Review Article

The Wish to Hasten Death in Patients With Life-Limiting Conditions. A Systematic Overview

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Abstract

Context. A systematic review of the wish to hasten death among people with life-limiting conditions was published in 2011. Since then, other reviews and primary studies have been published that have added to knowledge regarding the conceptual definition, aetiology and assessment of the wish to hasten death.

Objectives. To provide an updated synthesis of the literature on the wish to hasten death in people with life-limiting conditions. Methods. An overview of systematic reviews and primary studies was conducted, using an integrative review method. PubMed, CINAHL, Scopus and Web of Science databases were searched, from their inception until 2023. We included all systematic reviews published to date and all primary studies not included in these systematic reviews.

Results. Eleven systematic reviews and 35 primary studies were included. We propose that the phenomenon may usefully be considered as existing along a continuum, defined by the extent to which thoughts of dying are linked to action. A total of nine assessment tools have been described. The reported prevalence of the wish to hasten death appears to be influenced by the wording used in assessment instruments, as well as by the cut-off used when applying a particular tool. Depression, pain, functional disability, decreased sense of meaning in life, the sense of being a burden and reduced quality of life are the most widely reported related factors.

Conclusion. This overview underscores the need for clinical strategies that can identify different manifestations of the wish to hasten death among people with life-limiting conditions. J Pain Symptom Manage 2024;000:e1-e25. © 2024 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

Key Words

Advanced illness, assistance in dying, cancer, palliative care, suffering, systematic review

Key Message

This overview describes the impact of different conceptualizations of the desire to die on outcomes. Life-limiting conditions shape individual experiences, with clinical interviews proving reliable. Our results highlight the need for enhanced clinical responses to the wish to hasten death, standardized assessment tools for prevalence estimation, and routine screening in clinical settings.

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Introduction

People facing the end of life may experience a desire to die. 1-4 This desire can be a spontaneous reaction that is not necessarily associated with a particular disease or heightened suffering, but rather reflects the peaceful acceptance of death by a person of advanced age.^{5,6} Alternatively, it may emerge as a response to suffering in the context of a life-limiting condition, where

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it can entail a more frequent and intense desire to die that is associated with unbearable suffering, in which case it may lead the person to plan how they would take their life or to request assisted dying.⁷⁻⁹ In the context of advanced disease, the term "wish to hasten death" is commonly used to refer to the desire to die expressed by patients who feel unable to go on living.¹⁰ Hereinafter, we will use the term "desire to die" when referring to the concept in its broadest sense, which includes the wish to hasten death but is not limited to it. 11

A systematic review on the wish to hasten death among people with life-limiting conditions was published in 2011.⁶ Since then, a number of other reviews have been conducted, focusing on different aspects of this phenomenon: the experience of patients who express a wish to hasten death, 4,12 instruments for assessing this wish, 13 and moral understandings of patients who express such a wish, ¹⁴ among others.

The literature to date has highlighted the fluctuating, ambivalent and complex nature of the wish to hasten death, and hence the need for a holistic approach and a deeper understanding of patients' experiences. 15–18 Numerous authors have stressed the importance of developing clear and agreed terminology for describing this wish so as to avoid misunderstandings and ensure that patients receive the best possible care. 5,16,19-21 A further issue to consider is how the clinical phenomenon of the wish to hasten death may be impacted by the legalization of euthanasia and assisted suicide in some countries, insofar as this creates a context in which patients may potentially request and receive assistance with dying.

Aim

To provide an updated synthesis of the literature on the wish to hasten death in people with life-limiting conditions, focusing on patients' lived experience of such a wish, tools for assessing it, the frequency and prevalence of the wish to hasten death, and related factors.

Method

Design

An overview of systematic reviews and primary studies was conducted through a literature search of the following databases: PubMed, CINAHL, Scopus, and Web of Science. We included all systematic reviews published to date and all primary studies not included in these systematic reviews. The search strategies were executed during July 2021 and updated in February 2023.

Eligibility Criteria

The inclusion criteria were: (1) studies whose specific focus is the wish to hasten death (referred to using this or a similar term) and those in which this wish is one of the experiences considered when exploring the desire to die more broadly; (2) the perspective reported or the data collected corresponded to people with life-limiting conditions; and (3) articles published in indexed journals and written in either English or Spanish. Studies involving pediatric and elderly samples (in which no specific reference is made to a lifelimiting condition) were excluded, as were those conveying perspectives and/or analyzing documentation on the legal or ethical aspects of the wish to hasten death among patients with life-limiting conditions.

Search Strategies

We applied two strategies: one to identify systematic reviews, the other to identify primary studies not included in these reviews (see Table 1).

The literature search was conducted by a single researcher and verified by a further two researchers. Screening involved selection of retrieved citations by

Table 1 **Search Strategies**

Search Strategy for Systematic Reviews

Search Terms "wish to hasten death" (Text Word) "desire for death" (Text Word) 3 "wish to die" (Text Word) "desire to die" (Text Word) 5 "desire to hasten death" (Text Word) "desire for hastened death" (Text Word) "suicide, assisted" (MeSH Terms) "euthanasia " (MeSH Terms) "MAiD" (Text Word) 10 "medical assistance in dying" (Text Word) 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 11 19 "paediatric*" (All Fields) "pediatric*" (All Fields) 13 "child*" (All Fields) 14 15 12 OR 13 OR 14 OR 15 (meta-analysis [Filter] OR review [Filter] OR systematicreview 16 [Filter]) 17 FINAL SEARCH: 11 NOT 15 AND 16 Search Strategy for Primary Studies

"wish to hasten death" (Text Word) 2 "desire for death" (Text Word)

3 "wish to die" (Text Word)

"desire to die" (Text Word) 4

5 "desire to hasten death" (Text Word)

6 "desire for hastened death" (Text Word)

"suicide, assisted" (MeSH Terms)

"euthanasia" (MeSH Terms)

9 "MAiD" (Text Word)

10 "medical assistance in dying" (Text Word)

11 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10

12 "paediatric*" (All Fields)

"pediatric*" (All Fields) 13

'child*" (All Fields) 14

15 12 OR 13 OR 14 OR 15 (2017:2023[pdat]) 16

FINAL SEARCH: 11 NOT 15 AND 16

title, abstract and full text. We reviewed the reference lists of all included studies and conducted additional hand searching to identify any relevant documents that had been missed by the digital search. The entire sample of records was double reviewed using RAYYAN.²² Disagreements were resolved by discussion within the research team (see Supplementary Figs. 1 and 2 for the study selection process).²³

Data Extraction

Information from quantitative studies was collected in a data matrix. Data from qualitative studies were coded using ATLAS.ti 9.

Synthesis Methods

We used the integrative review method described by Whittemore and Knafl,²⁴ which allows for the synthesis of data from different sources and the establishment, a priori, of themes to explore. We followed the data analysis process proposed by these authors, which includes data reduction, display and comparison, and conclusion drawing. Data from included studies were analyzed in relation to four themes: the lived experience of the wish to hasten death; tools for assessing the wish to hasten death; frequency and prevalence of the wish to hasten death, and related factors. After analyzing the data matrix and coding the qualitative studies, we identified a further theme to explore definitions of the desire to die.

Quality Appraisal

The studies included were evaluated using the CASP checklist for systematic reviews²⁵ (see Supplementary Table A) and the Mixed Methods Appraisal Tool (MMAT) for both quantitative and qualitative reports (see Supplementary Tables B and C).²⁶

Results

Forty-six reports were included in the overview: 11 systematic reviews and 35 primary studies (Table 2). We will now discuss the main findings.

The lack of terminological precision makes it difficult to obtain reliable prevalence estimates for this phenomenon. The terms used include thoughts of dying, genuine wish to die, wish to die, desire to hasten death, desire to die, wish to hasten death, and desire for early death or requests for euthanasia or assisted suicide. ^{8,19,21,39,64,65} One way of reflecting this diversity is to consider the desire to die as existing along a continuum, defined by the extent to which thoughts of dying are linked to action. Some patients express a vague desire to die, which may take the form of an acceptance of death, the wish for a spontaneous death or the hope that suffering will soon be over. Others experience a wish to hasten death but without taking any specific action towards this goal, although they do

not rule out doing so in the future. ^{43,49,62} Finally, some patients both express a wish to hasten death and take steps towards achieving this (by requesting medical assistance in dying, attempting suicide or refusing life support).

