service and the Princess Alexandra Hospital Palliative Care Consulting Service for their enthusiasm, cooperation and consideration during the course of the study.

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