

Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review

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Purpose: Patients' desire for hastened death within the context of advanced disease and palliative care is a controversial topic, frequently discussed in the international literature. Much of the discussion has focused on opinion and debate about ethical matters related to hastened death. Not many research studies seem to have specifically targeted why palliative care patients may desire hastened death, and few have focused on clinical guidelines for responding to such requests. **Methods:** Using a systematic literature review process, we evaluated the research evidence related to the reasons patients express a desire for a hastened death, and the quality of clinical guidelines in this area. **Results:** Thirty-five research studies met the inclusion criteria related to reasons associated with a desire for hastened death. The factors associated with a desire to die were often complex and multifactorial; however, psychological, existential and social reasons seem to be more prominent than those directly related to physical symptoms, such as pain. Much of the evidence supporting the reasons for these statements is based on: (a) patients' perceptions of how they may feel in the future, and (b) health professionals' and families' interpretations of why desire to die statements may have been made. Several publications provided expert opinion for responding to requests for physician-assisted suicide and euthanasia. In keeping with this limited research base, there is a lack of evidence-based guidelines for clinical care that addresses the desire to die among terminally ill patients. Most literature has focused on discipline specific responses, with minimal exploration of how clinicians might respond initially to a statement from a patient regarding a desire to die. **Conclusions:** In order to advance understanding of the complex issue of desire for hastened death in the context of palliative care, research should focus on studies with patients who have actually made a desire to die statement and the development of guidelines to help health professionals respond. Direction for research in this area is described. *Palliative Medicine* 2006; **20**: 693–701

Key words: desire to die; euthanasia; palliative care; research and guidelines; suicide

Introduction

The desire for hastened death has been an increasingly debated topic in the palliative care literature.^{1–6} Several studies have explored the incidence of desire for hastened

death in the context of advanced disease; however, the approaches used have been, to a large extent, inadequate due to methodological challenges associated with this area of research.^{7,8} The prevalence of 'underground' euthanasia activities further complicates the formulation of an accurate account of incidence.^{9,10} Clarification of terminology is needed for the broad spectrum of patients' requests for hastened death: from a passive wish to have death occur but no active plans to hasten death, requests for specific interventions to hasten death, to specific thoughts or plans for committing suicide. The clinical issues surrounding each are likely to vary. Some requests

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for a hastened death or expressions of a desire to die may not constitute a specific request for suicide or hastened death,⁶ and may, therefore, be missed in typical data collection approaches.

From the data available, it appears that an occasional desire to die statement (DTDS) may be common in patients receiving palliative care, although a pervasive desire for hastened death is relatively infrequent, and the desire for death may fluctuate.^{11–14} The incidence of suicide is greater in cancer patients and those with chronic illnesses than in the general population. This risk is reported to increase in those with more advanced stage disease.^{15,16} Empirical studies of patients with advanced cancer and AIDS have identified that approximately 8–15% of patients may express an interest in a desire for hastened death. Studies with less rigorous approaches report higher levels.^{1,17,18} In one jurisdiction, where physician-assisted suicide (PAS) is legal, approximately 20% of patients considered hastening their death.¹⁹

It has been shown that patients with Motor Neurone Disease have higher rates of desire for hastened death than patients with other advanced incurable illnesses.¹⁹ Those who overtly request assistance with euthanasia may represent as few as 1% of dying patients, and only 1 in 10 of those patients actually takes a lethal injection.¹² In one study, 27% of patients with cancer thought about seeking assistance with suicide, yet only 2% actually discussed it.²⁰ From the available evidence, DTDSs in patients with advanced disease are not uncommon, thoughts about hastened death are likely to be more common than expressed statements; therefore, the incidence may be higher if patients were encouraged to voice their wishes.

Given the likelihood that health care professionals may receive or witness a DTDS, they should be adequately prepared to respond appropriately.²¹ However, the quality of research related to why patients may desire a hastened death has been questioned.⁶ A synthesis of relevant evidence to help guide health professionals at these clinical moments was deemed to be useful. Therefore, we undertook an evaluation of the evidence related to the reasons for desire for hastened death in patients with advanced disease, and reviewed clinical guidelines that offered strategies for responding to a DTDS.