From this perspective, the desire to die may be considered a broad phenomenon that includes both sporadic thoughts about dying and explicit requests to end one's life. ^{15,46,55} It is nevertheless unclear how different points along this continuum might be distinguished, for example, to what extent the wish to hasten death overlaps with or is distinct from suicidal ideation. ^{49,54,58}

Despite this lack of terminological clarity affecting the field in general, 22 of the studies included in this review do include a definition of the wish to hasten death, and of these, 12 cite the operational definition proposed by a consensus group.⁵

The lack of clear terminology notwithstanding, it is generally agreed that the wish to hasten death is a complex phenomenon, due not only to its multifactorial origin but also because it may fluctuate over time. 14,44,53 Studies have found that a desire to live and the desire to die may alternate or even be present simultaneously, and hence a patient's wishes may come across as ambiguous or contradictory. 14,30, 66

The Lived Experience of the Wish to Hasten Death

Fifteen qualitative studies have explored the experience of patients who express a wish to hasten death. The findings of seven of these studies were analyzed and synthesized in a meta-ethnography published in 2012.⁴

This meta-ethnography was updated five years later to include a further seven qualitative studies.¹² Two reviews have been conducted of qualitative studies aimed at exploring patients' experience of being a burden to others ³⁹ and of voluntarily stopping eating and drinking.³⁰ Since then, only one qualitative study has been published.⁵⁴

The wish to hasten death is inseparable from the experience of suffering. Indeed, suffering is an overarching theme among patients who express such a wish, and it encompasses not only the physical but also the psychological, existential/spiritual and social dimensions. In the presence of advanced disease, a person's sense of dignity and identity is threatened, and the suffering they experience can pervade their whole being. From a phenomenological perspective, the experience of time is also a feature of the experience of these patients. The anticipation of imminent death in the face of incurable disease may lead a person to despair, while in many cases the fear of what the future holds (will I suffer?) can make the present more difficult to manage.

Rodríguez-Prat et al.

 ${\it Table~2} \\ {\it Characteristics~of~the~Included~Studies}$

Authors, Year, and Country	Research Question/Aim	Setting	Population	Study Design	Sample
Systematic reviews Bellido et al. ¹³ (2017) Spain	To identify and analyze existing instruments for assessing the wish to hasten death.	Palliative care unit Hospice Home care Amyotrophic lateral sclerosis (ALS) unit	Terminally ill	Systematic integrative review	50 primary studies
Dees et al. ²⁷ (2010) Netherlands	To provide a systematic overview of descriptions of unbearable suffering and current views on suffering of patients in the context of a request for euthanasia and assisted suicide (EAS).	Home recruited through advocacy organizations Cancer facility Palliative care Nursing home Hospice	Persons with an actual request for EAS	Systematic review	55 primary studies
Erdmann et al. ²⁸ (2021) Germany	To examine the wish to die in ALS and to analyze the determinants and motives for different end-of-life options.	1	ALS patients	Systematic review	213 primary studies
Mishara et al. ²⁹ (1999) Canada	To present a synthesis of research and evidence on factors affecting the desire of terminally ill or seriously chronically ill persons to hasten death.	Not reported	Epilepsy Head injuries Huntington's Chorea Gastrointestinal diseases AIDS Cancer Asthma Hypertension Gastrointestinal Diseases Cardiovascular diseases and Hypertension Renal Disease and Hemodialysis patients AIDS	Systematic review	350 reports
Monforte-Royo et al. ⁶ (2011) Spain	To summarize knowledge about the wish to hasten death among people with end-stage disease.	Not reported	Cancer patients AIDS Amyotrophic lateral sclerosis Chronic kidney failure Elderly population Chronic respiratory and cardiac failure	Systematic review	282 primary studies
Monforte-Royo et al. ⁴ (2012) Spain	To understand the experience of patients with serious or incurable illness who express a wish to hasten death.	Home recruited through advocacy organizations Cancer facility Palliative care Hospice HIV Ontario Observational Database	Cancer patients/hospice patients AIDS Persons expressing a wish to die	Systematic review and meta- ethnography	7 primary studies
Rodríguez-Prat et al. ¹² (2017) Spain	To understand the experience of patients with life-threatening conditions who express wish to hasten death.	Home recruited through advocacy organizations Cancer center Palliative care Hospice HIV Observational database	End-stages disease: Cancer patients/hospice patients AIDS Persons expressing WTD	Systematic review and meta- ethnography	14 primary studies

Table 2
Continued

Authors, Year, and Country	Research Question/Aim	Setting	Population	Study Design	Sample
Rodríguez-Prat et al. ¹⁴ (2018) Spain	To analyze the moral understandings of patients who express a wish to hasten death.	Home recruited through advocacy organizations Cancer facility Palliative care Hospice HIV Ontario Observational Database	End-stage disease (cancer patients/hospice patients) AIDS Persons expressing a wish to die	Systematic integrative review	14 primary studies
Rodríguez-Prat et al. ³⁰ (2018) Spain	To describe to what extent voluntarily stopping eating and drinking may be considered an expression of a wish to hasten death.	HIV Ontario Observational Database Inpatient palliative care unit Home palliative care Pain and palliative care unit Hospice Outpatient clinic Patient advocacy organizations	HIV/AIDS Terminally ill cancer	Systematic review	7 qualitative studies
Rodríguez-Prat et al. ³¹ (2019) Spain	To explore the feeling of being a burden among advanced patients who had expressed a wish to hasten death.	Home recruited through advocacy organizations Cancer facility Palliative care Hospice HIV Ontario Observational Database	End-stage disease (cancer patients/hospice patients) AIDS Persons expressing a wish to die	Systematic integrative review	16 primary studies
Rodríguez-Prat et al. ³² (2021) Spain	To analyze what role autonomy and control may play in relation to the WTD expressed by people with life-limiting conditions.	Home recruited through advocacy organizations Cancer center Palliative care Hospice HIV Observational database	End-stages disease: Cancer patients/hospice patients AIDS Persons expressing WTD	Systematic integrative review	27 primary studies
Primary Studies Belar et al. ¹⁵ (2021) Spain	To establish the prevalence of WTHD and to characterize this phenomenon in the Spanish cultural context.	Palliative care	Cancer ALS Chronic diseases	Cross-sectional study	201 participants
Bellido-Pérez et al. ³³ (2018) Spain	To compare the Desire for Death Rating Scale (DDRS) and the Schedule of Attitudes toward Hastened Death (SAHD—5) and to analyze patient opinions about assessment of the wish to hasten death.	Palliative care	Cancer	Cross-sectional study	107 participants
Bernard et al. ³⁴ (2017) Switzerland	To explore the relationship between spirituality, meaning in life, the wish to hasten death and psychological distress in palliative patients, and to examine the extent to which these non-physical determinants influence quality of life.	Palliative care	Cancer	Cross-sectional study	206 participants
Breitbart et al. ³⁵ (2018) USA	To compare the effects of individual meaning- centered psychotherapy on spiritual wellbeing, sense of meaning, quality of life and wish to die, as compared with supportive psychotherapy and enhanced usual care.	Cancer facility	Cancer	Cross-sectional study	321 participants

Rodríguez-Prat et al.

