



# Mental disorders and the desire for death in patients receiving palliative care for cancer

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## ABSTRACT

**Objectives** The desire for death in terminally ill patients is associated with depression and anxiety, but not all patients who report it meet criteria for mental disorders. We examined the characteristics of subgroups of palliative cancer patients who expressed a desire for death that occurred either with or without a concurrent depressive or anxiety disorder.

**Design** Cross-sectional survey.

**Setting** Eight Canadian palliative care programs.

**Participants** 377 patients with cancer.

**Main outcome measures** Desire for Death Rating Scale; Structured Interview of Symptoms and Concerns.

**Results** Most participants (69.5%) had no desire for death. Of the remainder, 69 (18.3%) acknowledged occasional transient thoughts, and 46 (12.2%) reported an apparently genuine desire to die. In the latter group, 24 individuals (52.2%) were diagnosed with a mental disorder and 22 (44.8%) were not. Individuals with no serious desire for death and no mental disorder reported the least distress in physical, social, existential, and psychological symptoms and concerns; those with a mental disorder and a significant desire for death reported the most. The subgroup of patients with a serious desire for death but no concurrent mental disorders still reported increased distress due to physical symptoms and social concerns, as well as a higher prevalence of global suffering.

**Conclusions** The expression of a desire for death by a terminally ill patient should raise a suspicion about mental health problems, but is not in itself clearly indicative of one. Nevertheless, it may serve as a catalyst to review the individual's physical symptom management and interpersonal concerns, and overall sense of suffering.

## INTRODUCTION

The societal interest in the euthanasia/assisted-suicide debate has encouraged research into the prevalence and correlates

of the desire for death in the terminally ill. This research has shown that the desire for death is actually quite common among patients with advanced, life-threatening illnesses.<sup>1</sup> In palliative care settings, it has been found that 11–55%<sup>2–9</sup> of patients experience such a desire at least transiently, and from 3–20%<sup>2–6 8–12</sup> report a more pervasive and apparently sincere wish to die.

Although there have been inconsistencies, various studies have reported low to moderate correlations between the desire for death and pain,<sup>3 7 13–15</sup> fatigue and other physical symptoms,<sup>7–11</sup> weak social support,<sup>3 4 7 11</sup> diminished functional status,<sup>9 15 16</sup> low quality of life,<sup>2 9 15</sup> anxiety<sup>11 12 15</sup> and hopelessness.<sup>2 8 9 14 16–19</sup> Perhaps the most well-replicated correlation, however, has been with measures of depression.<sup>2 3 6–10 12 14–16 19–21</sup> Indeed, every study that has looked for an association between depression and the desire for death has found one, and Brown *et al*<sup>22</sup> reported that *all* such patients were clinically depressed.

Nevertheless, research based on structured diagnostic interviews has reached the more tempered conclusion that mental disorders are evident among many, but not all, terminally ill patients who express a desire for death. In most studies, the prevalence of diagnosed disorders among these individuals has ranged from 47–80%.<sup>2 3 6 8 10 19</sup> This suggests that the desire for death is often embedded in a broader context of clinically significant psychological distress, but not always. Qualitative studies have confirmed that there may be different pathways by which individuals arrive at a desire for death. Nissim *et al*<sup>23</sup> reported that a hastened death is sometimes seen as a hypothetical



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exit strategy that could forestall an anticipated experience of suffering. For some patients, however, this desire is not hypothetical at all, but real and immediate. Even in these cases, Nissim *et al*<sup>23</sup> identified a dichotomy; for some, the desire for death is an expression of despair, whereas for others it is a manifestation of letting go. In the present study, we hypothesize that the former pathway may be more characteristic of those patients who also have significant psychological disorders, whereas the latter pathway may be more likely among those who are not necessarily clinically anxious or depressed, but who have reached a stage of illness at which they are ready for death to come. Our main goal, therefore, is to examine the characteristics of patients with advanced cancer whose desire for death is embedded in these two different pathways: either with or without a concurrently diagnosed mental disorder.