Methods

Search strategy

The literature search was conducted using Medline, CINAHL, Psychlit, and the Cochrane databases for articles published in English from 1990 to September 2005, representing the contemporary perspectives on this topic. Cherny's palliative care database was also

searched.²² Search terms used were: death, suicide, desire to die, hastened death, euthanasia, communication, suicide, advanced cancer, advanced disease, malignant disease, palliative care, hospice care, research, incidence and guidelines. Names of key authors in the area were also included in the search. The reference lists of publications were inspected for additional articles not previously identified by the search. Key palliative care books were also reviewed.^{23–28}

Inclusion and exclusion criteria

Publications that noted in the title or abstract that their purpose was to outline reasons for desire to die requests and/or guidelines on how to respond to a DTDS were reviewed. Further inclusion criteria were research papers and the inclusion of patients with incurable disease where death was expected (eg, advanced cancer). Studies in which the patient made a specific request for PAS or euthanasia were also included. Studies in languages other than English were excluded.

Data extraction and validity assessment

Table 1 details the categorization approach, including the type of research and samples used. Given the limited research undertaken in this area (and apparent absence of intervention research), the studies are presented by a description of the study type rather than ranking each study according to a hierarchy of evidence. When a number of reasons for a DTDS were documented, in quantitative studies, the three most common reasons were noted in the review. Research-based articles were reviewed by at least two co-authors to verify agreement on the outcomes of the data extraction process.

Results

Reasons for desire for hastened death

The initial review process identified 1354 citations. Closer scrutiny identified 196 abstracts that seemed relevant for the purpose of this review. Full text analysis revealed 35 research studies that met the search criteria. Table 1 provides an overview of the reasons identified in the literature.

The most common factors associated with a desire for hastened death appear to be: burden to others, loss of autonomy (and an associated desire to control the circumstances of death), physical symptoms (such as pain), depression and hopelessness, and existential concerns and fear of the future.

However, only eight studies involved patients who had made a DTDS and described the reasons they provided for their request. This finding indicates that, to date, most studies ($n=12$) are based on patients' perceptions of how they may feel in the future about desire for

Table 1 Potential reasons for desire for hastened death extracted from research studies (n = 35)

Sample	Country/setting and underlying disease	Research method	Factor(s)	Author(s)	
Patients' opinions about why they may have a desire for hastened death in the future (ie, asked as a research question) (n = 13)	Canada, cancer; palliative inpatient unit	Survey/self report questionnaire and interviews	Uncontrollable pain or other severe physical symptoms; deterioration in QOL; burden to others	Wilson <i>et al.</i> ⁶⁹	
	US, cancer, outpatients clinic	Survey/self report questionnaire and interviews	Control over timing of death; relief from pain and suffering	Sullivan <i>et al.</i> ⁷⁰	
	Canada, cancer; palliative inpatient unit and outpatients	Survey/self report questionnaire	Hopelessness; burden; loss of dignity	Chochinov <i>et al.</i> ⁷¹	
	Canada, cancer; inpatient and home palliative care	Survey/self report questionnaire	Being a burden to others	Suarez-Almazor <i>et al.</i> ⁷²	
	US, cancer; palliative care unit	Survey/self report questionnaire	Depression; hopelessness	Breitbart <i>et al.</i> ⁷³	
	US, HIV/AIDS	Survey/self report questionnaire	Experience with death of a friend/family member; suicidal ideation; quality of social supports	Breitbart <i>et al.</i> ⁷⁴	
	US, amyotrophic lateral sclerosis	Survey/self report questionnaire	To control circumstances of death; hopelessness	Ganzini <i>et al.</i> ⁷⁵	
	Greece, cancer; palliative care inpatient unit	Survey/self report questionnaire	Pain; poor quality of life	Mystakidou <i>et al.</i> ⁷⁶	
	Greece, cancer, palliative care inpatient unit	Survey/self report questionnaire	Depression; anxiety	Mystakidou <i>et al.</i> ¹	
	US, cancer, hospital palliative care service	Survey/self report questionnaire	Depression; low social support; poor spiritual well being	O'Mahony <i>et al.</i> ²	
	Norway, cancer; palliative care inpatient unit	Qualitative study	Fear of painful death; poor quality of life; lack of hope	Johansen <i>et al.</i> ⁶	
	Canada, cancer; palliative care inpatient unit	Self report and interview	Hopelessness	Chochinov <i>et al.</i> ⁷⁷	
	Canada, cancer: palliative care inpatient unit	Self report and interview	Depression; pain; low family support	Chochinov <i>et al.</i> ¹³	
Patients who had made a DTDS and reasons for the statement (n = 8)	Australia, cancer; inpatient and home palliative care	Survey/self report questionnaire	Depression; being a burden; low social support; anxiety	Kelly <i>et al.</i> ⁷⁸	
	Canada, HIV/AIDS	Qualitative study	Loss of self	Lavery <i>et al.</i> ⁷⁹	
	Canada, HIV/AIDS	Qualitative study	Anticipated physical suffering; loss of autonomy	Mishara ¹⁵	
	US; cancer; inpatient and home palliative care	Qualitative study	Avoid the dying process; perceived unendurable suffering; control over time of death; gesture of altruism – to relieve family of burden; abandonment by God, expression of despair	Coyle and Sculco ⁸⁰	
	US, ALS, inpatient unit	Qualitative study	Fear of suffocation; fear of pain and other symptoms	Bascom and Tolle ¹²	
	US, AIDS, neurological and cancer; community	Qualitative study	Illness related experience (eg, pain, loss of function); loss of sense of self; loss of control; fears about the future	Pearlman <i>et al.</i> ⁴⁴	
	Hong Kong, cancer; inpatient and home palliative care	Qualitative study	Burden to family; existential suffering; physical deterioration; poor quality of care; fear of future	Mak ³	
	US, AIDS, ALS, dementia, vascular disease and cancer in variety of settings	Qualitative study	Psychiatric disorders; alcohol abuse; personality traits	Bharucha <i>et al.</i> ⁵⁵	
	Family members' opinions of patient's reason for DTDS (n = 2)	US, bereaved family caregivers	Survey/self report questionnaire	Symptom distress; sadness	Tolle <i>et al.</i> ¹⁹