Table 2
Continued

Authors, Year, and Country	Research Question/Aim	Setting	Population	Study Design	Sample
Busquet-Durán et al. ³⁶ (2021) Spain	To investigate the prevalence and evolution of the wish to hasten death in home care, analyzing its relationship with physical, emotional, spiritual, ethical and social/family unrest.	Home palliative care	Cancer Neurological disease Fragility Dementia Organ failure	Longitudinal observational study	1,677 participants
Cheung et al. ¹⁹ (2020) New Zealand	To examine the interplay of demographic, clinical and psychosocial factors routinely collected by a standardized clinical instrument, the interRAI Resident Assessment Instrument for Palliative Care (interRAI-PC), in people with a prognosis of less than 12 months who wanted to die.	Palliative care	Cancer Non-cancer patients	Cross-sectional study	771 participants
Crespo et al. ³⁷ (2020) Spain	To compare perceived health-related quality of life, dignity and self-efficacy in patients with advanced cancer who either do or do not express a wish to hasten death.	Oncology unit	Cancer	Comparative cross- sectional study	153 adult patients with advanced cancer
Crespo et al. ³⁸ (2020) Spain	To evaluate the practical potential and acceptability of questions about the wish to hasten death in the palliative care initial encounter.	Palliative care	Cancer	Proof-of-concept single-arm unmasked trial.	30 advanced cancer patients, 16 inpatients and 14 outpatients in their first palliative care clinical encounter.
Freeman et al. ³⁹ (2016) Canada	To explore members of the sample who expressed the "wish to die now" and to identify the factors associated with the risk for depression within this group.	Palliative care	Cancer and non-cancer patients	Cross-sectional study	
Gouri-Devi et al. ⁴⁰ (2017) India	To examine belief in religion/spirituality and cultural attitudes to life and death that are prevalent in India, using a specifically designed questionnaire.	Neurology services	ALS patients	Cross-sectional study	20 ALS patients
Guerrero-Torrelles et al. 41 (2017) Spain	To analyze the relationship between the wish to hasten death and meaning in life and to propose a theoretical model of functional relationships between the wish to hasten death, performance status, depression and meaning in life.	Palliative care	Advanced cancer patients	Cross-sectional study	101 patients
Hagens et al. ⁴² (2017). The Netherlands	To explore which trajectories people take to seek demedicalized assisted suicide, through opencoding and inductive analysis of in-depth interviews with 17 people who receive(d) demedicalized assisted suicide from counsellors facilitated by the De Einder foundation.	De Einder Foundation	Advanced patients	Cross-sectional study	17 people
Hatano et al. ⁴³ (2021) Japan	To identify the proportion of terminally ill cancer patients with a desire for hastened death (DHD); to identify the reasons for DHD; and to identify common patterns of subgroups in terminally ill cancer patients with DHD.	Palliative care	Terminally ill	Cross-sectional study	971 participants
	, 1	Palliative care	Advanced cancer	Longitudinal	1,313 participants

Table 2
Continued

Authors, Year, and Country	Research Question/Aim	Setting	Population	Study Design	Sample
Hiratsuka et al. ⁴⁴ (2020) Japan	To explore diverse factors associated with spiritual wellbeing in a secondary analysis of a multicenter prospective cohort study involving patients admitted to palliative care units in Japan.				
Julião et al. ⁴⁵ (2016) Portugal	To assess the prevalence and associated demographic, physical, psychiatric and psychosocial factors for demoralization syndrome in Portuguese patients with advanced disease.	Palliative care	Terminally ill	Cross-sectional	80 participants
Julião et al. ⁴⁶ (2017) Portugal	To determine the influence of dignity therapy on demoralization syndrome, the desire for death and a sense of dignity in terminally ill in- patients experiencing a high level of distress in a palliative care unit.	Palliative care	Terminally ill	Cross-sectional study	80 participants
[ulião et al. ⁴⁷ (2020) Portugal	To evaluate the prevalence of desire for death and its associations within the setting of a tertiary home-based palliative care unit.	Home-based palliative care	Terminally ill	Cross-sectional study	122 participants
Kissane et al. ⁴⁸ (2022) Australia	To implement routine use of the Psycho- existential Symptom Assessment Scale (PeSAS) as a screening tool in Australian palliative care services and discern the symptom prevalence identified.	Palliative care	Terminally ill	Cross-sectional study	1,405 participants
Kolva et al. ⁴⁹ (2017) USA	To use methods grounded in item response theory to analyze the psychometric properties of the SAHD and develop an abbreviated version of the scale	Palliative care services Cancer unit	Advanced cancer or AIDS	Cross-sectional	1,076 participants
Liu et al. ⁵⁰ (2022) China	To evaluate the incidence of desire for hastened death among patients with advanced cancer and to identify factors associated with desire for hastened death.	Cancer hospital	Advanced cancer	Cross-sectional study	227 participants
Mon et al. ⁵¹ (2020) Myannmar	To describe various dimensions of end-of-life experiences among patients with advanced cancer.	General hospital, oncological unit	Outpatient oncology clinics	Cross-sectional study	195 patients with stage IV cancer
Monforte-Royo et al. ⁵² (2017) Spain	To assess the wish to hasten death among patients with life-threatening conditions.	Palliative care	Advanced illness	Cross-sectional	101 palliative inpatients
Monforte-Royo et al. ⁵³ (2018) Spain	To test a model in which perceived loss of dignity and control are proposed, along with symptoms of depression and functional impairment, as risk factors for the wish to hasten death in advanced cancer patients.	Oncology unit	Advanced cancer	Cross-sectional study	193 patients in an oncology unit

Table 2
Continued

Authors, Year, and Country	Research Question/Aim	Setting	Population	Study Design	Sample
Ohnsorge et al. ⁵⁴ (2019) Switzerland	To investigate the wish to die of palliative patients in four different dying trajectories: neurological diseases, organ failure, frailty due to age and cancer.	A variety of palliative care facilities: hospice, a palliative ward, specialized units in acute care hospitals, a clinic for neurological diseases, several nursing homes and outpatient palliative care.	Palliative cancer and non- cancer patients, their families and health professionals in different palliative care settings	Qualitative semi- structured interviews.	62 palliative cancer (n = 30) and non-cancer (n = 32) patients (10 neurological disease; 11 organ failure; 11 frailty), their families and health professionals in different palliative care settings (248 interviews)
Parpa et al. ⁵⁵ (2019) Greece	To investigate the relationship between hopelessness and desire for hastened death and examine whether depression has a moderator and/or mediator role in this relationship in patients with advanced cancer.	Out-patient palliative care unit	Advanced cancer	Cross-sectional	102 patients with advanced cancer
Pergolizzi et al. ⁵⁶ (2020) Spain	To understand the influence of age group on the perception of dignity, considering changes in quality of life and the wish to hasten death in patients with advanced cancer.	Oncology unit	Advanced cancer	Cross-sectional	194 patients in an oncology unit
Porta-Sales et al. ⁵⁷ (2019) Spain	To assess the opinion of hospitalized patients with advanced cancer about the proactive assessment of the wish to hasten death.	Oncology unit	Advanced cancer	Cross-sectional	194 patients in an oncology unit
Robinson et al. ²⁰ (2017) Australia	To investigate whether depression, demoralization, loss of control and low self- worth mediated the relationship between global quality of life and desire to hasten death.	Acute palliative care hospital sites	Cancer Cardiovascular disease Neurological disease Renal failure	Cross-sectional study	162 participants
Rodríguez-Mayoral et al. ⁵⁸ (2019) Mexico	To describe the prevalence and factors associated with the desire for hastened death in advanced cancer patients assessed by a palliative care psychiatrist.	Palliative care (psychiatric assessment interview)	Cancer	Cross-sectional study	64 participants
Rodríguez-Mayoral et al. ⁵⁹ (2023) Mexico	To validate and abbreviate the SAHD for use among patients attending the palliative care service of the Instituto Nacional de Cancerología in Mexico.	Palliative care (psychiatric assessment interview)	Cancer	Cross-sectional study	225 participants
Rosenfeld et al. ⁶⁰ (2018) USA	To provide a rigorous test of the mechanism of change in Meaning-Centered Group Psychotherapy (MCGP) using the data from two randomized controlled trials (RCTs) at different periods of time.	Cancer facility	Advanced cancer	RCT	2 RCTs that compared MCGP (n=124) with supportive group psychotherapy (n=94)