## METHODS

### Study design

This project is a secondary analysis of data from the Canadian National Palliative Care Survey (NPCS), a multicentre, cross-sectional study of patients receiving palliative care for cancer. NPCS interviews were conducted between May 2001 and March 2003.

### Sample

A detailed description of the recruitment procedures and demographic characteristics of the NPCS participants are reported in previous publications.<sup>24 25</sup> Participants were recruited from among consecutive admissions to inpatient palliative care units, hospital consultation services, or home care. Inclusion criteria included that: (1) the patient had a diagnosis of cancer and had been informed of the prognosis; (2) a palliative care clinician estimated that survival duration was under 6 months; (3) the patient was deemed to be cognitively competent and medically stable enough to participate in the interview and (4) the patient could converse in English or French.

A total of 377 patients provided complete information regarding the desire for death and details relevant to the diagnosis of depression and anxiety disorders. An earlier NPCS report addressed the overall prevalence of mental disorders.<sup>26</sup> As yet, however, there has not been an explicit focus on the co-occurrence of these disorders with the desire for death.

### Procedure

Patients were interviewed by professional staff who conducted face-to-face, semistructured interviews. The interviewers all had previous clinical experience in palliative care nursing, psychology, social work, or education. They were trained in the specific interview protocol at a central two-day workshop before recruitment began.

### Ethics

The protocol was approved by the research ethics boards of all institutions involved, including: Memorial

University of Newfoundland Human Investigation Committee; Centre hospitalier universitaire de Québec, comité d'éthique de la recherche; The Ottawa Hospital Research Ethics Board; SCO Health Service Research Ethics Board; The Ottawa Institute for Rehabilitation Research and Development Research Ethics Committee; University of Manitoba Health Research Ethics Board; University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research; Alberta Cancer Board Research Ethics Committee; University of Alberta Health Research Ethics Board (B: Health Research); Caritas Health Group Research Steering Committee; British Columbia Cancer Agency Research Ethics Board; Kelowna General Hospital Institutional Research Review Committee; University of British Columbia Providence Health Care Research Ethics Board. All patients provided written informed consent prior to participation.

### Measures

#### Demographic and social characteristics

The interview began by reviewing basic demographic characteristics. It then proceeded to cover a range of issues associated with the individual's experience of various physical and psychological problems.

#### Structured Interview of Symptoms and Concerns

The Structured Interview of Symptoms and Concerns (SISC)<sup>27</sup> assesses end-of-life issues through the use of single-item screening that covers common physical symptoms (six items: general malaise, pain, drowsiness, nausea, weakness, breathlessness), social concerns (four items: social isolation, interpersonal communication problems, self-perceived burden to others, financial difficulties), existential issues (six items: spiritual crisis, difficulty accepting, general dissatisfaction with life, loss of dignity, loss of resilience, loss of control), and mental-health problems (four items: anxiety, depressed mood, loss of interest or pleasure in activities, and hopelessness). Two additional items assess the overall sense of suffering and the desire for death.

Each item on the SISC begins with a structured lead question into the presence of a particular symptom or concern. This is followed by questions probing into the severity of the issue, which is then rated by the interviewer on a seven-point scale (anchored at 0=no problem and 6=an extremely severe problem). For each symptom or concern, a score=3 represents a 'moderate' level of severity, and is the threshold at which the symptom or concern has been identified by the participant as a significant problem. This threshold has been used in previous research to identify the prevalence of clinically significant problems in particular areas.<sup>3 25 28 29</sup>