Table 1 (Continued)

Sample	Country/setting and underlying disease	Research method	Factor(s)	Author(s)
Health professionals' opinions of patients' reason for DTDS (n = 12)	UK, bereaved relatives	Survey/self report questionnaire	Unrelieved physical symptoms; unrelieved psychological issues; dependency on others	Seale and Addington-Hall ⁸¹
	Italy, palliative care doctors and nurses	Medical history review and interviews	Loss of autonomy; burden to families; depression	Filiberti <i>et al.</i> ⁴³
	US, palliative care nurses and social workers	Survey/self report questionnaire	To control circumstances of death; readiness for death; loss of independence	Ganzini <i>et al.</i> ⁸²
	US, oncologists	Survey/self report questionnaire	Pain; burden to family	Emanuel <i>et al.</i> ⁸³
	Netherlands, physicians	Survey/self report questionnaire and interviews	Avoid loss of dignity; unbearable or hopeless suffering	Haverkate <i>et al.</i> ⁸⁴
	Netherlands, general practitioners	Survey/self report questionnaire	Fear of pain; deterioration; hopelessness	Marquet <i>et al.</i> ⁸⁵
	US, physicians	Survey/self report questionnaire	Discomfort other than pain; loss of dignity; fear of uncontrollable symptoms	Meier <i>et al.</i> ⁸⁶
	US, oncology physicians and other subspecialties	Survey/self report questionnaire	Loss of control; being a burden; loss of dignity	Back <i>et al.</i> ⁸⁷
	US, physicians involved in assisted suicide	Survey/self report questionnaire	Loss of autonomy; loss of capacity to participate in enjoyable events; loss of dignity	Oregon Department of Human Services ⁴²
	US, palliative care social workers	Survey/self report questionnaire	Poor quality of life; concern for suffering; desire to maintain independence/control	Arnold <i>et al.</i> ⁸
Australia, doctor who provided euthanasia	Qualitative study and public texts	No point to life; to avoid dying phase; hopelessness; depression	Kissane <i>et al.</i> ⁸⁸	
US, palliative care physicians	Qualitative study	Physical symptoms; psychological issues; existential suffering	Kohlwes ⁴¹	
US, oncology nurses	Qualitative study	Control over circumstances of the dying process	Volker ⁸⁹	

hastened death, rather than on patients who had actually expressed a desire for hastened death. Other evidence is based upon health professionals' and families' interpretations of why DTDSs may have been made. Families' perceptions of why patients may have made a DTDS were obtained in the bereavement period. The accuracy of their perceptions may have been limited by recall bias, and the emotional distress of the bereavement period. From the data related to patients who had actually expressed a desire for hastened death, it seems that psychosocial and existential factors seem to be more common than those directly related to physical symptoms, such as pain. However, in other studies fear of pain was commonly acknowledged.

Although the review provided a broad set of factors associated with the desire to die, some of these variables are poorly defined, making it difficult to translate these results into clinical practice. For example, statements about poor quality of life, deterioration and psychiatric disorders were not consistently described or measured.

Only seven studies included non-cancer populations. Reasons for DTDSs may be different for these individuals, especially for those with chronic and debilitating disease, and those with a lengthy prognosis. Ten of the 35 studies were conducted in countries outside North America, indicating that the majority of research in this area has occurred in the US and Canada.