Authors, Year, and Country Research Question/Aim	Research Question/Aim	Setting	Population	Study Design	Sample
Vehling et al. ⁶¹ (2017) Germany	To investigate the co-occurrence versus independence of demoralization with mental disorders and suicidal ideation to evaluate its features as a concept of distress in the context of severe illness.	Inpatient, outpatient, rehabilitation	Cancer	Cross-sectional study 430 participants	430 participants
Vehling et al. ⁶² (2021) Germany	To explore subtypes of thoughts of death, death wishes, suicidal ideation and behavior and their association with mental disorders and demographic and disease—related characteristics.	Oncological inpatient clinics at acute care hospitals Specialized outpatient cancer care facilities Cancer rehabilitation centers	Cancer	Cohort study	2141 participants
Voltz et al. ⁶³	To evaluate effects on depressiveness, hopelessness, wish to hasten death, death anxiety, patient-health professional relationship on desire to die-conversations with palliative patients	Ambulatory palliative care settings	Cancer Neurological disease Geriatric Multimorbidity Chronic obstructive pulmonary disease	Prospective mixed- methods cohort study	T0: $n = 85$ T1: $n = 64$ T2: $n = 46$

Different authors have proposed that when attempting to understand the expression of a wish to hasten death, it is important to consider reasons, meanings and functions. 12,54 Reasons are the multiple factors that can lead a person to express a wish to die, and they may be physical (tiredness, nausea/vomiting, dyspnea, pain, loss of functional ability), psychological (depression, hopelessness, feeling useless), social (dependency, the perception of being a burden to others or of making loved ones suffer) or existential/spiritual (perceived loss of identity, dignity, autonomy and meaning in life). 4,12,31,54 Meanings reflect what the person is implicitly or explicitly expressing through the wish to hasten death. In the context of illness and suffering, some people may feel unable to cope and wish to spare their loved ones from the burden of seeing them suffer, while others may wish to go on living but not in this way. In these cases, the expression of a wish to hasten death should not be interpreted simply as a request for assistance in dying but rather as the manifestation of a more profound thought, feeling or experience, of a present need that is going unmet. Finally, the functions of a wish to hasten death reflect the purposes that its expression may serve. The function of an expressed wish to hasten death is primarily understood as a means of communication and/or a form of control.¹²

The only qualitative study published over the past five years explored the meanings of a wish to hasten death, ⁵⁴ comparing the wish to die and patients' experience across four dying trajectories. The results showed that while a wish to die is always underpinned by reasons, meanings and functions, the specific nature of different dying trajectories lends particular characteristics to the phenomenology of such a wish. Patients with neurological diseases tended to be more concerned with how and in what setting they would die and how they could cope with physical decline. They feared physical suffocation, dependence on others and becoming immobile. For persons with organ failure the wish to die was experienced in the context of their oscillating between life-threatening health crises and periods of stability. Accordingly, it was both a reaction to the crises they had already experienced and a hypothetical wish for the future, in the event that a further crisis occurred.

Finally, some studies have highlighted the need to consider patients' moral understandings of the wish to hasten death, as well as the socio-cultural context in which they live. 14,31,32 Moral understandings have been defined as the set of values, beliefs, thoughts and assumptions that underpin a person's world view. Research suggests that the socio-cultural context and a person's assumptions about dignity and autonomy, about the value of life in particular circumstances and about the meaning of suffering are all important aspects to consider when seeking to understand an

individual's experience of a life-limiting condition. 14,30,32,66

Tools for Assessing the Wish to Hasten Death

Assessing the wish to hasten death is a challenge, due to the complexity of the issue and the vulnerability of this population. Furthermore, a variety of instruments with different cut-off points have been used for this purpose, making cross-study comparisons difficult.

A systematic review of instruments for assessing the wish to hasten death was published in 2017.¹³ The authors analyzed 50 primary studies and identified seven different measurement instruments, the two most widely used (in 45 of the 50 studies) being the Desire for Death Rating Scale (DDRS) and the Schedule of Attitudes toward Hastened Death (SAHD). Three of the seven instruments were developed for a specific study and have not been used subsequently in other research.

Since 2017, two new instruments have been described. The Assessment of the Frequency and Extent of the Desire to Die (AFEDD)³⁶ is a semi-structured interview comprising an initial screening question, which, if answered in the affirmative, is followed by a further two questions that enquire about the frequency and intensity of the wish to hasten death. A strength of the AFEDD is its sensitivity for identifying (presence) and quantifying (frequency and extent) the wish to hasten death. The other instrument is the Wishto-Die Questionnaire (WDQ), which was used in a study of patients with amyotrophic lateral sclerosis. The WDQ comprises 18 items referring to seven domains, although one of these ("death wish") is represented by just a single item.

Of the primary studies included in this review, 23 used one of the aforementioned instruments to assess the desire to die. Nine studies used the SAHD, most commonly in its original 20-item version, although the short form has also been employed. Three studies describe the development of a short form of the SAHD (in US, ⁴⁹ Spanish ³³ and Mexican populations ⁵⁹). These versions include either five or six items, of which only three (items 4, 10, and 13 of the original scale) are common to all three short forms. Validity evidence for these short forms is consistent with that reported for the original scale. Six of the studies reviewed used DDRS, while a further six employed the AFEDD. The WDQ has only been used in one study. The remaining articles we analyzed used less specific assessment methods, namely questions taken from clinical interviews such as the Composite International Diagnostic Interview (CIDI), the Hexagon of Complexity (HexCom)³⁶ or the Psycho-existential Symptom Assessment Scale (PeSAS).48

Analysis of the content of these instruments shows that, to some extent, they explore different aspects of the wish to hasten death. The SAHD enquires about anticipated physical and emotional suffering and its relationship to the wish to hasten death, whereas the DDRS takes the form of a semi-structured interview that explores whether the patient has ever experienced a desire die, and if so, how serious and pervasive this is. Some comparative studies have considered the extent to which asking about different aspects of the wish to hasten death may yield different results in terms of the nature of the phenomenon and its prevalence. When different instruments have been administered in the same sample, the results obtained do differ. Table 3 summarizes the main instruments.

Frequency and Prevalence of the Wish to Hasten Death

Three systematic reviews have summarized prevalence data for the wish to hasten death. The earliest of these drew attention to the considerable variability in prevalence rates across 282 studies, which was considered to be partly due to the lack of standardized instruments. In response to this, Bellido-Pérez et al. conducted a review of instruments used to assess the wish to hasten death and reported the prevalence rates obtained when administering them to patients. The studies included showed a low-to-moderate proportion of patients manifesting a wish to hasten death, in the range of 1.5%–35%, depending on the cut-off score used.

Fifteen articles included in the present synthesis reported prevalence data, ranging from 0.17% of patients with advanced cancer when using a DDRS cutoff score of ≥ 1 to 44% of patients in palliative care expressing any form of a wish to die (from the presence of ideas of death to requests for assisted dying). A study that used a DDRS cut-off of ≥4 reported a higher prevalence of the wish to hasten death (20.5% of patients in home palliative care)⁴⁶ than was observed when the same instrument was applied in a sample of palliative care outpatients in Spain (5.6%). ³¹ In two Spanish studies, the prevalence of the wish to hasten death was higher when assessed with the AFEDD $(18\%)^{15}$ than with the SAHD-5 (8.8%). 55 Prevalence rates of similar magnitude have been reported in studies using the HexCom $(6.67\%)^{36}$ and the inter-RAI (between $6.7\%^{39}$ and 9.3%).¹⁹

Factors Related to the Wish to Hasten Death

Related factors refer to those variables that can be measured quantitatively to examine their impact on the expression of a wish to hasten death. Three of the 10 reviews included in this overview provided a synthesis of related factors in the literature. There is consensus that socio-demographic factors (younger age and higher socioeconomic status, as well as the socio-cultural context, including lower religiosity) are associated with or predictive of such a wish. Several

 $Table\ 3$ Characteristics of Instruments Used to Assess the Wish to Hasten Death. The HexCom, \$^{36}\$ the PeSAS, \$^{48}\$ and the InterRAI PC\$^{19,39}\$ are not Included Because They are Designed to Assess Needs in Palliative Care Rather Than Specifically the Desire to Die