#### Depression and anxiety disorders

Depression and anxiety disorders were assessed with the SISC mental health questions in conjunction with items drawn from the Primary Care Evaluation of Mental Disorders clinician interview guide (PRIME-MD).<sup>30</sup> The PRIME-MD is based on the diagnostic criteria

outlined in the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (DSM-IV),<sup>31</sup> and provides a quick screening method for a range of discrete diagnoses. The present modification involved the substitution of the original PRIME-MD screening questions for depressed or hopeless mood, loss of interest or pleasure in activities, and anxiety, with corresponding items from the SISC. The SISC approach provides a more in-depth discussion of these issues, and ensures that the symptom ratings adhere to severity thresholds specified in the DSM-IV.<sup>32</sup> The remaining symptom criteria for each disorder were retained from the PRIME-MD interview, which allowed for the diagnosis of major depression, major depression in partial remission, minor depression, dysthymia, panic disorder, generalised anxiety disorder, anxiety disorder not otherwise specified and anxiety disorder secondary to a general medical condition.<sup>26</sup>

**Desire for death**

The SISC lead question for the desire for death asked, ‘Do you ever wish that your illness would progress more quickly so that your suffering could be over sooner?’ If the participant responded affirmatively, follow-up questions included: ‘Do you ever wish for death?’ ‘How often do you feel this way?’ ‘Is it quite constant, or are there times when you do not feel that way?’ ‘Do you pray for death to come soon?’

The lead and follow-up questions were derived from those reported by Chochinov *et al.*<sup>3</sup> As with other SISC items, the desire for death was rated on a 0 (no desire for death) to 6-point (extreme) scale, with a rating of 3=‘moderate’ corresponding to the respondent’s having ‘a genuine desire for early death that is reported to be consistent over time, but he/she is not consumed with the prospect’. This cut-off has been used in previous research to identify individuals with a ‘serious and pervasive’ desire to die.<sup>2 5 6 8 10 11 19</sup>

**Analysis**

SPSS statistical software package (V.18) was used for all analyses. Many of the distributions for individual SISC items, including the desire for death, were positively skewed, indicating that most participants

reported minimal difficulties in those areas. For some analyses, therefore, the SISC scores are categorised with regard to whether the participant indicated that the symptom or concern was a significant problem (ie, scores  $\geq 3$ ). The SISC data for these individual symptoms and concerns were then analysed using a non-parametric approach. In order to provide a broader perspective, however, we also computed subscale scores by summing the original item ratings within the a priori dimensions of physical symptoms, social concerns, existential issues and psychological problems.<sup>25</sup>

We first examined the prevalence of the desire for death in the entire sample at the different severity levels. Participants were then classified into two groups scoring either above or below the cut-off on the desire-for-death rating scale. Preliminary analyses were undertaken to compare these two groups, and are reported in online supplementary table S1.

Next, participants were divided further into subgroups of individuals who either did, or did not, meet DSM-IV diagnostic criteria for a depressive or anxiety disorder. These four groups were then compared, using analyses of variance for continuous variables and  $\chi^2$  analyses for categorical.

**RESULTS**

**Sample characteristics**

The 377 participants included 169 males (44.8%). The mean age of participants was 67.2 years (SD=12.9), and the median survival duration until death was 63 days. The majority of participants were Caucasian (94.4%). There were 91 (24.1%) participants who met criteria for an anxiety or depressive disorder.

**Prevalence of the desire for death**

The distribution of scores on the desire-for-death rating scale is shown in table 1. Although the majority of participants (69.5%) had no desire for death, there were 115 (30.5%) individuals who experienced at least an occasional wish to die (scores  $\geq 1$ ). Of this group, 46 (12.2% of the entire sample) participants

**Table 1** Distribution of scores on the desire-for-death rating scale (n=377)

Desire for death score	Description	Number of patients	%
0	No desire for death	262	69.5
1	Minimal—eg, only occasionally has fleeting thoughts	38	10.1
2	Mild—eg, sometimes feels he/she would like an early death, but not always	31	8.2
3	Moderate—eg, has a genuine desire for early death that is reported to be consistent over time, but is not consumed with the prospect	11	2.9
4	Strong—eg, most of the time feels a pervasive wish for death to come soon	14	3.7
5	Severe—eg, almost all of the time has a strong desire for death to come; prays for death	9	2.4
6	Extreme—eg, constant strong desire for death to come soon; thinks of little else; often prays for death	12	3.2

received moderate-to-extreme scores, and are considered to have had a serious desire for death.