The main approaches used to gain an understanding of the reasons for a desire for hastened death were based on surveys, administration of instruments, or in depth interviews. Given the absence of intervention research in this area, no studies rated as high level evidence, and all would be classified as descriptive research.^{29,30}

Guidelines for health professionals

Abstracts that offered strategies for responding to an initial DTDS were identified from the initial 1354 abstracts. Of the 64 full text articles retrieved, no research-based articles were found. Although there have been useful attempts to guide health professionals on

how to respond to a DTDS in the palliative care setting,^{3,12,31,32} all were based on the opinion of one or two authors rather than on research evidence. Others focused on physicians' or psychiatrists' responses to specific requests for assisted suicide, and were also based on clinical experiences and opinion.^{20,33–40}

One study described the assessment and response practices of 20 physicians to a specific request for PAS, but the purpose was to describe rather than to evaluate practices.⁴¹ Back *et al.*,⁴⁰ described the qualities of clinician–patient interactions valued by patients and their families. However, the research was conducted with patients who had made a specific request for PAS, and did not focus on initial responses to DTDSs. Nonetheless, the findings reinforced the importance of very good clinician communication skills in dealing with a DTDS.

Discussion

Reasons for desire for hastened death

Commensurate with the views of others,^{42–44} the reasons for making a DTDS were often multiple and complex. Some desires for hastened death may fluctuate over time,^{6,19} reinforcing the need for ongoing comprehensive health professional assessment. From our review of the literature, it appears that factors associated with patients' DTDSs may be categorized according to the following broad areas: (1) expression of feelings and current reactions to their circumstances (eg, fears regarding death, the loss of autonomy and control that can accompany severe illness – which may consist of a remark that is not intended to be interpreted as a formal request for hastened death); (2) a communication of distress and suffering (psychosocial, existential/spiritual, or physical) and/or a communication to explore options for relieving their distress (eg, desiring information about their disease/symptom management, wanting access to other social supports or health professionals/resources); (3) seeking information about suicide or euthanasia as a response to (1) or (2); and (4) specifically seeking health professional assistance with hastened death or acknowledging an intent for suicide.

Some of the reasons point to the importance of relationships as a possible predictor of a DTDS. For example, feelings of being a burden to family and dependency on others may provide cues about the importance of discussing relationships and feelings of dependency. Concerns related to dignity and loss of autonomy were also consistently stated, providing some useful directions for appropriate interaction and support for these patients. Fear of the future, including the potential for unrelieved pain, was commonly reported.

Guidelines for health professionals

The lack of research-based guidelines to support health professionals as they attempt to respond to a DTDS is cause for concern. There are a number of strategies for assessing suicidal ideation in the palliative care setting,¹¹ recommendations for the psychosocial care of adults with cancer,⁴⁵ psychotherapeutic interventions for enhancing well being at the end of life,⁴⁶ and strategies for addressing spiritual issues.^{47–50} These approaches, however, do not sufficiently differentiate between health professionals from different health disciplines and their initial response and plan for care of patients who have made a DTDS. The evidence base for some recommended approaches is less than optimal, and the suggested strategies are based on in-patient palliative care settings that may not be relevant to home-based palliative care.

In addition, some recommendations urge that health professionals seek urgent psychiatric consultation for any patient who is at risk for suicide.^{45,51} Notwithstanding the practical limits in some situations, such recommendations provide an important impetus to develop protocols and service pathways to ensure effective liaison with specialist mental health advice, consultation and support. There may be a need to build the skills and confidence among staff working with dying patients, not only in the assessment of common psychological and psychiatric aspects associated with the wish to die, but also in discussing the important clinical role of mental health advice and assessment with the patient and family.

Although many deaths occur in hospitals, the preceding palliative care most commonly occurs at home.⁵² Therefore, any recommendations developed must be relevant to the home setting, and be clinically meaningful for health professionals, such as general practitioners, nurses, pastoral care workers and social workers. Likewise, recommendations are needed to respond to the needs of older persons requiring palliative care in residential care settings.

Future research

Further research is required to advance our understanding of the complex issue of DTDSs in the context of palliative care. For example, assessment of reasons for a DTDS may be enhanced with exploration of the reliability and validity of the Desire for Death Rating Scale (DDRS),¹³ and the Schedule of Attitudes toward Hastened Death (SAHD).^{17,53} Some authors in our review used these instruments.^{1,2} However, further testing of these instruments will aid in determining whether a DTDS corresponds to an actual request for assisted suicide or suicide attempt.