Assessment Instrument	Format	Conceptual Framework	Characteristics	Population in Which Instrument Has Been Applied
Schedule of Attitudes toward Hastened Death (SAHD) ^{20,33} -35,41,49,50,55,60,63	Questionnaire	Assesses anticipated physical and emotional suffering and direct thoughts about facilitating one's death	20 dichotomous items (true/false) Score range 0–20, with score above 10 indicative of a wish to hasten death	Advanced cancer Palliative care ALS AIDS Neurological disease Geriatric Multimorbid Chronic obstructive pulmonary disease
Schedule of Attitudes toward Hastened Death— Short version 49,53,59,67	Questionnaire	Assesses anticipated physical and emotional suffering and direct thoughts about facilitating one's death	5 or 6 dichotomous items (true/false) Score range 0−5, with score ≥2 indicative of a wish to hasten death	Advanced cancer
Desire to Die Rating Scale (DDRS) ^{13,33,37,45–47}	Clinical interview	Assesses if the patient has ever experienced a desire for death, and the frequency and severity of that desire	One initial screening question with a dichotomous response format (yes/no). Individuals who respond "yes" to the screening question are then asked a further three questions, each rated on a scale from 1−6. Scores ≥1 indicate some degree of desire for death. As this is a semi-structured clinical interview, the metric properties have not been reported in any study.	Cancer Palliative care & Hospice AIDS
Assessment of the Frequency and Extent of the Desire to Die (AFEDD) ³⁸	Clinical interview	Assesses the presence, intensity and extent of the wish to hasten death	One initial screening question with a dichotomous response format (yes/no). Individuals who respond "yes" to the screening question are then asked a further two questions, the responses to which are categorized by the clinician on a 4-point scale (from 1–4). The total score therefore ranges from 2–8, and higher scores indicate a stronger desire to die. As this is a clinical interview, the metric properties are not reported.	Advanced cancer
Wish to Die Questionnaire (WDQ) 40	Questionnaire	Evaluates the perspective towards life and death of a person with a progressive fatal disease such as amyotrophic lateral sclerosis	The instrument comprises 18 items, each with three response options (agree, disagree, cannot say). Items refer to seven domains: religiosity/ spirituality, belief in karma, meaning of life, hope, family support, financial support and death wish. Only one item (item 17) refers to the death wish domain. The study reports adequate metric properties for the instrument.	Amyotrophic lateral sclerosis

studies have highlighted the sense of being a burden to others and the absence of a social support network as risk factors. 6,27,31,47 Regardless of whether the wish to hasten death was considered solely in the context of requests for euthanasia/assisted suicide²⁹ or under broader terms such as expressions of suffering, ^{4,27} it is agreed that related factors have the same multidimensional origin as the wish to hasten death itself, that is to say, they may pertain to the physical, psychological, existential/spiritual and social domains. Accordingly, in the context of end-of-life care, the wish to hasten death is considered a clinically relevant phenomenon that may emerge primarily as a reaction to multifactorial suffering. 4,12 This emphasis on multifactorial suffering reflects both the different variables that have been identified as predictors of the wish to hasten death, as well as the variety of reasons and meanings associated with such a wish that have been described in qualitative studies of patients' lived experience. 11,52 Table 4 summarizes the information on the prevalence of the wish to hasten death and related factors.

Around 30 of the studies included in this review reported analyses describing a variety of related factors. The related factors measured showed recognition of key issues in the experience of patients that have been outlined above. Depression was the most commonly reported related factor, insofar as (1) it was characteristic of groups with higher rates of the wish to hasten death (based on frequency measures), 40,47 (2) it emerged as a significant predictor in regression analyses, ^{18,37,56} and (3) it was repeatedly identified as a mediator in models of the wish to hasten death. 20,41,53 Regarding physical symptoms, pain and functional disability were reported to be the most consistent physical problems by nine studies. 15,19,39,41,43,47,56,57,62 decreased sense of meaning in life emerged as a consistent predictor and mediator in models of the wish to hasten death. 19,34,36,43,60

The sense of being a burden and reduced quality of life or wellbeing were also described as related factors in a number of studies. 29,37,47,57 In line with reviews, the socio-demographic variables age and sex (female) were factors associated with the wish to hasten death. In reference to age, however, one study⁶² reported that older age was more often a predictor of the wish to hasten death, whereas another 19 reported that groups with thoughts of death or suicidal ideation were significantly younger than those without any such thoughts or suicidality. A novel contribution of the latter study is that it locates the wish to hasten death along a continuum of suicidality in patients with cancer. Finally, several studies have moved beyond traditional statistical methods of correlation and regression when exploring factors related to the wish to hasten death, employing instead more advanced methods such as structural equation models^{41,53} or latent class analysis.⁶² These analyses not only show the complex and multifactorial nature of the wish to hasten death but also provide a more coherent framework for understanding the shared characteristics and pathways by which different factors may influence one another in the manifestation of such a wish.

Discussion

The aim of this overview was to provide an updated synthesis of the literature on the wish to hasten death among people with life-limiting conditions. The review has considered the definitions and terminology used in referring to this phenomenon and has examined the findings regarding the lived experience of patients with advanced disease who express a wish to hasten death, the prevalence of this wish and instruments for assessing it, and the factors related with its emergence.

The wish to hasten death is a complex phenomenon that has been widely studied. Although many of the studies reviewed include a definition of this wish, there remains considerable variation in the terminology used. Our aim in the present overview was not to compare the relative merit of these different terms but rather to synthesize the findings from all recent studies of relevance to the phenomenon. To reflect the terminological diversity we propose that the desire for death may usefully be considered as existing along a continuum, defined by the extent to which thoughts of dying are linked to action.

It is worth noting at this point that whether or not a desire to die leads to action being taken is a complex question that will be influenced by, among other factors, the cultural setting. Acting on a desire to die (e.g., requesting euthanasia or assisted suicide) is likely to be more common in countries where assisted dying is legal, such as The Netherlands or Switzerland. However, despite the large body of research into the wish to hasten death and medical assistance in dying (MAID) more generally, no studies to date have explored longitudinally what happens subsequent to expressions of a desire to die, which may vary depending on how palliative care is interpreted and approached in a particular context. The findings of studies that report professionals' level of training and confidence in managing the wish to hasten death lead us to speculate that in countries where MAID is legal, the expression of a desire to die may simply be interpreted as a signal that activates the assisted dying protocol. In Spain, where palliative care is not a separate medical specialty and little training is offered to professionals on how to approach the desire to die, one study found that most requests for assistance in dying (394 of the 458 recorded) were dealt with by general practitioners and neurologists, ⁶⁸ it being unclear whether they had specific training in palliative or end-of-life care.

 $Table\ 4$ Selected Systematic Reviews and Primary Studies (Published Within the Past Five Years) That Report Quantitative Assessment of the Desire for Death and Which Include Results for Prevalence and/or Related Factors

Author(s)	Instrument/Assessment of WTHD	Prevalence	Statistical Analyses	Related Factors
Systematic revi	iews			
Bellido-Pérez et al. ¹³	Desire for Death Rating Scale (DDRS) Schedule of Attitudes toward Hastened Death (SAHD) Modified DDRS Modified DDRS introduced into the Structured Interview for Symptoms and Concerns (SISC) Visual analogue scale Questions developed by authors (x2)	DDRS between 3% and 35% SAHD between 1.5% and 28%	Not applicable	Not reported
Erdmann et al. ²⁸	Not applicable	Not applicable	Not applicable	 Physical impairment Psychosocial factors Socio-demographic status Socio-cultural context
Monforte- Royo et al. ⁶	Not applicable	Depending on scale/ question, reports range from 2% to 56%	Not applicable	 Pain Depression Hopelessness Feeling of being a burden With better management of physical pain, psychological and spiritual aspects, including social factors, are the most important determinants of a wish to hasten death
Mishara et al. ²⁹	Not applicable	Not reported	Not applicable	 Pain Suffering Quality of life Clinical depression Individual differences in coping strategies Prior attitudes toward suicidality and illness
Primary studie Belar et al. ¹⁵	Assessment of the Frequency and Extent of the Desire to Die (AFEDD)	36/201 (18%) in the first interview and 26/165 (16%) in the second interview	The relationship between the dimensions of the frequency of appearance and extent of the desire to die was established using χ^2	 Pain or other symptoms, psychological aspects Feeling of being a burden on the family Existential aspects Poor perception of their own dignity
Bellido-Pérez et al. ³³	Schedule of Attitudes toward Hastened Death—5 (SAHD- 5) Desire for Death Rating Scale (DDRS)	SAHD-5 = 13/107 patients (12.1%) at risk for wish to hasten death DDRS = 6/107 (5.6%) moderate-strong desire for death	using _A	
Bernard et al. ³⁴	Schedule of Attitudes toward Hastened Death (SAHD)		Linear regression with wish to hasten death as dependent variable	 Spiritual wellbeing Lack of meaning in life
Breitbart et al. ³⁵	Schedule of Attitudes toward Hastened Death (SAHD)		Treatment effects analyzed with a series of mixed models	Treatment with meaning-centered psychotherapy improved scores on SAHD (indicating reduced wish to hastened death)
Busquet- Duran et al. ³⁶	HexCom model ^a	112/1677 (6.67%); wish persisted at follow-up in 78/112 (71.6%) of patients		 Spiritual distress Lack of meaning Lack of connection Psycho-emotional distress Ethical distress