### Prevalence of mental disorders

Psychological disorders were more common among those with a serious desire for death ( $p < 0.001$ ). Of the 46 participants in this group, 24 (52.2%) met DSM-IV criteria for either depression ( $n=8$ ), an anxiety disorder ( $n=1$ ), or both ( $n=15$ ), whereas 22 (47.8%) did not. Of the participants with no significant desire for death ( $n=331$ ), 67 (20.2%) met criteria for a mental disorder and 264 (79.8%) did not. Thus, the participants with a serious desire for death were about 2.5 times more likely to be diagnosed with a psychological disorder.

### Mental disorders and the desire for death

We then examined the demographic characteristics and symptom profiles among four groups of participants who varied in the presence/absence of a DSM-IV disorder, as well as in the presence/absence of a serious desire for death.

There were no significant differences between the four groups in gender, marital status, living arrangement, education and median survival duration,  $ps > 0.19$ . However, they differed with respect to age,  $F(3, 373) = 4.14$ ,  $p = 0.007$ . Participants with a mental disorder but no significant desire for death ( $M = 63.2$  years,  $SD = 13.1$ ) were younger than those with no disorder, either with a serious desire for death ( $M = 72.6$  years,  $SD = 11.3$ ) or without ( $M = 68.0$  years,  $SD = 12.9$ ),  $ps < 0.04$ . Participants with a diagnosed disorder and a serious desire for death ( $M = 65.0$  years,  $SD = 11.0$ ) did not differ from any of the other groups.

The rates of problematic symptoms and concerns are shown in table 2. On the total subscale scores, there were overall differences on each of the physical,  $F(3, 373) = 17.95$ ,  $p < 0.001$ , social-relational,  $F(3, 373) = 11.10$ ,  $p < 0.001$ , existential,  $F(3, 373) = 17.60$ , and psychological,  $F(3, 373) = 88.15$ ,  $p < 0.001$ , dimensions. At the level of individual symptoms and concerns, there were group differences in 18 of 20 comparisons ( $ps < 0.008$ ), as well as in the global of experience of suffering ( $p < 0.001$ ).

Pairwise posthoc comparisons were conducted to identify the specific contrasts that accounted for these overall effects. They revealed that individuals with no mental disorder and no significant desire for death had lower scores on all four SISC subscales than both groups of patients with mental disorders ( $ps < 0.001$ ).

Not surprisingly, the two groups diagnosed with mental disorders also had more severe psychological symptoms than patients who reported a serious desire for death in the absence of a disorder ( $ps < 0.001$ ). The latter group also had lower existential distress than those who had a desire for death and a mental disorder ( $p < 0.001$ ), but they were similar in this regard to those who had a mental disorder alone ( $p > 0.10$ ).

These three groups (ie, serious desire for death with a disorder, serious desire for death without a disorder, no serious desire for death with a disorder) did not differ from one another on the subscale scores for physical symptoms or social concerns ( $ps > 0.094$ ).

When the two groups with mental-health diagnoses were compared, those with a significant desire for death were found to have more severe difficulties in the existential and psychological domains ( $ps < 0.001$ ).

The last pairwise contrast involved comparisons of patients with or without a serious desire for death who did not meet diagnostic criteria for an anxiety or depressive disorder. This is an important comparison because it examines the profile of individuals who express a desire for death that is independent of a concurrent mental health problem. Indeed, these groups did not differ in their total score ratings for either psychological or existential issues ( $ps > 0.34$ ). However, individuals with a serious desire for death did report more severe physical symptoms ( $p = 0.01$ ) and more distress around social concerns ( $p < 0.001$ ). Of the individual problems, a greater percentage of those with a desire for death reported ongoing difficulty with the physical symptoms of general malaise, drowsiness, weakness and breathlessness ( $ps < 0.05$ ), as well as with the social concerns of isolation and self-perceived burden to others ( $ps < 0.01$ ).