Clarification of the empirical links between the attitudes and behaviours of patients within this context is one of the key challenges for researchers.^{6,15} A long

tradition of psychological research demonstrates that the correlation between attitudes and behaviours is poor: intention to act is a far stronger predictor of actual behaviour.⁵⁴ Furthermore, variables that are directly linked to DTDSs require much more investigation. It would be useful to know whether factors, such as personality style, social support, age, spirituality issues and quality of life are potential predictors for a DTDS.^{2,15,18,46,48} The link between depression, hopelessness and a DTDS also requires further exploration,^{2,6,55} together with the influence of cognitive impairment.⁵⁶ Johansen *et al.* hypothesis that desire for hastened death may serve as a coping strategy for some patients seeking some sense of control, even if they do not actually deliberately shorten their lives, also seems worthy of investigation.⁶

The setting within which future DTDS research is conducted is important because the site of care may be an important variable in determining factors associated with reasons for these requests.¹⁷ None of the studies reviewed had taken place in an aged care environment. In addition, a patient's disease stage may be an important factor associated with a DTDS; this issue has been largely neglected in studies thus far.¹⁵

Cultural variations may also exist in relation to DTDSs. To date, the overwhelming majority of studies related to factors associated with hastened death have been undertaken in the US and Canada. Values, beliefs and customs vary and what may be considered relevant in one country, may not be acceptable elsewhere.¹⁵ For example, in some societies, suicide may be considered acceptable in certain circumstances.¹⁸ Different beliefs apply within Christianity, and what constitutes a good death in Spain, for example, might be quite different to American expectations.^{18,57,58} More evidence-based understanding about families' involvement in end-of-life decision making and responses to DTDSs is warranted.¹⁵ Additionally, further research to examine the relationship between health professionals and patients in these situations may offer some useful insights regarding the health care context within which these requests may come forward.⁵⁹

Our review has confirmed that much of the research associated with requests for assisted suicide has focused on patient responses to hypothetical vignettes and clinician recall. These approaches may not be transferable to real-world scenarios.¹⁷ Therefore, more studies are required that involve interviews over time with those patients who have requested assisted suicide. Although this type of research is difficult due to ethical and practical constraints, this methodology is important to pursue, particularly in settings where assisted suicide is legal.¹⁷ These recommendations should be extended to future research associated with DTDSs, which may not necessarily be associated with suicidal ideation.

Given the fact that some patients who make a DTDS may have a major psychiatric condition, particularly depression, routine screening for psychological distress in palliative care patients is highly recommended.² However, further research is required that allows for accurate and prompt diagnosis relevant to this population. Although screening tools can be used to detect probable psychological distress, accurate diagnosis requires a structured clinical interview.⁶⁰ These interviews may be difficult to conduct in this population,⁶¹ and the reliability and validity of the measures need to be addressed. Consequently, explorations of practicable screening approaches that are valid, reliable and clinically applicable are required. Patient competence is also an important consideration. Although encouraging work is being undertaken to assess competence in terminally ill people for research purposes,⁶² this research needs to be extended into clinical practice so that health professionals may be better placed to assess whether a DTDS constitutes a serious statement of intent.

Although advance care planning is recommended to promote meaningful participation in health care decisions,⁶³ the uptake and utility of advance care directives has, however, thus far proved suboptimal.⁶⁴ Hence, issues of uptake of advance directives and the links between these types of discussions and subsequent DTDSs need further exploration.

Given the minimal research associated with health professional responses to DTDSs, the way forward appears to be the development of consensus-based recommendations. These should then be tested for their clinical utility. The focus of guidelines should be on how health care professionals might respond to a desire to die statement in the first instance, given that wishes for hastened death may fluctuate and may often not extend to an actual desire for suicide or euthanasia.⁶

In summary, future research should focus on patients' reasons for DTDSs using longitudinal approaches.^{17,65} Although the ethical and methodological issues that underpin this type of research are recognized,⁶⁶ future studies exploring DTDSs should not be compromised by inappropriate gate keeping.⁶⁷ Excluding patients who might be psychologically distressed is likely to result in samples with systematic biases.¹⁷

Conclusion

This paper demonstrates that the factors associated with a desire for hastened death are varied and complex. Only a small number of studies have involved patients who have expressed a wish for hastened death. In addition, there is a lack of evidence-based clinical guidelines to aid health professionals to respond to such expressions.

Important questions remain – can health professional interventions reduce the incidence of DTDSs and if so, what interventions may reduce desire for euthanasia and/or suicide?¹⁵ Specific and attentive care strategies that promote dignity and quality life may prove valuable in lessening the incidence of DTDS.⁶⁸ Further research related to the factors associated with desire to die and the utility of clinical guidelines in this area are required, in order to effectively guide future practice.

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