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Table 4 Continued

Author(s)	Instrument/Assessment of WTHD	Prevalence	Statistical Analyses	Related Factors
Cheung et al. ¹⁹	Outcome variable was the single interRAI-PC item "Want to die now" (yes vs. no)	238/771 (9.3%) responded yes to "Want to die now"	Compared individuals who responded yes to the item "Want to die now" with those who answered no. Binary logistic regression was used to determine predictors of the variable "Want to die now"	 Older age Awareness of terminal prognosis Not finding meaning in day-to-day life Pain High level of depression
Crespo et al. ³⁷	Desire for Death Rating Scale (DDRS): case group ≥ 1 and control group = 0	51/300 (0.17%)	Group comparisons using ANOVA or Kruskal—Wallis test depending on whether or not the variable had a Gaussian distribution	 Overall quality of life Emotional functioning quality of life Dignity related distress Perceived self-efficacy
Crespo et al. ³⁸	Assessment of the Frequency and Extent of the Desire to Die (AFEDD)	2/15 outpatients (14.3%) and 8/16 inpatients (50%) expressed desire to die		
Freeman et al. ³⁹	interRAI PC assessment instrument	308/4840 (6.7 %) voluntarily expressed a 'wish to die now'	Multivariate logistic regression	 Not being married/widowed A shorter estimated prognosis Depressive symptoms Functional impairment Too much sleep (excessive amount) Feeling completion regarding financial/legal matters Struggling with the meaning of life
Gourie-Devi et al. ⁴⁰	Wish-to-Die Questionnaire (WDQ): An 18-item questionnaire focusing on the wish to die in the context of prevailing religious belief systems in India	5/20 (25%) had a wish to die, 1/20 (5%) had suicidal ideation		 Depression Hope/hopelessness Belief in karma Religion/spirituality Lack of financial support
Guerrero- Torrelles et al. ⁴¹	Spanish adaptation of the Schedule of Attitudes toward Hastened Death (SAHD)		Path analysis model	 Functional status Dependence Wish to hasten death mediated by lack of meaning in life through greater depression
Hatano et al. ⁴³	Patient's expressions of desire for hastened death to family member or medical professionals during the patient's stay at the palliative care unit	174/971 (18%) had desire for hastened death	Hierarchical cluster analysis using Ward's methods	 Dependency (most frequent reason) Burden to othersInability to engag in any pleasant activitiesMeaning-lessness/loss of valuePain was significantly more frequent in patient who desired lethal drug administration than in those who did not Patients in Cluster 1: More likely to have physical distres such as dyspnoea, pain and other physical symptoms Patients in Cluster 2: Dependency Being a burden to others Patients in Cluster 3: Hopelessness Distress owing to the inability to engage in any pleasant activities Depressed Patients in Cluster 4: Profound fatigue Opioid dosage was lowest

The Wish to Hasten Death in Advanced Patients

Table 4 Continued

Author(s)	Instrument/Assessment of WTHD	Prevalence	Statistical Analyses	Related Factors
Hiratsuka et al. ⁴⁴	Physician recall after patient's death of expressed wish for		Multivariate logistic regression	 Patients in Cluster 5: Existential suffering Hopelessness Physical symptoms Poorer spiritual wellbeing
Julião et al. ⁴⁵	hastened death Desire for Death Rating Scale (DDRS)		Multivariate analysis and Poisson regression	The desire for death was not signif cantly predicted by demoralization
Julião et al. ⁴⁶	Yes/no Cut-off score ≥4 on the Desire for Death Rating Scale (DDRS)	Entire cohort 16/80 (20%); Dignity Therapy (DT) group prevalence 9/41 (23%) at baseline, 0/ 41 (0%) at post-test; Control group prevalence 7/39 (17%) at baseline, 6/ 39 (14.3%) at post-test	model Analysis used Fisher's exact test for independent group comparisons (DT group vs. controls) and McNemar's test for paired comparisons between each time-point (T2 and baseline) within each study group	syndrome • Dignity (Dignity Therapy significantly reduced the desire for death)
Julião et al. ⁴⁷	Desire for Death Rating Scale (DDRS) score ≥ 4	25/122 (20.5%)	Retrospective analysis of all desire for hastened death entries registered in an anonymized database from October 2018 to April 2020	 Performance status Drowsiness, shortness of breath Wellbeing Depression Anxiety Will to live Sense of being a burdenAdaptation
Kissane et al. ⁴⁸	Psycho-existential Symptom Assessment Scale (PeSAS)	Severe: 107/1405 (7.6%) Moderate: 132/1405 (9.4%) Clinically significant: 239/1405 (17%)	Exploratory graph analysis to show associations between symptoms, represented by connecting lines for the partial correlations between symptoms	Strongest partial correlation with pointlessness through hopelessness as a central node
Kolva et al. ⁴⁹	Schedule of Attitudes toward Hastened Death (SAHD)	Moderate: 30/389 (7.7%) High: 30/389 (7.7%)	оутросто	
Liu et al. ⁵⁰	Chinese version of the Schedule of Attitudes toward Hastened Death (SAHD-CV)	71/227 (31.3%)	Binary logistic regression analysis	 Protective factors: Follow-up visits Average and high quality of life Risk factors: Severely disturbed sleep Symptoms that severely interfered with mood Symptoms that severely interfered with relations with other people
Mon et al. ⁵¹	Asked patients whether they ever wished their life would end sooner (yes/no/not sure)	80/195 (41%) of patients reported that they wished their life would end sooner		• None
Monforte- Royo et al. ⁵²	Assessment of the Frequency and Extent of the Desire to Die (AFEDD)		SEM for assessing mediation using a path analysis model to assess antecedents of the wish to hasten death	 Depression and perceived loss of dignity mediated the effects of per- ceived loss of control and func- tional impairment on the wish to hasten death
Monforte- Royo et al. ⁵³	Spanish version of Schedule of Attitudes toward Hastened Death (SAHD-SV)	21/101 (20.8%) higher risk		
Parpa ⁵⁵	The Greek Schedule of Attitudes toward Hastened Death (G-SAHD)		Bootstrapping regression analysis with the PROCESS method was used for mediation analysis	 Hopelessness Depression

Table 4 Continued

Author(s)	Instrument/Assessment of WTHD	Prevalence	Statistical Analyses	Related Factors
Pergolizzi et al. 56	Assessment of the Frequency and Extent of the Desire to Die (AFEDD)		Multiple linear regression analysis	 Older age Greater physical symptoms and dependency associated with per- ceived dignity (subscale of Patient Dignity Inventory)
Porta-Sales et al. ⁵⁷	Assessment of the Frequency and Extent of the Desire to Die (AFEDD)	46/193 (23.8%)	Spearman rho correlational analysis	Worse performance statusLower quality of lifeHigher anxietyHigher depression
Robinson et al. ²⁰	Schedule of Attitudes toward Hastened Death (SAHD)		Multiple mediation model with bootstrapping sampling	 Direct effect of global quality of life on WTHD mediated by: Depressive symptoms Loss of meaning and purpose Loss of control Low self-worth
Rodriguez- Mayoral et al. ⁵⁸	Defined as the presence of ideas of death and/or suicidal ideation and/or request for euthanasia and/ or medically assisted suicide request	28/64 (44%)	Univariate logistic regression was performed between the characteristic of interest (desire for hastened death) and each variable to explore possible associations	 Female Major depressive disorder or an anxiety disorder
Rodriguez- Mayoral et al. ⁵⁹	Mexican Schedule of Attitudes toward Hastened Death – Short version (SAHD-Mx): 6 items			Performance statusDepression
Rosenfeld et al. ⁶⁰	Schedule of Attitudes toward Hastened Death (SAHD)		Mediation analysis	Change in meaning and peaceChange in faith
Vehling et al. ⁶¹	15-item Death and Dying Distress Scale (DADDS)	Moderate death anxiety: 105/382 (27.4%)	Network analysis	 Anxiety related to "running out of time" Fear of prolonged death closely related to fear of suffering
Vehling et al. ⁶²	Composite International Diagnostic Interview for Oncology (CIDI-O) ^b		Latent class analyses to define subtypes of suicidality	Longer time since diagnosis Higher number of physical symptoms Significantly more likely to suffer from a mental disorder
Voltz et al. ⁶³	Schedule of Attitudes toward Hastened Death (SAHD)		Descriptive analysis	 No significant changes, and no deterioration on any of the outcomes. Trends pointed toward potentially relieving effects of a desire to die conversation in patient depressiveness.