A final analysis was undertaken of the ratings on the single item that inquired about the participant's global level of suffering. The proportion of patients with high levels of suffering was greatest among the group with a concurrent mental disorder and a serious desire for death. Over 83% of these patients suffered to a clinically important degree, which was significantly greater than each of the other groups ( $ps < 0.003$ ). Those with neither a serious desire for death nor a mental disorder suffered the least (13.6%;  $ps < 0.003$ ). The remaining two groups had comparable overall rates of suffering (44.8% for no serious desire for death and a mental disorder versus 40.9% for a serious desire for death and no mental disorder;  $p = 0.43$ ).

## DISCUSSION

In the first part of this study, we found that 30.5% of the participants experienced a desire for death at least transiently, with 12.2% reporting a more serious desire that was rated as an apparently genuine wish. Both prevalence estimates are within the ranges reported by previous investigators.<sup>2-12</sup> We also found that 52% of those with a serious desire for death met diagnostic criteria for a depressive or anxiety disorder. As in previous research based on diagnostic interviews,<sup>2 3 8 10 19</sup> mental disorders were much more prevalent among those with a serious desire for death than those without. Therefore, the expression of a desire for death by a terminally ill patient should raise a suspicion about mental health problems; by itself, however, it is not definitively diagnostic of one.

**Table 2** Symptoms and concerns reported by participants with or without a serious desire for death, broken down by the presence or absence of a mental disorder

Symptom or concern	No serious desire for death (n=331)		Serious desire for death (n=46)		p Value
	No disorder (n=264)	Disorder (n=67)	No disorder (n=22)	Disorder (n=24)	
<b>Physical problems</b>					
General malaise	89 (33.7)	37 (55.2)	14 (63.6)	18 (75.0)	<0.001
Drowsiness	65 (24.6)	30 (44.8)	12 (54.5)	14 (58.3)	<0.001
Nausea	31 (11.7)	18 (26.9)	6 (27.3)	9 (37.5)	<0.001
Weakness	140 (53.0)	43 (64.2)	17 (77.3)	22 (91.7)	<0.001
Breathlessness	65 (24.6)	17 (25.4)	8 (36.4)	8 (33.3)	0.54
Pain	74 (28.0)	33 (49.3)	7 (31.8)	13 (54.2)	0.001
Total (M, SD)	9.3 (5.6)	13.2 (6.7)	13.3 (6.1)	16.4 (5.1)	<0.001
<b>Social-relational concerns</b>					
Social isolation	12 (4.5)	17 (25.4)	7 (31.8)	8 (33.3)	<0.001
Communication problem	2 (0.8)	2 (3.0)	2 (9.1)	2 (8.3)	0.007
Burden to others	53 (20.1)	24 (35.8)	10 (45.5)	11 (45.8)	0.001
Financial problem	20 (7.6)	12 (17.9)	1 (4.5)	1 (4.2)	0.04
Total (M, SD)	2.2 (2.4)	4.4 (3.8)	4.8 (3.6)	5.0 (4.3)	<0.001
<b>Existential issues</b>					
Loss of resilience†	19 (3.8)	8 (12.1)	2 (9.1)	13 (54.2)	<0.001
Loss of dignity	9 (3.4)	9 (13.4)	2 (9.1)	5 (20.8)	0.001
Loss of control	5 (1.9)	9 (13.4)	3 (13.6)	8 (33.3)	<0.001
Spiritual crisis‡	4 (1.5)	5 (7.5)	1 (4.8)	1 (4.2)	0.07
Difficulty accepting	17 (6.4)	9 (13.4)	1 (4.5)	6 (25.0)	0.007
Dissatisfaction with life	7 (2.7)	8 (11.9)	1 (4.5)	3 (12.5)	0.006
Total (M, SD)	1.9 (2.4)	4.7 (3.8)	3.0 (2.9)	7.7 (6.3)	<0.001
<b>Psychological difficulties</b>					
Anxiety	10 (3.8)	29 (43.3)	0 (0.0)	18 (75.0)	<0.001
Depression	7 (2.7)	29 (43.3)	0 (0.0)	16 (66.7)	<0.001
Loss of interest/pleasure*	10 (3.8)	27 (40.9)	2 (9.1)	14 (58.3)	<0.001
Hopelessness‡	4 (1.5)	21 (31.3)	3 (13.6)	14 (58.3)	<0.001
Total (M, SD)	1.9 (1.9)	7.8 (3.9)	2.9 (2.4)	11.5 (4.6)	<0.001
<b>Global considerations</b>					
Suffering	36 (13.6)	30 (44.8)	9 (40.9)	20 (83.3)	<0.001

Table entries are n (%) of participants who endorsed specific symptoms or concerns at a moderate-to-extreme level; p values are based on  $\chi^2$  tests for individual symptoms and concerns and one-way analyses of variance for total scores. Total scores refer to the mean of the summed item ratings within each of the physical, social-relational, existential and psychological dimensions.

\*One patient with missing data.

†Two patients with missing data.

In the terminology of Nissim *et al*,<sup>23</sup> we considered that the desire for death among patients with a concurrent mental disorder was more likely to represent an 'expression of despair' rather than a 'manifestation of letting go'. As such, it was possible that patients who arrived at the desire for death via this pathway would differ in other clinically relevant ways from patients with no concurrent mental health problem. In this context, there were several major findings. First, it was evident that patients who had neither a serious desire for death nor a mental disorder were experiencing the least problematic course of illness. They differed from patients with concurrent mental disorders in all dimensions of symptoms and concerns, and also experienced less physical and social distress than those with a serious desire for death in

the absence of a disorder. Hence, this group appears to have been coping well and achieving optimal palliative care outcomes. Importantly, this was also the largest group in the study, comprising 70% of the participants.

The psychological items of the SISC provided the initial basis for screening for the core symptoms of the depressive and anxiety disorders. It was to be expected, therefore, that individuals diagnosed with these disorders would report greater psychological distress than those who were not, even if the latter group expressed a significant desire for death. This was indeed found. However, a second major finding was that patients with a serious desire for death and a concurrent mental disorder were experiencing the most difficult course of illness. The extent of their

psychological and existential distress was greater than that of all other groups, including those with a mental disorder but no significant desire for death. They also had the most pervasive experience of suffering.

Apart from more severe psychological symptoms, patients with a mental disorder but no serious desire for death were similar to those with a desire for death but no mental disorder on the existential, social, and physical symptom dimensions. They also had similar rates of global suffering. They were younger, however. An association between younger age and psychological distress has been noted in other research, including previous reports from the NPCCS.<sup>25 26 28 29</sup> It may be that younger individuals experience a more acute sense of untimely death that presents a risk for depression and anxiety,<sup>26</sup> have less developed coping strategies for dealing with death, have more concern about the welfare of dependants, or are simply more willing to disclose psychological problems.<sup>26 28 33</sup>

In some respects, the most important findings involve comparisons between the two subgroups of patients who had no concurrent mental disorders. A concern about the desire for death in the context of euthanasia or assisted suicide requests is that depression and anxiety may result in cognitive distortions, perhaps transitory, that bias the decision to end one's life.<sup>3</sup> Presumably, this bias is absent among those who have no particular mental health concerns. Another central finding, therefore, is that patients with a serious desire for death in the absence of a disorder still reported a higher degree of physical symptom distress and were more likely to endorse a sense of suffering. They were also more likely to acknowledge difficulties with social isolation and to feel like a burden to others. Interestingly, these social constructs figure prominently in a new 'interpersonal' theory of suicidal behavior,<sup>34</sup> which apparently has some applicability to medical populations.<sup>35</sup> The present findings suggest that it is perhaps relevant to the desire for death in the terminally ill as well.