^aHexCom model classifies the desire to anticipate death into: Low complexity (no or sporadic manifestation); Medium (persistent desire that requires specific treatment); or High (persistent desire that is considered potentially refractory).

Regarding instruments for assessing the wish to hasten death, the DDRS (Desire for Death Rating Scale) and the SAHD (Schedule of Attitudes toward Hastened Death) are by far the most widely used in the literature to date. Closer examination of their content suggests, however, that they address different aspects of the desire to die, a reflection perhaps of how the conceptualization of a wish to hasten death and, therefore, the focus and wording of items is shaped by cultural assumptions. The fact that three short versions of the SAHD 33,49,59,69 developed in different countries only have three of the original scale items in common is an illustration of this. A potential limitation affecting both

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the SAHD and the DDRS concerns the extent to which they are able to distinguish an acceptance of death in the end-of-life context from a full-blown wish to hasten death (i.e., one accompanied by suicidal ideation). Of the two, the DDRS is readily applicable in clinical practice, whereas the length of the SAHD (20 items in the full version) and the direct wording of some of its items may make it better suited to research, the context for which it was originally designed. ¹³

Some of the assessment instruments used to date take the form of a semi-structured clinical interview, and hence their psychometric properties are not reported. However, in fields such as psychiatry the

bCIDI-O assesses the 4-week prevalence of thoughts of death, death wishes, suicidal ideation and suicidal behavior, as well as mental disorders.

clinical interview is widely regarded as an adequate and reliable tool, and in this respect instruments such as the AFEDD (Assessment of the Frequency and Extent of the Desire to Die) may be considered suitable for use in the end-of-life context. Overall, the lack of standardized assessment tools that may be routinely applied in clinical practice is clearly one of the factors that make it difficult to obtain reliable prevalence estimates for the wish to hasten death. Further research is needed in this regard.

A related issue to consider here is that there has traditionally been a degree of reticence among healthcare professionals to enquire about a wish to hasten death, ⁶⁹ whether for fear that it may be distressing for patients or because of a perceived lack of training in how to respond in the event that such a wish is expressed. Importantly, however, a recent study found that asking patients with advanced cancer about a possible wish to hasten death is not upsetting, ⁶³ and in fact many of them appreciated the opportunity to discuss this. ⁵⁷ This suggests that proactively asking about a wish to hasten death can help to open up a space for conversation about dying and the end of life, and may identify sources of suffering that might otherwise have remained hidden. ⁶³

Numerous studies have examined factors related to the emergence of a wish to hasten death in people with a life-limiting condition, and there is a good degree of consensus regarding certain risk factors such as depression. However, although it has been estimated that around 25% of patients with cancer experience depressive symptoms, and between 6% and 13% of them fulfil the criteria for a diagnosis of major depression, 70 routine screening for these forms of distress is not always performed in cancer settings. 71

Although several of the studies analyzed in the present synthesis include patients with different life-limiting conditions (AIDS, neurodegenerative disease, organ failure, etc.), study samples tend to be primarily composed of patients with cancer. For instance, there is only one review focused specifically on people with amyotrophic lateral sclerosis (ALS). A noteworthy aspect of this review, however, is that while the authors describe determinants of the wish to hasten death that are broadly similar to those reported for other clinical populations, they also provide specific details pertaining to patients with ALS, for example, that they are more likely to refuse invasive (as opposed to non-invasive) life-sustaining treatments. The qualitative study by Ohnsorge et al.⁵² similarly found that the specific nature of different dying trajectories (neurological disease, organ failure, frailty due to age and cancer) lends particular characteristics to the phenomenology of the wish to die. Taken together, these results highlight the importance of being sensitive to the concerns and challenges associated with particular life-limiting conditions

so as to remain alert to potential risk factors for the emergence of a wish to hasten death. More research targeted at specific populations, including different types of cancer, is therefore needed to provide a deeper understanding of similarities and differences in patients' experiences. It should also be noted that although a poorer prognosis,³⁷ the time since diagnosis, 72,73 younger age, higher socioeconomic status and lower religiosity have all been identified as risk factors for a wish to hasten death, 27,61,74 they have yet to be explored in qualitative studies, and doing so would help to shed light on their significance for patients. In summary, longitudinal studies examining different disease trajectories, case-cohort studies and comparative analyses of different clinical populations could all add to our understanding of the wish to hasten death in people with life-limiting conditions.

Strengths and Weaknesses of the Study

The present overview provides an updated synthesis of the scientific literature on the wish to hasten death among people with life-limiting conditions, examining the findings of the most recent systematic reviews and primary studies on this issue (the primary studies alone included over 16,000 participants). While many of the conclusions are not in themselves new, the review nonetheless has a number of strengths. One is that by taking into account and seeking to integrate the diverse range of terms that are used in this field, we were able to propose that the desire to die be considered as existing along a continuum, defined by the extent to which thoughts of dying are linked to action. In our view, this serves to complement the consensus definition of the wish to hasten death that was published by an international working group in 2016. A further strength of the present review is that we describe the conceptual framework underpinning each of the tools for assessing the wish to hasten death that have been described in the literature. To date, research related to these tools has been limited either to describing their psychometric properties or to reporting the prevalence of the wish to hasten death when they are applied in a given population. However, it is also important to consider how the way in which different tools conceptualize the desire to die may influence the results obtained (e.g., do they focus on the same or different aspects of the phenomenon?), and also whether the wording used is geared more towards research or clinical practice. This is important information for clinicians to consider when choosing an instrument with which to explore a possible wish to hasten death in their patients.

A limitation of this review is that we only included studies that explored the wish to hasten death from the perspective of patients. Although some studies have explored the perspective of professionals and/or patients' families, we opted here to focus on patients, due to the difficulties implied in integrating data obtained from different informants. A further potential weakness concerns the diversity of research reports we included (i.e., primary studies and systematic reviews, studies using different methods and with different aims). Although this heterogeneity might be considered a strength, it also makes a detailed analysis of the data more challenging. For example, the studies included were carried out in a wide variety of sociocultural contexts, in some of which euthanasia and assisted suicide have been legalized. What is lacking from the present review, therefore, is a more detailed discussion of how the characteristics of these different cultural contexts may influence the expression of a wish to death, as well as of the broader ethical issues that emerge from this research.²⁹

Finally, although we tested different search strategies before settling on those used for this review, the fact that a number of studies were only retrieved through additional hand-searching suggests that the strategies used may not be sufficiently sensitive. A related issue concerns our decision to include not only studies whose specific focus was the wish to hasten death but also those in which this wish was one of the experiences considered when exploring the desire to die more broadly. By extending the scope of the review in this way we sought to maximize the number of studies identified (and hence the amount of information obtained), although it is possible that we have overlooked some studies, due to the wide variety of terms that are used to refer to different aspects along the continuum of the desire to die.

Despite synthesising all the literature on the phenomenon of the WTHD, there are still questions to be answered, especially as regards how to approach it clinically and how best to alleviate the underlying suffering. More studies are needed in the search for solutions from a clinical point of view, and the EAPC Task Force on the WTHD (https://eapcnet.eu/eapc-groups/task-forces/wish-to-hasten-death/) is currently engaged in efforts to address this.