Although we initially regarded a serious desire for death in the absence of a mental disorder as a 'manifestation of letting go' rather than an 'expression of despair', it appears that this desire is, nevertheless, embedded in a more complex clinical presentation. Thus, even when a formal mental disorder has been ruled out, a patient's report of a desire for death may serve as a catalyst to review physical symptom management, interpersonal concerns, and the overall sense of suffering.

There are several limitations to the study that must be noted. First, it was conducted as a secondary analysis of an existing dataset. Although the measures are appropriate to the purpose, dividing the sample into four subgroups, each with or without significant symptoms and concerns, resulted in small numbers of participants for some comparisons. Moreover, all the patients were receiving palliative care for cancer, and the prevalence

of mental disorders and the desire for death may be different in other patient groups. A third limitation is that the study addresses patients' experience of the desire for death rather than direct requests for euthanasia or assisted suicide. Although participants in the NPCCS were asked about their interest in receiving a physician-hastened death, only 22 individuals reported a readiness to end their lives in this way.<sup>24</sup> This group was considered too small to subdivide on the basis of mental disorders. As we reported elsewhere, most (83%) patients with an interest in receiving euthanasia also had a serious desire for death. Conversely, however, only 39% of those with a serious desire for death would have opted for euthanasia, at least at the time of the interview. Thus, the desire for death and the desire for euthanasia are not synonymous,<sup>1 36</sup> and it is possible that they have differing associations with mental disorders.

Levene and Parker<sup>37</sup> reviewed 21 studies pertaining to depression among people who have made explicit requests for euthanasia or assisted suicide. They concluded that in The Netherlands and the US State of Oregon, which permit these practices in some circumstances, 8–47% of patients who make such requests have high levels of depression. It is unclear, however, whether this rate is elevated in comparison with other patients with terminal illness. Moreover, even when depression is present, it is uncertain whether it is actually critical in either motivating the requests or in rendering the patients incompetent to make them. In The Netherlands, it has been found consistently that depressed patients are more likely to have their requests refused,<sup>38–40</sup> suggesting that practitioners do appreciate the role of potentially treatable psychological problems.

There may be a paradox, however. Jurisdictions that permit euthanasia or physician-assisted suicide usually justify these practices as a way of providing relief from 'unbearable suffering'.<sup>41 42</sup> Our results suggest that the experience of suffering is much more prevalent among those terminally ill individuals who have concurrent psychological disorders; yet in The Netherlands, these patients are apparently less likely to have their requests granted. Perhaps there is considerable societal acceptance of euthanasia as a way to assist patients in letting go at the end of life, but more hesitation when it is used to relieve their expression of despair. It may also be that healthcare providers make a distinction between despair that may or may not be remediable. Although these two pathways to the desire for death are distinct conceptually, in practice they may not be mutually exclusive.

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**Contributors** KGW designed the study, obtained ethics approval, conducted analyses, drafted the paper, and is guarantor. TLD undertook data cleaning and analyses, and drafted the paper. HMC designed the study, obtained ethics approval, collected data, and revised the draft paper. SC, PRG, KM, MDL, FOS, DK, and RLF obtained ethics approval, collected data, and revised the draft paper.

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## ON-LINE DATA SUPPLEMENT

### Comparisons of Patients With or Without a Serious Desire for Death

#### *Demographic, Social, and Clinical Characteristics*

Participants with or without a serious desire for death were comparable with respect to gender, age, marital status, living arrangement (alone versus other), and education,  $ps > .10$ . The groups also had comparable median survival durations (68.5 days from the time of the interview for those with a serious desire for death vs. 61 days for those without,  $p = .33$ ).