Conclusion

The wish to hasten death is a complex phenomenon that has been widely studied, although understanding and addressing it has been hampered by the lack of standardized terminology in the literature. Assessment instruments also appear to conceptualize the phenomenon in different ways, and this issue is further complicated by the fact that the experience or manifestation of a wish to hasten death is influenced by both individual and sociocultural factors. All this makes it difficult to integrate the findings of different epidemiological studies. Although the determinants of a wish to hasten death (the reasons, meanings, and functions) appear

to be broadly similar across different patient populations, it is important to consider how a particular individual's experience is shaped by the specific characteristics of their life-limiting condition.

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Quality	Apprais	sal of th	e Includ	led Studies	Using the	CASP	Checklist for	Systematic	c Reviews
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		Bellido et al. (2017)	Dees et al. (2010)	Erdmann et al. (2021)	Mishara et al. (1999)	Monforte- Royo et al. (2011)	Monforte- Royo et al. (2012)	Rodríguez- Prat et al. (2017)	Rodríguez- Prat et al. (2018)	Rodríguez- Prat et al. (2018)	Rodríguez- Prat et al. (2019)	Rodríguez- Prat et al. (2021)
A. Are the results of the review	Did the review address a clearly focused question?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
valid?	Did the authors look for the right type of papers?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
A. Is it worth continuing?	Do you think all the important, relevant studies were included?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Did the review's authors do enough to assess quality of the included studies?	Yes	Can't Tell	Can't Tell	Can't Tell	Can't Tell	Yes	Yes	Yes	Yes	Yes	Yes
	If the results of the review have been combined, was it reasonable to do so?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
B: What are the results?	What are the overall results of the review?	See Table 1	See Table 1	See Table 1	See Table 1	See Table 1	See Table 1	See Table 1	See Table 1	See Table 1	See Table 1	See Table 1
	How precise are the results?	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
C: Will the results help locally?	Can the results be applied to the local population?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Were all important outcomes considered?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	Are the benefits worth the harms and costs?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

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Supplementary Table B

Quality Appraisal of the Included Studies Using the Mixed Methods Appraisal Tool (MMAT) for Quantitative Reports

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	Belar et al., (2021)	Bellido- Pérez et al., (2018)	Bernard et al., (2017)	Breitbart et al., (2018)	Busquet- Durán et al. (2021)		Crespo et al., (2020)			, De	vi et al., T 017) e	Guerrero- Forrelles et al., 2017)		t Hatano) al., (202	et Hiratsu (2020)	ıka Juliao et al. (2016	3
S1. Are there clear research questions?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	s Y	'es	Yes	Yes	Yes	Yes	Yes
S2. Do the collected data allow to address the research questions?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	s Y	'es	Yes	Yes	Yes	Yes	Yes
4.1. Is the sampling strategy relevant to address the research question?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Y Y	es	Yes	Yes	Yes	Yes	Yes
4.2. Is the sample representative of the target population?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	s Y	es	Yes	Yes	Yes	Yes	Yes
4.3. Are the measurements appropriate?	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Y	'es	Yes	Yes	Yes	Yes	Yes
4.4. Is the risk of nonresponse bias low?	No	Yes	Yes	Yes	No	No	Yes	Yes	Yes	No	N	No .	Yes	Yes	Yes	Yes	Yes
4.5. Is the statistical analysis appropriate to answer the research question?	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Car	n't tell Y	'es	Yes	Yes	Yes	Can't tel	l Can't tell
	Juliao et al. (2020)	Kissane et al. (2020)	Kolva et al. (2017)	Liu et al. (2022)	Mon et a (2020)	ll. Monfor Royo et (2017)		et al. al. (2	019)	Pergolizzi et al. (2020)	Porta et (2019)	al. Robi et al (201	. Ma	yoral et		Rosenfeld et al., 2018	
S1. Are there clear research questions?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	,	Yes	Yes	Yes	Yes	5	Yes	Yes	Yes
S2. Do the collected data allow to address the research questions?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	,	Yes	Yes	Yes	Ye	5	Yes	Yes	Yes
4.1. Is the sampling strategy relevant to address the	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	•	Yes	Yes	Yes	Yes	5	Yes	Yes	Yes

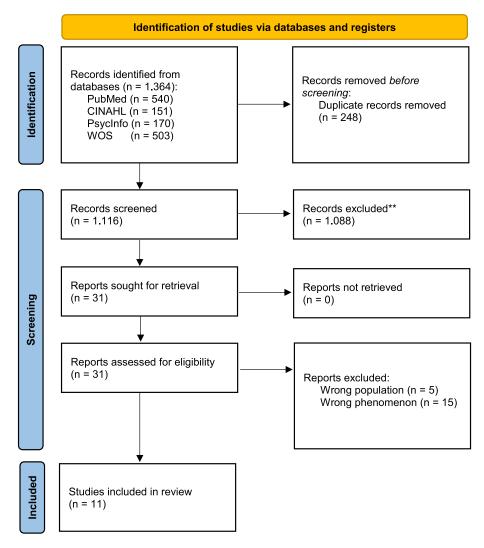
Supplementary Table B Continued

	Juliao et al. (2020)	Kissane et al. (2020)	Kolva et al. (2017)	Liu et al. (2022)	Mon et al. (2020)	Monforte- Royo et al. (2017)	Monforte- Royo et al. (2018)	Parpa et al. (2019)	Pergolizzi et al. (2020)	Porta et al. (2019)	Robinson et al. (2017)	Rodríguez- Mayoral et al. 2019		Rosenfeld et al., 2018	Vehling et al. (2021)
research question? 4.2. Is the sample representative of the target	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
population? 4.3. Are the measurements appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4.4. Is the risk of nonresponse bias low?	Yes	Yes	Yes	No	No	No	No	No	Yes	No	No	No	Yes	Yes	Yes
4.5. Is the statistical analysis appropriate to answer the research question?	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell

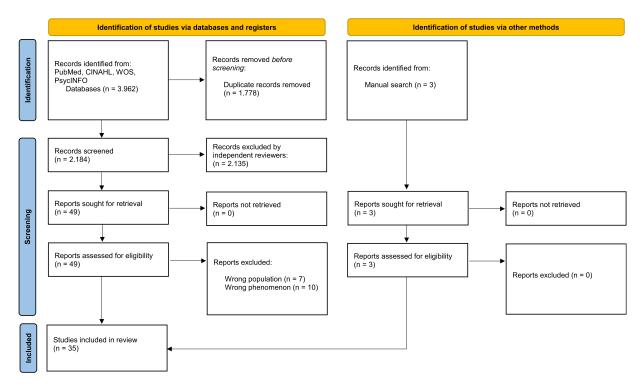
tive Reports

Supplementary Table C
Quality Appraisal of the Included Studies Using the Mixed Methods Appraisal Tool (MMAT) for Mixed Methods and Qualita-

		Ohnsorge et al. (2019)	Voltz et al. (2022)
Screening questions	S1. Are there clear research questions?	Yes	Yes
	S2. Do the collected data allow to address the research questions?	Yes	Yes
Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	Yes	
	1.2. Are the qualitative data collection methods adequate to address the research question?	Yes	
	1.3. Are the findings adequately derived from the data?	Yes	
	1.4. Is the interpretation of results sufficiently substantiated by data?	Yes	
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	Yes	
Mixed Methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?		Yes
	5.2. Are the different components of the study effectively integrated to answer the research question?		Yes
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?		Yes
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?		Yes
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?		Yes



Supplementary Fig. 1. Flow diagram for systematic reviews. *From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/.



Supplementary Fig. 2. Flow diagram for primary studies. *Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers). **If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools. *From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

To summarize systematic reviews that examine the definitions, assessments, and associated factors underlying the wish to hasten death (WTHD) in advanced illnesses. Inclusion Criteria

- Systematic review
- Focus on any phenomena related to the WTHD (e. g., from desire to die to requests for euthanasia) in patients

Exclusion Criteria

- Focus on professionals
- Focus on legal, ethical, moral perspectives and/or documentation
- Not SR