#### *Structured Interview of Symptoms and Concerns*

Supplementary Table 1 shows the prevalence of individual symptoms and concerns as rated on the SISC, as well as the total scores for each of the subscales. The total subscale scores were significantly higher among patients with a serious desire for death, indicating greater symptom distress, on each of the physical,  $t(375) = 5.15, p < .001$ , social-relational,  $t(375) = 3.86, p < .001$ , existential,  $t(375) = 3.60, p < .001$ , and psychological,  $t(375) = 4.94, p < .001$ , dimensions.

With respect to individual problems, patients with a serious desire for death were more likely to experience difficulties with the physical symptoms of general malaise, drowsiness, nausea, and weakness ( $ps < .005$ ), although there was no significant difference between groups in the prevalence of moderate-to-severe pain ( $p = .093$ ). The two groups also differed in the rates with which they reported social concerns around isolation, difficulties communicating with family, and the sense of having become a burden to others ( $ps < .01$ ), as well as in existential issues regarding loss of resilience, loss of dignity, and loss of control ( $ps < .03$ ).

There were significant differences between the groups on all of the psychological symptoms assessed by the SISC ( $ps < .001$ ), with prevalence rates among those with a serious desire for

death that were 3-5 times higher than among those without. Overall, patients with a serious desire for death were more likely to acknowledge a general sense of suffering ( $p < .001$ ).

### Supplementary Table 1

#### Symptoms and Concerns Reported by Patients With or Without a Serious Desire for Death

Symptom or Concern	No Serious Desire for Death (n=331)	Serious Desire for Death (n=46)	P-value
<b>Physical Symptoms</b>			
General malaise	126 (38.1)	32 (69.6)	< .001
Drowsiness	95 (28.7)	26 (56.5)	< .001
Nausea	49 (14.8)	15 (32.6)	.004
Weakness	183 (55.3)	39 (84.8)	< .001
Breathlessness	82 (24.8)	16 (34.8)	.104
Pain	107 (32.3)	20 (43.5)	.093
Total ( <i>M, SD</i> )	10.05 (6.0)	14.91 (5.8)	< .001
<b>Social-relational concerns</b>			
Social isolation	29 (8.8)	15 (32.6)	< .001
Communication problem	4 (1.2)	4 (8.7)	.009
Burden to others	77 (23.3)	21 (45.7)	.002
Financial problem†	32 (9.7)	2 (4.3)	.184
Total ( <i>M, SD</i> )	2.6 (2.8)	4.9 (3.9)	< .001
<b>Existential issues</b>			
Loss of resilience‡	18 (5.5)	15 (32.6)	< .001
Loss of dignity	18 (5.4)	7 (15.2)	.022
Loss of control	14 (4.2)	11 (23.9)	< .001
Spiritual crisis‡	9 (2.7)	2 (4.4)	.388
Difficulty accepting	26 (7.9)	7 (15.2)	.09
Dissatisfaction with life	15 (4.5)	4 (2.3)	.190
Total ( <i>M, SD</i> )	2.5 (3.0)	5.5 (5.5)	< .001
<b>Psychological difficulties</b>			
Anxiety	39 (11.8)	18 (39.1)	< .001
Depression	36 (10.9)	16 (34.8)	< .001
Loss of interest/pleasure†	37 (11.2)	16 (34.8)	< .001
Hopelessness‡	25 (7.6)	17 (37)	< .001
Total ( <i>M, SD</i> )	3.1 (3.4)	7.4 (5.7)	< .001
<b>Global considerations</b>			
Suffering	66 (19.9)	29 (63.0)	< .001

Note: Table entries are n (%) of participants who endorsed specific symptoms or concerns at a moderate-to-extreme level;  $p$  values are based on Fisher's exact tests for individual symptoms

and concerns and *t*-tests for total scores. Total scores refer to the mean of the summed item ratings within each of the physical, social-relational, existential, and psychological dimensions; † one patient with missing data; ‡ two patients with missing data.

